

**Major health service transformation and the public voice: conflict, challenge or
complicity?**

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Abstract

Objectives: Calls worldwide for major reconfigurations of health care systems have been accompanied by recommendations that wideranging stakeholders be involved. In particular, patients and the wider public are seen as critical contributors as both funders and beneficiaries of public health care. But public involvement is fraught with challenges, and little research has focused on involvement in healthcare transformation initiatives. This paper examines the design and function of public involvement in reconfiguration of health services within the English NHS.

Methods: Qualitative data including interviews, observation and documents were collected in two health care ‘transformation’ programmes; interviews involved including public and professional participants. Data were analysed using parallel deductive and inductive approaches.

Results: Public involvement in the programmes was extensive but its terms of reference, and the individuals involved, were restricted by policy pressures and programme objectives. The degree to which participants descriptively or substantively represented the wider public was limited; participants sought to ‘speak for’ this public but their views on what was ‘acceptable’ and likely to influence decision-making led them to constrain their contributions.

Conclusions: Public involvement in two major service reconfiguration programmes in England was seen as important and functional, and could not be characterised as tokenistic. Yet involvement in these cases fell short of normative ideals, and could inadvertently reduce, rather than enlarge, public influence on system-reconfiguration decisions.

Keywords: Patient and public involvement; representativeness; health service transformation

Introduction

Demographic, clinical and social shifts are putting pressure on health care systems in Europe and elsewhere, and prompting calls for the reconfiguration of the delivery and organisation of health services.^{1,2} Change can cause controversy however, especially where there is strong scepticism about the motives behind proposed reforms.^{3,4} In response, policy development and implementation is increasingly moving from ‘top-down’ models towards approaches that seek to involve a wide range of stakeholders.^{2,5} Stakeholders include not just clinical and managerial staff within health care organisations, but also patients and the wider public, who are increasingly seen to offer a legitimate contribution to service reconfiguration,^{2,6} and who can derail unpopular changes.³

In England, the pressure for change has increased with an increasingly constrained budget for the National Health Service (NHS) alongside growing demand. Ongoing reform efforts are focusing on a shift from the hospital into the community.⁷ However, the pace of change has been criticised,⁸ arguably hampered by the complex, pluralistic nature of health care organisation in England that is characterised by both competition and interdependency between a host of provider bodies.^{9,10} Recently, NHS organisations have been required to collaborate more closely to produce regional ‘Sustainability and Transformation Plans’ (STPs) that incorporate system-wide changes to “deliver the right care, in the right place, with optimal value.”¹¹

The involvement of patients and the public in major reconfigurations of health services is enshrined in legal frameworks and policy guidance, nationally^{12,13} and internationally.² Extensive public involvement is perceived to be “a key issue for achieving successful system transformation,”² and according to NHS England,¹² “the best proposals [for service change] are characterised by early and on-going engagement through all stages of the process, where

communities are involved as partners in actively developing proposals.” Yet initiatives for service change have consistently been criticised for failing to account appropriately for public opinion and public involvement, which are often characterised by secrecy around politically sensitive changes,¹⁴ and by a focus on securing support for a predetermined vision over engaging the public in system redesign.¹⁵ In England, inadequate community and stakeholder engagement has been among the most common reasons for reconfiguration proposals to be referred to the health ministry,¹⁶ especially where plans were perceived as financially driven.¹³

These tensions are also highlighted in the wider academic literature on public involvement. ‘The public’ is a heterogeneous entity comprising multiple, sometimes conflicting, interest groups, with for example ‘the public’ in their role as taxpayers and service users likely to have different wants and expectations from service reform.^{17–19} Arguments for public involvement are variously premised on its potential technocratic benefits and on a democratic, normative rationale, but these arguments too may be conflicting.^{20–22} Consequently, forms of public involvement that satisfy all expectations are elusive. Approaches are often criticised for failing to include the breadth of publics,^{23,24} for prioritising public participants that are more easily accessible,^{22,24} or for involving the public in a tokenistic or superficial manner.^{25,26}

There have been few systematic examinations of public involvement in major service change. Studies in England have focused on the dynamics of public opposition to (rather than involvement in) service reconfigurations such as hospital mergers and closures^{4,27–29} or have highlighted the role of public involvement but without examining it in detail.^{15,30} In this paper, we draw on data from two case studies of involvement in major service reconfiguration in England to contribute to better understanding of (i) the drivers behind the approaches taken to public involvement in health care reconfiguration; and (ii) the consequences for the form taken by involvement, and its ability to both provide active input and fulfil legal requirements.

