A modern NHS requires collaborative leadership with patients as leaders at decision-making tables

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The story of the NHS can be recast as a narrative on power. Faced with the threat of a BMA strike, the founder of the NHS, Aneurin Bevan, conceded that GPs would retain the freedom to run their practices as small businesses. Consultants were given more money, and allowed to keep their private practices. In Bevan’s own words: “I stuffed their mouths with gold.”

The battle between policy makers and medical professionals and institutions centres on notions of “accountability” (how money is spent) and “quality” (how care is delivered). Both “sides”—managerial and medical—badge themselves as people’s sole advocates. Doctors still as advocates for patients and the government as advocates for citizens, despite deep changes in the healthcare context.

In effect, we have a “patient-centred” NHS being run by system leaders who are the managerial and clinical elite. It is akin to a “woman-centred” organisation being run by men.

During the junior doctors’ strike in 2016, for example, “patient safety” became the mantra for both the BMA and government. But each side interpreted what that meant through their own frame of reference. Nobody bothered to ask patients. This, despite a letter in *The BMJ* from patient leaders asking for a voice in the dispute.

It is time to challenge this binary debate as to who speaks for patients and citizens. We can speak for ourselves. Unfortunately patient and public engagement is undertaken usually via two main approaches—“feedback” or “representation.” The former buffers patients from power as feedback is narrowed to people’s experiences of services (rather than what matters more widely) and professionals deciding what can be done. The latter relies on “representatives” being slotted in to institutionally narrowly defined committees.

Thus, the jewels of wisdom and insight that people experiencing illness and the healthcare system are lost or undervalued. If the modern NHS is to survive, it requires new forms of collaborative leadership that model partnership.

There are good examples of where “patient leadership” is beginning to work and plenty of examples of “patient partnership” work in improvement. *The BMJ* has been ahead of the game in furthering the cause. There is an emerging movement of “patient leaders”—entrepreneurs, activists, quality improvement specialists, and digital pioneers set to revolutionise healthcare.

But within NHS citadels, these improvement efforts are not matched in terms of corporate practice, health economy decision making, or policy making power.

Patients and the public have been excluded from senior decision making roles in structures created around new “models” of care design and delivery. This includes “sustainable transformation plans.” Subsequently, issues that should be discussed openly with patients and citizens as part of decision-making are happening behind closed doors.

This includes issues like whether to spend money on “low priority procedures” or carrying out “clinically effective commissioning.” These all affect patient choice. Discussions on integration affect how money is “shared” across different providers and re-structuring of commissioning has an effect on different models of care.

The problem with suppressing dialogue is that it undermines trust and transparency—the key ingredients of collaborative leadership.

Is there a renewed fear of public engagement, due to the heat of political ideology? I sometimes wonder whether the mythologising of the NHS is part of the problem—creating a climate of polarisation and volatility, and driving decision making underground. It reminds me of my grandpa. When his driving grew erratic, my dad said: “don’t let’s talk about his driving. It will kill him if we do.” I remember thinking “it will kill him if we don’t.”

Our work at Sussex MSK Partnership (Central) provides a different way forward. As a patient director, I try to create spaces for people to talk and work together. For example, our group of patient and carer partners has established its value in improvement work. Now, we are piloting how partners can be part of multi-disciplinary team meetings across our clinical pathways and thus be embedded in decision-making in a way that mirrors my role as patient director at executive level. But there is still a long way to go, and all of the work that we are doing is happening at a time of huge operational pressures.

The NHS has changed in 70 years. It now has to change again to adapt to the rising patient and citizen movement. I don’t want to save the NHS if saving it means preserving the status quo. I don’t think Bevan—always for the people—would have wanted it that way.

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*David is also writer in residence at The Bethlem Gallery. On 5 July, he is leading a day of creative dialogue with artist Beth Hopkins, on “what does the NHS mean to you?”*

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From the archive, Patient perspectives