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# Prudent health care and patient activation

An appraisal prepared for the Planned Care Programme

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The views and opinions expressed in this appraisal are those of the authors and do not necessarily reflect the official policy or position of the Welsh Government or its agencies including NHS Wales. We have endeavoured to attribute published work accurately but many themes and ideas in this area emerge and are freely shared through networks and events in which we have gratefully participated.

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### **Summary**

Prudent healthcare is Wales' blueprint for the co-production of better, more integrated health and social services by identifying and prioritising need, choosing treatments wisely through partnership, and reducing inappropriate variation through the application of evidence based approaches. It heralds an unprecedented democratisation of decisions about what and how services are provided and fosters patient responsibility as well as rights – in short, it is a grown up plan for a grown up NHS, building on its founding principles of equity and fairness to create a service which meets the changed needs of people in the 21<sup>st</sup> century.

The Planned Care Programme is part of that plan and challenges assumptions about roles and responsibilities, seeks to develop new partnerships and changed relationships between the public and providers, and patients and professionals, and to harness the power of communities and new technologies to provide services people need and will use.

Central to the Programme is finding ways of empowering patients to take greater control over their health, backed by evidence that this leads to better outcomes and lower costs.

This paper examines the concept of the activated patient, defined as one who is able to exercise informed, healthy choices and who predominantly uses services to support those choices. It describes the behaviours and roles adopted by those who have the knowledge, skills and confidence to take this responsibility and those who do not and who, as a direct result, become increasingly dependent.

It examines the evidence that activated patients enjoy better health and, that when they do become ill, they have better outcomes. It also examines ways of increasing activation so that more people can benefit from the advantages offered. Many of the ways of improving activation rely on psycho-social and community based interventions which are not amenable to clinical methods of evaluation – new interventions need new forms of measurement.

In particular the paper examines the case for using the Patient Activation Measure (PAM) as a patient reported outcome measure, applicable across a wide range of conditions. Some consideration is given to other approaches.

The paper emphasises the evidence that efforts to improve levels of patient activation are only likely to be successful and sustained if they are supported by a whole systems approach involving the training of clinicians in new ways of working and the alignment of administrative procedures, including organisational performance measures and incentives, so that responsible behaviours are supported and encouraged.

It also acknowledges that the bulk of evidence in support of improving patient activation as a health goal is derived from efforts to improve activation among those with long term conditions. Do such efforts provide similar benefits for more episodic encounters such as

elective surgery? The paper suggests that a study could be undertaken to explore the use of community based interventions using the PAM as an indicator of outcomes to build local confidence in both non-clinical intervention and the measure itself.

#### 1. Introduction

### **Prudent Healthcare**

- 1.1 The four pillars of prudent healthcare are linked by a common theme improving health by changing the way health services are used and provided<sup>1</sup>. Successful organisational change results in people behaving differently and is most likely to occur if expectations, roles and rewards are aligned to support people make and sustain those behaviours<sup>2</sup>.
- 1.2 Prudent healthcare seeks to create *partnerships* in securing individual health (cocreation) and the means by which care and support is designed and delivered (coproduction). It also seeks to address issues of *priorities* so that those with the greatest need are supported by early and appropriate care based on *evidence* of 'what works' and to provide care on the basis of 'what's needed', and *does no harm*.
- 1.3 As the Prudent White Paper³ points out, the NHS often gives out mixed messages by misaligning the motivational elements needed for improved health for both users and providers. Nowhere is that clearer than in the role of the patient in securing and maintaining their own well-being. A system that takes little account of patient preference and that assumes no patient insight or knowledge and doles out the same treatment to all, regardless of context, is likely to produce both dependency and lack of compliance simultaneously. One which solely measures and rewards system targets is likely to reinforce the behaviours which perpetuate unequal relationships, inequality of access and to continue to deliver treatments the system can provide rather than those which patients need. So different measures are needed.
- 1.4 To achieve care focused on patient need or Person Centred Care (PCC) requires a simultaneous shift, not just in emphasis but in core assumptions about roles, responsibilities, behaviours and systems elements of clinical practice. PCC is the application of a different and emerging model, itself difficult to define, and adapted to a range of medical, social and personal needs in settings which are themselves subject to local variation and flux. It is part of a much larger social movement which is redefining the relationship between the citizen and the system and is driven by forces as varied as technology, austerity and demography. Prudent health care is a balanced response, based on consultation.

<sup>&</sup>lt;sup>1</sup> Mark Drakeford Making Prudent Healthcare Happen Conference Address Cardiff 9th July 2015

<sup>&</sup>lt;sup>2</sup> Reinhardt, R.B., Reinhardt, J.V., Aristigueta, M.P. (2012) *Managing Human Behaviour in Public and Non-profit Organizations*, 3rd edn. Thousand Oaks: SAGE.

<sup>3</sup>rd edn., Thousand Oaks: SAGE.

<sup>3</sup> Bradley, P and Wilson, A. (2014) *Achieving prudent healthcare in NHS Wales*, Cardiff: Public Health Wales. [Online]. Available at:

http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/Achieving%20prudent%20healthcare%20in%20NHS%20Wales%20paper%20Revised%20version%20%28FINAL%29.pdf (Accessed 28<sup>th</sup> August 2015)

### Planned care and the planned care programme

- 1.5 Planned care is the name given to those services and treatments which are not carried out in an emergency, often those to which patients are referred by their GP. Most people benefit from some form of NHS planned care several times in their lifetime. Conditions resulting in poor eyesight, difficulties in movement, chronic muscular skeletal pain in adults and common childhood complaints such as hernia, squints and repair of cleft lip or palate account for around 50 percent of NHS activity and 40 per cent of expenditure. Demand for these kinds of treatment and care continues to rise and, despite both increases in funding and locally led improvements in efficiency, the gap between supply and demand is forecast to get wider.
- 1.6 The Planned Care programme was initiated by the Minister for Health in September 2014 with a remit to improve patient experience and establish sustainable services. Its initial focus is on:
  - Ophthalmology.
  - · Orthopaedics.
  - · Ear Nose and Throat.
  - Urology.
- 1.7 Likely sources of change were identified as:
  - Better capacity and demand measurement to identify gaps and opportunities for improvement.
  - Identification and reduction of unnecessary variation.
  - The promotion of holistic care.
  - Patient empowerment.
  - Costing pathways to identify value.
- 1.8 This paper is mainly about patient empowerment, also referred to as patient activation.<sup>4</sup>

<sup>&</sup>lt;sup>4</sup> The term patient activation is used in this paper to include enabled, empowered, informed and other terms indicating a degree of ability and responsibility in looking after their own health.

# 2. What are activated patients?

# **Defining activation**

- 2.1 There are a number of ways of 'defining' activation, the two most common being to describe the behaviours which mark out active as opposed to passive patients or to describe the role assumed by the patient in relation to the health care system responsible or dependent<sup>5</sup>. The distinction between behaviours and roles may be useful if we are seeking to change the way health services are used and provided.
- 2.2 Behavioural approaches assume that patients display activated or passive behaviours because their contact with the system continuously supports and rewards those behaviours over other behaviours. The medical-sociological literature on roles suggests the role adopted by the individual patient is set by societal expectations to conform to norms based on social status and power relationships<sup>67</sup>.
- 2.3 Table 1 below contrasts extremes of patient behaviour in relation to activation and the different roles that patients can play. It is important to recognise that both patient behaviour and adopted role are responses to the health system they are presented with. So, changing individual behaviours, or even the roles played out by doctor and patient within a consultation, requires organisational changes to systems and processes to reinforce those new behaviours and support a different set of expectations. What's on offer in turn depends on the model of medicine underpinning the systems and processes.

<sup>&</sup>lt;sup>5</sup> Active/passive, responsible/dependent is the authors' terminology based on the descriptions given.

<sup>&</sup>lt;sup>6</sup> Roter, D. (2000) *Doctors Talking with Patients/Patients Talking with Doctors: Improving Communication in Medical Visits*, 2nd edn., Westport, Conn: Praeger.

<sup>&</sup>lt;sup>7</sup> Fischer, M. and Ereaut, G. (2012) When doctors and patients talk: making sense of the consultation. [Online]. Available at: <a href="http://www.health.org.uk/publication/when-doctors-and-patients-talk-making-sense-consultation">http://www.health.org.uk/publication/when-doctors-and-patients-talk-making-sense-consultation</a>. (Accessed: 11th December 2015).

Table 1 Patient behaviours and roles8

Activated patient	Passive patient	Responsible patients	Dependent patients
behaviour	behaviour	see their role as	see their role as
Display interest and	Show little interest in	The prime manager of	Passive sufferers of
take responsibility for	the part underlying	their condition.	random episodes of ill
their underlying health	health needs play in		health.
needs.	determining their well-		
	being.		
undertake behaviours	Ignore early symptoms,	A source of expertise	Dependent on medical
such as diagnosing	delay or do not seek	as far as their condition	professionals for an
and treating minor,	help when they need it.	is concerned.	understanding of their
self-limiting conditions;			condition.
Work in partnerships	Do not systematically	Partners and equals in	Recipients of care.
with health professional	follow medical advice.	securing help when	
to select the most		they are unwell.	
appropriate form of			
treatment for more			
serious illness.			
Actively manage long	Quickly revert to not	Experts in their	Complying with others
term conditions.	managing their health	condition as it affects	judgements about
	when they are no	them.	treatment.
	longer being treated.		

# Most likely to say.

Better safe than	It will probably clear	I was able to describe	The doctor should
sorry	up	my symptoms to the	have noticed
		professional	
I arranged an	My partner made me	I understand my	Just tell me what to
appointment because	see the doctor.	condition and need	do/what would you do?
I noticed something		some help weighing up	
unusual.		the options.	

- 2.4 What lies behind these differences is both complex and variable. Research by the US National Cancer Institute<sup>9</sup> identified a number of cognitive constructs related to patient empowerment including:
  - Dispositional optimism.
  - Illness representations.
  - Implementation intentions.
  - Normative beliefs.
  - Locus of control/vulnerability.
  - Self-efficacy.
  - Social influence/social support.

