People Power and Health

A Green Paper on Democratising the NHS

DH

About the Democratic Health Network

The Democratic Health Network (DHN) provides policy advice, information, research, training and a forum for the exchange of best practice in partnerships between local government and health. The DHN is a partner organisation with the Local Government Information Unit.

Authors: Alyson Morley and Fiona Campbell

Foreword

What would a really democratic health service look like – one where people have a real say on priorities, the type of services available and how they are run? Should we think of NHS users as patients, customers or citizens? What is the difference between involvement, ownership, democratic participation or representation in health? What is the right level for decision-making about health issues: the national, the regional or the local? What should be the role in health and healthcare of existing democratically elected representatives in local authorities?

All these questions have been raised during the controversy over foundation hospitals, but their implications extend well beyond how individual hospitals are run. The authors of this Green Paper have analysed and clarified some of the conflicting assumptions underlying recent arguments about the appropriate form of democracy for the NHS. They present a set of principles that should underpin any governance structures for health services, and a series of options based on those principles. Any one of these options would be better than the complicated set of governance for NHS institutions, commissioning bodies, partnerships of all sorts, patient and public involvement and accountability that we have at present.

I welcome this pamphlet from the Democratic Health Network as the starting point for a much-needed debate. I look forward to taking part in the debate and to seeing issues of democracy and accountability in our national health service being discussed in party manifestos in the run-up to the next general election.

David Hinchliffe MP
Chairman
House of Commons Health Committee

People Care about the NHS

In a country of constantly shifting public attitudes and expectations, there is one enduring truth: most people care more about the NHS than about any other political issue (MORI research 1998). But almost all accountability has been to the Secretary of State rather than to people locally. Hearing the clatter of every falling bedpan was seen by its founders as a metaphor for keeping in close touch with the local workings of the early NHS. On the one hand, such upwards accountability has increasingly been presented as unacceptable micro-management and control freakery and on the other, what little local accountability there was has been chipped away by successive governments of all political persuasions. Despite the present Prime Minister's commitment to *"sweep away the quango state"* (Tony Blair, 1995) quangos of the unelected great and good to manage health services have proliferated under Labour.

The debate about foundation trusts adds to concerns about the democratic deficit in the NHS. The government has linked the financial freedoms and new regulatory structure for foundation trusts with the apparently attractive ideology of a "new localism" and "new mutualism", the stated intention of which is to hand back power and ownership of health services to local communities. Thus, opposition to foundation trusts can be presented as opposition to increased local democracy.

The proposed new governance arrangements (being debated in the House of Lords at the time of writing) for foundation trusts should not be allowed to close down the argument. The arrangements are wholly inadequate to ensure that these institutions are really held to account by local people. The new "members", who will be the legal owners of foundation trusts, will be a self-selecting group drawn from a constituency proposed by the trust itself. The three-tier governance structure, in which the members elect representatives to the governing board, which itself only has a loose influence over the real holders of power – the management board – means that most members will

be far removed from decisions about services. The debate about foundation trust governance should be seen as a starting point for a renewed discussion about the kind of local control and influence we want for our National Health Service; and the forms of democracy and engagement that will best serve the interests of patients and the public.

This Green Paper raises fundamental issues about the nature and meaning of democracy in the context of the New Labour project of modernising the NHS. It proposes the essential elements of a new model of democracy for the NHS and suggests some options that build on these components. We hope that these options can inform discussions about the balance between the central and the local, national standards and local responsiveness, equity and choice, representative and participatory democracy in healthcare. We do not believe that the necessary trade-offs in getting this balance right have been honestly presented by any political party. In the run-up to the expected general election in 2005, it is time for all political parties to address these issues in their manifestos.

Modernising the NHS – the Real Issues

Underlying the apparently simple changes to the structure of the NHS is a complex interplay of issues driving the government's agenda for public services.

