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The Transparent NHS?

AIMS Journal 2006, Vol 18, No 4

Nadine Edwards guides us through the new, 'easy to negotiate' NHS

The NHS has evolved a great deal since its introduction in 1948. Through a system of taxation, it was designed to provide health care to all, regardless of income.

At that time, there was a general belief that modern medicine was based on infallible, scientific principles, that experts had greater knowledge than lay people (the public) and that doctors provided the best care possible.

Since then, scandals in health care, lay pressure groups, consumerism and dwindling resources among other things, have raised doubts about science, the selfregulation of medicine, and NHS management, and have changed public expectations[1,2]. So while there was no mechanism for involving the public when the NHS was set up,[1,3] over the last decade, the notion of 'patient and public involvement' has gradually become embedded in Government rhetoric about the 'New', and 'modern' NHS. The public no longer expects to be a passive recipient of healthcare.

'*The professional paternalism that traditionally characterized public experiences of the health service, with patients being passive recipients of technocratic and medical expertise, now appears outmoded*[2].'

A raft of Government documents chart the evolution of patient and public involvement (PPI), typically stating that the NHS must:

move away from a system of patients being on the outside, to one where the voices of patients, their carers and the public generally are heard and listened to through every level of the service, acting as a lever for change and improvement[4] *and promote 'a fundamental change in our relationships with patients and the public', moving 'from a service that does things to and for its patients to one which is patientled, where the service works with patients, to support them with their health needs*[5].

The idea of public participation is not confined to health, nor is it only a British phenomenon[6,7,8]. It forms part of a complex movement which is raising questions about democracy, and in particular about the distribution of wealth and power, nationally and globally[9]. I have focused this article on some of the new mechanisms for public participation in healthcare, because many of us represent the public on a variety of committees and some of us have been involved in complaining about care and attempting to improve services. One of the issues consistently raised by this work, is that it is difficult to gain information about the NHS, how different bodies within it link together and how we, as lay people, can

contribute to changing healthcare policies.

In England and Wales, the 'new' and 'modern' NHS, has swept away one of the previous mechanisms for patient and public involvement by abolishing Community Health Councils (CHCs), replacing them with an array of new organisations. Criticisms about CHCs included that they had three functions 'under one roof ' - advocacy, advice and representation, failed to represent minority groups and young people adequately, did not include primary care in their remit, and because of being outside the NHS, 'may have provoked an unnecessarily adversarial relationship with hospitals'10. This rang alarm bells with some voluntary organisations (including AIMS), who were concerned that one of the functions of the new structures must therefore be to fragment advocacy and representation, and reduce legitimate conflict between the public and health services. Some felt that strengthening the role of CHCs, that were often well connected with their local communities and had years of experience in the field of participation, would have been a better option for patients and the public11.

The Commission for Patient and Public Involvement in Health (CPPIH), underpinned by the 2001 Health and Social Care Act which made involving and consulting the public compulsory' rather than 'discretionary'12, was to be the key to bringing the voices of patients and the public into the heart of the NHS.

My description of the new structure (below) is incomplete, partly because as fast as I could find out about NHS committees, some disappeared, others changed and new ones appeared. They were difficult and time consuming to find out about, and often discoveries of yet more bodies were entirely serendipitous. For example, during an on line search, I happened across the National Association of Patient Participation. This charity, part funded by the DoH, provides a forum for discussion between patients and professionals, supports people on patient participation groups, and provides a range of free services and publications on patient participation including a useful 'jargon buster' (seewww.napp.org.uk).

There are many criticisms of the new structures designed to enable equitable and systematic patient and public (PPI) involvement. A main one is that there are now so many PPI bodies (nationally and locally) with illdefined remits, that the structure is far too complicated and unwieldy to be effective. Ironically while the House of Commons Health Committee13 stated that it is 'particularly crucial that new arrangements are as clear and simple as possible, so that NHS patients, particularly those from disadvantaged groups, are able to negotiate the system with confidence and ease', 'even ministers were allegedly baffled by it'6. Indeed, citizens would need both resources and persistence to begin to develop some understanding about how and where they might raise concerns and receive support for this.