Based on <a href="http://www.kingsfund.org.uk/publications/supporting-people-manage-their-health">http://www.kingsfund.org.uk/publications/supporting-people-manage-their-health</a>
 National Cancer Institute (2008) Health Behavior Constructs: Theory, Measurement and Research [Online] Available at: <a href="http://cancercontrol.cancer.gov/brp/constructs/index.html">http://cancercontrol.cancer.gov/brp/constructs/index.html</a> (Accessed: 28th August 2015).

The constructs all relate in one way or another to the patient's ability or willingness to make choices.

- 2.5 Health literacy has long been recognised as a key component of a patient's capacity and capability to manage their health. The World Health Organisation (WHO) describe health literacy as: "as the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" 10. Health literacy improves the chances of making the right health choices for individuals and at population level. 11
- 2.6 The concept of patient activation underpins many of the techniques used in PCC<sup>12</sup> all of which seek in one way or another to shift the role of the patient and the behaviours involved towards taking more control and responsibility for choices and decisions about their health(with congruent changes in the role and behaviours of medical professionals). Readiness also plays a part, whether readiness to assume responsibility for a particular condition<sup>13</sup> or to engage with a particular medium<sup>14.</sup>
- 2.7 An issue identified by the Health Foundation's 'ideas to action' document is that there are perhaps too many competing theories, techniques and measures, stemming from a poorly defined construct. Of late, this has become the focus for much work on the integration of both methods and measurement to promote implementation<sup>15</sup>.
- 2.8 Hibbard's<sup>16</sup> research puts forward the view that three major patient factors (levels of knowledge, skill and confidence) account for differences in levels of activation and that these are largely independent of age, social class, education and other factors traditionally associated with differences in patient behaviours. Moreover, the levels of these factors can be measured and the results correlated with outcome measures thereby creating a predictive link between activation levels and health outcomes. The most useful feature of Hibbard's work, for our current purposes, is that knowledge, skills and confidence are capacities rather than cognitive states, and as such can be enhanced.

<sup>12</sup> Ahmad, N., Ellins, J., Krelle, H. and Lawrie, M. (2014) Person-centred care: from ideas to action, London: Health Foundation. [Online] Available at: <a href="http://www.health.org.uk/publication/person-centred-care-ideas-action">http://www.health.org.uk/publication/person-centred-care-ideas-action</a> (Accessed: 28<sup>th</sup> August 2015)

<sup>13</sup> Márcio Flávio Moura de Araújo, Ana Maria Parente Garcia Alencar, Thiago Moura de Araújo, Marta Maria Coelho Damasceno, Joselany Áfio Caetano, Lorena Barbosa Ximenes, Neiva Francenely da Cunha Viera (2012) 'Readiness for enhanced self-health management among people with diabetes mellitus', Acta Paul Enferm., 25(1), pp. 133-139.

<sup>&</sup>lt;sup>10</sup> World Health Organisation (2009) Track 2: Health literacy and health behaviour 7th Global Conference on Health Promotion: track themes [Online] Available at: <a href="http://www.who.int/healthpromotion/conferences/7gchp/track2/en/">http://www.who.int/healthpromotion/conferences/7gchp/track2/en/</a> (Accessed: 28th August 2015).

<sup>&</sup>lt;sup>11</sup> Ibid.

<sup>&</sup>lt;sup>14</sup> Koopman, R.J., Petroski, G.F., Canfield, S.M., Stuppy, J.A. and Mehr, D.R (2014) 'Development of the PRE-HIT instrument: patient readiness to engage in health information technology', BMC Fam Pract, 15(18), pp.

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15 De Silva, D (2014) Helping measure person-centred care, London: Health Foundation. [Online] Available at: http://www.health.org.uk/publication/helping-measure-person-centred-care (Accessed: 28<sup>th</sup> August 2015)

16 Hibbard, J. and Gilburt, H. (2014) Supporting people to manage their health: An introduction to patient activation, London:

Kings Fund. [Online] Available at: <a href="http://www.kingsfund.org.uk/sites/filed/field\_publication\_file/supporting-people-manage-health-patient-activation-may14.pdf">http://www.kingsfund.org.uk/sites/files/kf/field/field\_publication\_file/supporting-people-manage-health-patient-activation-may14.pdf</a> (Accessed: 28<sup>th</sup> August 2015)

# 3. What interventions help to activate patients?

### Lessons from the literature

- 3.1 Coulter and Ellins, in a systematic review of patient focused interventions, mapped activities against quality improvement goals (see Table 2)<sup>1718</sup>. We have added a third column to their analysis which maps activities and goals against the three factors advanced by Hibbard as accounting for differences in levels of activation which demonstrates that most of the interventions in the review address one of more of these three factors. Some interventions may not impact on an individual's confidence level in managing treatment but on general confidence in services.
- 3.2 Coulter and Ellins do not attempt to rank the interventions in any way, indeed they point out that they are non-comparable in many respects, but nonetheless it serves as a useful reference point for thinking about interventions which may improve patient activation.

Coulter, A. and Ellins J. (2006) Patient-focused interventions A review of the evidence, Oxford: Picker Institute [Online].
 Available at: <a href="http://www.health.org.uk/publication/patient-focused-interventions">http://www.health.org.uk/publication/patient-focused-interventions</a> (Accessed: 30<sup>th</sup> July 2015)
 Coulter, A. and Ellins, J. (2007) 'Effectiveness of strategies for informing, educating, and involving patients', British Medical

<sup>&#</sup>x27;° Coulter, A. and Ellins, J. (2007) 'Effectiveness of strategies for informing, educating, and involving patients', British Medica Journal, 335(7), pp. 24-27.

Table 2 Examples of patient focused intervention activities

Quality improvement goal Interventions		Patient activation area		
		addressed		
Improving health literacy	Written health information	Knowledge		
	Alternative format resources	Knowledge		
	(e.g. internet)			
	Targeted low literacy	Knowledge		
	initiatives			
	Targeted mass media	Knowledge		
	campaigns			
Improving clinical	Communication skills training	Skills		
decision making	for clinicians			
	Coaching and question	Skills, confidence		
	prompts for patients			
	Patient decision aids	Knowledge, skills, confidence		
Improving self-care	Self-management education	Knowledge, skills, confidence		
	Self-monitoring and treatment	Skills, confidence		
	Self-help groups and peer	Confidence		
	support			
	Patient access to personal	Knowledge, confidence		
	medical information	Kanada da a abilla		
Improving nations actors	Patient centred telecare	Knowledge, skills		
Improving patient safety	Infection control  Adherence to the tree tree and	Skills		
	Adherence to treatment	Knowledge, skills, confidence		
	regimes	Confidence		
	<ul> <li>Patient reporting of adverse drug events</li> </ul>	Confidence		
	Equipping patients for safer	Knowledge, skills, confidence		
	healthcare	Triowieuge, skiiis, comidence		
	Preventing wrong site surgery	Knowledge		
Improving access	New modes of	Knowledge		
, , , , , , , , , , , , , , , , , , , ,	communication			
	Remote teleconsultation	Knowledge		
	Walk-in centres	Knowledge		
	Outreach clinics	Knowledge		
Improving the care	Patient surveys	Confidence		
experience	Provider choice	Confidence		
	Advocacy and complaints	Confidence		
Improving service	Patient participation groups	Confidence		
development	and forums			
	Consultation and deliberative	Confidence		
	methods			
	Lay representation	Confidence		
L	l .	l .		

3.3 Coulter and Ellins' research strongly suggests that interventions relating to health literacy, shared decision making and self-care/ management are most likely to impact on patient activation, not least because they are about developing capacity and opportunity for patients to exercise choices.

### **Health literacy**

3.4 Health literacy is fundamental to patient engagement. If individuals do not have the capacity to obtain, process and understand basic health information, they will not be able to look after themselves effectively or make appropriate health decisions. The public want more information than they currently receive and health professionals tend to overestimate the amount of information they supply. Information (e.g. leaflets) can be used as an adjunct to professional consultation and advice has been shown to improve health knowledge and recall, particularly when it is personalised to the individual.

# Shared decision making

3.5 Most patients expect to be given information about their condition and the treatment options and they want clinicians to take account of their preferences. Individuals tend to express different role preferences depending on the circumstances, so clinicians need to ask patients what role they want to play instead of making assumptions based on observable characteristics. Communication skills training should be the main mechanism by which clinicians learn about and gain competencies in the principles and practice of shared decision making. Coaching for patients in communication skills and question prompts can have a beneficial effect on knowledge and information recall. These interventions also empower patients to become more involved in decisions.

# Self-care/management

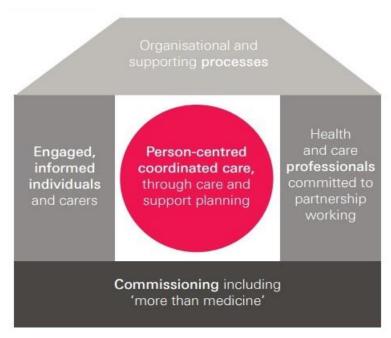
3.6 Self-care interventions vary considerably in their objectives, content, method of delivery, duration and target population. To talk of the effectiveness of 'self-care interventions' (or even of 'self-management education') is, therefore, misleading. Information-only patient education has limited effectiveness, and improvements in outcomes other than knowledge have not been found. Educational programmes teaching practical self-management skills are more effective than the provision of information alone. Self-management education has been associated with improvements in knowledge, coping behaviour, adherence, self-efficacy and symptom management. There is also some evidence of a reduction in health service utilisation and cost, and enhanced patient quality of life. While self-management education leads to short term improvements in health behaviour and dimensions of health status, these effects tend to diminish over time. By contrast, quality of life effects are more likely to be sustained beyond the Intervention period.

- 3.7 Successful interventions, therefore, rely on:
  - Personalised information.
  - Skills training for clinicians and patients.
  - Education in self-management.

### **Lessons from implementation studies**

- 3.8 In the UK, two major implementation studies demonstrate improvement in patient activation within a context of a realignment of services.
- 3.9 The 'Year of Care' introduced a patient focussed approach to the management of diabetes. The change centred on the production and review of an individualised and jointly produced care plan, coupled with tailored support for self-management. Services were realigned to be more local and accessible and included multidisciplinary approaches to co-morbidities and the re-allocation of tasks within clinical teams. The approach has been further developed as 'The House of Care' and applied to a range of long term conditions with considerable success measured by both patient reported and clinical outcomes. Figure 1 shows the 'House of Care' with patient enablement as the left hand wall.

