

## Introduction

For me, the biggest challenge in participation is getting the insights we generate to contribute to positive change.

I have spent the last year as a civil servant in the UK Government's Department of Health, trying both to develop participatory approaches and to have them taken on board by civil servants and ministers.

In many countries, including France and Germany, the state authorities responsible for health usually undergo some form of election from local citizens. When deciding what to spend money on, or where to locate hospitals, there is therefore usually some form of democratic accountability. In the UK's National Health Service, by contrast, health authorities are appointed by ministers in the central government.

Under the Conservative government, there was a move, as has been discussed in Cornwall & Gaventa (this issue), towards a 'user/chooser' model. Under this patient-as-consumer approach, the Thatcher/Major government's initiatives centred around giving patients a stronger voice via such mechanisms such as the NHS charter, while a lot of accountability and responsibility was devolved to the local level. It was therefore local officials rather than the Health Minister who were typically in the firing line when things went wrong.

A classic case of this devolution of responsibility was the case of Child B, where a ten-year-old girl from Cambridge was refused a particular treatment for her leukaemia that cost around seventy-five thousand pounds. What was interesting about the case was not just the issue of deciding whether it was a good use of limited resources, but that it was the chief executive of Cambridgeshire Health Authority, Steven Thornton, not the Health Minister, who went on the TV and radio to defend the decision.

Since coming to power in 1997, the Labour government has tried to reclaim that central accountability and combat the 'lottery of care', whereby your chances of treatment on the NHS for some conditions depend on where you live. There is also an increasing realisation that in a health

care system with limited resources, it is not so much a case of taking right or wrong decisions, but going through a process that has transparency and legitimacy.

One of the problems with the 'user/chooser' model in the NHS was that it led to a tendency for resource-allocation to be overtly influenced by the more vocal patients' groups. Multiple sclerosis is a classic example of this. It is a terribly debilitating condition and treatment costs around ten thousand pounds a year. At the same time less dramatic diseases, especially of the elderly, get less resources, partly because there is less lobbying on their behalf.

In response to these dilemmas, governments risk trapping themselves in a private research mode, where they carry out large numbers of opinion surveys and focus groups that are commissioned and held privately, with the results never becoming open to public debate. The new freedom of information laws may make these findings quietly available to those people who know where to get them from. However, this does not normally create public pressure that could persuade the government to act on the insights such processes create.

Most of the pioneering of citizens' juries and citizens' panels in the UK was in relation to health policy, so the Department has been able to tap into work carried out by organisations such as the Institute for Public Policy Research, some of which is described in the article by Clare Delap (this issue).

Perhaps the best known example of public participation by the Department of Health was the recent consultation of health users and UK citizens as part of the preparation of a long term plan for the NHS. Traditionally civil servants would provide advice on which ministers could act, but the government decided it wanted to develop a more inclusive approach. Previous reforms under the Conservatives, such as the internal market, had generated huge resistance by those who were charged with implementing it. In planning its reforms, Labour decided to include all possible stakeholders in the health service, including doctors, nurses, ancillary staff, chief executives, patients' groups and so on. To involve these groups, they

set up Modernisation Action Teams to organise different aspects of the plan.

The wider public involvement strategy began with the distribution of twelve million leaflets, which asked the public what their three top priorities were for spending the additional money as promised by the government. Although this was largely seen as a PR exercise, it did produce half a million responses. When analysed, this provided hard evidence about the additional priorities for healthcare identified in the survey that ministers might not otherwise have considered.

Following the leaflet campaign, the department commissioned a public opinion survey on people's perceptions of, and priorities for, reforms. Finally, we held two public fora: one in London and one in Leeds, where a hundred people, recruited to match a sample of the general public, were brought together for one day to discuss their priorities. The hundred were split up into six groups along the lines of the Modernisation Action Teams referred to above, to whom, along with the Health Minister, their conclusions were fed back at the end of the day.

The political context demanded that this whole process had to be carried out within a three to four month period, which led to the loss of a lot of the richness and depth of peoples' insights. But what did come out was that there was a whole range of softer issues that politicians had largely ignored, especially to do with quality of care. For many people this did not just mean the technical quality of an operation, it meant being listened to; talked with rather than talked at. These perspectives were quite influential and the new NHS Plan, published in July 2000<sup>1</sup>, has a whole chapter devoted to patient empowerment. The proposals contained within it could potentially work towards a health service, where the voice of patients and citizens are stitched throughout the service, from the bottom to the top.

Another government reform introduced the new National Centre for Clinical Excellence, an expert body made up mostly of doctors and other medical professionals. Under the government's plans this would work in parallel with a citizens' council that actually looks at the value judgements behind decisions taken; those decisions related to issues such as quality of life. In this way it may be possible to build citizen and patient voices into decisions that are going to be taken everyday, which can feed into national strategic choices.

What perhaps has not been realised yet is that people need time to build up preconditional capacities in their communities. The drive for speed from government leads

to real problems for patients' groups and communities that want to become involved. On top of that there is the widespread cynicism about the extent to which the government really wants to listen, or is capable of it.

The challenge is two-fold. On the one hand, governments have to learn to listen to the public and involve them in public policy debates and solutions, and demonstrate change as a result. But on the other hand, those promoting public involvement must understand, and to some extent accept, the pressures of decision making and develop models that can be used within realistic time frames and budgets. At the moment much practice is based on ideal research conditions, with years of evaluation and an increasing distance from practical application of the results. Overall, however, I believe that in the UK, there is now a real opportunity for the public to be involved in the shaping of public policy.

**Jo Lenaghan. Email: [Jo.Lenaghan@doh.gsi.gov.uk](mailto:Jo.Lenaghan@doh.gsi.gov.uk)**

### Notes

Jo Lenaghan is a civil servant at the Department of Health providing advice to ministers on a wide range of strategic issues. This article was written in a personal capacity drawn from her previous experience of working at the Institute for Public Policy Research (IPPR). For further information regarding involvement and citizens' juries, contact Vicki Combe at IPPR. Email: [v.combe@ippr.org.uk](mailto:v.combe@ippr.org.uk).

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<sup>1</sup> The NHS Plan Department of Health. See: [www.doh.gov.uk/nhsplan/htm](http://www.doh.gov.uk/nhsplan/htm)