"Behind what are presented as modest and sensible administrative reforms, bigger political and ideological issues are at stake."

John Mohan, 2003.

The big ideological and political issues referred to by Mohan include:

- extending choice and the implications for other government priorities such as reducing inequalities

- the meaning, or meanings of democracy – in particular the role of the patient as citizen and consumer and the policy shift from representative to participatory democracy
- national standards and local autonomy, and the potential conflict between the two
- the meaning of ownership and involvement, and the distinctions between them and democracy.

Choice and Equity

Extending choice in healthcare is something that few would be brave enough to argue against. Tony Blair is a big fan of choice:

> *"Choice mechanisms enhance equity by exerting pressure on low-quality or incompetent providers. Competitive pressures and incentives drive up quality, efficiency and responsiveness in the public sector. Choice leads to higher standards."*
>
> Tony Blair, 2003.

But what price are we prepared to pay for extending choice? While it may have real benefits to some patients, it may be at the expense of equity – equity being another key principle for the NHS (Kings Fund, 2003). And what is the real driving force behind extending choice in the NHS?

The government fears that the middle classes are not prepared to stay with the NHS unless they are given more choice. In a recent speech to the New Health Network, the Secretary of State for Health set out the government's real agenda about choice. He talked of the existing two-tier health services where those who could afford it went private while the rest of us had no choice but to use the NHS:

> *"I want to make sure that those two tiers do not operate for the next sixty years and that we give the same rights and privileges and choices to all NHS patients."*
>
> John Reid, 2003.

In other words, if you make the NHS more like the private sector, the middle classes will not abandon it. But is the rise in private healthcare significant? King and Mossialos suggest this has been driven more by the growth in employers' health schemes than it has been by a widespread disillusionment with the NHS leading individuals to arrange private health insurance for themselves (D R King and E Mossialos, 2002). So the Government's fear of a mass desertion of the NHS by the middle classes may be unfounded.

Of course, choice can have benefits for the individual and some choices, such as choice of a woman doctor or ability to choose the date and time of appointments significantly improve satisfaction with health services. But personal choice for the benefit of those who can exercise it should not be confused with democratic control of services for the benefit of a whole community or nation. Such confusion is reinforced by a consumerist understanding of citizenship.

Consumer or Citizen?

The citizen as consumer

A constant theme of government policy is the need to re-engage citizens with their communities, local services and local democratic structures. Citizenship is being redefined in consumerist terms by the government, with individuals being encouraged to act on the basis of their own self-interest rather than the good of the community (Catherine Needham 2003). In her pamphlet espousing public services and citizen involvement, Hazel Blears talks of the need

"...to reform not just the structures of citizenship but the culture of citizenship, motivated primarily by selfish or individual interests... I believe that local people will get involved... If they can genuinely answer for themselves the question, What's in it for me?"

Hazel Blears, 2003.

If it is naïve to believe that all of those who volunteer, stand for election or work as community activists act always from purely altruistic motives, it is also cynical in the extreme to assume that people will only be motivated by self-interest. Indeed, the difference between a citizen and a consumer is that the former is defined in relation to a society, whereas the latter is defined only in relation to their own interests.

The consumerist approach is also evident in the way local democracy is viewed by government. For example, from early on, proposals for the governance of foundation trusts were based on the presumption that patients of a particular institution should have a privileged role in electing the governors of that institution; and unelected patient and public involvement forums are being set up to give patients and ex-patients a special role in monitoring the work of NHS trusts and primary care trusts.

By contrast, local authorities are elected on the basis that all those who live in the area have an interest in council services, whether or not they are users of particular services and that elected representatives represent more than their own interests. The proliferation of proposals for institution or agency-focused boards, trusts, and foundations will encourage a narrow focus on the services provided by a particular institution to its customers, rather than a strategic approach to ensure close co-operation and co-ordination of services across a whole community.