Figure 1 House of Care Framework<sup>20</sup>



<sup>&</sup>lt;sup>19</sup> Diabetes UK and NHS Diabetes (2011) Year of Care: Report of Findings from the Programme. NHS England: London. [Online] Available at: <a href="http://www.health.org.uk/sites/default/files/YearOfCare\_report.pdf">http://www.health.org.uk/sites/default/files/YearOfCare\_report.pdf</a> (Accessed: 28th August 2015).

<sup>20</sup> De Iongh, A., Fagan, P., Fenner, J. and Kidd, K. (2015) A practical guide to self-management support: Key components for successful implementation. [Online]. Available at: <a href="http://www.health.org.uk/sites/default/files/APracticalGuideToSelfManagementSupport.pdf">http://www.health.org.uk/sites/default/files/APracticalGuideToSelfManagementSupport.pdf</a> (Accessed: 15th December 2015).

- 3.10 The House of Care model is a 'whole systems' approach where everything is geared to facilitating the central process –the collaborative care planning consultation. Significantly the model is very clear that the patient must be both 'prepared' for the consultation and given appropriate support. In other words, informed, engaged patients don't just happen. A choice of support methods needs to be in place, including non-clinical support such as peer mentoring. The model also calls for the careful selection of metrics to reflect both clinical and patient reported outcomes which support clinicians to practise new skills in new partnerships. This model has been further developed by the Coalition for Collaborative Care (C4CC) to include practical implementation support.<sup>21</sup>
- 3.11 A second implementation project 'Co-creating Health' piloted an approach to implementing self-management support that comprised three components<sup>22</sup>:
  - I. The Self-Management Support Programme (SMP): A patient education programme for people with long-term conditions, supporting them to develop the knowledge, skills and confidence they need to manage their own condition and work in effective partnership with their clinicians.
  - II. The Advanced Development Programme (ADP): A skills training programme for clinicians, helping them to develop the knowledge, skills and confidence to support people living with long-term conditions to self-manage effectively.
  - III. The Service Improvement Programme (SIP): A programme to put systems and processes in place that support people to manage their own health.
- 3.12 This represents an integrated approach involving behaviour change in clinicians and patients, supported by systems changes. The SMP specifically targets the three factors advanced by Hibbard as underpinning patient activation. The summary of the Health Foundation's evaluation of the programme notes that:
  - Adopting self-management approaches requires long-term behaviour change, and the interventions to achieve these also need to be long-term. The successful implementation of self-management support requires initial training programmes for both clinicians and people with long-term conditions to be followed up with ongoing support. The techniques which appear to be most effective include buddying systems, telephone coaching and peer support.
  - Self-management support must be normalised into existing ways of working
    within health economies. It cannot be an 'add-on' but needs to be embedded
    within care pathways and commissioning contracts. It needs to be led by those
    ultimately responsible for planning and delivering care for people with long-term
    conditions in each health economy, transcending condition-specific clinical teams
    and individual enthusiasts.

<sup>&</sup>lt;sup>21</sup> Coalition for Collaborative Care (2015) Coalition for Collaborative Care: long-term conditions, Available

at: <a href="http://coalitionforcollaborativecare.org.uk/">http://coalitionforcollaborativecare.org.uk/</a> (Accessed: 15th December 2015).

22 Health Foundation (2014) Co-creating Health. London: Health Foundation. [Online] Available at: <a href="http://www.health.org.uk/programmes/co-creating-health">http://www.health.org.uk/programmes/co-creating-health</a> (Accessed: 28th August 2015).

- Techniques to support self-management, including agenda-setting and goal-setting, were well received and implemented following training. Implementing goal follow-up, however, proved significantly more challenging and there was poor implementation. This was largely because it required significant changes to the clinical micro system, and indeed the broader delivery system, in order to embed changes in practice and behaviour.
- Co-delivery is an important way of changing patients' and clinicians' perceptions.
  There were benefits from having every training course, whether for clinicians or
  people with long-term conditions, jointly facilitated by a healthcare professional
  and someone living with the condition, working in equal partnership. This
  innovative co-delivery model is identified as an important way of changing patient
  and clinician perceptions of their role in healthcare.
- 3.13 Overall the evidence suggests that interventions to increase patient activation need to be focused on:
  - Improving general or condition specific health knowledge.
  - Providing opportunities to practice skills including self-advocacy.
  - Building confidence in new roles.
- 3.14 Additionally interventions benefit from:
  - Being tailored to individual levels of activation and group level of ability.
  - Co-delivery of programmes.
  - The use of peers as mentors and tutors.
  - Being part of an integrated strategy for change.
- 3.15 A further study is being carried out in England where the focus is on the measurement of activation. NHS England is supporting six healthcare organisations (five Clinical Commissioning Groups (CCGs) and the Renal Registry) between 2014 and 2016 to pilot the use of the Patient Activation Measure (PAM) (see section 5 for more details) in the delivery of range of approaches for improving care through supporting self-management in order to understand how the measure could best be implemented and used in the NHS context. Project leaders and commissioners from the six organisations meet regularly as a learning set facilitated by the Health Foundation to share learning as the projects are implemented.
  - They initially received support from an independent consultant.<sup>23</sup>
- 3.16 NHS England and the Health Foundation have commissioned Leicester University to undertake a mainly qualitative evaluation of these pilots<sup>24</sup>. Early evaluation findings

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<sup>23</sup> Andrew Rix

<sup>&</sup>lt;sup>24</sup> In addition, the Health Foundation's will conduct a quantitative study of PAM use and outcomes across the six organisations.

were published in November 2015<sup>25</sup>. Table 3 summarises the interventions employed by the six pilots<sup>26</sup>.

Table 3 Overview of NHS PAM Pilots

Organisation	Project name service	Patient population	PAM function
NHS Horsham and Mid-Sussex CCG and NHS Crawley CCG	Tailored Health Coaching Pilot Musculoskeletal (MSK) Service Tier 3 Weight Management Service	Long-term conditions/medium risk of health care use     Rheumatoid arthritis      Obesity	<ul><li>Tailoring and outcome</li><li>Outcome</li><li>Outcome</li></ul>
NHS Islington CCG	<ul> <li>Care planning in general practice</li> <li>Diabetes Self-Management Programme</li> <li>The Expert Patient Programme</li> <li>Bariatric Service: weight regain intervention programme</li> </ul>	<ul><li>Long-term conditions</li><li>Diabetes</li><li>Long-term conditions</li><li>Obesity</li></ul>	Outcome     Outcome with the potential for tailoring
NHS Sheffield CCG	<ul> <li>Citywide long-term condition management</li> <li>Diabetes self-management in primary care</li> <li>Community mental health management</li> </ul>	<ul> <li>Long-term conditions/those at risk of unplanned hospital admissions</li> <li>Diabetes</li> <li>Mental health</li> </ul>	<ul><li>Tailoring</li><li>Tailoring and outcome</li><li>Tailoring</li></ul>
NHS Somerset CCG	<ul> <li>House of Care and SQPS framework</li> <li>DAFNE diabetes self- management</li> <li>Mindfulness-based cognitive behavioural therapy groups</li> </ul>	<ul> <li>Long-term conditions</li> <li>Diabetes</li> <li>Mental health and long-term conditions</li> </ul>	<ul><li>Outcome</li><li>Outcome</li><li>Outcome</li></ul>
NHS Tower Hamlets CCG	Commissioning diabetes educational self-management Esteem self-management  Managing your health and wellbeing  Your Move	<ul> <li>Diabetes</li> <li>Long-term conditions and mental health conditions</li> <li>Long-term conditions and those with uncontrolled symptoms</li> <li>Older adults with long-term conditions</li> </ul>	<ul> <li>Tailoring and outcome</li> <li>Tailoring and outcome</li> <li>Tailoring and outcome</li> <li>Tailoring and outcome</li> </ul>
UK Renal Registry	Valuing Individuals:     Transforming     Participation in Chronic     Kidney Disease	including dementia     Chronic kidney disease	Outcome, possibly tailoring

<sup>&</sup>lt;sup>25</sup> Armstrong, N., Tarrant, C., Martin, G., Manktelow, B. and Liz Brewster, L. (2015) *Independent evaluation of the feasibility of using the Patient Activation Measure in the NHS in England*: Early Findings, London: NHS England. <sup>26</sup> Adapted from p.11 lbid

- 3.17 The use the interventions listed above and the use of the PAM as a measure were seen as effective in realising the wider service changes the organisations were seeking to achieve in terms of moving away from a healthcare-provider focused, paternalistic model of service delivery to a more personalised, holistic, multi-provider model in which the patient is given the most appropriate support to self-manage. All pilots undertook preparatory work and in some cases, small pilots before designing their projects. This enabled the organisations to think about how best to implement PAM in their contexts, and where significant service redesign was required, to secure engagement from stakeholders and ensure that provision is joined up. Stakeholder engagement was also used to promote awareness and train staff particularly where PAM is being used as a tailoring tool.
- 3.18 No outcome data is yet available from the study, which focuses on the types of interventions and the process of using the measure. The Health Foundation's Data Analytics unit is collecting individual health data from the sites together with patient activation levels and longer term will be able to provide an in depth analysis of the relationship between the two<sup>27</sup>.

# Clinician support for patient activation

- 3.19 Hibbard et al adapted PAM to develop a tool to measure clinician support for patient activation, the CSPAM score. CSPAM measures clinician attitudes about the patient role in the care process using 14 items. CSPAM was validated in a 2009 survey amongst primary care clinicians in the USA and UK which found variable levels of support for patient activation<sup>28.</sup>
- 3.20 NHS England have recently published the findings of a survey exploring current attitudes and beliefs of 1759 clinicians (including 778 doctors, 595 nurses and 386 allied health professionals) using CSPAM<sup>29</sup>. Findings from the 2015 survey were generally consistent with the 2009 survey:
  - Clinician attitudes to patient activation remain variable with a wide range of CSPAM scores recorded (36.4 – 100).
  - Support for patient activation tended to be linked to role with nurses having a higher average score (75.9) compared to doctors (70.1). Age, gender or geography did not affect CSPAM score.
  - Clinicians are more supportive of self-management that is in accordance with clinical advice; they are less supportive of patients being independent seekers of information or undertaking independent actions when caring for themselves at home.

