WHOSE NHS IS IT ANYWAY?

A national debate on an accountable NHS

"And as we seek to devolve more responsibilities to the local level, we will also explore the ways of improving the legitimacy and accountability of primary care trusts and of the commissioning decisions they make on behalf of their local communities.

"It will not be the NHS of the passive patient - the NHS of the future will be one of patient power, patients engaged and taking greater control over their own health and their healthcare too."

Gordon Brown 2008

THE DEBATE

A national debate is needed on what we expect from PPI and how it can be delivered. Answers are needed to these questions, from professionals, NHS non-executives, the public and patients.

❖ Is there enough local accountability in the NHS?

❖ What would be gained by greater accountability? What might be lost?

❖ Are elections the best way to deliver greater accountability?

❖ What role should local authorities play, if any, in promoting local NHS accountability?

❖ What kind of accountability is needed and is it different for those who commission services and those who provide services?

❖ How can the inevitable tensions be managed?

This paper is designed to kick off a national debate about localism and accountability in the NHS. It joins in other voices raising similar issues at academic, political and theoretical levels\(^1\)\(^2\)\(^3\)\(^4\). Here, the NHS Alliance and the Socialist Health Association offer a set of practical policy proposals as a vision to open up the debate. We suggest that this will require a fundamental revision of approach and culture, but not necessarily a huge change in existing mechanisms – it may be possible to put much of this in place with developments of existing systems.
LOCALISM VS LOTTERY?

Local decision making and local accountability in the NHS is seen as desirable. But wouldn’t that lead to the much criticised postcode lottery?

If decisions are irrational, based not on evidence but on subjective judgements or the whims of those with power, then yes, it would.

But just as good healthcare should be tailored around the needs of the individual patient, so good localism is about tailoring service provision around the needs of the population.

For instance, an area with a predominantly young population needs more resources in maternity and child services than one with a large proportion of elderly people. A town that has a large BME population will need sickle cell services, whereas its predominantly white neighbour may not. Local planning must take account of needs like these. A centrally determined, standardised plan would be highly risky.

An illogical postcode lottery is bad for patient care and destructive of public trust. But we all need to understand – and communicate to the public – that services need to be planned around people, collectively as well as individually.

In a responsive NHS, an analysis of expenditure would reveal significant differences in spend between areas, but the reasons for those differences would be clear – and local involvement would be explicitly one of them. Not a random post-code lottery, but a planned and necessary set of differences.

WHY IS ACCOUNTABILITY IMPORTANT?

It is a moral imperative

The NHS has very limited democratic accountability. Foundation Trusts are regarded as an exception but even here there is evidence that they may fulfil that function ineffectively. The Secretary of State for Health is the only elected member of the NHS. In a democratic state, this is surely unacceptable.

It is a practical imperative.

There is evidence to show that accountability:

- improves outcomes for individual patients through shared decision-making
- improves the pathways of care
- helps to create better services, when a collective voice is heard and responded to
- Since it is not possible for everything to be a priority, it is important that local citizens are involved in decision-making around rationing of health care.
It is a political imperative.

Increasing involvement of local populations, particularly if using community development, is likely to:

- improve citizenship, encouraging people to take more interest in their local community
- be popular with the electorate. People say that they want to be influential in decisions on their own care and also as citizens on local priorities but they are not clear about how this should work.
- improve health. Community development supports an increase in social networks which are significantly health protective.

It is a financial imperative

Increasing experience shows that harnessing patient views can lead to significant savings. The Renal Modernisation Initiative in Guys Hospital showed:

- The approx cost savings through empowering 20% more patients to have dialysis where they wished was around £500,000.
- Although the total cost of nocturnal dialysis was a few percent higher than conventional dialysis, the QOL benefits and medication cost savings were substantial.

WHAT DOES ACCOUNTABILITY MEAN?

Collective accountability. This is a definition described by the Kings Fund. It applies both to citizens who are not involved with the NHS at the moment, and patients who are. It describes a ladder of accountability:

- **taking into account:** the shaping of activities and priorities (forexample, through consultation with citizens and stakeholders)
- **giving an account:** explaining actions that have been taken (for example, through performance plans and reporting systems)
- **holding to account:** actions taken by citizens and service users once they have heard the account given (for example, a process of scrutiny with resulting action such as through the ballot box)
- **redress:** a right to redress when services have not been delivered to an appropriate standard.