See if you can understand the new, 'clear and simple' arrangements for public involvement and participation within your NHS without giving up, going to sleep, or feeling completely bamboozled.

Patient and public involvement (PPI) bodies recently or currently in operation

While health services are structured similarly across England, Scotland, and Wales, there are notable differences. However, all seek to include lay people.

England

Strategic Health Authorities (SHAs) 28 SHAs were set up in England in 2002 to manage local health services on behalf of the Secretary of State, and provide a link between the NHS and the Department of Health. Their job is to develop strategies for improving health services in their areas, ensure that these are of high quality and running well, increase services, and integrate national health priorities into local services.

Primary Care Trusts (PCTs) - formerly Primary Care Groups (PCGs), are primary care led health organisations. They are made up of health practitioners and lay people and are responsible for commissioning secondary care and delivering primary care that meets the needs of the populations they serve. They report directly to SHAs.

Patient and Public Involvement Forums (PPIFs) Patient Forums were set up as independent statutory bodies in 2002. These became the current Patient and Public Involvement forums (PPIs) and have been set up in each NHS Trust and PCT area. They are expected to consult with patients and carers, bring their views to, and advise Trusts and PCTs in order to enhance the quality of NHS services, and monitor these services from the patients' perspectives. They are entitled to visit Trusts, and unlike Maternity Services Liaison Committees (which many AIMS members are on), their reports and recommendations have to be responded to by the Trusts (within 20 days), supposedly giving them some leverage and influence. They can also refer concerns to Overview and Scrutiny Committees (see below), appoint a forum member to a Trust, and raise concerns with senior NHS management or national bodies. They are expected to promote public involvement in every area of health by providing training and support to empower local communities, (particularly excluded groups), to identify and take action on issues affecting their health. They are also expected to monitor the effectiveness of Patient Advice and Liaison Services and Independent Complaints Advisory Service (see below) in their local areas. Any member of the public can contact a Forum about health services, or an issue that has arisen during their care, but the Forum cannot deal with individual complaints. Because of concerns about how citizens were appointed to PPIs, the DoH PPI team decided that NHS Appointments Commission would appoint forum members[5]. The Government rejected concerns expressed by forum members that the Commission was not independent and had no experience with the voluntary sector.

Forum Support Organisations (FSOs) were designed to support the PPI forums. But these FSOs were drawn from existing voluntary organisations which often lacked the resources and expertise to be able to provide the support needed[6].

Patient Advice and Liaison Services (PALS) have been set up in every Trust to help patients and their families quickly resolve concerns. PALS are hospital run and accountable to Trust Boards. As well as providing immediate information, support and help, they are expected to put people in touch with other support groups, inform them about the complaints procedure, put them in touch with ICAS, and identify

problem areas for Trusts and PPI Forums. These have been haphazard in practice and are not always accessible to those who need them6.

Independent Complaints Advocacy Service (ICAS) This service was to be managed by the Commission for Public and Patient Involvement in Health (CPPIH - see below). It is a free, independent service designed to provide support for those who wish to make complaints about NHS treatment or care. People have reported mixed experiences of these, as the service provided depends on the independence, knowledge and experience of those in these organisations.

Health Scrutiny Committee The Health and Social Care Act 2001 provides specific powers for *Overview and Scrutiny Committees (OSCs)* to look at local NHS provision as part of their role in health improvement and in reducing health inequalities for their local populations. OSCs scrutinise health services and are expected to provide opportunities for communities to influence local health policies. Recently, members of OSCs and PPI Forums have expressed the need to clarify the roles of these committees in relation to each other, to avoid duplication and foster partnership working. The Centre for Public Scrutiny has been allocated the task of providing advice to OSCs and Forums on this.