Methods

Our analysis draws on a study of public involvement in the development of regional plans for service reconfiguration in the NHS. This included qualitative data collection between November 2015 and September 2016 in two English regions where NHS organisations were working together towards system-wide health service reconfiguration. We label these programmes ‘Transforming Care in Weffolk’ and ‘Care Closer to Home in Esshire’. The selection of programmes is best described as a convenience sample: access was secured through connections with key stakeholders made in the course of the early stages of the study. The intended objectives of the two cases exemplified those being pursued across England,^{7,11} and each involved a wide range of NHS commissioning and provider organisations, local authorities, and other stakeholders.

Data collection included: interviews about the programme and its public involvement processes with key stakeholders including programme staff and involved members of the public; observation of involvement meetings; and documents including strategy and planning documents and minutes of meetings we could not attend. In both sites staff were predominantly administrative and managerial by background, including dedicated public engagement officers, senior programme officials, and communications managers. Data collection was more extensive in Weffolk, where the programme was more advanced; accordingly our analysis drew primarily from this case study, using data from Esshire’s programme to corroborate or question findings from Weffolk. In total we conducted interviews with 55 participants (32 in Weffolk; 23 in Esshire), and observed 14 meetings (nine Weffolk; five Esshire).

Our approach to analysis combined inductive and deductive approaches.³¹ Deductively, we developed an initial coding framework from the literature on public involvement; inductively, we supplemented this with new codes based on unanticipated themes found in the data. We modified, developed and amalgamated codes as we read and re-read data sources. Coding was accompanied by ongoing discussion among the authors. [Author1] drafted an

integrated analysis of the findings, which was developed and agreed by all authors. Due to limitations of space, we rely on interview excerpts to illustrate our findings, although our analysis drew on the entire dataset.

Findings

We focus first on the programmes' priorities and the way these permeated expectations around the scope of public involvement in the development of their plans. Then we consider the involvement process—and particularly how the perceived purpose of involvement influenced the selection of participants and the roles they undertook. Finally, we examine the nature of the contribution offered by participants, and their relationship with the wider public.

Due to the sensitivity of the subject and some of the data, we refer to interviewees only as 'professional participants' (including all staff) and 'public participants' (involved patients and members of the public, not employed by health care organisations).

The transformation context

In both programmes, stakeholders who were involved closely with the transformation plans expressed a strong sense of urgency, driven by both the policy discourse that framed change as crucial to sustain the NHS,⁷ and more proximate pressures from national authorities to move plans towards approval. Development of plans for reconfiguration had to follow a stepwise process detailed in national guidance.¹² Plans would ultimately be subject to a formal public consultation, but to reach this stage, national guidance required assurance that the plans passed the government's four tests for reconfiguration, including evidence of "strong public and patient involvement."¹³ Professional participants sought to address this requirement.

"It's an assurance level put in by NHS England, they look for evidence of what engagement you've already undertaken, to inform the plans that you're putting forward to them. [...] If it's something where we think we're going to have to go to formal

consultation, then we would do what we need to do in terms of engagement.”

(Professional 16)

The risk of delay in approval, or of later legal challenge to the process, was prominent in interviews with professional participants. Public involvement was given sustained, senior level attention, even if for them the case for change seemed clear:

“We have to go through the gateway process [mandatory review] and all this clinical review stuff, and we have to tick the box to say that we are going to go through a lengthy consultation about everything, even though to everybody sat round the board who has looked at the data, the issue is clear as the nose on your face: this is what you should do.” (Professional 3)

Accordingly, the programmes undertook a wide range of public facing activities, including not only active public involvement processes but also broader communications and engagement events.