Individual accountability

- shared decision-making at the consultation, if the patient wants it
- good, appropriate information for the patient when they want it
- choice of place of referral
**PPI AND CHOICE.**

As currently construed, “Choice” and Public and Patient Involvement (PPI) are different. Choice is seen by the Department of Health (DH) as an individual’s ability to get what they want from the system, mainly in referral, but in future, over management of their care.

PPI is a more holistic, collective approach where the local population, as well as individuals – and the public as well as patients – offer recommendations for good practice that affects and influences the delivery of care for all. Choice is subsumed within PPI.

There is also a more fundamental tension between equity and choice: those most able to exercise choice to their advantage are likely to be the educated, articulate, assertive and influential. In other words, those least likely to have care needs. Their exercising of choice can be at the expense of those with less power and influence. Choice can actually increase inequalities in both access to health care and in health outcomes.

There remains an urgent need to ensure that, in the new NHS, PPI is integrated into decision-making in such a way that:

- local recommendations are heard
- local recommendations are debated
- local recommendations are responded to

**WHAT STATE IS ACCOUNTABILITY IN NOW?**

**Looking good**

The principle of patient and public involvement is established in law. Clear statements of principle abound, which is very welcome: World Class Commissioning and Section 242 have detailed and inspiring approaches.

PCTs know far more about their populations than ever before. There are an increasing number of examples of good practice.

Foundation Trusts are designed with accountability built-in.

We know far more about how shared decision-making improves outcomes, generally improving outcomes and reducing use of services.

The combination of LINKs and Overview and Scrutiny Committees offer a new and optimistic approach to accountability in the NHS.

**Not looking good.**

However, there is only occasional evidence of actual change on the ground stemming from PPI.
The democratic process in Foundation Trusts in many cases does not appear to be effective.  

We do not know how LINKs will perform.

So far as individual involvement is concerned, there have been great strides, but:

- proven techniques are not used
- record access is not yet available
- clinicians on the whole do not manage patients with co-production of health in mind. Nurses, however, are far better at this than doctors

In general, the NHS does not see the need to be responsive to its populations. The legal framework is not strong enough to ensure responsiveness from NHS organisations.

**HOW SHOULD WE MANAGE THE TENSIONS THAT RESULT FROM IMPLEMENTING PPI?**

The nature of PPI puts strains on a system designed to be top-down.

**Local accountability means less control for the centre.**

Currently accountability is almost exclusively upwards to the DH and ministers. Local accountability will inevitably result in priorities in line with local needs and aspirations within the framework of medium term national health outcome targets. This could also be described as a postcode lottery – but we need to be clear that this is a media-spun pejorative term that obscures the fact that tailored services will vary. In fact, NOT responding to local need is likely to have health disbenefits. A postcode lottery is random – we are advocating planned differences.

It may be that we shall have to agree a core of services that have to be the same everywhere, and a penumbra that can be varied.

**Accountability may widen inequalities**

Those with the least resources may have less voice and therefore be effectively excluded. This would be mitigated if a national target for reducing health inequalities is maintained.

**People may recommend changes that are unacceptable to clinicians**

Clinically ineffective treatments, for instance.

**Local people may not be able to make sophisticated decisions about the allocation of healthcare budgets**

The evidence is that, where this is handled with care as in South Birmingham, local views can be collectively effective at influencing PCT policy.
HOW CAN THE NHS LEARN FROM OTHER GOOD EXAMPLES OF ACCOUNTABILITY?

Department of Communities and Local Government

DCLG is responsible for, among other things, Local Authorities. It has long championed community development and is steeped in involvement far more than Health. One example of what Health could plagiarise is “Together we Can”11

Finland

The residents elect the supreme decision-making body, the municipal council. The council has the general decision making authority in local affairs. Local government is separate from central government, and the municipal bodies are partly independent of the state.

Local authorities run the country’s comprehensive and upper secondary schools, vocational institutions and polytechnics, provide adult education, provide child day-care, welfare for the aged and the disabled, and a wide range of other social services. In addition, they provide preventive and primary care, specialist medical care and dental care and promote a healthy living environment.

IS DEMOCRATIC ACCOUNTABILITY NEEDED IN THE NHS?

Yes: it is the only way of ensuring “holding to account” and “redress”. It will encourage citizenship. If it includes staff, it will encourage a joint approach between staff and patients.

No: it can be cumbersome. It may encourage inequalities. It may need extra structures.

It is not clear what the public would prefer12. That is no surprising because there has been no national discussion about these issues.

On balance, we favour some degree of democracy. Different approaches should be trialed in different places at different levels, involving a variety of structures.