Health Action Zones (now disbanded) were set up in areas of particular need and were expected to work with minority groups (DoH 1999) to improve health in their communities. They were set up in 26 of the most disadvantaged areas of the UK to foster involvement, partnership and participation in disadvantaged communities. These 'large area-based initiatives were intended to improve health and reduce health inequalities through processes of partnership working and community engagement'14. Ironically, these initiatives probably did more to involve the public and respond to the needs of disadvantaged communities than most of the other committees described here. (Sure Start now provides a potential avenue for public involvement that has community development input and is not as limited by health structures.)

National and Local Compacts were initiated by the Government in 1997 in England, Scotland and Wales and the national compacts were launched in 1998, 'to build and sustain equal and effective partnership arrangements between statutory and voluntary sectors' (www.jrf.org/ knowledge/findings/social policy 251.asp.) They provide some guidance on how statutory bodies, and the voluntary and community sectors could work more closely in partnership (see www.thecompact.org.uk) but research suggests that time, commitment, and resources are needed and a report on the experiences of black and ethnic minority groups published in 2002 suggested that they were often unaware of these, and were not well represented or served by them (www.jrf.org.uk/ knowledge/findings/socialpolicy/122.asp).

Commission for Patient and Public Involvement (CPPIH) was established in 2003 as an independent, non departmental, public, short life body to oversee setting up and maintaining a framework for PPI Forums. At a national level the CPPIH was charged with being a champion for patients, submitting reports to the Secretary of State for Health about issues of patient and public involvement from PPI Forums, and collating and feeding back on good practice initiatives to the Forums, while Local Networks of the CPPIH were seen as a way of involving patients and the public at local level, along with Patient and Public

Involvement forums. Its overall role was to set standards and monitor how well patients and the public are being involved in the health services. In the event, the CPPIH appeared to be overwhelmed with the task of helping to establish PPI. A 2004 Review of Arms Length Organisations recommended its early abolishment.[6,14]

Health Improvement and Modernisation Programmes (HIMPs) were set up to translate national policy into local action, and identify local health needs through collaboration and partnership with voluntary and community organisations, local authorities, other NHS bodies and local doctors, nurses and other health care professionals.

The Commission for Healthcare Audit Inspection (CHAI) was set up to be a new, independent regulator. Part of its role was to assess PPI at every level of the NHS and to consult with patients and the public. Foundation Trusts are expected to be accountable to this national body, as well as to local PCT Commissioners and local communities.

National Patient Safety Agency (NPSA) encourages staff, organisations and more recently individuals, to report 'adverse incidents' so that it can gather and analyse this information and share it across the NHS to provide crucial information and learning for all.

Public Health Observatories (PHOs) were set up following a Government White Paper, Saving Lives: Our Healthier Nation. They were created to work in partnership with researchers, regional and local health policymakers and practitioners, to monitor trends in health and its determinants, highlight future health problems and assess the health impact of past and future policies.

Independent Reconfiguration Panel (IRP) was established in 2003 to provide advice to the Secretary of State for Health on publicly contested proposals for health service changes in England. This means that when local agreement cannot be reached, the local OSC can refer the case to the Secretary of State, who can then ask the IRP for advice. It also spreads good practice and gives support and advice to the NHS and other interested bodies on successful service changes, in the hope of avoiding disagreements. The IRP is an independent, advisory non-departmental public body (www.irpanel.org.uk)

Healthcare Commission) has taken over from the Commission for Healthcare Improvement (CHI) with an expanded role. Launched in 2004, it is an independent body, set up to improve the quality of health care and public health. It inspects the quality and value for money of health care and public health, and helps patients and the public get the best information about health care. It has a range of statutory duties which include assessing the quality of health care, reviewing Trusts' performances, regulating the independent health care sector, publishing information about the state of health care, looking at unresolved complaints against NHS organisations, promoting the coordination of reviews and assessments, and investigating serious failures in the provision of health care.