<sup>28</sup> Hibbard, J.H., Collins, P.A., Mahoney, E and Baker, L.H. (2009) 'The development and testing of a measure assessing clinician beliefs about patient self-management' Health Expectations, 13(1), pp. 65-72

<sup>&</sup>lt;sup>27</sup> Awaiting reference via THF website

clinician beliefs about patient self-management, Health Expectations, 13(1), pp. 65-72.

<sup>29</sup> Sharma, L., Manning, L. and Mehta, P. (2015) How much do clinicians support patient activation? A survey of clinician attitudes and behaviours towards people taking an active role in their health and care, London: NHS England.

- The survey also found variation in behaviour and practice; clinicians were more likely to alter their approach according to a person's level of skills, knowledge and confidence and less likely to ask people what changes they wanted to focus on.
- Reported barriers to supporting patient activation include: clinician skills and levels of understanding; time constraints during consultations; insufficient resources and support services, unhelpful pathways and processes; patient ability or willingness to take a more active role in their care.
- Support needs identified included: improved service design including longer appointment times; additional support and education for patients; communication and motivational interviewing training for clinicians.
- 3.21 The report outlined how NHS England and other organisations (e.g. Royal College of General Practitioners, Health Education England, the Coalition for Collaborative Care) can support the delivery of patient centred care by addressing three key areas:
  - Better support for clinicians.
  - Targeted support for system change.
  - Support for individuals to engage in their health and care.
- 3.22 Overall the need to address these three areas is in line with the evidence that a whole systems approach is needed for the successful implementation of personalised care.

# 4. Do activated patients have better outcomes?

### **Approaches to measurement**

- 4.1 Assessments of whether activated patients have better outcomes rely on two types of measurement:
  - In traditional biomedical models of medicine the outcomes that matter in health systems are clinical ones – either directly (morbidity, mortality) or indirectly (bioclinical indicators) and system outcomes (patients treated, costs) and this is reflected in what is measured. Clinical measurements equate strongly to clinical interventions.
  - The biopsychosocial model recognises the importance of both individual and social determinants of health (choice of diet, availability of social support) and the values placed on non-clinical outcomes (satisfaction with treatment, quality of life), by patients and the public more widely. Measurement of psycho-social outcomes tends to be less clear cut than purely clinical measurement, not least because social constructs are often difficult to define operationally and in any event more than one outcome may be intended from the intervention.
- 4.2 These contrasting approaches to what is measured are reflected in assessments of whether patient activation produces better outcomes.
- 4.3 A 2014 review<sup>30</sup> of measures of PCC (which included activation, self-management, empowerment and a number of related terms) concluded that, given the difficulties of definition, triangulation of a range of measures was necessary in order to form a judgement about improved outcomes. This was the initial approach taken by the two UK implementation projects where early results focused on whether processes were working (for instance, improvements in attendance at and satisfaction with appointments) coupled with proxy measures using patient reported outcomes via questionnaires. This allowed evaluators to make early assessments at programme level. However, clinical data was collected and continued monitoring of the House of Care model now shows significant improvement in clinical indicators for patient populations with access to this model of care. While there are issues of comparability between sites involved in the pilot study, the evidence does show significant improvements in the accepted three clinical measures for control of diabetes<sup>31</sup>.

<sup>&</sup>lt;sup>30</sup> Silva De, D (2014) Helping measure person-centred care. London: Health Foundation [Online]. Available at: <a href="http://www.health.org.uk/sites/default/files/HelpingMeasurePersonCentredCare.pdf">http://www.health.org.uk/sites/default/files/HelpingMeasurePersonCentredCare.pdf</a> (Accessed: 28<sup>th</sup> August 2015)
<sup>31</sup> NHS England (2014) Enhancing the quality of life for people living with long term conditions – The House of Care. London: NHS England. [Online] Available at: <a href="http://www.england.nhs.uk/house-of-care/">http://www.england.nhs.uk/house-of-care/</a> (Accessed: 28th August 2015)

4.4 Table 4 shows the improvement in Tower Hamlets, an area of considerable deprivation and where the population contains a number of high incidence groups.

Table 4 Tower Hamlets: diabetes indicators change 2009 - 2012	Table 4 Tower	Hamlets:	diabetes	indicators	change 2	009 - 2012
---------------------------------------------------------------	---------------	----------	----------	------------	----------	------------

Indicator	2009	2012
HbA1c <7.5%/58mmol/mol	37%	55%
BP ≤145/85	70%	90%
Cholesterol <5mol/l	65%	83%

4.5 Initial evaluation of the Co-Creating Health project focused on process data and outcomes as reported by patients and practitioners<sup>32</sup>. However, as the techniques involved become embedded, research is being conducted which compliments patient reported data with more clinically oriented results. Turner et al<sup>33</sup> evaluated a group-based self-management programme patients living with one of four long-term conditions (LTCs): chronic obstructive pulmonary disease, depression, diabetes, and musculoskeletal pain. A range of validated measures was used to assess the impact of the training programme.

### 4.6 They found that:

- Health-related quality of life (ES 0.06, p = 0.04), and health status (ES 0.33, p < 0.001) were significantly improved.</li>
- Patients' anxiety (ES 0.37, p < 0.001) and depression (ES 0.31, p < 0.001) significantly improved.</li>
- Patients reported significant improvements in patient activation (ES 0.65, p < 0.001), with 53.9% of all patients reporting a meaningful ≥4 point improvement.
- Patients also reported significant improvements in their self-management skills (p values from p < 0.001 top = 0.028).
- 4.7 However it should be noted that while the measures used are considered to be valid proxies for aspects of health and well-being, they are not clinical outcomes per se.
- 4.8 At site level various impacts were reported including:
  - People with depression used significantly fewer consultant appointments and bed days, and had reduced anxiety and depression.
  - People with diabetes had improved clinical outcomes (glucose control, lipids and renal function).
  - People with depression were less likely to have consultations with specialists at the mental health trust.

<sup>&</sup>lt;sup>32</sup> Firefly Research and Evaluation (2013) *Sustaining and spreading self-management support Lessons from Co-creating* Health phase 2 [Online] Available at: <a href="http://www.health.org.uk/publication/co-creating-health-evaluation-first-phase">http://www.health.org.uk/publication/co-creating-health-evaluation-first-phase</a> (Accessed: 28th August 2015)

August 2015)

33 Turner, A., Anderson, J.K., Wallace, L.M. and Bourne, C. (2015) 'An evaluation of a self-management program for patients with long-term conditions', Patient Education and Counseling, 98(2), pp. 213-219

- Several sites reported reduced did not attend rates for appointments since the programme was introduced, particularly where individuals had received agendasetting prompts prior to their appointments.34
- 4.9 The two implementation studies reported above were not set up as experiments in the biomedical tradition and as such do not provide robust evidence of impact. They do however provide valuable insights into what works and what is important to patients. Increasingly, patient reported outcomes are seen as valid measures of both individual health and well-being and system performance in their own right. Collins discusses this in greater detail in his 2014 paper<sup>35</sup>.
- 4.10 Pilot sites in the NHS England study have commissioned their own outcome studies and will report in due course, but early indications are that these are in line with the other two studies. The Health Foundation's quantitative analysis (see 3.18) is expected to make a major contribution to knowledge about service usage and individual activation levels.

See more at: <a href="http://www.health.org.uk/programmes/co-creating-health#sthash.WnPjXpjR.dpuf">http://www.health.org.uk/programmes/co-creating-health#sthash.WnPjXpjR.dpuf</a>
 Collins, A (2014) Measuring what really matters: Towards a coherent measurement system to support person-centred care, London: Health Foundation, [Online]. Available at: <a href="http://www.health.org.uk/publication/measuring-what-really-matters-towards-">http://www.health.org.uk/publication/measuring-what-really-matters-towards-</a> coherent-measurement-system-support-person-centred (Accessed: 28th August 2015)

- 5. Using the Patient Activation Measure (PAM) to measure patient activation.
- 5.1 Section 4 noted that the evidence for the positive relationship between patient activation and positive health outcomes is difficult to assess because it is difficult to define, isolate and measure independently from other variables. As a result, historically, multiple indicators have been used and triangulated
- 5.2 PAM combines measures of skills, knowledge and confidence and is the most commonly used single measure<sup>3637</sup>. Completed by the patient, with support where appropriate, PAM comprises 13 statements covering beliefs, confidence and management of health related tasks and self-assessed knowledge. Patients are asked to rate the degree to which they agree/disagree with each statement producing a combined score of between 0 and 100 which represents the person's concept of themselves as an active manager of their own health and healthcare<sup>38</sup>.
- 5.3 The scores are divided into four 'levels of activation' based on experience and observation; providing 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 (see Table ). The 0 to 100 score is the most useful for determining patient progress or assessing the impact of patient activation interventions.

Table 5 Levels of patient activation

Level 1	Individuals tend to be passive and feel overwhelmed by managing their own
	health. They may not understand their role in the care process
Level 2	Individuals may lack the knowledge and confidence to manage their health
Level 3	Individuals appear to be taking action but may still lack the confidence and
	skill to support their behaviours.
Level 4	Individuals have adopted many of the behaviours needed to support their
	health but may not be able to maintain them in the face of life stressors

The PAM has been validated across a range of healthcare systems, languages, 5.4 cultures, demographic groups and conditions<sup>3940</sup>. 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. These observations are important because it suggests there is

<sup>&</sup>lt;sup>36</sup> Hibbard, J. and Gilburt, H. (2014) Supporting people to manage their health: An introduction to patient activation. London: Kings Fund. [Online]. Available at: http://www.kingsfund.org.uk/sites/files/kf/field/field\_publication\_file/supporting-people-manage-health-patient-activation-may/4.pdf (Accessed: 30<sup>th</sup> July 2015)

The PAM is licensed by the US company Insignia Health LLC who charge a fee for licensing.

