We need strategy for patient involvement in the NHS

The UK government is heavy on the hyperbole of empowering patients but lacks a robust strategy, says **Sarah Thornton**

Respect for a patient's individual autonomy is an accepted principle in modern medicine. In the past half century, the concept of autonomy has usurped medical paternalism in almost all of its forms and has aspired to promote patients from passive recipients of care to partners in planning their own treatment.[1] Now the concept has extended beyond individual autonomy to an expectation of empowerment at the population level.

The notion of patient empowerment is reflected in the development of regulation and guidance, and phrases such as "patient led care," "putting patients at the heart of the NHS," and "shared treatment decision making" abound. Since the NHS Plan in 2000, the UK government has promised to "encourage the involvement of citizens in redesigning the health service from the patients' point of view."[2]

Despite the strong rhetoric, however, there has been no consistent strategy for involving patients. The approach to enabling patients and the general public to have more say about how services are planned and developed has been piecemeal,[3] and the bodies set up to facilitate patient involvement have been transient.

The first of these to be established, the Commission for Patient and Public Involvement in Health (CPPIH), was abolished four and a half years later in the Department of Health's cull of NHS arm's length bodies.[4] The CPPIH's patient forums were replaced by Local Involvement Networks (LINKS)—which, although similar in structure, had greatly reduced powers of monitoring, inspection, and involvement.[5] LINKS, in turn, were abolished when national Health and Wellbeing Boards were established in 2012, with their brief to bring together those involved in healthcare, as well as lay representatives from HealthWatch, England's national consumer champion, to jointly plan how they can best meet local health and social care needs.

Throughout the restructuring the aspiration of patient empowerment has persisted, but the lack of continuity has led to fragmented approaches that have delivered little. Even now, despite their patient centred remit, the Health and Wellbeing Boards are reported to be resorting to "taking an imaginative approach to engaging with stakeholders."[6]

MALCOLM WILLETT

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Fourteen years on from the NHS Plan, the strategy for involving citizens in redesigning the health service from the patients' point of view remains unclear to those who have the task of delivering it.

The lack of direction about how to enable meaningful patient involvement does not mean that the principle lacks significant support. Without clear guidance, however, patient empowerment has been confined largely to providing patients with the opportunity for greater information about the treatment being planned for them; improving patient choice about where and when to be treated; and facilitating, using hospital based patient advocates, opportunities for patients to complain.[7]

Patients' views have been collected using ad hoc hospital surveys, without knowing the right questions to ask. Lay positions have been created on patients' forums and citizens' panels without any assurance that the views of incumbents represent the views of the general patient population. In short, despite the noble rhetoric of patient empowerment, the reality has been incoherent and disparate.

Without a framework for a more organised approach, the government has condoned the unstructured involvement of patients by saying, "All sources of user feedback enable providers to assess the quality of their services."[8] Although it is true that the piecemeal collection of patient feedback—such as standalone surveys, crowd-sourcing, online sites that document patients' experiences, and the Patient and Public Involvement Specialist Library—may help to provide context, these do not represent an organised approach to identifying or defining, at a population level, the way in which patients would like the NHS to work.

The question now is: can what has so far been the hyperbole of patient empowerment be made to work? The guidance on participation recently published by NHS England persists with the rhetoric around patient centredness.[9] It promises that commissioning will be underpinned by robust public and patient involvement. The articulation is powerful, the intention is laudable, but the tools proposed for ensuring involvement amount to a recommendation metric (the friends and family test) that will give NHS England a satisfaction rating but will not explain the rating or say how to improve it. The focus on introducing another measurement highlights how little understanding there is of the difference between patient measurement and patient involvement. Disappointingly, the plan says nothing about what "robust public and patient involvement" there may be beyond the friends and family test.

But how might a systematic approach be developed? The commercial sector uses process mapping of the customer journey, to understand their customers at the population level. Similar methods have occasionally been used at a local level in the NHS to identify bottlenecks and reduce delays and to improve care processes for patients and staff.[10] This process mapping has also been suggested as a systematic way of altering the focus of care towards the activities most valued by patients.[11]

Now is the time to explore further whether process mapping of the patient journey can move patient involvement and empowerment beyond the hyperbole.

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EDITORIAL, p 8

NO HOLDS BARRED Margaret McCartney

A trial to extend breast cancer screening may be unethical

A trial extending the ages at which UK women are eligible for breast cancer screening was registered in 2010. Its target is "at least" three million participants.[1] But was government policy to extend it, regardless of the trial's findings?

