Patient and Public Engagement
Landscape & Applications
Patient and Public Engagement is the science of supporting people to make better healthcare decisions; shaping health services in partnership with local communities and using patients’ insights to improve health service delivery.

Engaged Patients: The Next Blockbuster Drug

We live in a time of profound change. Informed, assertive patients are challenging the supremacy of the traditional medically-led model as never before. We can all be armed with the latest evidence sourced from Wikipedia, support fora, blogs with expert patients and patient leaders, not to mention access to self-reported diagnostics for Long Term Conditions (LTCs).

Some patients can now be as equally knowledgeable and informed about their symptoms or condition as their GP and specialist clinicians, but still require their expert, medical experience to determine their treatment options. Whilst there is undoubtedly still a reassuringly high degree of trust in clinicians, it is clear that doctors don’t always know best, and that patients won’t always accept the first opinion.

Far from being an inconvenience, this patient-led challenge is one of the greatest assets we have. NHS England (NHSE) has estimated that around 15 million patients with LTCs provide 4,800 hours of self-care for every four hours of NHS care. Rather than concentrate solely on making these four hours more efficient, perhaps it’s worth spending more time on engaging with these patients and their carers to better understand and enhance self care? Engaged patients can cost 21% less to care for than disengaged ones; a recent study by Nesta estimated £4.4bn could be saved in the NHS through greater participation and self-management of LTCs. Platforms like NHS Choices have seen patients and carers provide constructive comments on NHS services and how they need to develop. IWantGreatCare has reached over one million patient reviews and ratings covering all services and healthcare professionals including hospitals, doctors, dentists, GP surgeries and GPs.

Engaged patients are the next blockbuster drug. This briefing provides a guide to the landscape and some practical insights into how NHS leaders can leverage evidence-based Patient and Public Engagement (PPE) techniques to help unlock this power.

PPE is more relevant now than it’s ever been

There are three reasons why the NHS needs engagement to survive and adapt in a cash starved world.

Firstly, more informed patients are healthier and less costly. It’s over a decade since Wanless predicted a £30bn difference (in 2002 prices) in the resources required by an NHS in 2022/23 where patients were fully-engaged in their own healthcare compared with an NHS in which patients simply continue to behave as they currently do. That statistic is even more relevant when the existing projections are for a budget shortfall of £21bn per annum (in 2014 prices) in 2020/21.

Secondly, difficult decisions are made easier when patients are involved in making them. Contentious service changes are easier when communities are involved in their design from inception. The evidence of the personal health budget pilots suggests that the same can be true at an individual as well as collective level.

Thirdly, in a world where things do go wrong – decisions which are co-produced and transparently reported are safer decisions. We live in a world where NHS staff are publicly slated when things go wrong, whether it’s the wrong diagnosis, a missed opportunity to intervene or simply poor care. In such a world, patients who are active, informed participants in their own care provide the positive and negative feedback the service needs to improve.

Perhaps actively engaged patients, participating in these discussions and the decision-making, are our best allies and safeguard against the pressures of austerity?

Hibbard J.H. and Green L., ‘What the evidence shows about patient activation: better health outcomes and care experiences, fewer data on costs’ Health Affairs 2013, 32:2207-14

i. The Business Case for People Powered Health’, NESTA, April 2013
Navigating the PPE landscape

Anyone encountering PPE for the first time would be easily excused for being put off by the flurry of policy, terminology and behaviours can play in helping to address the challenges.

Throughout these years there have been islands of good practice, but the relatively benign financial climate and a funding regime that rewarded additional activity fostered a sense that engagement was a ‘nice to have’. Engagement professionals were niche enthusiasts, distanced from the excitement and focus on signing contracts, managing commissioning cycles and invoice validation regimes.

As the financial pressures truly hit in 2010, engagement professionals struggled to demonstrate a track record in PPE making a significant difference in the short to medium term. Not least because commissioning organisations in the process of being dissolved, merged or deconstructed were continually distracted.

But the financial pressures haven’t gone away and the growing number of local and national initiatives continue to collectively highlight the role that engaged citizens and aligned clinician behaviours can play in helping to address the challenges.

Theme 1: The rise of the informed patient

Independently, patients either through condition-centric groups or individually, have become more and more engaged in their own health. The internet and social media platforms create opportunities for patients to access information, share knowledge and stimulate change where traditional institutions are slow to adapt. We are now starting to see improving levels of health literacy, more individual participation in health decisions and the growth of Patient Networks (Expert Patients). A great example of the later being the blog run by Monmouth Advisory Board member, Michael Seres – one of the first bowel transplant patients in the UK.

 Patients are now actively being developed as leaders. For instance, the work being done by Anya de Iongh in Dorset delivering self-management coaching to patients. In Bradford, we’re seeing the development in primary care of community champions creating the next generation of patient leaders.