Simultaneously, however, there was a sense that this same policy context made thoroughgoing public involvement more challenging. Perhaps influenced by the sense of urgency conveyed by politicians, think tanks and national leaders, professional participants felt that large parts of the programmes were not up for debate: if local NHS provision was to remain sustainable, change of this nature was compulsory:²⁷

“If all clinical evidence points to us doing something, and we have got public and patient involvement, and even if every single person says, ‘No, we don’t think that’s a good idea,’ but clinically, it is the only safe option, we are going to do that. You cannot veto that.” (Professional 9)

For professional participants, therefore, whatever guidance recommended,¹³ it was far from evident that all aspects of plans should be subject to public involvement, or that involvement should stretch throughout the proposal-development process:

“I understand the argument for people getting involved at an early stage, but for me

there is a stage before that. There has to be a time where clinicians can safely discuss what the options are without causing alarm to people because a lot will be discounted. [...] We don't want to alarm people. We don't want to set hares running. We want to be able to talk because these are what we think are sensible options.” (Professional 2)

The weight of expectation about what the plans would deliver, then, meant professional participants were alert to the need to demonstrably involve the public in developing proposals, but also created doubts about exactly what should and should not be exposed to public scrutiny and input, reflecting tensions in the wider public involvement literature.^{18,23,26} These drivers also manifested in the way public participants were recruited for the process.

Populating involvement: challenges of representativeness

The imperative for involvement meant that professional participants worked hard to ensure that it was included in all clinical aspects of their programmes, but this was easier in some areas than others. Direct experience of and interest in the issues covered was seen as desirable, but not always easy to obtain, especially given the pressing timescales:

“Practically, people don't have that amount of time and we can't find people because there's not anyone interested in volunteering for some obscure condition that not very many people have. [...] There's a lot of people that have got an interest in cancer, but there's far less people that have got an interest in nephrology. For example.” (Professional 10)

Involvement leads sought to recruit participants who combined interest in the area with enthusiasm and relevant skills:

“Basically what we asked for were two or three key things. One was around why they wanted to join the group, just wanting to know what their motivation round joining the group was. ‘What could they bring to the group?’ was the other question that we posed. And what's their interest around this? How could they contribute?” (Professional 11)

The result was public-involvement groups populated primarily with individuals who had experience of such work in the past, recruited through networks or a ‘tap on the shoulder’ from a professional or fellow public participant who knew they could be relied on to contribute.^{23,24} The following route into the groups typified the descriptions given by the public participants in our sample:

“I was invited by a friend who’s on the Healthwatch board [consumer champion body] if I would be interested in going on a committee. [...] There were a set of workstreams offered. I had musculoskeletal problems. [...] It was something where I felt I did have some of my own knowledge, and obviously, because of that, I knew people who also had musculoskeletal problems, and I felt I could represent them as a voice.” (Public 23)

“I have been involved with health starting as a non-executive director of a primary care trust. Going back to around about to the year 2000 onwards. [...] I] was very active with [patient and public involvement] and then more recently there have been formal opportunities through Transforming Care [in Weffolk].” (Public 7)

Professional participants expressed some concern at this preponderance of helpful but familiar faces: “semi-professional patient voices who end up on different committees” (Professional 5). Some public participants, too, noted that their profile looked rather different from the wider public. They felt they could struggle to provide input that they felt would reflect the views of the wider public:

“It’s mainly white, retired people. And, you know, I fit in a younger age bracket, but not by much.” (Public 24)

“There is an interesting debate to be had about how any of us fulfilling these roles really are genuinely representing the ordinary patient in the street. I think we take our life’s experiences and the contacts that we have to input our best guestimate of how the typical person in the street might view something. But hand on heart, I think it’s quite difficult for all of us to be able to point to a constituency that’s helped us arrive at the

decision we've had.” (Public 18)

Representativeness, both descriptive (the degree to which the demographic characteristics of those involved reflected those of the wider public) and formal (the connection and accountability from public participants to the wider public),²⁰ was thus problematic. Moreover, the involvement process itself added further challenge to any sense of accountability to a wider constituency. Much of the activity of the public-involvement groups was bound by rules of confidentiality, preventing professionals from discussing it with those outside the process ahead of formal consultation:

“It's things that we can't, I can't, talk about because it's not out in the public domain yet, and it's all still being worked on and NHS England are looking at it as well. So the Transforming Care, it all has to go through NHS England and be approved by them before we can go out to consult.” (Professional 7)

The public that came to be involved in the transformation programmes thus had limited representative legitimacy, at least if judged in terms of descriptive or formal representativeness.²⁰

Involvement's function: voicing or mediating public opinion?

