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Education and debate

Public involvement in health care

Dominique Florin, Jennifer Dixon

The NHS needs to be clear about the aims and how to achieve them

The government is promoting public involvement in health care as part of new NHS policy.^{1,2} Proposals include allowing the public to elect members of the governing boards of foundation trusts³ and primary care trusts' obligations to engage with the public.⁴ However, clarity and consensus are lacking about what public involvement means in health care, why it is desirable, and whether current policies will meet the desired objectives. We examine the latest policies and their potential effects.

What public involvement means

Public involvement and other allied terms are used to mean a variety of activities or objectives. In this article we use public involvement to refer to the involvement of members of the public in strategic decisions about health services and policy at local or national level—for instance, about the configuration of services or setting priorities. Public involvement is different from patient involvement, which refers to the involvement of individual patients, together with health professionals, in making decisions about their own health care. Clearly, a spectrum of possible involvement of patients and the public exists between these two extremes. For example, user involvement may refer to a group of patients helping to shape a particular service. Arnstein defined another spectrum of public involvement, ranging from professionals giving information to the public to a genuine hand over of power and decision making to the public.⁵

Why is public involvement desirable?

Advocates of increased public involvement argue that public services are paid for by the people and therefore should be shaped more extensively by them, preferably by a fully representative sample.⁶ One assumption made is that greater public involvement will lead to more democratic decision making and, in turn, better accountability, but, as we discuss below, neither is necessarily the case. A second assumption is that more public involvement is an intrinsic good. This belief is based on values or ideology and thus cannot be tested, but it is often allied to beliefs that can be tested empirically. For example, one associated belief is that as many healthcare issues have important ethical as well as technical dimensions, involving the public may help ensure health policy decisions better reflect the values

of the community. This belief could be tested by assessing how far the mechanisms for involving the public help to reach a generally accepted view on an ethical dilemma. Public involvement is encouraged for these reasons in national bodies such as the National Institute for Clinical Excellence and the Human Fertilisation and Embryology Authority.

A second argument for increasing public involvement is that it will make services more responsive to the individuals and communities who use them and that more responsive services will lead to improved health. Underpinning these assumptions is the belief that professional definitions of benefit in health care can be at best only partial; only the users or local communities themselves know what they need, and it is ultimately their assessment of benefit that matters.

Public involvement policies

Policies to encourage public involvement in the NHS are not new. Previous governments have used various policies to attempt to redress the long standing democratic deficit in the NHS, with mixed success. The immediate predecessors to the current policies date back to the introduction of the internal market, choice, and competition into the NHS in 1990,⁷ followed by the Local Voices initiative in 1992.⁸ A review of policies from 1948 to 1997 suggests that public involvement in the NHS decreased over this period.⁹ In contrast, Klein and New reviewed the period from 1990 and concluded that there had been a moderate increase in democracy in the NHS.¹⁰ Since the Labour

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government came to power in 1997, a new raft of policies has been introduced with the stated aim of increased public or patient involvement or the allied aim of increasing choice (box). But will these policies meet the objectives of increased democratic input and responsiveness?

Democratic input

The policies described in the box may increase public involvement in the NHS but not necessarily in a way that is representative of the population. There are many methods of involving the public—for instance, citizens' juries, direct forms of participatory democracy, representative democracy, and public polling on particular decisions—all of which have pros and cons. Although not all forms of involvement have to be directly representative, research has shown that the choice of method and approach must be linked to the particular aims of specific initiatives.¹² Without this link, public involvement is unlikely to be translated into a decision that is representative of the public view or indeed meaningful. Also, as shown by Arnstein, genuine involvement requires transfer of power.⁵ Longstanding professional and managerial interests in the NHS may resist such a transfer, and this could result in token public involvement with no real impact on decision making. Indeed, health service managers have expressed scepticism about the red

tape and complexity of new public involvement arrangements.¹³

Current policies to increase public involvement are piecemeal and disparate. For example, the difference in the methods used to involve the public in foundation trusts and primary care trusts has no basis in evidence. It may result in confusion and differing perceptions of the legitimacy of decisions taken by foundation and primary care trusts.¹⁴ In general, more thinking is needed on:

- The appropriate degree and methods of public involvement at all levels of decision making in the NHS
- How initiatives in the NHS, and possibly in other parts of the public sector such as local government, can complement each other
- The balance between public and expert involvement in decision making.

Examining these issues could be a role for the new Commission for Patient and Public Involvement.

Even if recent policies were successful in encouraging representative and meaningful public involvement, they may not increase accountability. Weale outlined a central conflict in the governance of the NHS: voters elect a government that is responsible for the NHS and accountable to parliament through the secretary of state for health for the tax funding spent (Weale A, paper to the Health Equity Network conference at King's Fund, London, 11 November 2002). This democratic system gives voters little chance to influence local health services directly, and thus there is little accountability to local communities. But this imbalance may be appropriate given the central tax funding of the NHS—a point ignored in recent policies. Recent initiatives seek to increase local accountability, but this can happen only if democratic accountability to the secretary of state is reduced.