The National Institute for Clinical Excellence (NICE), the Centre for Health Information (CHI) and other bodies were set up as independent organisations responsible for providing national guidance on the promotion of good health and improving standards in treatment of ill health, technologies and

procedures in health care (including maternity services). They are expected to focus on both research and practice. All are expected to include lay membership (AIMS members have served on these16). Lay members are also included in clinical governance in a range of committees - in maternity this is often through Labour Ward Forums. In 2005 NICE joined with the Health Development Agency to become the new National Institute for Health and Clinical Excellence (also to be known as NICE).

Scotland

Health Boards There are 15 boards responsible for all aspects of health in Scotland, including protection, improvement and promotion. These new NHS Boards are required to rationalise decision making structures and provide greater accountability and transparency. The*Clinical Standards Board for Scotland (CSBS)* is a special health board with responsibility for developing and running a national system of quality assurance and accreditation of clinical services in the NHS in Scotland.*Local Health Care Co-ops (LHCC)* In an attempt to remove the internal market in healthcare, fundholding was replaced by LHCCs in 1999. They were set up to promote joint working and service development in local areas by working in partnership with other agencies, patients and local communities, bringing together all the professionals responsible for the delivery of front line services, to plan and deliver service improvements that effectively meet the needs of their communities. The LHCC Best Practice Group Report in 2006, highlighted variability among LHCCs, and a need for more support from the local health care system for their further development.

NHS Quality Improvement Scotland (NHSQIS) This was set up in 2002 to work with NHSScotland and the public to look at improving the quality of NHS services by developing guidelines for practice, improving communication between the NHS and the public, and ensuring responsiveness to patients' needs. The organisation is charged with taking a lead in public involvement at every level, by involving the public in monitoring and evaluating services, making sure that basic requirements for involvement such as access and travel costs are in place, developing relationships with relevant organisations that represent the public, building capacity among lay people, targeting those who might not usually get involved and providing people friendly information17. It is designed to be 'entirely independent of Government and NHSScotland' and has the power to 'intervene itself, for example, in response to public concern'18.

Scottish Health Council (SHC) Unlike in England, the Health Councils have been reorganised and re-launched as the Scottish Health Council, a national structure 'redesigned to support the new emphasis on patient and public involvement in the NHS'18. Local branches have been replaced with one SHC in each Health Board region. Its focus has changed from being a spokes organisation for patients, to one on PPI. NHSScotland, in its proposals for the new Health Council suggested that 'strong, independent external scrutiny needs to be provided by a robust body independent of the local NHS'18. Thus: 'The Scottish Health Council has been set up as an independent champion of patient and public involvement in the NHS. It will set and monitor new standards for how the NHS engages with patients, publish its findings and provide an independent verdict on how well the NHS Boards are delivering their new statutory duty of involving the public in their work. One of its proposed powers is to require NHS Boards to repeat

consultations if it considers that they have not been carried out adequately[18].

Independent Advice and Support Service (IASS) IASS is a free service for users of local health and Community Care Services. This is a very recent development in Scotland to provide help for those wishing independent advice and help with complaints. Its development is to be supported by a Central Support Unit based at Citizens Advice Scotland by the end of 2006. The complaints system in Scotland does not include PALS or ICAS. Instead, patients are expected to use the Citizen's Advice Bureau (CAB) or contact one of the two main advocacy services in Scotland[19].

Are we impressed?

