Revolutionising the NHS with Patient Power

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Introduction

AN OPM POLICY PAPER

This paper highlights how patient power can be used to transform all levels of the health service - from shaping policy and system reforms, effecting service delivery changes, to transforming the dynamic between patients and their healthcare providers. In it we draw on OPM’s own experiences, as well as good practice examples from a recent OPM-hosted seminar, and consider how the health service can put the needs and wants of patients at the heart of everything it does through effective patient and public involvement.

The insights and experiences of patients and the public have the potential to revolutionise the health service. This isn’t merely an aspiration; it is an observation.

As OPM has seen from our own work in North East Lincolnshire, Newcastle, Cardiff and many other places across the country, evidence indicates that in places where patients are involved in decision-making, patient experiences and outcomes are better. One example is ParkinsonNet, a regional network of care communities and healthcare professionals specialising in Parkinson’s disease who have used the power of information technology to establish a collaborative care culture which, according to the BMJ, “empowers patients, promotes self-management, improves the quality of care, decreases institutionalised care, and lowers healthcare costs.” In our own evaluation of The Health Foundation’s Making Good Decisions in Collaboration (MAGIC) programme, which looked at Shared Decision Making (SDM) in primary and secondary care, we found that between 70 percent and 75 percent of clinicians reported positive effects on various aspects of their day-to-day practice due to their involvement in the programme.

Policy makers have recognised the transformative potential of patient and public involvement for many years. Since the Health and Social Care Act came into force last year however, engaging patients and the public about the future of the NHS is no longer an option for commissioners, but an obligation. Developments like the Friends and Family test and conditions in the new Clinical Commissioning Group (CCG) assurance framework have shifted the emphasis on engaging patients and the public from something important, to something integral to the health service’s future. It was no coincidence that on his first day in the job Simon Stevens, the new NHS England Chief Executive, pledged to “get serious about patient power” and “boost the critical role that patients play in their own health and care.”

There is of course a big difference between doing patient engagement and doing it well. At a recent OPM seminar there was broad agreement among the many participants that in order to deliver the kind of outcomes mentioned above, the old paternalistic mind-set - where health professionals engage and patients are engaged with - must be cast out. Instead, informed patient collaboration, both with clinicians and with leaders and managers must take place at all levels of the health service. This will require a concerted and joint effort to bring about permanent change in the cultures of NHS patients, clinicians and managers.
Involving patients in health policy and strategy

If patients and the public are to contribute to decisions concerning the planning and management of their care, then their voices must be heard at all levels of the NHS - from the board to the ward. Furthermore, if we accept that patient voice is currently a largely untapped resource, then it follows that the approaches best suited to accessing and harnessing patient power will have to be more innovative and radical than those currently being used.

At the governance level, culture change and strong leadership will be essential in bringing about a situation where patients and public can influence how services are commissioned and delivered. Senior leaders will have to be convinced by the relevance of patient and public involvement in regards to the NHS’s change agenda. They will also have to create a shared understanding of this vision; show commitment and provide support in its implementation; and support managers, clinicians and other front-line staff to make patient involvement an integral part of their job. In this area NHS England is certainly practicing what it preaches, having created two separate Director for Patients and Information and Head of Patient and Public Voice posts.

As with any new approach there also needs to be space for experimentation, even failure. Thus, there is a need for strong leadership that supports these agendas, provides necessary resources, and encourages the sharing of and championing of good practice. As part of this, engagement activities should be recognised as valuable use of time that can contribute to improving outcomes.

Case Study: NHS Citizen

NHS Citizen is an innovative approach to connecting the public with the decision-making infrastructure of the NHS. Intended as a way for citizens to hold the board of NHS England to account, it is currently being designed in the ‘open’ with a series of public workshops underway throughout the country.

The current format revolves around three connected spaces:

1. Discover – where information and opinions are collected from the public through both online and offline sources.

2. Gather – where specific issues can be discussed and collaborated on.

2. Assembly Meetings – where priority issues will be considered by both the public and the NHS England Board in face-to-face consultations twice a year. The Assembly will also be able to commission Citizen Panels to consider particularly difficult issues.

In this way, NHS England is hoping to create a new democratic mechanism for communicating with the public, while simultaneously increasing the opportunities for participation and contribution from all NHS citizens.

Such ambition does not come without dilemmas, but this is partly what makes NHS Citizen so exciting. It faces as many problems as any similar project, but it has decided to deal with them transparently as they occur, encouraging the public to talk about these issues in meetings via blog posts and on twitter to help generate a collective solution. The extent of this culture change should not be underestimated. Citizens are being actively involved in all the complicated, difficult, challenging bits of the NHS, not just those designed suitable for public ‘participation’.