London. [Online]. Available at: <a href="http://www.kingsfund.org.uk/sites/files/kt/field/field-publication-file/supporting-people-manage-health-patient-activation-may14.pdf">http://www.kingsfund.org.uk/sites/files/kt/field/field-publication-file/supporting-people-manage-health-patient-activation-may14.pdf</a> (Accessed: 30<sup>th</sup> July 2015)

39 | Ibid <sup>38</sup> Hibbard, J. and Gilburt, H. (2014) Supporting people to manage their health: An introduction to patient activation. Kings Fund:

<sup>&</sup>lt;sup>40</sup> Mukoro, F. (2012) Summary of the Evidence on Performance of the Patient Activation Measure (PAM) [Online]. Available at: http://selfmanagementsupport.health.org.uk/media\_manager/public/179/SMS\_resource-centre\_publications/PatientActivation-1.pdf (Accessed: 30th July 2015)

not homogeneity in a particular group when it terms of engaging with health information or health promoting behaviours. Scores suggest only moderate correlation between activation and socio-economic status i.e. just because someone has a higher socio-economic status does not mean they are more activated and more likely to engage with their own health, likewise individuals from lower socio economic backgrounds are not necessarily less activated.

- 5.5 The PAM has provided correlational evidence of improved outcomes for patients, on the basis of retrospective and prospective studies which show that
  - More highly activated patients are more likely to have clinical indicators in the normal range. Patient activation has been linked with health outcomes among healthy patients, as well as outcomes among patients who have many different types of physical and mental health conditions.
  - Studies using the same instrument reveal evidence to suggest a significant link between patient activation scores and health care costs, with more-activated patients having lower rates of hospitalisation and re-admittance and fewer visits to accident and emergency departments, even after controlling for disease severity and demographics. 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<sup>41</sup>.
  - 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.
  - Additionally it is reported that more highly activated patients have significantly more positive experiences of care with more activated patients with chronic diseases reporting higher-quality interpersonal exchanges with doctors, greater fairness and more out-of-office contact with doctors than less activated patients. More highly activated patients report better care experiences than do less activated patients when seeing the same doctor indicating 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<sup>42</sup>.
- 5.6 Overall the evidence that activated patients have better outcomes is persuasive but, in the case of implementation studies, methodologically clouded. The PAM provides valid and reliable evidence, albeit for a quite narrowly defined construct.

<sup>&</sup>lt;sup>41</sup> Hibbard, J. and Gilburt, H. (2014) Supporting people to manage their health: An introduction to patient activation. London: Kings Fund. [Online]. Available at: <a href="http://www.kingsfund.org.uk/sites/files/kf/field/field\_publication\_file/supporting-people-manage-health-patient-activation-may14.pdf">http://www.kingsfund.org.uk/sites/files/kf/field/field\_publication\_file/supporting-people-manage-health-patient-activation-may14.pdf</a> (Accessed: 30<sup>th</sup> July 2015)

<sup>42</sup> Armstrong N. Tarragt C. Martin G. Marktolow B. and Liz Browstor L. (2015) Independent availation of the feesibility.

<sup>&</sup>lt;sup>42</sup> Armstrong, N., Tarrant, C., Martin, G., Manktelow, B. and Liz Brewster, L. (2015) *Independent evaluation of the feasibility of using the Patient Activation Measure in the NHS in England*: Early Findings, London: NHS England.

# **Piloting PAM in the UK**

- 5.7 The current NHS England pilots are using one or more of three broad approaches to using PAM: to measure the effectiveness of an intervention in supporting patient activation; as a tailoring tool at individual or population level to ensure patients are receiving the most appropriate types of support for their level of activation; and as a combined outcome and measurement tool. The evaluation suggests that the pilots need to give further thought about what change in patient activation score they might reasonably expect to see following any particular intervention, and over what period of time this might be achieved, especially where PAM is being used as an outcome measure in itself. In addition, all pilots are seeking to measure other outcomes, alongside patient activation, to ensure the impacts of any interventions are fully captured, including: health care service utilisation, patients' clinical outcomes, patient engagement, and patient experiences of care. However there is a variation in the extent to which the relationships between PAM and other data is likely to be examined.
- 5.8 A number of practical issues of implementing PAM have been observed including:
  - The timing of PAM measurement, e.g. whether it is linked to a specific event (such as an annual review or a change in treatment or health state) or determined by time since commencement and/or completion of an intervention. The pilots are approaching this differently and according to the needs of their patient cohort and the intervention.
  - The administration of PAM measurement e.g. whether it is completed by the patient independently or with a health care professional or completed in person, over the telephone or electronically. The evaluation noted administration is linked to how PAM is being used e.g. if it is a tailoring tool it needs to be completed in advance of the consultation, if it is being used as an outcome measure for an intervention, consideration should be given to the reliability issues of the person actively delivery the intervention also collecting data to measure its effectiveness. Responsibility for who processes the data also needs to be considered and capacity to analyse the data generated was also a concern for some pilots.
  - Access to PAM data needs to be considered in particular whether patients themselves will be provided with information on their activation level and how this can best be communicated.
  - Language and literacy issues were also a concern to pilots, with mediated completion being a common option in such cases.
- 5.9 Pilots reported a number of early stage challenges in implementing their projects around clinical buy in, validity of using PAM in a UK context and compatibility of IT systems. However, pilots were able to cite early successes including: good response rates to baseline surveys (where administered); successful stakeholder engagement

events; early learning outcomes regarding implementation approaches; and enthusiasm and potential awareness of the uses of PAM.

# Other approaches

- 5.10 The Listening Organisation<sup>4344</sup>, NHS Wales's blueprint for patient feedback, pointed out that no single measure should be relied upon to inform or measure change. 'Helping Measure Patient Centred Care'<sup>45</sup>, the Health Foundation's review of available measures, points out that although there is no shortage of available measures, assessing their suitability is problematic. Matching measures to purpose is confounded if the measure forms part of the purpose (or is part of the intervention).
- 5.11 Additionally, measures designed for one purpose may become unreliable if used for another. Aggregating scores from individuals to cohort and population levels may, for instance, become unreliable if collection methods are not very highly standardised. Measures, including the PAM, designed to inform practice (the 'conversation' between patient and doctor, for instance) may be reported very differently if it is known they will also be used to make judgements about practitioner performance.
- 5.12 There are also context issues<sup>46</sup>including how receptive (or believing) opinion formers in health organisations are in the evidence produced by the measure. In other words, measures must not only be valid and reliable, they must also be credible. The University of Leicester evaluation of the NHS England PAM pilots touches on this<sup>47</sup>. Despite considerable testing and revalidation in the UK, pilot sites still had doubts about the applicability of the measure in an NHS context. Other approaches include:

### **Ophelia**

5.13 Developed by Deakin University, OPtimising HEalth Literacy to Improve HeAlth and equity takes as a starting point that health literacy is the basis for self-management and health improvement<sup>48</sup>. Health literacy is broadly defined as a person's ability to seek, understand and use health information and healthcare services. The measure is based around the Health Literacy Questionnaire which is comprehensive measure

<u>OExperience%20of%20Care.pdf (</u>Accessed: 11th December 2015).

45 De Silva, D (2014) *Helping Measure Patient Centred Care.* [Online]. Available at:

http://www.health.org.uk/sites/default/files/PerspectivesOnContext\_fullversion.pdf (Accessed 11th December 2015)

47 Armstrong, N., Tarrant, C., Martin, G., Manktelow, B. and Liz Brewster, L. (2015) Independent evaluation of the feasibility of using the Patient Activation Measure in the NHS in England: Early Findings, London: NHS England.

<sup>&</sup>lt;sup>43</sup> Matthias, J (2013) *The Listening Organisation: Ensuring care is person-centred in NHS Wales.* [Online]. Available at: <a href="http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/1000%20Lives%20Plus%20-">http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/1000%20Lives%20Plus%20-</a>

<sup>%20%27</sup>The%20Listening%20Organisation%27%20white%20paper%20WEB.pdf (Accessed 11<sup>th</sup> December 2015)

44 Spencer, M. and Puntoni, S. (2015) *Listening and learning to improve the experience of care: Understanding what it feels like to use services in NHS Wales.* [Online]. Available at: <a href="http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/Listening%20and%20Learning%20to%20Improve%20the%2">http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/Listening%20and%20Learning%20to%20Improve%20the%2</a>

http://www.health.org.uk/sites/default/files/HelpingMeasurePersonCentredCare.pdf (Accessed 11th December 2015)

Health Foundation (2014) Perspectives on Context. [Online] Available at:

<sup>&</sup>lt;sup>48</sup> Batterham, R.W., Buchbinder, R., Beauchamp, A., Dodson, S., Elsworth, G.R. and Osborne, R.(2014) 'The OPtimising HEalth LiterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform', BMC Public Health, 14(694), pp. [Online]. Available at: <a href="http://www.biomedcentral.com/1471-2458/14/694">http://www.biomedcentral.com/1471-2458/14/694</a> (Accessed: 16<sup>th</sup> December 2015).

that focuses on nine separate domains of health literacy and provides a detailed profile of the health literacy challenges a person might experience. The results from an individual's questionnaire can be used to tailor subsequent interventions.

5.14 However, the measure can also be used as a starting point for identifying the health interventions needed at a community or population level and provides a process for involving communities in health care planning and development (co-production). Like the House of Care Model this is a whole systems approach that recognises the need to engage patients, clinicians and the organisational and other supporting processes to realign not just health care but all inputs to wellbeing.

### I.ROC

5.15 In Scotland, Penumbra has developed I.ROC (Individual Recovery Outcomes Counter) to measure the recovery journey of people who use their mental health services<sup>49</sup>. It utilises

the HOPE Model of wellbeing:

- Home a safe and secure place to live.
- Opportunity to pursue meaningful leisure, recreation, education and work possibilities.
- People as friends, confidantes and supporters.
- Empowerment fully involved in decisions affecting own life.
- 5.16 I.ROC consists of three indicators for each of the four areas of HOPE that form the basis of Penumbra's model of wellbeing. Each of the indicators has been validated as a factor linked to recovery. Scores can be analysed at a personal, service and organisational level. At an individual level the measure facilitates the personalisation of services to improve the wellbeing of service users. At an organisational level it can be used to provide comparative data between units providing the same service and it could be used as a basis for comparing different services. Unlike the other examples cited in this paper it is condition specific and relies on a definition of well-being and recovery defined by patients.
- 5.17 In both the examples there is an explicit intention to use the data generated at a number of levels. The development of the PAM did not include this aim specifically so care needs to be taken with its use, particularly in respect of the practicalities and motivations for data collection.