The new structures designed to replace and build on the role of the Community or Local Health Councils, and embed patient and public involvement at every level of NHS services, have already received a series of serious criticisms, including that:

- the DoH failed to work with the outgoing CHCs and did not transfer CHC staff to support the new Patient and Public Involvement forums, losing years of knowledge and skill (this was less the case in Scotland).
- the new structures lack democracy and there is no guidance for how to seek out and work with the socalled 'hard to reach' groups.
- there is no requirement for PCTs to show how involvement has impacted on healthcare decisions, thus PPI lacks the power to influence services[6,2]. 'Patients may be becoming more assertive and knowledgeable about health care, but they still have relatively low political leverage'.
- the healthcare agenda is still preset to reflect medical and managerial concerns. Beverley Beech asks 'is consumer involvement worth it when the agenda is set by others ... And will we be fighting the same battles in another 50 years time?'[20].
- tokenism is alive and well - 'longstanding professional and managerial interests in the NHS may resist such a transfer [of power to the public], and this could result in token public involvement with no real impact on decision making'[21].
- The fragmentation of PPI reduces its power - policies to increase involvement are 'piecemeal and disparate'[21].
- none of the new bodies, (such as PALS, ICAS or OSCs have any kind of overview or the power to involve patients or the public in decision-making about health[9].
- PPI is low on the list of NHS financial priorities, thus lack of funding, resources and training remain key barriers to it. Research prior to the setting up of the new PPI structures found that for Primary Care Groups (now Primary Care Trusts), PPI was challenging and the Groups' skills, resources and ability to support this were limited[6,2]. Some consumer groups (including AIMS) feel unable to meet the demands made upon them and complain that while NHS organisations need to be seen to be consulting them, they do not provide resources to assist them[20,22]. In England, even before the 571 forums representing 301 PCTs and 270 NHS Trusts, requiring over 10,000 lay people were set up, volunteers were leaving them soon after joining them, because of lack of

resources, support and clarity.

- continually changing structures in health provision undermine PPI. For example, Alan Milburn (Secretary of State for Health from 1999-2003) wanted all hospitals to become Foundation Trusts by 2007-8. This would make PPI forums obsolete and cause yet another raft of changes in public involvement, thus incurring further costs[13]. Overall the complexities and fast changing nature of PPI structures make it almost impossible for people to participate, even in the way designated for them, far less contribute to meaningful debates about, or influence health and healthcare.
- cultural barriers within the NHS remain unaddressed: 'Whether these proposed structural changes will overcome the barriers to participation, many of which concern the culture of the NHS and the attitudes of the staff, patients and the general public, is highly questionable'[2].
- there is no particular reason to either believe or disbelieve that the current policies on public involvement will result in greater or more effective involvement[21]. There is little research in this area and we have little knowledge about involvement or how to measure its impact. Indeed: 'Patient and public involvement has tended to be isolated from mechanisms for improving services and the link between involvement, and service change and improvement often remains tenuous'[6].

The criticisms appear to confirm that public participation is essentially an information and feedback mechanism to improve existing services: 'Public involvement is thus used to inform decision makers not to devolve power to local communities'[2]. Even in the best of circumstances, the public is expected to work within rather than challenge narrow definitions of health.

In our efforts to improve health services, we might want to continue to engage with PPI, but we might also examine how successful community development projects have brought about changes in policy. This occurs when communities are encouraged to define health in their own terms, challenging existing meanings of health, and the policies that consistently maintain their ill-health through poverty and discrimination. The time commitment, dedication, initiative and courage demonstrated by those who insist that poor housing, toxic environments, violence, and lack of access to services are central to health, and work towards change is phenomenal.[23] In comparison to this deep engagement with issues of well being, the new structures for involving the public look woefully superficial and inadequate. Some of the lessons from community development include:

- Going to the public repeatedly and establishing ongoing dialogue rather than inviting one or two individuals to attend occasional committee meetings
- Respecting peoples' experiences and knowledge by accepting definitions of health that acknowledge that poverty in all its guises is the main underminer of health
- Devolving power to communities, by responding to its concerns
- Thinking creatively rather than creating more committees.

References

1. Hogg, Christine and Williamson, Charlotte (2001) Whose interests do lay people represent?

Towards an understanding of the role of lay people as members of committees. Health Expectations, 4, pp.2-92.