The policy on foundation trusts is interesting in this respect. The secretary of state will be barred from intervening in the running of foundation trusts unless the trust is failing. Instead, foundation trusts are to be accountable nationally to a new independent regulator, the Commission for Healthcare Audit and Inspection, and locally to primary care trust commissioners and the local population. How far this policy will strengthen local accountability depends on the behaviour of all the national and local bodies concerned, in particular the role of the independent regulator and the foundation trust. Will foundation trusts act on the views of the membership about the quality of local services, for example?

Responsiveness

The policies described above offer several ways to increase local involvement in decision making in health care. This might be expected to increase the responsiveness of services and hence improve health. These assumptions can be tested empirically, through patient surveys and by monitoring health outcomes. However, a recent systematic review concluded that although involving patients has contributed to changes in the way services are provided, little convincing evidence exists that these changes have improved quality of care, satisfaction, or health outcomes.¹⁵ This may be because of a lack of good research in an area that is methodologically fraught. It could also be because of

Current policies to encourage public involvement

New statutory duties placed on NHS organisations (NHS trusts, primary care trusts and strategic health authorities) by the Health and Social Care Act 2001 to make sure that patients and the public are consulted at an early stage about planning and organisation of services⁴

Patient Advisory and Liaison Services to be set up in every NHS trust to provide information and on-site help for patients

An Independent Complaints Advocacy Service provided locally, operating to national standards
Patients forums to be set up in every NHS trust to "bring the patient's perspective" to management decisions. Forums will be able to elect a member to sit on the trust board as a non-executive director

A "voice" to be set up in each strategic health authority area—a professional group acting as a local resource to help communities

The Commission for Patient and Public Involvement in Health is to set standards, provide training, and monitor new arrangements

Local authority overview and scrutiny committees, made up of elected councillors, now have powers to scrutinise the NHS.¹¹ The committees can review any aspect of NHS care locally and call NHS managers to account for their actions. They have the power to refer any potential change to the Secretary of State for Health for a final decision

The public will be able to become involved in the running of NHS foundation trusts by becoming members.³ Members will be the legal owners of the trust and will be able to elect representatives on to a board of governors and have a right to be consulted about changes to services

well established practical difficulties in effective ways of involving the public. These include lack of time and other resources; lack of interest among health service professionals and putative participants; and a lack of knowledge of how to translate public involvement into changes in health services.¹²

An alternative to public involvement, another approach to increasing the responsiveness of health services is patient involvement—giving individual patients a greater say in their care and treatment choices. Interventions to increase patient involvement have been shown to have positive health benefits.¹⁶ Patients can be enabled to take a greater role in decisions affecting their health care through several methods—for example, formal support for shared decision making and taking central control in the management of chronic diseases, as pursued by the Expert Patient Programme.¹⁷ Recent research into managed care organisations in the United States has shown that patient involvement is pursued more than public involvement.¹⁸

Another relevant policy is the patient choice initiative, which seeks to offer patients a choice of providers for elective (and in future chronic) care.¹⁹ The desire of patients to have greater choice is highlighted in patient surveys. But as many have pointed out, encouraging greater patient choice may actually undermine the influence of local democratic input in decision making, as patients choose to bypass local services rather than try to influence them through more collective means such as membership of a foundation trust. The fundamental question here is how much value policy makers place on improving responsiveness of care compared with other objectives such as equity of access and efficiency.

Conclusion

The aims of public involvement in health care need to be more clearly thought out. If the goal is greater democratic input, more clarity is needed about the type of decisions for which public involvement is most appropriate, the methods that are most effective and cost effective, and how different initiatives complement each other. Without such a rigorous approach, ad hoc and piecemeal policies will cost the NHS and the public time, effort, and resources, without conferring any significant benefit. The new Commission for Patient and Public Involvement has a key role in developing a clear approach to public involvement interventions and arranging for their evaluation. If greater responsiveness of services is the goal, greater public involvement may not be the most effective policy, at least by itself. Other approaches, such as involving individual patients more in choices about their health care decisions, may be more promising. However, the opportunity cost of achieving other desirable objectives in the NHS, such as equity and efficiency, will need to be clearly spelt out.

Contributors and sources: Dominique Florin is a general practitioner, public health physician, and health service researcher. She has a special interest in public and patient involvement in health care. Jennifer Dixon has a background in health services research, public health, and policy analysis. She has published widely on NHS reform.

Summary points

Currently UK policy is to increase public involvement in the NHS

Two aims for the policy are often cited: to increase democratic input into decision making and to increase the responsiveness of services to patients

The methods used to promote public involvement are inconsistent and it is not clear whether they will achieve either aim

The new Commission for Patient and Public Involvement should clarify the aims of public involvement in the NHS and evaluate initiatives

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Endpiece

Owning up

A man should never be ashamed to own he has been in the wrong, which is but saying, in other words, that he is wiser today than he was yesterday.

Alexander Pope (1688-1744), *Miscellanies*, vol II, *Thoughts on various subjects*

J G Fairer, St Jean D'Angély, France