<sup>&</sup>lt;sup>49</sup> University of Edinburgh (2014) *Introduction to I.Roc* [Online] Available at: <a href="http://www.penumbra.org.uk/wpcontent/uploads/2011/06/Introduction-to-I.-ROC.pdf">http://www.penumbra.org.uk/wpcontent/uploads/2011/06/Introduction-to-I.-ROC.pdf</a> (Accessed 16th December 2015)

### 6. Does patient activation meet prudent principles?

### Introduction

6.1 Table 5 shows how patient activation supports the principles of prudent healthcare. It is largely based on the outcomes described in section 5 (column 2) but also points to enabling processes which emerge from the literature and the techniques which support them (columns 3 and 4). Barriers and possible solutions (columns 5 and 6) were identified from various implementation studies.

# Principle 1: Achieve health and wellbeing with the public, patients and professionals as equal partners through co-production

6.2 The requirement is to change current roles to reflect a partnership approach and a shift in emphasis to reflect maintaining health as an equal priority to dealing with illness. Patient activation is all about putting the patient in the driving seat by increasing capability. Although there are techniques which are known to achieve these changes, the prevailing culture and work practices are significant barriers. Skills training for patients and medical staff are known to help, as is better information and better means of sharing it. Time constraints are also a problem but these can be overcome by apportioning the work involved differently within the care team using coproduction as a lever for change. Aligning performance measures to patient focussed outcomes is a must: the number of patients over 70 whose PAM score improves would, for instance, tell us quite a lot about reducing dependency on services.

# Principle 2: Care for those with the greatest health need first, making the most effective use of all skills and resources

6.3 The requirement is not just for prioritising needs but to involve patients in the process. More activated patients make fewer demands and so prioritise themselves lower. Training patients in self-management is an investment and there is evidence that this can be done well by peer supporters, a largely untapped skill resource. Targets that emphasise waiting times may not reflect patient need. Alternative targets and measures can be developed that reflect their priorities, including the exercise of choice. Activated patients have better adherence to treatment and make fewer unscheduled health interventions.

### Principle 3: Do only what is needed, no more, no less; and do no harm

6.4 The requirement is for appropriate treatment. Activated patients make informed choices rather than uninformed demands. Providing individualised information and supporting understanding develops activation levels but requires flexible pathways driven by a care plan. More patient centred measures, like PAM, can add a qualitative dimension to waiting list targets. There is a huge difference between 'waiting' on a waiting list and 'watchful waiting' as part of a care plan. Activated patients do the watching.

# Principle 4: Reduce inappropriate variation using evidence based practices consistently and transparently.

- 6.5 The requirement is not to stop variation but to have variation with good cause, reflecting both clinical need and patient preferences. Activated patients make more appropriate choices. Activated patients preferences are part of the evidence. Prudent healthcare is a model of medicine based on patients taking responsibility for their own health and playing an active part in managing their well-being. Patient activation is about changing the way people use services stemming from their individual capacity to assume that responsibility. Prudent healthcare is also about organising systems and provision to encourage patients to take that responsibility. Levels of patient activation are a good indicator of whether systems and provision are fit for purpose.
- 6.6 Using patient activation as an overarching health goal and a reliable measure of activation as a performance management tool for assessing whether the goal is being achieved has much to recommend it as an approach.

Table 6 Prudent healthcare and patient activation

Prudent Principle	Meets principle by	Enablers	Techniques	Barriers	Solutions
1. Achieve health and wellbeing with the public, patients and professionals as equal partners through coproduction.	<ul> <li>Places greater emphasis on patient responsibility and clinician role in support</li> <li>Increased responsibility, less dependency</li> <li>Partnership working</li> <li>Focus on maintaining health and wellbeing.</li> </ul>	<ul> <li>Change in roles</li> <li>Change in relationships</li> <li>Change in attitudes to health</li> </ul>	<ul> <li>Shared decision making 50</li> <li>Care planning</li> <li>Team approaches to care</li> <li>Patient education</li> </ul>	<ul> <li>Culture/habits</li> <li>Wrong skills</li> <li>Time to do things differently</li> <li>Targets and measures.</li> </ul>	<ul> <li>Training</li> <li>Co-production, restructure         work to reflect need (flexible         appointments, use of skill mix)</li> <li>Improve patient information         (option grids)</li> <li>Realign measures (PROMs,         Patient Experience).</li> </ul>
2. Care for those with the greatest health need first, making the most effective use of all skills and resources.	<ul> <li>Needs         assessment         includes need for         support in         becoming more         activated, not just         clinical symptoms</li> <li>Patient acquires         new skills</li> </ul>	<ul> <li>Diagnosing the person, not the condition</li> <li>Patient as asset, not cost</li> <li>Training as an investment.</li> </ul>	<ul> <li>Shared decision making</li> <li>Self-management support</li> <li>Expert Patient Programme</li> </ul>	<ul> <li>Lack of clinical resource</li> <li>Emphasis on clinical measures</li> <li>Waiting list and other targets.</li> </ul>	<ul> <li>Provide health coaching</li> <li>Develop patients as health coaches</li> <li>Measure patient activation</li> <li>Measure patient centred care.</li> </ul>

<sup>50</sup> Shared decision making

Prudent Principle  3. Do only what is needed, no more, no less; and do no harm	<ul> <li>Increased skill levels in patients results in self-treatment.</li> <li>Meets principle by</li> <li>Informed choice results in fewer and less invasive treatments.</li> </ul>	<ul> <li>Enablers</li> <li>Change in roles</li> <li>Change in relationships</li> <li>Change in attitudes</li> <li>Improved access to and use of information.</li> </ul>	Community based training and support.  Techniques  Multiple pathways Increased use of do nothing, watch and wait Prescribing guidelines SDM/Decision	Barriers     Lack of outcomes data     Culture/habits     Wrong skills     Time to do things differently     Targets based on outputs not outcomes.	Solutions  Training Realign measures (PROMs, Patient Experience) Improve patient information (Option Grids).
4. Reduce inappropriate variation using evidence based practices consistently and transparently.	Treatment based on need not precedent.	<ul> <li>Improved access to and use of information</li> <li>Information on high and low rates of activity</li> <li>Promotion of better quality care where it is clear what the right rate.</li> </ul>	support.  Explicit care pathways  SDM/ Decision support  The use of guidelines and audit to measure adherence to guideline.	<ul> <li>Culture/habits</li> <li>Wrong skills</li> <li>Time to do things differently</li> <li>Targets based on outputs not outcomes.</li> </ul>	<ul> <li>Training</li> <li>Facilitate informed patient choice</li> <li>Improve patient information (Option Grids)</li> <li>Realign measures (PROMs, Patient Experience)</li> <li>Systematically and routinely collate and publish data on (local and national) variations.</li> </ul>

#### 7. How can patient activation be applied to planned care?

### Patient activation and planned care

- 7.1 The evidence presented so far suggests that activated patients do better and present less demands on health systems. It also suggests that although patients have varying underlying levels of activation, the basic components of activated behaviours – having the knowledge, skills and confidence to assume responsibility for their own health and well-being - are capacities that can be increased given the right support. There are some good indications of what the right support looks like.
- 7.2 Although much of the evidence mainly relates to people with long term conditions, and multi-morbidities, the lessons also apply to everyday health as they show that the shift to taking responsibility for personal well-being is reflected in areas such as diet and exercise and taking care of routine or minor illness.
- 7.3 Levels of activation are not, however, independent of the health care system patients face and many aspects of current provision steer patients towards taking a passive role. Chief among these aspects are clinician behaviours and system expectations, both of which are heavily dependent upon and reinforced by performance measures.
- 7.4 The experience of major initiatives to implement care which is more person centred strongly suggests that changes in patient activation levels are only likely to come about and be sustained if a whole systems change model, like the House of Care, is adopted. This may not be as difficult as it seems, not least because there is:
  - Dissatisfaction with current practises, especially those which result in over or inappropriate treatment<sup>5152</sup>.
  - Constraint on budgets<sup>53</sup>.
  - Opportunities presented in both methods of communications and treatments by new technology<sup>54</sup>.
  - An untapped community resource<sup>55</sup>.

<sup>&</sup>lt;sup>51</sup> Mulley, A., Trimble, C. and Elwyn, G. (2012) *Patient's Preferences Matter: Stop the silent misdiagnosis*. [Online]. Available at: http://www.kingsfund.org.uk/sites/files/kf/field\_publication\_file/patients-preferences-matter-may-2012.pdf (Accessed: 16th

December 2015).
52 Academy of Medical Royal Colleges (2015) Choosing Wisely Programme: A briefing. [Online]. Available

at: <a href="https://www.aomrc.org.uk/doc\_download/9830-choosing-wisely.html">www.aomrc.org.uk/doc\_download/9830-choosing-wisely.html</a> (Accessed: 16th December 2015).

53 Roberts, A. and Charlesworth, A. (2014) A decade of austerity in Wales? The funding pressures facing the NHS in Wales to 2025/26. [Online]. Available at: http://www.nuffieldtrust.org.uk/publications/decade-austerity-wales (Accessed: 16th December 2015). <sup>54</sup> National Institute for Health Research (2014) *Health Technology Assessment*, Available

at: <a href="http://www.nihr.ac.uk/funding/health-technology-assessment.htm">http://www.nihr.ac.uk/funding/health-technology-assessment.htm</a> (Accessed: 16th December 2015).

55 Department of Health (2006) Our health, our care, our say: a new direction for community services. [Online]. Available at:

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/272238/6737.pdf (Accessed: 16th December 2015).

7.5 Table summarises what patients need to be more activated, the health workers role in meeting the need and the systems requirement to support patients and health workers. This is based on the three underlying components of activation suggested by Hibbard.