We’ve also seen significant breakthroughs in self-care & management of LTCs driven by patients – the central line holder showcased at NHS England’s recent patient led innovation workshop being just one example.

Across all such initiatives what is remarkable, and consistent, is the extent to which individual patients have taken control of their own condition(s).

Theme 2: Changing clinical ‘behaviours’

Our second theme is the studding progress the NHS has made towards creating and engaging this informed patient.

 With the standout success of NHS Choices, which now claims over 27 million hits per month, the NHS has often found it difficult to engage individual patients in a dialogue about their health. Two examples of this slow progress are:

  - Information prescriptions still sit at the periphery of accepted commissioned services – despite the lobbying work done by the Patient Information Forum.
  - Progress on developing and adopting Shared Decision Making tools has been slow – despite work undertaken to develop a portfolio of resources.

Theme 3 - Money & politics:

Our third theme argues that a step change in the role of patients is necessary, both politically and financially.

The political first. Initiatives such as the introduction of Patient Choice in the mid-2000s and the current focus on Personal Health Budgets (PHBs) asks patients to take more of a role in decisions about their own care. Progress towards PHBs for NHS care has been slow, only now is there to be a significant ramping up of political will, focusing initially on those with continuing healthcare needs interaction between clinicians and patients. Making this change, by its very nature, is going to be long and slow.

It requires changes to training for new and existing staff to adapt to new ways of working and changing expectations – such as NHS England’s Medicines Optimisation Patients Panel which has pressed for a more active, personalised contact between pharmacist and patient.

Examples of how increased activation can reduce utilisation of services include:

  - Enabling patients to continually manage their condition rather than treating symptoms.
  - Encouraging lifestyle management over prescription treatment.
  - Reducing “incorrect” contacts and more efficient use of appointments.
  - Reduced avoidable admissions.


More recently, NHS have backed the House of Care – that brings together national guidance, published evidence, local case studies and information for patients and their carers about how to access services. It also includes tools and resources required to achieve person-centred coordinated care and how these can be effectively commissioned.1 At their heart these initiatives, like many others, are about changing the culture, content, format and style of the

More recently, NHS have backed the House of Care – that brings together national guidance, published evidence, local case studies and information for patients and their carers about how to access services. It also includes tools and resources required to achieve person-centred coordinated care and how these can be effectively commissioned.1 At their heart these initiatives, like many others, are about changing the culture, content, format and style of the interaction between clinicians and patients. Making this change, by its very nature, is going to be long and slow.

It requires changes to training for new and existing staff to adapt to new ways of working and changing expectations – such as NHS England’s Medicines Optimisation Patients Panel which has pressed for a more active, personalised contact between pharmacist and patient.2

The PAM is widely used in the US, and its application in the UK is on the rise, endorsed by organisations such as The Kings Fund. Applications include:

- Assessing ability to self-manage.
- Identifying “low activation level” populations to tackle health inequalities.
- Tailoring support and education to increase activation.

There is evidence showing a strong positive correlation between high PAM scores, improved health outcomes and lower cost of care. This means that patient activation can help support sustainability as well as quality of patient care.

4 Levels of patient activation

1. Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.

2. Individuals may lack the knowledge and confidence to manage their health.

3. Individuals appear to be taking action, but may still lack the confidence and skill to support their behaviours.

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 stresses.

1 http://www.england.nhs.uk/2013/09/25/transpart/

1 http://www.england.nhs.uk/2013/09/25/transpart/
Individual engagement delivers operational savings

At an individual level, good engagement is about helping to put individual patients in control of their own health and supporting them in working with clinicians to make the best decisions for their own situation.

To be successful though a good Patients in Control strategy has to support the core objectives of the healthcare system, namely to maximise self-directed care, shift activity to the lowest cost setting – usually home – and support better use of the clinical workforce. Making these changes supports providers in achieving operational savings – whether these be shortening lengths of stay, keeping patients out of hospital or reducing the number of medication errors.

Our model encourages commissioners to assemble a range of patient engagement capabilities across their health system and align these with their core commissioning disciplines rather than see them as discreet service lines operating in silos. For example, investing in health coaching for patients with LTCs to support them to stay out of hospital rather than pick up the bill when they continually re-admit.

Figure 3: Linking individual participation interventions to the achievement of the strategic & operational challenges faced by healthcare providers.

Health Coaching
Health coaching/self-care enables patients to make more informed decisions about treatment options.
Savings: LTCs account for 70% of NHS budget; Health coaching can reduce A&E and inpatient costs by up to 20%.

Who to target? Patients most at risk of hospital attendance/admission – risk stratification and use of PAMs to segment.

How to engage? Programmes tailored to local needs, identifying future role models.

Medicines Optimisation
>£12bn p.a. is spent on medicines, yet only 16% of patients prescribed a new medication take it as prescribed. In primary care alone over £300m of medicines are wasted each year.