There is such a thing as society

The distinction between consumers and citizens is an important one for other reasons as well. Increases in scientific and technological knowledge, particularly in the sphere of genetics, mean that decision making about health may often take on an ethical dimension. Decisions about ethical matters belong in the social and political sphere, that is in the sphere of democracy, not in the medical or professional or commercial sphere. Increases in knowledge and technology create new and often costly treatment options. In a world in which rationing of health care happens, new options create new ethical

dilemmas. And decisions about rationing should be made in the context of wider societal values. Consumer choice should not give an individual or even a small group of individuals the right to a moral judgement on whether a young person rather than an older person should have an expensive operation or whether a costly new drug should be offered to a few at the expense of a cheaper treatment for many. Such decisions can only be made by reference to values that extend beyond the remit of medical judgement or a consumerist approach. This must remain a powerful argument for democratic and accountable decision-making processes that recognise the collective role of individuals as citizens embedded in society.

Does new localism mean the end of old democracy?

Government rhetoric promotes local democracy while existing democratic structures are being systematically sidelined in favour of new directly elected bodies set up to manage individual services. Matthew Taylor asks:

"What price 'joined up government' in a world of locally elected police authorities, foundation trusts and schools managed directly by Whitehall?"

Matthew Taylor, 2003.

Hazel Blears is not worried by this question and sees the new localism as the saviour of local government. She asserts that "the way to tackle declining legitimacy and engagement in local politics is more, not less, local democracy." But what is proposed is simply a fragmentation of what already exists, based on a new consumerist and individualist redefinition of democracy.

The Central and the Local

There is widespread concern with falling voter turnout and a population that is largely apathetic and cynical about their ability to change things by voting, but if we want to reduce the growing health inequalities across the country, provide equality of access to health and healthcare and maintain national standards, resources will still need to be allocated and standards set at the national level. This means we need a solution that combines representative democracy nationally, with a greater sense of involvement locally.

The meaning of ownership and involvement

We all collectively own the NHS and its institutions. That fact has been beyond dispute, at least until foundation trusts came along. The government is right to question the extent to which local people feel they have a say in their local health services. But is legal ownership, in the sense of having a £1 share in a foundation trust, either an advance in democracy, or a necessary or sufficient condition for the involvement of local people? Ownership is certainly not the same thing as democracy. We do not own our elected representatives on local councils, for example, and it would be considered quite contrary to democratic principles if a section of the electorate were able to control councillors by virtue of having a privileged financial or legal stake in their work.

Blears contends that:

"state ownership of the NHS is not sufficient and that a shift from imagined to real ownership would be welcomed by local people and be a marked improvement on the current situation."

Blears, 2003.

But, if this is the case then is the converse true: that real ownership by a small, self-selecting group would make the majority who are not the legal owners feel even more excluded and detached? Ownership, in the literal, legal sense, by the few does not guarantee a sense of involvement by the majority.

We need to move away from an approach which sees institutions competing for stars and special status with limited public involvement based on individual consumerist concerns. That way lies the possible destruction of, not just the NHS as a public institution, but the culture of public services.

"The fundamental danger is that consumerism may be fostering privatised and resentful citizens whose expectations of government can never be met, and cannot develop concern for the public good that must be the foundation of democratic engagement and support of public services."

Catherine Needham, 2003.

Based on the analysis of the issues outlined above, we set out the principles that ought to underpin democratic governance of a national health service. The principles are true to the values on which the NHS was built and recognise the need to ensure equity and fair allocation of scarce resources.

Principles for NHS Democracy

Democracy is a concept with many different interpretations. Clearly, democracy for the NHS (in common with other public services) must be more than simply voting (or not) every couple of years for a remote representative. Our vision of democracy for the NHS includes the following elements:

Diversity

No single form of democratic accountability will be sufficient to represent the diversity of needs and concerns that exist within and between communities. This means that a democratic NHS will have an accountability framework that includes accountability at national, regional and local levels and that this accountability may take different forms at different levels.