Currently, only women aged 50-70 are eligible for breast screening. This trial randomises centres to invite women for extra screening at ages 47-50 and 70-73, or not.

On 9 July 2014 David Walker, chairman of the UK National Screening Committee—which makes evidence based recommendations to the government—told the Commons science and technology committee, "We have not decided to implement the age extension, although we support the trial to see whether we should be implementing it. Once the trial is complete we will make a recommendation."[2]

Public Health England says that age extension is being phased in and is expected to be complete in England by 2016.[3]

The usual screening invitation comes with extra information…it does not mention the possibility of net harm

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The research ethics committee application, whose chief investigator, Julietta Patnick, is director of NHS Cancer Screening Programmes, noted "limited evidence" on the value of extra screening, adding, "Regardless of this study, the age range for breast screening is being extended from ages 50-70 to ages 47-73."

Department of Health policy in 2007[4] and 2011[5] was for screening services to extend the age range or take part in the trial[5]—but this wasn't merely politics.[4] Mike Richards, the department's national clinical director for cancer and end of life care, told *The BMJ* in 2011, "A further extension from 47-73 is, on the advice of independent academics and with the support of the ACBCS [Advisory Committee on Breast Cancer Screening], being introduced through randomisation."[6] This policy seems to have been used to justify the trial in the research ethics committee application; but the benefits of age extension are uncertain.

And do women even know that they are participants? The researchers request no individual consent. The usual screening invitation comes with extra information saying that "the phasing-in of the age extension is randomised" so that "the net benefit can be scientifically evaluated." But it does not mention the possibility of net harm.

In the ethics committee application, the risk of overdiagnosis to three million more screened women is not spelled out. It justifies potential harms because the age range "is being extended anyway."

And yet, the National Screening Committee has given no recommendation for age extension. What's more, Michael Marmot's 2012 review stated, "The impact of breast screening outside the ages of 50-69 years is very uncertain."[7] Shouldn't someone tell this to the women taking part in the trial?

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BMJ BLOG OF THE WEEK Neal Maskrey

Feeling the force of the QOF

My generation of doctors began their medical careers in very different circumstances to now—one where competence was implicit. But, after several decades of serial NHS disappointments, disasters, and scandals, new doctors enter a brave new world.

We now have highly structured foundation and specialist training, revalidation, and, in general practice, one of the world's largest pay for performance programmes: the quality and outcomes framework (QOF). As I write those letters, QOF, I hear the collective intake of breath from GP readers. There's a moment in *Star Wars*, when Obi-Wan Kenobi shudders after detecting the cries of millions of people as Princess Leia's home planet Alderaan is destroyed by the evil empire's Death Star. Believe me, I feel the force. I know that the QOF is controversial. Bear with me.

Introduced in 2004, the QOF meant that—almost overnight—25% of GPs' practice income became dependent on meeting a range of clinical, organisational, and patient experience indicators. A number of studies have examined whether quality of care improved as a result; disappointingly, the effects seem to be limited and short term.

Perhaps a minority of practices were at last motivated to improve the organisation of care for chronic diseases, but the effect was short lived. And the downside is sensitive consultations interrupted by electronic tick boxes, along with accusations that the QOF distorts clinical focus, with an emphasis on things that can be measured, rather than what is important. Does the pop-up box on the computer, reminding the GP to take the patient's blood pressure, help or hinder care when the patient has come because their wife of 40 years died last week?

It was all very predictable. There's a general principle called "the inverted U" that was first described by Yerkes and Dodson. As an example, take the care of people after a myocardial infarction. Several medicines have a good evidence base for secondary prevention of ischaemic heart disease, but if the organisation of care is poor then these medicines may not be provided and the quality of care suffers. Make the care happen with incentives, data, and external standards, and the uptake of the evidence based interventions improves.

But if evidence based care becomes rules based care, then people who shouldn't be taking—or who don't want to be taking—one or more of the medicines may end up on them.

The downside is sensitive consultations interrupted by electronic tick boxes

Quality initially improves with better organisation, and then suffers with continuing coercion.

For the QOF, it seems clear that the effects of pay for performance are less than payers would wish, and the policy has had unintended consequences. So when we are struggling with improving the quality of healthcare, and considering coercion (making it happen) or support (helping it happen), perhaps we should think of this principle? All together now: not too much, not too little.

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