Notwithstanding such challenges, public participants sought to make helpful contributions to the programmes, drawing on their own knowledge and presenting questions and comments that they felt wider members of the public would put forward. In particular, given the focus of the programmes on spatially reorganising care, they were keen to ensure that the proposed changes did not disadvantage particular geographical areas of the large, diverse counties of Weffolk and Esshire:

“[Care Closer to Home in Esshire] is about preventing people from going into hospital, really. It's a very good idea, but you've got to have the staff that are properly trained and qualified. And enough of them to carry out this care in the community.” (Public

11)

“[The commissioners were saying,] ‘Look, if we move *x* out of here, where will it go and what hospitals will we close?’ It was real tough stuff which they’ve got to think about, and I was able to give, ‘Well what if you do this, what if somebody from north Weffolk is trying to get to central Weffich, fine, but have they tried to get to south Weffich and they’ve got to catch a bus, how do they do that?’” (Public 19)

By public participants’ own account, they saw their role as helping to ensure that the transformation plans worked for the breadth of the potential patient population. They did not, however, see it as within their remit to question the principles underlying the programmes, or their overarching direction of travel. Indeed, they were largely supportive of what they acknowledged was a controversial set of changes—and they acknowledged that this meant their views could be at odds with those of much of the wider public:¹⁷

“Financially, we can’t stay as we are so and we’ve got this opportunity to tap into a package of money for health that will help us achieve some short-term financial savings probably. But, in the longer term—I’m trying not to be too cynical—I think it *is* going to give services closer to home, closer to where people need them, and giving people more flexibility and accessibility.” (Public 15)

“The hard decisions are things like closing or changing the remit of a major part of Weffolk Teaching Hospitals, moving an awful lot of care out in the community, against a tide of public opinion which is very largely that they’d rather just go to the big hospital, even though it’s far more expensive and not sustainable. [...] One of the hardest things is going to be to get the public to accept that you don’t get to a big hospital all the time.” (Public 16)

This view, of course, was not shared by all the public. In both areas, campaign groups affiliated to national movements such as Keep Our NHS Public³² challenged the notion that programmes such as Transforming Care and Care Closer to Home were clinically desirable and financially

viable. But membership of such groups and of the official public involvement forums rarely overlapped, as the sole individual who belonged to both groups in Weffolk noted:

“As soon as I joined, went on the PPI, it was as though there was an assumption that everybody there agreed with Transforming Care, and I was the only person not coming from that point of view, for reasons that you know: I’m in a campaign against privatising the health service.” (Public 4)

Moreover, even as they expressed what they saw as the most pressing concerns for the wider public, public participants actively filtered these views. They distinguished between what they considered the more reasonable perspectives of the public, and the views of those with particular sectional interests, or who were attached to what participants saw as outmoded approaches to health care provision:

“There’ll be a lot of sceptical members of the public who, ‘Well this is going to be trying to save money’. It isn’t about saving money; it’s about making efficiencies and making money work better. And it’s getting that across to the public. [...] There was a very small group, I call them saboteurs really, got involved in [the proposed closure of a community hospital. ...] When it was explained to them why the hospital had to close, most of them understood; a few didn’t like it.” (Public 19)

“I think most people are always ready to engage and I think that is our first option. Somehow, I don’t know if some people still believe we are best off with the banner-waving brigade and stand outside; I think that we are past that now, I think most people appreciate that we have got to have a mature discussion.” (Public 7)

Accordingly, public participants came to occupy something of a mediating role. They made judgements about what aspects of public feeling they fed into the programmes, on the basis of their (perceived) reasonableness and potential to be heard, which depended in part on their alignment with the wider direction of travel of the service reconfigurations:

“NHS England has now a patient and public involvement strategy but it’s all words,

unless the clinicians and the managers are convinced that the voice is valuable. And the voice is only going to be valuable if it's an informed voice. There's nothing worse than somebody just talking about their own experience or the experience of their neighbour next door endlessly. Instead of saying what are the fundamental issues, instead of thinking and understanding that you can't have a general hospital in every small town."

