

Foreword

The health service ultimately belongs not to the politicians who like to sing its praises, or the staff who deliver it, but to the public who fund it and the patients who use it. That's why their active involvement in the NHS is important, if anything more so now that the government has invested more of their money in it and, increasingly, encouraged them to approach it as consumers, rather than simply recipients of care.

In the second of our series of BMA papers on the future of the NHS in England in its sixtieth year, we look at the concept of public and patient involvement, focusing on the new mechanisms that are being put in place as part of a drive to give local communities more say in commissioning services.

Our verdict is that they are at risk of having the opposite effect, and that patient voice is in danger of being seriously weakened. If we are genuinely to increase the involvement of ordinary people in their health service, we need to give them far more effective fora for expressing their views. This paper outlines how that might be achieved and we hope it will provide a stimulus to the public, the profession and, particularly, to the government to ensure that the necessary changes are made. As the NHS reaches sixty, it needs to mature into an effective patient and professional partnership delivering a service that really meets the needs of those who use it.



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A handwritten signature in black ink that reads "Juliet Dunmur".

1 Introduction

- 1.2 Through the BMA's Caring for the NHS campaign the medical profession has demonstrated its desire to play a leading part in recasting health service reform and express an enduring commitment to the NHS. Whilst there has been a vocal critique of a large number of specific reforms introduced since the year 2000, the medical profession, in chorus with other groups allied to the NHS, has repeatedly voiced the more general concern that the volume of reform to which the NHS in England has been subject, and the pace of its introduction in recent years, has both destabilised the health service and alienated large sections of its dedicated staff.
- 1.3 The BMA, however, has not simply criticised reform from a distance but instead chose to accept the responsibility of advancing alternative perspectives that might better achieve the objective of an NHS fit for the 21st century. To this end, the BMA has urged the Government to enter into a constructive and meaningful dialogue with the medical profession, other NHS professionals, the public and patients in order to realise a new approach to reform that will safeguard the future of the NHS.
- 1.4 The BMA has been proactive in this respect, consulting widely – not only amongst the medical profession but engaging all parties whom share a relationship with the NHS – and developing proposals for a way forward that will ensure the NHS can deliver improving health to the population in an efficient and equitable manner, honouring a set of shared values and principles to which all those that are invested in the NHS can subscribe.
- 1.5 In its discussion paper, 'A rational way forward for the NHS in England' the BMA stressed the need to embed in the NHS clear structures that allow the full involvement of the public and patients in key decision making processes. Central to this thinking was the recognition that an NHS of the future could only operate legitimately if meaningful and transparent PPI was suitably evidenced in the development, planning and delivery of NHS reform.
- 1.6 Having been mandated by BMA Council to further develop the BMA's proposals in this area this paper sets out in more detail the reasoning behind this approach and offers recommendations on the necessary structures and processes that will ensure PPI is robustly established as an integral and collaborative process in the NHS in order to develop productive partnerships between patients, the public, health professionals and policy makers.

2. The need for public and patient involvement (PPI)

- 2.1 During the past decade the public has had its expectations of the NHS significantly raised as a result of the recent unprecedented levels of investment in the service, government rhetoric and the offer of a more consumerist approach to healthcare. As a result, patients do increasingly want and expect to be treated as consumers of healthcare e.g. requesting more information about treatment options and demanding to be more involved in making the decision about what option to follow.¹
- 2.2 Such developments and the subsequent growing emphasis on patient choice, have the potential to transform the manner in which future services are shaped as the nature of individual referral decisions and associated treatment pathways impact upon the shape of the NHS. Consequently, there needs to be a balance between the individual as a consumer, choosing and using services, and as a citizen, responsibly playing a part in how services should be delivered.
- 2.3 The public, who as taxpayers pay for the health service and use it, have a right to be engaged in its design and development. A service can only be responsive to its users if those users (and potential users) are involved. Public involvement should therefore be integral to decisions concerning what services are provided, how they are provided, issues of quality setting, and the monitoring and maintenance of standards of care. This form and level of public involvement should offer service providers and commissioners the opportunity to better understand the needs of the public. However, it is a concern that exercises of involvement are often only merely placatory.
- 2.4 It is a fact that healthcare policy decisions, at whatever level they are made, will undoubtedly affect patients' experience of the NHS, their future well-being and lives. It can be argued, therefore, that patients have an unquestionable moral and ethical right to play a meaningful role in developing such policies. Certainly, engaging patients in health policy decision-making helps to ensure that policies reflect patients' needs and preferences, and this must ultimately make for more responsive healthcare and, in a publicly funded health service, it also serves to deliver increased accountability.
- 2.5 In our view, at this time of challenge for the NHS, with ever-rising costs and demands on its resources as a result of new technologies, advances in medicine and changing demographics, PPI has never been more important than it is now. Moreover, with the NHS also subject to continued, and wide-scale reform driven both from the centre and locally – sometimes in response to the aforementioned pressures, sometimes in response to political imperatives – PPI must be embedded in the processes informing those crucial decisions, such as service reconfiguration, which will impact on national and local service provision and on many aspects of the public's healthcare. It is vitally important that there is public agreement where possible for these changes, rather than simply having them imposed. Moreover, greater public participation in decision-making can foster a better understanding of the realities of resourcing and provision that are facing the NHS which, in turn, will allow for more informed decision making.