# Knowledge

- 7.6 Health literacy is important at two levels. People need to understand how everyday activities impact on their health and their role in choosing wisely. When faced with illness they need specific information and they need it quickly<sup>56</sup>.
- 7.7 But people vary in their ability and motivation to seek and access data, so information needs to be available in different forms and media to encourage access and understanding. An understanding of the patient's level of activation will help clinicians to signpost patients to the most appropriate source. The availability of accessible information is an important factor in patients' ability to increase their level of activation. Making patients aware of treatment choices at the point of diagnosis is more likely to engage them in exploration than introducing options when a treatment has been offered.

### **Skills**

7.8 The relationship between health professional and patient can be put on a more equal footing if the patient asks the right questions<sup>57</sup>. Patients can develop these skills and be supported on them through the use of coaches and mentors. Health care professionals can develop skills in eliciting questions, thereby avoiding making wrong assumptions about a patient's current knowledge and capacity to add to it. Care plans provide an opportunity for exploring options and preferences in partnership and have been shown to improve adherence.

### Confidence

7.9 Confidence is enhanced if patients trust the source of support<sup>58</sup>. This applies to all who are involved, not just the doctor or nurse. In multi-disciplinary setting this extends to trust in the team. Care plans create a common currency and positive feedback about adherence and ability to self-manage are motivating influences in activation.

<sup>&</sup>lt;sup>56</sup> Kowalczuk, J. and Rix, A. (2014) *Tell me more: improving communications to support patient's understanding and awareness of research.* Cardiff: NISCHR and Velindre NHS Trust

<sup>&</sup>lt;sup>57</sup> Ask 3 Questions is based on: Shepherd, H.L., Barratt. A., Trevena, L.J., McGeechan, K., Carey, K., Epstein, RM., Butow, P,N., Del Mar, C,B., Entwistle, V. and Tattersall, M,H. (2011) 'Three questions that patients can ask to improve the quality of information physicians give about treatment options: a cross-over trial.', Patient Educ Couns., 84(3), pp. 379-85 [Online]. Available at: <a href="http://www.ncbi.nlm.nih.gov/pubmed/21831558">http://www.ncbi.nlm.nih.gov/pubmed/21831558</a> (Accessed: 22nd October 2015).

<sup>58</sup> Rowe, R. and Calnan, M. (2006) 'Trust relations in health care—the new agenda', The European Journal of Public Health,

pp. 4-6 [Online]. Available at: <a href="http://eurpub.oxfordjournals.org/content/eurpub/16/1/4.full.pdf">http://eurpub.oxfordjournals.org/content/eurpub/16/1/4.full.pdf</a> (Accessed: 22nd October 2015)

Table 7 Activation matrix

Domain	Patients need	Health worker role	Systems support
Knowledge	<ul><li>General health awareness</li><li>Understanding of their role</li></ul>	<ul> <li>Assessment of current understanding</li> <li>Setting out new relationships and processes</li> </ul>	Consistent messages geared to different levels of activation
	<ul><li>Specific condition knowledge</li></ul>	Providing appropriate information/facilitating learning	<ul> <li>Flexible pathways for different levels of activation</li> </ul>
	Awareness of options	Signposting based on current level of activation	Graduated options/easy access to information
Skills	Asking questions	Eliciting     questions/developing     activation	Flexible access to services
	Interpreting risk	<ul> <li>Providing understandable explanations</li> </ul>	Patient education programmes
	Self- management	<ul><li>Individualised care plan</li><li>Support and monitoring</li></ul>	<ul><li>IT support for care plans</li><li>Patient education programmes</li></ul>
Confidence	Support from trusted sources	Multidisciplinary working/team approaches/use of mentors and third sector	<ul> <li>Skill mix</li> <li>Commissioning patient focussed/ psychosocial interventions</li> </ul>
	Feedback	Routine use of care plans	Measures based on activation
	Feeling valued	Listening/joint target setting	Positive messages     about     responsibility/common     shared record

#### 8. What next?

### **Conclusions**

- 8.1 The evidence points to improving patient activation as an important step in improving health. It also points to the need to do this within a planned process which supports patients in their choices and recognises that patients have different needs. Recognising these needs is only the first step in a process which bases care around those needs.
- 8.2 We know that a range of psycho-social interventions can be effective in improving both clinical and patient reported outcomes, although measurement can be problematic. The reliance on patient reported outcome measures is seen by some as relatively weak evidence upon which to base changes in treatment which clinical measures show to be effective in the majority of cases.
- 8.3 The NHS response to managing planned episodic care has largely been based on the design and implementation of clinical pathways<sup>59</sup>. These determine, on the basis of clinical evidence and available resource, what a patient should normally receive. This systems oriented approach has much appeal in relation to managing workflow and quality. However, much system energy is expended monitoring pathways to the extent that the pathway may become an end in itself, not a means of supporting the patient. The kind of care envisaged by the prudent healthcare approach is more likely to see pathways as an interesting starting point for determining patient need, and while what happens to the 'average patient' is useful from a resource planning perspective, it is not a blueprint for the delivery of an individual's care. This requires individualised and integrated care planning<sup>60</sup>.
- 8.4 In the same way that the House of Care provides a holistic frame work which aligns behaviour, resources and systems, pathways could be redesigned to focus on decision points and the support patients need to manage the choices they have made. This includes data on the individual patient's ability to respond meaningfully to choice options. Various input measures, both socio-economic and, more specifically, relating to health literacy, have attempted to account for individual differences in the way choice options are exercised which in turn have tended to use Quality Adjusted Life Years (QUALYs) as the standard outcome measure.

<sup>&</sup>lt;sup>59</sup> Kinsman, L., Rotter. T., James, E., Snow, P and Willis, J. (2010) *'What is a clinical pathway? Development of a definition to inform the debate'*, BMC Medicine, 8(31). [Online]. Available at: <a href="http://www.biomedcentral.com/1741-7015/8/31">http://www.biomedcentral.com/1741-7015/8/31</a> (Accessed: 2nd November 2015).

<sup>&</sup>lt;sup>60</sup> Schrijvers, G., van Hoorn, A. and Huisk, N. (2012) 'The care pathway: concepts and theories: an introduction', Int J Integr Care, 12(Special Edition) [Online]. Available at: <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3602959/">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3602959/</a> (Accessed: 2nd November 2015).

- 8.5 The PAM has been shown to be a measure which accurately assesses individual patient underlying activation levels, changes in level over time, and through the use of specific activation enhancing activities, the effectiveness of those activities in increasing activation levels. Most importantly, there would seem to be good evidence that scores on the PAM correlate well with other measures of health outcome, including clinical ones.
- 8.6 The PAM can be used as both an ideographic and a normative measure. PAM scores allow clinical teams to tailor their style of intervention during the initial consultation recognising that some patients will be more engaged and others. The same score can be used as a baseline for an individual or a group of patients. Repeated use of the measure can track changes over time. Scores can also be used to measure the effectiveness of interventions both in the short term (*Did the intervention improve treatment decisions?*) and the longer term (*Has the intervention subsequent experience impacted on longer term health behaviours?*). A single measure which can be used in these ways clearly has convenience value in research and evaluation.

## **Planned Care Programme**

8.7 Within the Planned Care Programme there are a number of proposals to provide psychosocial and community based interventions as part of the choice support agenda. Assessing whether they will work and hence represent a worthwhile investment is problematic for four main reasons:

# I. Fidelity and design

Fidelity is the extent to which an intervention is delivered in accordance with its design and intention. Deviation from the design essentially means that the intervention as delivered becomes non-comparable. This presents a problem for those delivering the interventions who know that maximum individual impact is made by personalising delivery and the problem is compounded if the design has only a loose theoretical basis.

### II. Uptake

A major issue with any educational input is the extent to which uptake reflects need. The inverse care principal<sup>61</sup> often applies, meaning the worried well attend, with little additional benefit; while those most in need don't. Targeting is notoriously difficult, and even when initially successful, is subject to differential attrition; those who would benefit most are most likely to drop out. Deadweight is inevitable unless there is very precise targeting and tailoring of the intervention to meet specific needs.

### III. The counterfactual

A lot of what goes on in psychosocial interventions is about stimulating people to use knowledge and skills they already possess but lack the confidence to use. A characteristic of highly activated people is that their confidence levels

<sup>&</sup>lt;sup>61</sup> Appleby J. and Deeming C. (2001) 'Inverse care law.', Health Services Journal, 111(37)

already lead them to the kinds of behaviours which improve their skills and knowledge without any further assistance. A true control group would need to consist not just of those who were not offered the intervention but also those who denied themselves the opportunity to improve their own skills and knowledge.

### IV. Measurement

The individual's outcomes of psychosocial and community based programmes often rely on personal goal-setting and are in any event tempered by expectations: they are therefore difficult to compare. Even with standardised measures, relativities between individuals at the same point in time (normative measurement) may be harder to establish than individual change over time (idiographic measurement).

- 8.8 The use of the PAM could help in a number of ways:
  - Design of the intervention
     Defining levels of patient activation in behavioural terms allows training to be targeted at specific behaviours. PAM provides a behavioural framework linked to known improvements in health outcomes.
  - II. Targeting

PAM scores can be used to define or segment a population. This could lead to designing different interventions for those at different levels (improving effectiveness) or to targeting those whose needs are greatest (improving equality). Either way, the use of PAM to stratify or segment would decrease deadweight and increase additionality.

III. Control group selection

Being able to stratify a population on the basis of PAM scores/levels enables the generation of control groups with the same or different scores using a scale with strong links to health outcomes as opposed to matching characteristics which have less well developed associations. The 'behavioural' approach has advantages over the 'characteristics' approach as behaviours can, mainly, be changed whilst characteristics, mainly, can't.

IV. Standard measure

Using patient activation levels as a proxy for health itself and having a single standard measure makes comparisons across and between approaches and designs possible.