2. Rowe, Rosemary and Shepherd, Michael (2002) Public Participation in the New NHS: No Closer to Citizen Control? Social Policy and Administration. 36(3) pp275- 290.
3. Pickard Susan and Smith Keri (2001) A 'Third Way' for lay involvement: what evidence so far. Health Expectations 4 170-179.
4. Department of Health (2001) Shifting the Balance of Power within the NHS: Securing Delivery. Department of Health Publications. Free copies available www.doh.gov.uk/shiftingthebalance
5. Department of Health (2005) Creating a Patient-led NHS: Delivering the NHS Improvement Plan. Department of Health Publications. Available from dh@prolog.uk.com
6. Baggott, Rob (2005) A Funny Thing Happened On The Way To The Forum? Reforming Patient and Public Involvement In The NHS In England. Public Administration 83(3) 533-551.
7. Coulter, Angela (2002 Involving patients: representation or representativeness? Health Expectations 5 p1.
8. Shea, Beverley, Santesso, Nancy, Qualman, Ann, Heiberg, Turid, Leong, Amye, Judd, Maria, Robinson, Vivian,Wells, George,Tugwell, Peter and the Cochrane Muskuloskeletal Consumer Group (2005) Consumer driven health care: Building partnerships in research. Health Expectations 8 352-359.
9. Edwards, Nadine (forthcoming) Public Participation in Health Care:Women's Experiences on Maternity Services Liasion Committees.
10. Royal College of General Practitioners (2003) Patient and Public Involvement in the NHS Seventh Report of Session 2002-03. House of Commons Health Committee. RCGP Summary Paper.
11. Beech, Beverley (2005a) CHCs were better for your health. AIMS Quarterly Journal 17 (1) p15.
12. Crawford Mike J, Kutter Deborah, Manley Catherine, Weaver Timothy, Bhui Karmaldeep, Fulop Naomi,Tyrer Peter (2002) Systematic review of involving patints in the bplanning and development of health care. BMJ 325 pp1263
13. House of Commons Health Committee (2003) Patient and Public Involvement in the NHS. Seventh Report of Session 2002-03.TSO. Available on www.parliamentary.uk/parliamentary_committees/health_c ommittee.cfm
14. South Jane, Fairfax Pat and Green Eleanor (2005) Developing an assessment tool for evaluating community involvement. Health Expectations 8 64-73.
15. Patient and Public Involvement Team Department of Health (2005) Consultation on future support for patient and public involvement. Opinion Leader Research. Available at www.opinionleader.co.uk/pdfs/ 6_project_report_1.pdf.
16. Chippington Derrick, Debbie (2004) The truth behind the NICE Guidelines on caesarean section. AIMS Quarterly Journal 16 (3).
17. NHS Quality Improvement Scotland (2003) Patient Focus and Public Involvement. NHSQIS. Available at www.nhshealthquality.org
18. NHS Scotland (2003) A New Public Involvement Structure for NHSScotland. Patient FOocus and Public Involvement. A Draft for Consultation. NHSScotland.

19. Can I help You? Learning from Comments, Concerns and Complaints (2005) available at http://www.show.scot.nhs.uk/publications/me/complaints/d ocs/1guidance010405.pdf
20. Beech Beverley (2005b) The Politics of Childbirth, AIMS Journal,Vol 17, No1, p14-15.
21. Florin Dominique, Dixon Jennifer (2004) Public involvement in health care. BMJ 328 pp159-161.
22. Key, Elizabeth (2004) Consultation, consultation, consultation: a cynical view. AIMS Quarterley Journal 16 (1) p11.
23. Jones, Jane (1999) Private Troubles and Public Issues: A Community Development Approach to Health. Community Learning Scotland, Rosebery House 9 Haymarket Terrace Edinburgh EH12 5EZ