¹ Can choice for all improve health for all? The evidence on whether NHS patients can and should become consumers of healthcare. DH, November 2006

3 Current proposals for PPI

3.1 The government has been pushing forward with current reforms under the justification of ensuring a “patient-led” NHS. Section 242 of the NHS Act 2006 makes public consultation a legal requirement at the level of Primary Care Trusts (PCTs), Strategic Health Authorities (SHAs) and NHS Trusts with regard to:

- the planning and provision of local services
- the development and consideration of proposals for changes to the way services are provided
- decisions that will affect the operation of services.²

However, despite Section 242, there is no coherent guidance as to how effective participation can and should be achieved, and it is not clear how organisations will comply with this.

3.2 In December 2006 the *Local Government and Public Involvement Bill* was introduced into the Commons.³ The Bill aims to formalise, in legislation, the link between service providers, including local authorities, and local involvement networks (known as LINKs) at the level of local authorities. LINKs are envisaged to provide a framework for individuals and communities to have a stronger voice in their local health and social services by ensuring that the ‘needs, preferences and involvement of local people, including those that are seldom heard, are central to the planning, development and delivery of health and social care services.’⁴

3.3 LINKs will replace the current PPI Forums in April 2008 and be used to inform local authority Overview and Scrutiny Committees (OSCs) on public views on health and social care services. There will be fewer LINKs, one per local authority, than there are currently PPI Forums. There will be no over-arching national body such as the Commission for Patient and Public Involvement in Health (CPPIH) which provided administrative support for the PPI Forums. The CPPIH was abolished, as a result of a review of quangos, but then temporarily re-created, as without their support system PPI Forums were unable to function.

3.4 The remit of LINKs is very wide. Among their duties and functions are:

- to gather information
- to analyse the information and pass it on
- to be a means by which commissioners, OSCs and regulators access the views of the local population
- to encourage the public to participate in commissioning, scrutinising and reviewing services
- to be involved in the development of a prospectus-style document.⁵

3.5 The legislation charges local authorities to enter into contractual arrangements with host organisations to run their LINKs. The governance and membership of LINKs will be left to local arrangements. There is, therefore, a danger that with no national guidelines for type or number of members or funding for resources or training for members, there will be an inequity of public involvement between local authorities. In its response to the 2007 Health Select Committee inquiry into patient and public involvement, the BMA’s Patient Liaison Group (PLG) identified a number of possible strengths and weaknesses of LINKs over the current system:

2 http://www.opsi.gov.uk/ACTS/acts2006/ukpga_20060041_en_18

3 www.parliament.the-stationeryoffice.co.uk/pa/pabills/200607/local_government_and_public_involvement_in_health.htm

4 www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4137040&chk=U6PSmq

5 A Stronger Local Voice: A framework for creating a stronger local voice in the development of health and social care services. DH, 2006

Strengths:

- the smaller number of organisations may mean more capable people for recruitment to LINKs (rather than those spread between the current numerous PPI Forums)
- LINKs with populations that are well educated and able to dedicate time may work well
- LINKs will have the power to refer matters to Overview and Scrutiny Committees
- LINKs will have the power to inspect providers' premises.

Weaknesses

- LINKs with populations that are less well educated or less able to dedicate time may not work well
- there may be conflicting views within LINKs because of the size of areas covered and the priorities of particular localities
- LINKs may be too closely allied to local authorities to be independent of local politics and any conflicts of interest that may arise
- there is a danger of LINKs being patronised, out-thought and manipulated by managers
- the lack of national coordination for LINKs does not formally enable sharing of information, ideas and good practice.⁶
- Representation, capacity and resources will be key elements in enabling LINKs to work, but it is of concern that none of these were addressed in any detail in the consultation process or the Bill.