Medicines optimisation involves encouraging patients to take the right medicine(s) more consistently. At its best, it encourages a holistic view of costs across a care pathway and resists concentrating only on reducing one-off prescribing costs.

The RCS’s first principle in its guidance on medicines optimisation is the importance of understanding the patient experience. Guidance reinforced by work undertaken by Monmouth for NHS England in late 2013.

Access to Health Records

Ever since the Access to Health Records Act 1990 patients have had the statutory right to have access to their medical records.

94% of doctors surveyed believe all patients have at least some access to their electronic health record. Under the Data Protection Act 1998, doctors believe all NHS patients have a legal right to apply for access to health information held about them. This includes NHS or private health records held by a GP, optician or dentist, or by a hospital.

By March 2015 everyone will be able to book GP appointments and order repeat prescriptions online and get online access to their own medical records held by their GP.

http://www.personalhealthbudgets.england.nhs.uk/About/faq/12

Personal Health Budgets (PHBs)

Improved outcomes and reduced costs: NHS England’s evaluation demonstrated Personal Health Budgets greater than £1,000 represent an overall cost reduction of £3,100 compared with control groups. See http://www.personalhealthbudgets.england.nhs.uk/About/faq/

Reduced inpatient cost: Hospital costs are known to decrease significantly for mental health and continuing healthcare patients by £3,050 and £4,040 respectively compared with control groups.

Cost-effectiveness: PHBs realise net monetary value, when calculated by subtracting costs from all benefits including quality of life. This benefit is calculated at £2,300 per patient more than conventionally commissioned services.

Health Coaching
Health coaching/self-care enables patients to make more informed decisions about treatment options.
Savings: LTCs account for 70% of NHS budget; Health coaching can reduce A&E and inpatient costs by up to 20%.

Who to target? Patients most at risk of hospital attendance/admission – risk stratification and use of PAMs to segment.

How to engage? Programmes tailored to local needs, identifying future role models.

Medicines Optimisation
>£12bn p.a. is spent on medicines, yet only 16% of patients prescribed a new medication take it as prescribed. In primary care alone over £300m of medicines are wasted each year.

Medicines optimisation involves encouraging patients to take the right medicine(s) more consistently. At its best, it encourages a holistic view of costs across a care pathway and resists concentrating only on reducing one-off prescribing costs.

The RCS’s first principle in its guidance on medicines optimisation is the importance of understanding the patient experience. Guidance reinforced by work undertaken by Monmouth for NHS England in late 2013.

Access to Health Records

Ever since the Access to Health Records Act 1990 patients have had the statutory right to have access to their medical records.

94% of doctors surveyed believe all patients have at least some access to their electronic health record. Under the Data Protection Act 1998, doctors believe all NHS patients have a legal right to apply for access to health information held about them. This includes NHS or private health records held by a GP, optician or dentist, or by a hospital.

By March 2015 everyone will be able to book GP appointments and order repeat prescriptions online and get online access to their own medical records held by their GP.

http://www.personalhealthbudgets.england.nhs.uk/About/faq/12

Personal Health Budgets (PHBs)

Improved outcomes and reduced costs: NHS England’s evaluation demonstrated Personal Health Budgets greater than £1,000 represent an overall cost reduction of £3,100 compared with control groups. See http://www.personalhealthbudgets.england.nhs.uk/About/faq/

Reduced inpatient cost: Hospital costs are known to decrease significantly for mental health and continuing healthcare patients by £3,050 and £4,040 respectively compared with control groups.

Cost-effectiveness: PHBs realise net monetary value, when calculated by subtracting costs from all benefits including quality of life. This benefit is calculated at £2,300 per patient more than conventionally commissioned services.
Collective engagement: Not just good practice but essential too.

The natural counterpart to individual participation is collective participation. Collective participation is the discipline of helping healthcare providers and commissioners to engage with local populations to impact health behaviours and encourage citizen input into decisions regarding services provided locally. The last two years have seen the development of more robust systematised forms of collective engagement. In part, this represents a deliberate response to the challenge set out by the failures of public feedback and accountability at Mid Staffordshire. Leading the way are national initiatives from NHS England and Care Quality Commission (CQC).

NHS England’s Transforming Participation guidance set out strategic objectives for public participation. These included:

- The establishment of a national Citizen’s Assembly which can hold the Board of NHS England to account.
- The encouragement of local participation through a People’s Bank.
- A Participation Academy which encourages people to become more involved with their local NHS organisations.¹

The CQC’s Experts by Experience programme asks over 500 people who have experience of using care services to take part in inspections of health and social care services. During inspections, Experts by Experience spend time talking to people who use the service and observing the environment. Outside of the inspection process itself, they also attend events, consultations, staff training events and help the CQC develop it’s internal processes.²

Both these examples build on the principle that successful participation requires building longer term relationships with communities and bringing patients and the wider public into the decision making process. Putting in this ground work becomes essential when it comes to building the case for service redesign. Any NHS body considering changing the services it commissions or provides must be aware of its obligations to engage.