You can find out more about NHS Citizen here.
Involving patients in service improvement

NHS England has put a lot of thought into the design of their latest guidance Transforming Participation in Health and Care. The document, which supports the assurance process for CCG and NHS England commissioning, suggests commissioners should be able to demonstrate how ‘patients are in control’ of the healthcare they receive. Indeed they even suggest participating in Patient in Control programmes currently being developed and offered by commissioning support units and delivery partners such as OPM. But do patients, providers and commissioners really appreciate the value of such engagement? And how can patient engagement shape the design of services?

Transforming Participation in Health and Care refreshes the engagement cycle developed by InHealth Associates to illustrate the critical role for patients (and the public) in service redesign. Patient experiences can identify strengths and weaknesses in service pathways and care models. They can also identify the factors that matter the most from the patient’s perspective. The guidance cites long term conditions and urgent care as examples where patient involvement could particularly improve service redesign.

OPM has experience in this area having recently conducted an urgent care simulation for Bath and North East Somerset CCG. The simulation was designed to establish fundamental change across the whole health and social care system that would help Bath and North East Somerset CCG meet the challenge of rising demand for emergency care in a climate of limited or reducing resources. The exercise benefited from the involvement of a wide number of partners from the local area, including community representatives and service users, who helped to illustrate how the system behaves under pressure and to then reflect on what needs to be changed to avoid pressure at specific times of the year. One of the major learning points was the need to involve the community and voluntary sector much more, as both representatives of service users and the providers of potential solutions to statutory service pressures. As a direct result of the exercise a number of tangible improvements to plans have been made, further details of which can be read about here.

Elsewhere initiatives like the Year of Care approach in the treatment of diabetes or the Nesta-supported people powered health project in Lambeth have succeeded in uniting the lived experience of individuals and the learned expertise of professionals to improve health and wellbeing; a topic we have written about in a previous paper looking at coproduction in health and social care.

Commissioners benefit when they have a good understanding of what patient participation is

As examples like those above show, commissioners benefit when they have a good understanding of what patient participation is, and apply it in their approach to commissioning services. Working with others locally should be a central element to their approach. Partners such as the local Healthwatch, patient participation groups, and voluntary and community sector can be extremely valuable in helping CCGs to encourage communities and individuals to influence and control local commissioning.

Case Study: North East Lincolnshire CCG

North East Lincolnshire has implemented a way of working which ensures that clinicians, managers and community representatives are all directly involved in decisions concerning service improvement.

To do this, it has created an organisational structure that balances the inputs of clinical leaders (GPs on the CCG’s Governing body), service managers and representatives from the community forum. This approach ensures that all decisions are clinically-led, professionally managed, shaped by the community; or as one local clinician put it, that the CCG delivers care which is “responsive to community wishes and priorities.”
Involving patients in improvements to their own care

In many instances the notion of “doctor knows best” persists on both sides of the consultation table. This is due partly to the imbalance of knowledge and expertise between professionals and the public, and also to the deeply entrenched attitudes and relationships between doctors and patients. Many patients find allowing medical professionals to take responsibility for their treatment to be comforting, as it eradicates the uncertainty of making difficult decisions. Some clinicians too prefer this approach and view any deviation from it as an abrogation of professional responsibility.

However a growing body evidence suggests that when patients are more involved in decisions about their own care, outcomes improve. Evaluations of programmes as diverse as the enhanced recovery care pathway and the Department for Health’s information prescriptions pilot have shown that engaged patients are more satisfied with their primary care consultations and the outcomes of referrals to secondary procedures.

Shared Decision Making - “an approach where clinicians and patients make decisions together using the best available evidence” (Elwyn et al, BMJ 2010) - is another such initiative.

Unlike the traditional medical approach of “informed consent”, SDM is a technique characterised by informed choice. It is used in circumstances when there are multiple treatment options that have the potential to be equally as effective. Using SDM patients and clinicians work together to come to an agreement on a particular course of action, ensuring treatment prioritises what matters most to the patient. For example, in the treatment of early-stage breast cancer patients can often choose between a lumpectomy (surgery that preserves the breast), or mastectomy (which removes it entirely). The benefits and risks of both of these treatments are similar enough that the decision over which course of action to follow should be up to the individual patient.

In addition to epitomising the new NHS “no decision about me, without me” mantra perfectly, SDM also has money saving potential with some evidence indicating that using SDM patients tend to prefer less invasive and thus cheaper treatment options.

As simple and appealing as SDM may sound in theory, embedding it in practice is far less straightforward. SDM may be resource light, but it is time intensive, and the ability of GPs to fully embrace it within the tight period allotted for consultations remains a concern. Furthermore, if SDM is to counter the charge of being overly academic, which some currently level at it, then there is a need to both raise the awareness of patients about their potential to make decisions concerning their own care, and in some circumstances, to raise their capacity to do so effectively. Like any type of behavioural change, SDM is more likely to be successful if it is introduced by increment and made as easy as possible for people to adopt.
Dr David Thompson, a GP in the North East who spoke at our seminar, gave examples of how patients could be encouraged to share their views through being asked three questions about their values and experiences – as shown on the image below.