3.6 On 30 October 2007 the Bill received Royal Assent signalling that the Patient and Public Involvement Forums and their co-ordinating body, the Commission for Patient and Public Involvement in Health (CPPIH) would be replaced with 150 LINKs with each group covering all the publicly funded health and social care services in a local authority area – irrespective of who provides them. The legislation also updates and strengthens the duty on NHS bodies to involve and consult local communities about changes to services. The Department of Health suggest that LINKs will make it easier for communities to influence key decisions about local health services and hold those services to account. In summary, it is expected LINKs will:

- aim to represent everyone in the community – not just existing activists but also those not currently being heard;
- have the power to investigate issues of concern, demand information, enter and view services, make reports and recommendations, and refer issues to local councillors; and
- provide a one-stop-shop for the community to engage with care professionals and vice versa.

6 www.bma.org.uk/ap.nsf/Content/ppnhs~ppnhs04

- 3.7 In addition, the legislation changes the existing duty to consult by clarifying the notion of a 'significant' change to services, so that NHS bodies know when they should consult. It also gives PCTs a new statutory duty to respond to local people, explaining the activities they are undertaking as a result of patient and public feedback on their services."
- 3.8 The lack of detail on how LINKs will actually be managed and financed is of concern to patient groups and these concerns are echoed by the BMA. It is noteworthy that the currently existing PPI Forums have recently asked their members to write to Baroness Andrews, Parliamentary Under Secretary of State for the Department for Communities and Local Government, to express their belief that the Local Government and Public Involvement in Health Bill "fails to address many real concerns of patients and the members of the public, who want an effective voice in health and social care services" and, in effect, "will produce weak, vague and ineffective bodies to replace Patients' Forums."
- 3.9 There are seven key objections to the Bill:
- LINKs will have no fixed membership
 - LINKs will be very poorly funded
 - 'Participants' will have no powers
 - The Bill substantially reduces the capacity of patients and the public to exercise genuine influence over health care
 - Creates potential for serious conflicts of interests
 - Excludes monitoring of some health and social care services and all privately run NHS services
 - Doesn't allow for effective transition between Forums and LINKs – abolition date is 31 March 2008, well before LINKs will be established in most areas.

The Bill has no requirement to pay members expenses and no financial loss allowance. As it stands, we believe that the LINKs model proposed in the Bill will and is set to fail."

- 3.10 The BMA agrees that the Bill will fail to effectively promote engagement and suggests that it seems almost inconceivable that the already watered down PPI Forums, which had lost the statutory powers held by their forerunners Community Health Councils (CHCs), should be abolished in favour of a loose amalgamation of participants, who may be individuals or organisations, with funding held by the Local Authority, and which will be given to a 'host' organisation of their choice. The likelihood of LINKs remaining independent in these circumstances seems remote.
- 3.11 LINKs have been given a range of difficult and time-consuming duties. The task of collecting real public opinion is complex and time-consuming, particularly if it is to be done properly. However, we question whether LINKs will have the necessary capacity and resources to be able to carry out their responsibilities robustly and reliably, to the ultimate detriment of PPI. Representation on these new bodies would ideally reflect the population, but more important will be the ability of LINKs to reach all the constituent parts of its population served, including those traditionally excluded. Again, in their current proposed form we are not convinced LINKs will achieve this. In addition, the promised funding which equates to around £185,000 per LINK for the first three years appears inadequate when translated into set-up costs, salaries for a minimum number of staff, expenses for members, office accommodation and running expenses, let alone money for undertaking surveys of public opinion.

- 3.12 Continued interference by government with formal structures of PPI has damaged their effectiveness, with the naivety of the LINKs proposal being an illustration in point. There will be no national organisation of LINKs, so that if several local groups are finding the same problems or areas of good practice, that knowledge will be missed and the potential benefits of this learning will not be passed on to the NHS.