The encouragement of local participation through a People’s Bank.

What makes a Patient Centric organisation?

Many organisations state that they “put patients at the heart of what we do”, but sometimes this is a well intentioned sound bite far less evident in practice. Monmouth have developed and used a maturity model to help organisations including the CQC, HSCIC and Cancer Research UK to understand their current performance and where they need to improve to achieve their performance, this makes for worrying reading as the next decade is likely to bring significant levels of service redesign to address changing patterns of disease and financial pressures.³

1. The Independent Reconfiguration Panel (IRP) was set up as an independent body to advise the Secretary of State for Health on contested NHS reconfigurations in England. Its establishment was part of a package of changes to the arrangements for patient and community engagement in healthcare services first set out in the NHS Plan in 2000. http://www.irpanel.org.uk/lib/doc/learning%20from%20reviews3%20pdf.pdf

2. http://www.cqc.org.uk/content/involving-people-who-use-services
Insight and information

– Empowering individuals for better care and health.
– Harnessing information to better listen and engage with patients.
– Empowering organisations for quality improvement.

A wealth of information is routinely collected to track performance, safety, quality and satisfaction in healthcare. Specific to individual patients, these come in a bewildering blend of PROMs, PREMs and FFT — anyone encountering them for the first time could easily mistake it for an alphabetical soup. At their core, these tools and measures attempt to harness feedback from patients to provide insight into the impact that health interventions have from their individual perspectives.

• Patient Reported Outcome Measure (PROMs) are standardised validated instruments (question sets) to measure patients' perceptions of their health status, their functional status, and their health-related quality of life. They are usually designed to measure the impact of clinical interventions in a strictly clinical sense – did it improve the patient’s physical or mental condition in a meaningful sense, and if so, by how much?
• Experience – in turn is sub-divided between:
  • Satisfaction measures allow patients (or carers) to re-port their subjective view of the treatment received (e.g. would you recommend the service);
  • Patient Reported Experience Measures (PREMs) that collate patients’ objective care experience, focusing on specific aspects of the process (e.g. were you seen on time).

Together these measures provide an overall indicator of performance and more holistic view of quality. PROMs, in particular, can be utilised in various ways, including as a mechanism to support:
• Involvement in care by helping patients to understand & respond to changes in their own clinical conditions;
• Pathway redesign to reduce inappropriate, or unnecessary clinical interventions, for example unnecessary follow-up outpatient attendances; and
• Provider incentivising, by linking payments to outcomes.

The Friends and Family Test (FFT) introduced in April 2013 is in effect a national standardized patient satisfaction survey asking patients how likely they are to recommend the service to friends and family. It is used as an indicator of quality and performance with the first results published in July 2013. These found a wide nationwide variation in response rates and scoring, with some A&E services where some Trusts consistently received negative scores.

Past Francis and Berwick, NHS has invested heavily in post Francis and Berwick, NHS has invested heavily in

Figure 5: Differentiating between PROMs, PREMs and satisfaction measures

Social Media Monitoring

NHS England and a small number of providers and CCGs have started tracking patients’ and the public’s voice on social media to obtain a wider, uninhibited and unadulterated view and understanding of:
• How they are perceived as an organisation or brand, including patient or public perception and satisfaction of services.
• Any incidents that need to be addressed – with the platform acting as an alert system, highlighting any issue which requires immediate intervention.

Providers’ responsiveness to complaints, patient satisfaction and quality indicators is now taking centre stage. This follows post Francis and Berwick, NHS has invested heavily in and the Health Select Committee’s findings that “whilst some NHS organisations respond quickly and effectively to complaints, others are not so effective”.

Each week, circa 3,300 written complaints regarding NHS services in England are received, demonstrating that the NHS can and must do more to improve quality. FFT results are now required in providers’ annual Quality Accounts and it’s likely that clinical and patient led indicators will continue to coalesce as measures of performance.

Figure 6: Written complaints regarding NHS services 2002/3 – 2013/14

Source: www.hscic.gov.uk; Data on Written Complaints in the NHS - 2013-14, Publication date: August 28, 2014

• If and how services and communication with their community could be improved.

To date, social media monitoring initiatives have primarily been reactive. However, the technology can be used proactively to anticipate behaviour and understand lifestyle choices more clearly. The NHS of 2025 is likely to see social media intelligence as an accepted part of the decision-making process, as it has already become for many other major organisations.
For further information about issues raised in this paper, please contact Mark Duman
mark.duman@monmouthpartners.com or 07824 605 352