Equity within the health system

All options must recognise the importance of resource allocation that enhances equity in access to health services across the country and be based on health need rather than the cash-raising potential of individual services. No options should undermine existing policies to tackle growing health inequalities.

Devolving decision making

All options should uphold the principle of subsidiarity and other principles in the European Charter of Self-Government. Decision-making powers should rest with the most local level possible. But this does not mean abdicating national responsibility for equitable distribution of resources.

Good governance

Governance arrangements for all parts of the NHS must conform to best practice for public services. Wherever possible, meetings should be held in public with publicly available records and there should be accessible ways of local people finding out and contributing to the decision-making process.

Employees' participation

Employees are the NHS's most valuable resource. The full range of staff working within the NHS should be represented in governance structures at all levels within the NHS.

Public participation and citizens' involvement in other public institutions

Options for improving democracy within the health service should not erode the autonomy or authority of local councils and other existing democratic structures. While many people may seek more direct involvement in improving services, representative democracy is equally a legitimate way for the voices of the powerless to be heard.

A holistic approach

Democratic structures should discourage a narrow, medical model of health based on hospitals and institutions and encourage a holistic social model of community and public health.

Options for Extending People Power in the NHS

Here are some options for governance that conform to the principles outlined above. These options are not mutually exclusive or the only possibilities. We see them as the starting point for a debate.

Extending the role of local authorities

Local authorities take over the public and community health functions and take on responsibility for commissioning all health services, including free dental and optometry services.

This would provide a democratic basis for commissioning and providing healthcare, and also enable action to tackle health inequalities to be fully integrated into councils' community strategies, as part of their enhanced powers to promote the well-being of the local area. Councils could use some of the resources allocated to them centrally to fund healthy living centres run as co-operatives by local people. They would also have powers to monitor the provision of private healthcare, thereby helping to remedy the growing democratic deficit relating to the expenditure of public money in the private sector.

Local authority scrutiny of health extended to cover the health-related services provided by local authorities themselves and their commissioning role.

This role would have to be properly resourced by central government to enable proper involvement of local people in individual scrutiny reviews.

Democratising Primary Care Trusts

Direct elections to Primary Care Trusts' (PCT) boards, drawn from a residence-based electorate.

This would enable elected representatives to take a whole systems approach to improving NHS performance, rather than pitting individual institutions against each other as they bid for special status and individual freedoms to compete in a new health market. PCTs are responsible for commissioning health services closest to local people as well as providing community services themselves. They are well placed to promote a joined-up approach across whole health economies. With a broad commissioning role, elected PCT boards would also help remedy the democratic deficit relating to private healthcare.

We are not suggesting that lay people should be involved in clinical decisions. Rather, the involvement of lay members will assist clinicians in coming to decisions about issues with an ethical dimension that are informed by wider values.

PCTs set their own priorities and targets in line with local needs.

There is little point in electing representatives to the management boards of PCTs if PCTs are so constrained by government targets and priorities that they have no flexibility to respond to the needs and concerns of local people. It is entirely appropriate for the government to set clear, long-term outcome targets for health improvement: for example the current targets on reducing health inequalities. But PCTs are best placed to identify how long-term national targets should be met locally. PCTs will be required to develop action plans to demonstrate how national headline targets are to be met locally but they must be given the power and autonomy to set their own priorities.

Democratising patient and public involvement forums

Patient and public involvement forums made up of a combination of directly elected members with places reserved for patients and carers, nominees of the local authority and community and voluntary sectors.

There is a danger of patient and public involvement forums becoming enclaves of special interests, largely remote from the communities they were intended to represent. Direct elections for the majority of places on patient and public involvement forums, coupled with places reserved for local authority, community and voluntary sector nominations, would ensure that patient and public involvement forums were firmly anchored in their communities, as well as representing the interests of patients and carers.