### An example

Orthopaedic services

8.9 One intervention to provide 'schools' for those being considered for knee surgery run along patient education/health literacy lines is already well advanced. Given the small level of resource likely to be available for evaluation, the PAM could be used to provide evidence about its effectiveness overall and test out variations. A process map for this intervention already exists and it would be very easy to add in the collection of PAM data which could be incorporated into the patient record in much the same way as Oxford Knee Scores are. If there was a PAM score for every individual

referred to the orthopaedic consultants, the clinical teams themselves, given appropriate training, could tailor their explanations and explorations of options to the patient's ability to understand and engage with the choices available to them. For those patients for whom there were realistic clinical options, PAM scores could be used to target the intervention at those with the lowest levels of activation. As well as targeting those with greatest need, a fundamental prudent principle, the design could then be simplified to match the programme to the activation levels of the participants.

- 8.10 If the introduction of the 'schools' approach was different in some way in a particular location (for instance, the amount or timing of clinician training, the use of community mentors instead of clinical instructors in delivery, the timing and frequency of sessions) data would automatically be available on its impact on levels of activation which would allow adjustments to be made. Although initially this approach is very much based on improvement rather than research methodology, it would nevertheless provide robust data about the relationship between activation levels and whether patients opted for more or less invasive treatments and whether the effect of his type of intervention prevents overtreatment or is merely delaying full surgical intervention.
- 8.11 The introduction of the 'schools' approach will in any event need to be accompanied by:
  - Adaptation to the care pathway.
  - Co-producing the intervention.
  - Training of clinicians and other staff.
  - Possible work role changes e.g. the use of extended/enhanced role physiotherapists.
  - Alignment of administrative systems including content of communications with patients.
  - The introduction of individualised care planning.

All or any of which could be a source of variation. What would not be a source of variance would be the measure itself.

8.12 Depending on the outcome of the evaluation outlined above the methodology could be adapted to the evaluation and performance management of other psychosocial and community based interventions.

### Longer term actions and benefits

- 8.13 The use of the PAM would also contribute to achieving the goal of developing a future health service based on prudent healthcare principles by:
  - Redefining the patient/clinician relationship.
  - Targeting unwanted variation.
  - Improving access for those with greatest need.
  - Promoting choice through patient knowledge, skills and motivation.

- 8.14 The adoption of the principles of prudent healthcare and its implementation is a long-term, and, to some degree, an organic process which depends on small incremental successes in one area feeding interest in other areas. Patient reported measures are at least as important as clinical ones in feeding that interest, not least because Prudent Healthcare represents a significant cultural shift for all concerned.
- 8.15 Action needed to implement Prudent Healthcare is likely to include:<sup>62</sup>
  - Developing a national strategy which reflects the whole systems approach.
  - Provision of skills training for clinical staff and patients.
  - Developing a cadre of mentors.
  - Realignment of targets and measures to reflect patient led outcomes
  - Service reconfiguration and work restructuring based on co-production methods.
  - Developing flexible pathways.
  - Rethinking the ways in which patients are given and can access information.
  - Providing not just better information but better access and more individually tailored information.
- 8.16 The PAM can be used to demonstrate change at an individual and population level to measure incremental change and has the potential to play an important part in supporting the move to prudent healthcare. However, PAM can only influence and measure change if the systems it operates in supports change.

<sup>&</sup>lt;sup>62</sup>De longh, A., Fagan, P., Fenner, J. and Kidd, K. (2015) *A practical guide to self-management support Key components for successful implementation*. [Online]. Available at: <a href="http://www.health.org.uk/sites/default/files/APracticalGuideToSelfManagementSupport.pdf">http://www.health.org.uk/sites/default/files/APracticalGuideToSelfManagementSupport.pdf</a> (Accessed: 15th December 2015).

Prudent healthcare is Wales' blueprint for better, more integrated health and social services. It involves identifying and prioritising need, choosing treatments wisely through partnership, and reducing inappropriate variation through the application of evidence based approaches. It heralds an unprecedented democratisation of decisions about what and how services are provided and fosters patient responsibility as well as rights – in short, it is a grown up plan for a grown up NHS, building on its founding principles of equity and fairness to create a service which meets the changed needs of people in the 21<sup>st</sup> century.

The Planned Care Programme is part of that plan and a challenges assumption about the way service users and service professionals interact. The programme explores the power of individuals, communities and new technologies to provide services people need and will use. It acknowledges that the NHS often gives out mixed messages by misaligning the motivational elements needed for improved health for both users and providers. Nowhere is that clearer than in the role of the patient in securing and maintaining their own well-being. A system that takes little account of patient preference and that assumes no patient insight or knowledge but continues to dole out the same treatment to all, regardless of individual need, preference or context, is likely to produce both dependency and lack of compliance simultaneously.

Activated patients display interest and take responsibility for their underlying health needs and see themselves as the prime manager of their condition. They seek to work in partnerships with health professional to select the most appropriate form of treatment and are knowledgeable about their condition as it affects them. By contrast passive patients tend to be dependent on medical professionals for an understanding of their condition and expect that passive compliance with treatment will bring better health. There is strong evidence that activated patients enjoy better health and, that when they do become ill, they have better outcomes. Historically, levels of activation have been associated with literacy, education, age and social class; characteristics which are difficult to change.

The evidence now suggests that individuals learn to be active or passive and are responding to social and organisational cues which reinforce behaviours. The key to becoming an activated patient is to have knowledge and the skills and confidence to apply it and research evidence shows these underlying components are **not** fixed – rather they can be developed so that people can learn new behaviours. Services can also be re-designed to reinforce more active behaviours and when patients become more activated they actually make fewer demands on the service.

Given the evidence that more activated patients have better health outcomes and would appear to reduce costs, there is considerable interest in how levels of activation might be increased.

Reviews of programmes and projects to increase activation show that successful interventions involve: education or improved information; providing opportunities to practice skills including self-advocacy and; the development of self-confidence often through the use of peers as tutors and mentors. Further, a number of implementation studies also point to the need for a whole systems approach, including the need for training of clinical staff in new ways of engaging patients and for systems to be designed around supporting choice not enforcing compliance. They also demonstrate that many successful interventions for improving levels of activation are not clinical but are based on psychological techniques for empowering people drawn from community development. This approach views people as assets in whom investment yields both individual and wider social benefits. The key to understanding these benefits is measurement.

Health systems the world over recognise that clinical measures of health are important tools for ensuring effective treatment. However, there is a growing realisation that they do not tell the whole story and that individual and collective experiences of health care are important factors which impact directly on health outcomes, as well as on the levels and kinds of demands made on services as a whole. While clinical measures tend to be condition specific, focused on episodes of illness and adherence to evidence based practice (bad variation), patient centric measures recognise that wellness is complex and subjective and measures need to pick up not just variation but the reasons for it (choice or good variation).

What clinical and person centred measures share is that they are the starting point which should shape conversations about what the clinical diagnosis means and what treatment options are likely to be appropriate. Clinical measures on their own do not provide the understanding of patient behaviour and motivation which is required to optimise individual care planning and health outcomes. As a minimum, measuring patient activation and using the results in primary care settings has the potential to tailor consultations to the patients current levels of knowledge, skills and confidence and to identify opportunities to improve one or more of these factors. In more complex cases the level of activation can be used as an overall indication of improvement in well being.

There are a number of approaches to measuring patient activation. Some focus on knowledge and tend to be condition specific, others focus on broader concepts such as general health literacy which underpins the capacity to understand and manage aspects of individual health. Levels of knowledge and health literacy have both been shown to be associated with increased capacity to self manage long term conditions and achieve better health outcome whether measured by clinical or patient reported measures. These kinds of measures are often correlated with patient reported outcome measures (or quality of life measures) as well as clinical outcome measures to give a balanced view of outcomes.

The Patient Activation Measure (PAM) combines measures of skills, knowledge and confidence and is the most commonly used single measure. Completed by the patient, with support where appropriate, PAM comprises 13 statements covering beliefs, confidence and management of health related tasks and self-assessed knowledge. Patients are asked to

rate the degree to which they agree/disagree with each statement producing a combined score of between 0 and 100 which represents the person's concept of themselves as an active manager of their own health and healthcare. The scores are divided into four 'levels of activation' based on experience and observation; providing a means of understanding the patient's capabilities, beliefs and likely behaviours at different points along the scale.

The PAM has been validated across a range of healthcare systems, languages, cultures, demographic groups and conditions. 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. These observations are important because it suggests there is not homogeneity in a particular group when it terms of engaging with health information or health promoting behaviours. Scores suggest only moderate correlation between activation and socio-economic status i.e. just because someone has a higher socio-economic status does not mean they are more activated and more likely to engage with their own health, likewise individuals from lower socio economic backgrounds are not necessarily less activated.

Most importantly the PAM has strong correlations with clinical outcome measures so that improvement in an individual's PAM score is a good indicator of future health and well being. Further, there are encouraging results from attempts to use the PAM scores at a cohort or programme level to measure programme or intervention effectiveness.

Prudent health care seeks to fundamentally change the relationship between the patient and the health care system so that need is better met. Using patient activation as an overarching health goal and a reliable measure of activation as a performance management tool for assessing whether the goal is being achieved has much to recommend it as an approach.

### Further reading:

## Achieving prudent healthcare in NHS Wales

Dr Peter Bradley and Dr Alan Willson 1000 Lives Improvement, Public Health Wales 2014 Available at

http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/Achieving%20prudent%20healthcare/w20in%20NHS%20Wales%20paper%20Revised%20version%20%28FINAL%29.pdf

# Supporting people to manage their health: An introduction to patient activation

Judy Hibbard and Helen Gilburt

The Kings Fund 2014

Available at

http://www.kingsfund.org.uk/sites/files/kf/field/field\_publication\_file/supporting-people-manage-health-patient-activation-may14.pdf

# Measuring what really matters: Towards a coherent measurement system to support personcentred care

Dr Alf Collins

The Health Foundation 2014

Available at

http://www.health.org.uk/sites/default/files/MeasuringWhatReallyMatters.pdf
http://www.health.org.uk/sites/default/files/PatientFocusedInterventions\_ReviewOfTheEvidence.pdf

### Further information and the full version of the research paper are available at

Planned care programme Wales - <a href="http://gov.wales/topics/health/nhswales/planned/?lang=en">http://gov.wales/topics/health/nhswales/planned/?lang=en</a>

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