Example of an A6 flyer used in appointment letters, waiting areas, and consulting rooms, in Collingwood Surgery, North Shields.

There are of course many other ways patients and clinicians can work together to decide treatment options, including numerous improvements made possible by the rise of mobile health technologies. A great example is My Clinical Outcomes, an online platform which helps patients and doctors manage long term conditions: patients can track clinical conditions throughout the care cycle, and doctors can remotely monitor outcomes that matter to patients to inform decisions and ensure care quality. It enables patients to share self-recorded data with clinicians to both inform treatment options and close the feedback loop by letting doctors know what the effectiveness of treatment they prescribed was. It is crucial therefore that health professionals design as many ways as possible of increasing the chances of collaborative practice between patients and clinicians.

Case Study: The MAGIC Programme

The MAGIC programme brought together a small group of passionate frontline staff, managers and academics in NHS sites in Newcastle and Cardiff to implement and embed shared decision making at individual, team and organisation level.

The programme included skills development workshops for participating clinicians, the development and implementation of decision support tools for use in consultations, and a marketing campaign to increase organisational and patient awareness of SDM.

In evaluating the success of this programme OPM made a number of observations and recommendations which could encourage the implementation of Shared Decision Making elsewhere. These include:

• The importance of stronger and more widespread efforts to raise patients’ awareness of and capacity to engage with SDM (including support to patient representative groups)
• The creation of mapping tools to enable service managers and commissioners to understand how care pathways can support SDM and where the decision points lie
• The development of national measures that can enable NHS managers to monitor and track patient experiences of SDM and outcomes
• Provision of training and development programmes to support SDM, available to clinicians at all levels in the system
• The re-development of NHS and local authority information systems such as GP and NHS trust software systems so that SDM tools and information are readily available to clinicians and to patients, through patient records.

You can learn more about the MAGIC programme [here](#).
Conclusion

As with any transformative process, patient engagement is championed by a minority of innovators and resisted by a minority of those with slower uptake. The vast majority of both patients and health sector professionals will be convinced to work and interact together in new ways if a compelling case can be made for doing so. Engaging patients and the public meaningfully throughout the decision-making cycle can contribute to improving outcomes in care.

Mainstreaming patient power requires a supportive NHS culture, and shifting hearts and minds is needed as much as changing systems and policies. Change starts with setting new expectations for NHS leaders and health professionals, developing a champions network, and supporting workforce training and empowering commissioners to move patient power from the fringes to the centre. A great deal of emphasis is placed on methods of public and patient engagement, but embedding this way of working is about choosing a fit for purpose method or mix of methods - one size doesn’t fit all. There are plenty of new and innovative tools available that can be tailored and used in different contexts, such as social prescriptions, online access to GP records, and Patient Decision Making Aids. There’s also a wealth of services designed to encourage patient involvement in their own care, such as Personal Health Budgets, social prescribing, online peer support and the expert patient programme.

The uptake and effectiveness of these efforts is likely to increase as a robust evidence base grows around them. This of course relies on the creation of mechanisms to measure impact. As part of the MAGIC programme for instance, new simple measures were developed that could assess in ‘real time’ the extent to which patients felt involved in decisions about their care, with the data being fed back into clinical meetings to inform further improvement. Evaluating and measuring impact will not only be useful for ongoing learning, it also provides accountability mechanisms, which can support patients and the public to hold those who govern and implement NHS services to account.

As our case studies show, there are plenty of reasons to be optimistic the idea that health and social care shouldn’t be done to people, but with people, is catching on. NHS England in particular has made great progress in creating a new environment for patient and public involvement (through initiatives like NHS Citizen); but perhaps more significantly, they have also helped to raise patient and public involvement towards the top of the sector’s agenda.

There is also real potential to link patient and public involvement with the other transformative change currently taking place within the health service – the integration of health and social care. As we wrote in our previous policy briefing on this topic the success of health and social care integration is “predicated upon a change in mind-set from all those working in the field”, with “organisations and individuals required to collaborate better”. This striking similarity between the integration and the engagement agendas offers those working in the patient and public involvement field the opportunity to collaborate with integration colleagues and use the reforms currently taking place as a catalyst to enable patients to improve the NHS further.

About OPM

OPM helps local authorities, CCGs, community and acute sector providers and the voluntary sector to involve patients and the public in their decision making processes. We offer wide ranging support from strategy to evaluation as well as leadership development, commissioning support and master classes. This includes development and training for senior management teams and practitioners, as well as programme managers.