Democratising partnerships

Local authorities establish indirectly elected health and social care partnership boards that are open and accountable, both to local people and to the nominating bodies.

Local authorities are already working productively with health partners, the community and voluntary sector and service users to create "person-centred" services. But partnerships – responsible for large budgets and commissioning substantial contracts – have sprung up in an ad hoc fashion often without clear accountability to parent organisations or local communities. Furthermore, such partnerships are often dominated and driven by officers with little involvement of elected members or non-executive directors. Statutory partnership boards would be created with specified representation from elected members, health partners, service users and local people. They would be required to conform to best practice in relation to governance arrangements: their meetings would be held in public, minutes of the meetings and all other papers would be publicly available and time would be allocated in the meetings to hear the concerns of local people.

Health partnership boards would be chaired by and given administrative support by the local authority. Such boards would also be free to take over the running of health services, where this would aid the development of person-centred, integrated and seamless services.

Democratising health at the regional level

A duty and associated powers for regional assemblies to develop health strategies and to promote the health of the population for their regions.

The role of the regional assemblies in relation to health would build upon the role of the Greater London Assembly. They would have a duty to promote the health of the population of the region, including assessing the assembly's own policies and strategies to ensure they have a positive impact upon health. They would also be required to produce a regional health improvement plan which outlines how health inequalities are to be tackled. Each region would also appoint a Director of Public Health who would advise the regional assembly on all health issues.

Role of central government

Central government retains its responsibility to distribute and redistribute resources for health and set standards.

Distribution of resources would be based on need, with the aim of reducing health inequalities and setting and raising consistent standards. NHS bodies would not be able to dispose of assets and retain the surpluses, thus exacerbating inequalities between those that are asset-rich and those that are asset-poor (for example, because of differential land values). To avoid iniquitous postcode prescribing, central government would still set long-term outcome targets for health improvement for example for reducing health inequalities but it would be up to local decision, made in democratic forums, to identify appropriate milestones, short term targets and performance indicators, based on local needs and priorities.

Opening up the Debate

We have called this document a Green Paper because we genuinely wish to encourage discussion and generate ideas about how best to achieve real democracy and public involvement in the NHS. You may not agree with all the options outlined. You may have alternative proposals that you would like to see included in the final proposals. We positively welcome all contributions to this important debate. Please send your comments and proposals to:

DHN
22 Upper Woburn Place
London WC1H 0TB

Or email alyson.morley@dhn.org.uk.

References

Appleby, J, Harrison, A, Devlin, N, 2003, *What is the real cost of more patient choice?* King's Fund.

Blears, H, 2003, *Communities in control: Public services and local socialism, Fabian New Ideas 607*, The Fabian Society.

Department of Health, 2003, *Choice for all not the few*, London, Government News Network 0267.

King, D R & Mossialos, E, 2002, *The Determinants of Private Medical Insurance in England*, LSE Health and Social Care Discussion Paper Number 3.

Laing and Buisson, 2000, *UK Private Medical Insurance Market Sector Report.*

Mohan, J, 2003, *Reconciling Equity and Choice? Foundation Hospitals and the future of the NHS*, Catalyst Working Paper, London.

MORI Research on attitudes to the NHS www.mori.com

Needham, C., 2003, *Citizen consumers*, Catalyst.

Tony Blair, Speech to South Camden Community College, 23 January 2003.

The Local Government Information Unit (LGIU) is an independent policy and research organisation which produces information, advice, training and a lobbying service for its local authority and trade union members.

The LGIU is committed to protecting the environment. The paper used in this publication is Total Chlorine Free (TCF) and contains a minimum of 50 per cent recycled material.

DK/2K/1003

The Democratic Health Network

22 Upper Woburn Place, London WC1H 0TB
Tel **020 7554 2820**
Fax **020 7554 2802**
Email **info@dhn.org.uk**
Web **www.dhn.org.uk**

£5.00

ISBN 190373152 6