Key organisations that need to be considered are Local Authorities (LAs). LINKs will have formal ties with LAs and may offer a bridge from health to LAs. One argument that immediately arises is whether LAs could take on wider aspects of PPI. LAs have long experience of local involvement and are increasingly close to the NHS. Whether they could actually fulfil such a role confidently is unclear.

WHAT ARE THE CHARACTERISTICS OF APPROPRIATE ACCOUNTABILITY IN THE NHS?

There are a number of ideas that need to be followed. These can be read alongside World Class Commissioning competencies.

- Engagement with communities requires a proactive long-term dialogue.
- One-off consultations will also be required for specific issues.
- Democratic accountability will be needed in some areas.
• NHS organisations need to be seen to become responsive – recommendations by local populations drive the direction of the organisation.

• PPI is good for the NHS! NHS organisations need to agree that PPI is productive, leads to better services and is a key to successful outcomes.

• Accountability needs to be systematic and at industrial strength

• Engagement without exhaustion. Accountability needs to be efficient and not sap the strength of individuals nor organisations

• Engagement takes place at both individual and collective levels. At both the level of the consultation, face to face with the clinician, as well as a public, patient pathway level.

**COMMUNITY DEVELOPMENT IS KEY**

**Improving social networks through community development.**

Social connectedness and integration are good for health.  
Social relationships protect people against both physical and mental problems. Those with strong social networks get ill less often and recover more quickly. This is also true of control over work. Stronger social networks and control over your life and work show social gradients, with poorer people having fewer networks and less control.

Community development is a technique that can enhance social capital, social networks and improve a sense of control. In addition, it has been shown to improve the process of PPI. It is a standard approach in local authorities and now needs to be applied systematically to health. It would encourage a holistic approach to health at a local level and will enable closer working between PCTs and LAs.

**Policies:**

• community development (CD) to be developed in every PCT

• CD to support hard to reach people with LTCs and other disadvantages

• CD to be based on estates and become the basis of work with young people on health issues.

• CD to become a key approach for LINKs

• CD to support the development of PPI and PPGs at general practice and PBC levels.

• Health trainers to have CD skills
PPI WITH TEETH: PRACTICAL SUGGESTIONS FOR DEBATE

What patient-centredness and effective public and patient involvement could mean in practice at various levels of the Service is set out below. There are suggestions at every level to stimulate debate.

They all have one essential aspect in common. These options are about PPI with teeth. Public and patient involvement that impacts on real decisions, is able to influence and even lead change, and has the power hold decision makers to account. Token involvement is not enough. In today’s NHS, PPI needs teeth.

1. At individual, consultation level

   - Shared decision making for all patients who want it when they want it.
   - Patients to be given full access to their medical records
   - Patients to have ready access to Decision Aids to help them participate in clinical decision making.
   - The Expert Patient Programme to be expanded outside the current franchise
   - Patients and patients to be involved in the training of healthcare professionals at all levels of training. Patients as Teachers is one approach
   - More outreach to those currently not accessing services such as the young, men, some BME groups, homeless people, refugees and asylum seekers who may have specific health needs?

2. At General Practice level:

   - Elected Practice boards to work with the partners to run the practice should be offered as an option to practices
   - Patients are encouraged to work with staff to select new doctors and clinical staff
   - Every Practice should be to have a patient participation group or panel.
   - The Practice is incentivised to become responsive by:
     - The HCC/CQC demanding evidence that the practice has changed in response to patients’ views This needs to be given a far higher profile in performance management and inspection.
     - QOF incentives increased to do the same
     - Quality of care is in part defined by patients
     - The patient experience part of QOF to take up a larger proportion of the points
     - Practices will be encouraged to work with local community development workers
3. At Practice-based commissioning cluster level

- Community development workers are placed in each practice-based commissioning cluster
- Clusters to be aligned with LA neighbourhood areas
- Practice participation groups link up to advise the cluster
- Use existing neighbourhood forums and structures to draw in those who are currently not patients and to integrate health issues with the broader well-being issues.
- Patients are involved in:
  - Choosing priorities for investment and disinvestment
  - Monitoring quality
  - Identifying problem areas and successful areas of service provision
  - Deciding on how to spend any savings

4. At PCT and local authority level: a number of possibilities

- PCT Boards could be elected
- The PPI function of the PCT could be performed by LAs
- Local Authority councillors might have to form half of every Board
- Patients to become part of the Overview and Scrutiny Committee
- PCTs could take on Foundation Trust governance
- PCT Boards include one or more NEDs who have a specific brief for PPI
- Review the role of NEDs to ensure that they are accountable to the community
- Every PEC has lay representation. For instance, half the Board could be patient leads within PBC clusters
- Citizens’ views to be incorporated into the commissioning process in the following areas
  - Needs assessment
  - Choosing priorities for investment and disinvestment
  - Monitoring quality
  - Identifying problem areas and successful areas of service provision
  - Determining the shape of service development
  - Deciding on how to spend any savings
- The Healthcare Commission demands evidence that the local commissioners and providers have taken on board patients’ views in the areas specified above
5. **Hospital Trusts:**

- Foundation Trust governance is made more effective to ensure that members become more involved in the running of the Trust.
- Non-FTs take on similar governance.