(Public 16)

The participants' mediating function also worked in the other direction, helping to ensure that plans were communicated to the wider public in a manner likely to smooth rather than stir the public's concerns. This role was welcomed and cultivated by professional participants:

"If you're going to do something, close a hospital, for example, it's on the cards, and that's where we are now, how do you manage the rumours pre-consultation? My plea has been, 'How can you put forward a good story?' You shouldn't say, 'We're going to do this and we're going to close a hospital'; you should start with, 'Oh, you are going to have this new service, with a new outpatients' and something like that, and put the good before the bad. And I've said to them, 'You have to work on how you manage the rumour'." (Public 9)

"We have got one person already, Philip who sat on the committee for this, so he's already got that in-depth knowledge, and it's amazing to see him in meetings. [...] Because [the public] expect us to say things, and very often they won't believe us. Whereas if it's a patient who's been involved saying, 'Well, actually, this is how the process has worked and this is what people have told us', then it works quite well. So what we're trying to do is create six or seven more Philips to help us!" (Professional 6)

Public involvement in the programmes thus took on a functional, appreciated, but very particular role, and one that explicitly filtered the 'public input' they received.

Discussion and conclusion

This analysis illustrates how financial and policy pressure for urgent changes to the configuration of services, combined with the policy imperative to involve the public appears to hasten a very particular realisation of public involvement. We examined two programmes in England that sought to develop major service reconfiguration plans. The programmes included substantial public involvement activity and dedicated considerable resources to support it. But professional participants expressed concern about involving the public in all aspects of reconfiguration, arguing for the legitimacy of processes that took place in private, or at least under strict conditions of confidentiality. Practice, then, diverged from policy rhetoric that seems to encourage public involvement throughout the process.^{12,13} Public involvement in practice included a rather narrow section of the public, and one which saw its role as contributing in a relatively constrained way to the transformation plans' realisation, rather than co-creating them or critically scrutinising them, let alone opposing them.

This finding is in line with other recent studies of public involvement in health service development in England,^{23,24} but it is particularly problematic in the context of major change for two reasons. First, from a policy point of view, the realisation of public involvement appears to differ substantially from prescriptions that stress the importance of involving the public in a thoroughgoing manner, with detailed input into all aspects of reconfiguration.¹² The urgency of change appears to undermine such involvement, meaning that its benefit is lost, and potentially increasing the risk of later resistance from a public that does not feel engaged (or indeed from opponents to plans who search for an opportunity for legal challenge). Second, the approach to involvement taken falls far short of, *and even risks militating against*, normative ideals that see public involvement as a democratic process, as a means of enhancing democratic influence and local accountability.^{21,22,25,33} Achieving such ideals in practice is also fraught with difficulty, not least because of the challenges of constructing a representative mandate between those involved and the wider public in the absence of a formal electoral

relationship.^{20,23} Our analysis further shows that representativeness is also challenged by an approach to recruitment of public participants that draws on established networks, resulting in a demographically narrow group. In addition, concerns about confidentiality prevent this narrow group of public participants from developing a substantive relationship with the wider public. Those involved sought to speak on behalf of the wider public, but filtered their views, and included only those that they felt would be acceptable and thus influential, while opposing views were omitted.

Our analysis highlights that public participants performed their role in good faith, and professional staff appreciated the ability of those participants to translate plans for the wider public and provide input on what that wider public might think. But this role was perhaps best characterised as a proto-professional,^{24,34} technocratic one in which participants were valued for their mediating ability rather than because they could speak as members of the public. They were valued as “experts in laity”¹⁹ rather than as public representatives. These were hybrid roles in which public participants at least partly embraced a managerial mindset and managerial preoccupations, similar to the process of hybridisation that has been described for clinical managers.³⁵ Regardless of the value of this role, or the good faith in which it was enacted, this is quite distinct from the active involvement of the public as normally construed. Our observations further add to the evidence reported elsewhere about the tension between the ‘expert’ and ‘lay’ contributions that are simultaneously demanded of public participants.^{19,22} In this context, the notion of ‘public involvement’ could thus conceal a process whereby the views of some publics are actually actively eliminated from the process.

A key implication of our findings, therefore, is that those responsible for public involvement in large-scale transformation efforts should consider not only what they can do to maximise opportunities for involvement, but also whether some approaches inadvertently work against active and inclusive involvement beyond a small, selective group. As Stewart puts it, “where policy entreats staff to involve ‘the public’, it should be clearer whether this means

simply creating an opportunity for all affected to take part (knowing full well that the vast majority will not), or actually going out and ensuring that the views of the affected (however defined) are heard.”³⁶ Practitioners too, and indeed public participants themselves, should be conscious that well meaning, functional, valuable approaches to public involvement may also have downsides that counteract the very goals that drive it in the first place.

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