4 How to make PPI effective?

- 4.1 There is often a disconnection between what people are told needs to be done, for example reconfiguring a local service such as an A&E department, and what the public actually believes should be done. Effective PPI is a benefit to people and organisations because it allows them all the opportunity to engage in decisions about healthcare services, and because it can:
- Inform and educate the public and patient body
 - allow the public to assess outcomes, measure success and recognise where improvements or learnings have been made
 - allow the public to understand what constraints there are
 - allow commissioners and service providers to understand what the real issues are for the local population and therefore to make better decisions that will be more willingly accepted by the public.
- 4.2 PPI should not be misunderstood as the public and patients wanting to make or unduly influence clinical decisions. It is, in part, about facilitating patient autonomy and, together with clinical autonomy, holding managers to account. But getting the public involved will not happen through good intentions; it requires commitment, resources and building capacity for involvement to happen and be effective. The key is resources and capacity. PPI needs to be properly funded to enable whatever the organisational structure for PPI is at the time to be able to consult with the community it serves. This means engaging with service users, taxpayers and groups who traditionally do not, or cannot, get involved.
- 4.3 There are few people who have the capacity to really engage, and to find ways of engaging others. Capacity is about having time, self-confidence, access to technology, the ability to spend considerable amounts of time reading lengthy and often complex documents, political skills, committee experience and the availability to attend meetings during working hours as well as outside them. Those that do have the capacity should be supported. It is not the case that most people do not have the intellectual ability to participate because it is clear that they do. The jury system, for instance, shows that people can make rational and reasoned decisions about complex matters when given the information and time to do so.
- 4.4 Involving the public and patients is not straightforward. People as individuals and as members of groups can have diametrically opposed views. Commonly excluded groups such as those with language difficulties, learning difficulties, physical disabilities, mental health problems and those without the time available to commit through traditional means of involvement need to be reached and supported to enable participation. Once involved, it is important that people do not become distrustful of the process. This will happen if their participation is not acknowledged, or when their contribution does not appear to make a difference or at least be considered. Involvement must not be tokenistic or a matter of ticking boxes. This is in itself counter-productive.
- 4.5 Consideration also needs to be given as to where PPI is necessary. There are several layers of hierarchy in the health system which need to be held accountable, from the Secretary of State for Health through SHAs and hospital Trusts in secondary care, and PCTs and GP practices in primary care. The real power in these organisations follows the money. For the public to be truly engaged in the provision and delivery of services, it must be given the facts about costs, about how decisions are made in allocating resources, and about how money can be spent best to meet the needs of local people. And central to this process is the requirement of openness and transparency, the effective means through which legitimacy is secured.

5 Summary and recommendations

- 5.1 It should not be forgotten that choice in healthcare is not a choice most people want to make. Most people want to be completely well and not to need the health service at all. What patients want is good quality treatment and care, delivered in the most appropriate setting close to their home, by a professional team that they trust. In turn, doctors and other healthcare professionals want the resources and autonomy to be able to deliver that care.
- 5.2 In a market environment which has been created for providers to compete with one another for patients, PPI is not just necessary for NHS providers but also for private and third sector organisations commissioned to provide services financed by the public purse. This is particularly important in the context of the '*care closer to home*' agenda where policy decisions which cross the boundaries between healthcare and social care services have to consider quality, safety and equity.
- 5.3 PPI does not need to be prescriptive about methodology, but the BMA recommends the following principles which should underpin such processes, that:
- PPI should be a collaborative process with all voices in discussion helping to develop partnerships between patients, the public, health professionals and policy makers
 - the process should be ongoing and not just a periodical or one-off exercise
 - feedback mechanisms must be built into all PPI activities
 - the processes must be transparent
 - PPI activities must be accessible to all relevant groups
 - efforts must be made to specifically target hard to reach and marginalised groups in order to accommodate equality and equity within the PPI structures and the relevant health services.
- 5.4 The health service is not unique in being the only nationwide infrastructure that has a profound impact on the lives of the general public. It is, therefore, worth examining and learning lessons from other formal engagement structures. Such a model is that used by Community Police Consultative Groups (CPCGs). These groups have existed in most of the London Boroughs for some years, and have been found to be successful at representing community views to the police and, to some extent, vice versa. On LINKs, it is possible that they could work if given a valid system of governance, if seen to be independent and accountable, and if properly funded and resourced. The opportunity for a national body has been lost, and this gap may well be filled by other organisations with an interest in PPI such as the National Voices group of voluntary organisations.⁷
- 5.6 It is apparent that there is an increasing degree of professionalisation of PPI, and as a result it is becoming more difficult for 'ordinary' members of the public to become involved and have an effective voice. The BMA recognises that community engagement is difficult, and time consuming, and requires commitment from all concerned – government, managers, clinicians and other health and social care professionals – if it is to make a meaningful difference. However, it is essential that this challenge is met in order to deliver an NHS that has the capacity to respond to, and the confidence of, its public and patients in the 21st century.

⁷ National Voices. A proposal to strengthen the voices of service users, patients and carers in national health and social care policy making. National Voices, January 2007