6. **At National level:**

- Patient interests should be safeguarded by appropriately funded and supported Local Involvement Networks (LINKS) with defined rights (including unannounced inspection) and duties.
- Community Development will become a significant approach for LINKs.
- Link LAs and LSPs to adopt a community development approach to wider well-being agenda.
- A national body comprising LINKS representatives to promote the sharing of experience and good practice and to influence national policy and strategy.
- National Voices or a College of Patients to be made effective. This might be able to take a national strategic view of involvement.

**PUBLIC TRUST IN THE NHS: THE POTENTIAL OF PPI TO MAKE A DIFFERENCE**

Public and patient involvement can make a real difference at three levels: to individual healthcare, to the way GP practices deliver care, and how PCTs plan and deliver services.

It can also enhance public trust in the NHS.

In a remarkably short space of time, public trust in the health service appears to have diminished sharply. Hard figures demonstrate major improvements to healthcare: in heart disease, cancer care, waiting times and much more. The public doesn’t see it that way. Complaints are rising, patients are going to the Courts to get what they believe should be their entitlement, every newspaper seems to be looking for the next scandal. The NHS seems to have lurched into this situation without seeing where it was going.

Something has to be done to restore trust. Effective PPI is an essential tool to do exactly that.

Here we look at three areas that have figured largely in media headlines over the past year.

**Avoiding major scandals**

Individuals come in all sorts – more or less intelligent, more or less altruistic, more or less conscious of the public good. But collectively, the British public has always demonstrated considerable common sense. Effective PPI can harness
that. It can allow the NHS to understand the likely public reaction to its decisions, to appreciate the public mood and to tailor its actions accordingly.

Could good PPI have allowed Maidstone & Tunbridge Wells NHS Trust to have avoided a damning report from the Healthcare Commission? Might it have led to increased nurse numbers, improved patient care, even reduced the numbers of those who died from C.difficile infections? That is impossible to know now. But what is certain is that it could have alerted senior management to growing local anxiety about conditions at the hospital. And perhaps to effective action to address the reasons for that anxiety.

**Expensive drugs, irregularly provided**

Within the past few weeks, we have seen the distasteful spectacle of a PCT ordered by the High Court to reverse its decision not to provide costly drugs to a patient with kidney cancer. Several similar cases are pending, while one patient, who has opted to pay privately for Avastin, is now suing her local hospital over its decision to charge her for all her care. A leading QC’s opinion is that there is no legal basis for the NHS to prevent the patient from paying for the drug while continuing to receive NHS treatment.

How did we come to this? Adversarial dog fights between patients and the NHS benefit no-one. Nationally, the current situation appears to be completely irrational.

PCTs make local decisions, generally based on efficacy and cost, about high cost drug provision. Different criteria lead to different conclusions. If PPI was in place and effective, there would still be differences in provision, but they would be rooted in both clinical and community control.

Such decisions could be made with local people by involving those using high-cost drugs – those with cancer and those with macular degeneration, for instance. It would be essential to include in the discussion the trade-offs needed: if we spend £X on these drugs, we shall have to do less of Y process. Birmingham has already engaged local people in these kinds of discussions with positive results that altered PCT commissioning policy.

**GP Access:**

There seems to be a continuing question over GP access: in many areas, it still seems difficult to see a primary care clinician as easily as people want.

If PPI at a practice level were effective, patients would be working with practices to improve provision. In addition, if accountability were taken seriously, there might be sanctions on practices that failed to meet patient expectations.

It might be helpful for every practice to be required to write its annual business plan in conjunction with its patients – either through a Practice Participation Group or by some other process as suggested in this document. Then intended outcomes would be clear – as would any gaps.
Dr Brian Fisher  
NHS Alliance national lead for PPI

**References**

10. http://www.timesonline.co.uk/tol/life_and_style/career_and_jobs/public_sector/article3693405.ece  
11. http://togetherwecan.direct.gov.uk/  