Involving Patients and the Public in Healthcare

A Discussion Document

September 2001
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1. Introduction

1.1 The NHS Plan sets out the Government’s ambitions to create a patient-centred NHS. Our vision is to move away from an outdated system of patients being on the outside, towards a new model where the voices of patients, their carers and the public are heard through every level of the service, acting as a powerful lever for change and improvement. To give effect to this, the patient must be at the centre of everything the NHS does.

1.2 This document summarises the work carried out to develop the proposals in the NHS Plan to create a patient-centred NHS. It describes progress and implementation so far, and sets out the proposals that require legislation for strengthening patient and public involvement.

1.3 Professor Kennedy’s inquiry into the Bristol Royal Infirmary set out the principles which should lead to greater public and patient empowerment. The Government agrees with these principles, and our proposals for reform will ensure that these are acted upon throughout the NHS.

Principles underpinning public and patient empowerment as set out in the Kennedy Report:

• patients and the public are entitled to be involved wherever decisions are taken about care in the NHS;
• the involvement of patients and the public must be embedded in the structures of the NHS and permeate all aspects of healthcare;
• the public and patients should have access to relevant information;
• healthcare professionals must be partners in the process of involving the public and patients;
• there must be honesty about the scope of the public’s and patients’ involvement, since some decisions cannot be made by the public;
• there must be transparency and openness in the procedures for involving the public and patients;
• the mechanisms for involvement should be evaluated for their effectiveness;
• the public and patients should have access to training and funding to allow them to participate fully;
• the public should be represented by a wide range of individuals and groups and not by particular ‘patient groups’.

1.4 The Government will respond in more detail to the recommendations of the Kennedy report later this year.
The immediate focus of this document is the Government’s intention to legislate at the earliest opportunity to replace Community Health Councils with a set of arrangements that will:

- align the structures for patient and public involvement with the devolution of resources and power to the NHS frontline as outlined in *Shifting the Balance of Power within the NHS*;
- integrate the views of patients and citizens into every level of the NHS, and ensure that involvement and support is consistent throughout;
- make it easier to listen to patients’ voices across the NHS so that services reflect their needs;
- make it easier for citizens to contribute to strategic decisions so that services reflect and meet the needs of communities.

We will not only ensure that everything CHCs currently do will be picked up in the new arrangements, but that patient and citizen involvement will be strengthened and, as a result, will become part of day to day NHS activity. Annex A describes this.

We would welcome your comments on the proposals for the new arrangements and your suggestions as to how we can improve them. It is clear that the structural framework for the new arrangements needs to fit within the context of *Shifting the Balance of Power within the NHS*. However, key questions remain about how the new arrangements should operate to best effect. In this respect, we have set out a list of the key questions we would specifically like your views on, together of course, with any general points you may want to make. These questions are at Annex C.

We will consider all the feedback we receive in the context of any primary legislation that may be required, as well as subsequent secondary legislation and guidance that is produced. Where it would be helpful, we will undertake additional feedback exercises on regulations and guidance.

We are clear that changes must be made – and we are committed to making them. Your views on how we make our proposals as strong as possible, will help us ensure that patients, carers and citizens really are properly involved so they can influence their healthcare and health services in their community.

Details about how you can get involved and have your say are on page 15.
2. Executive Summary

2.1 This document signals the beginning of a discussion period on how the public and patients can be involved in and how they can influence the NHS. It builds on the proposals first set out in the NHS Plan and takes account of over a year’s worth of discussion, debate and developments.

2.2 In summary, the proposals are to replace CHCs and ACHCEW with

- statutory Patients’ Forums to facilitate and strengthen the patients’ voice;
- statutory bodies to be called Voice to strengthen and facilitate the public voice;
- and a new statutory national body called Voice – the Commission for Public and Patient Involvement in Health, to oversee the arrangements.

2.3 Details about how to comment on the proposals in this document are on page 15. Regional events will also be held – for further information about these please contact your local NHS Regional Office – the details are in Annex D.
3. Background

3.1 Just as change is needed elsewhere in the NHS, change is also needed in the way the NHS involves the public and patients – so that they can make a real difference to how the NHS works. The proposals outlined here reflect the Government’s determination to build on current best practice available to put patients and citizens at the heart of the health service.

Aligning structures

3.2 *Shifting the Balance of Power within the NHS* sets out our proposals to shift the power and resources in the NHS to front line staff, who understand the needs and concerns of patients, and to the people who use and pay for the services. This will mean change at all levels of the NHS and throughout the Department of Health.

3.3 Our intention is to take account of the new NHS, and ensure that there are opportunities for patients and the public to be involved at all levels, locally, strategically and nationally.

Integrating the views of patients and citizens through every level of the NHS

3.4 The NHS can learn from patients, carers and the public – we want to ensure their systematic involvement by making it easier for them to be involved and by creating a system that works for them and for the NHS.

3.5 Current structures relate to an outdated model whereby patients, carers and their representatives campaign to be heard from outside the NHS. It is our aim to ensure that, where appropriate, the voices of citizens, patients and their carers are on the inside, influencing every level of the service. This is an ambition we share with the Kennedy Report, which emphasised:

“...the priority for involving the public should be that their interests are embedded into all organisations and institutions concerned with quality of performance in the NHS: in other words, the public should be ‘on the inside’ rather than represented by some body ‘on the outside.”

Making it easier to hear and strengthen patients’ voices

3.6 It is clear that patient expectations are rising. People want an NHS that provides fast and responsive services within a national framework that ensures national standards are consistently high. But they also want an NHS that is responsive to their needs, listens to their views, and acts on their concerns – a patient-centred NHS.

3.7 The proposed reforms outlined in the *Shifting the Balance of Power within the NHS* are designed to better reflect patients’ needs by devolving power to frontline staff and breaking down barriers between services. But these reforms will not work unless they are informed by the views of people who use and deliver the service.
Transforming the NHS into a modern patient-focused service means not just extra investment or far reaching structural reforms. It means changing the culture and the way the NHS works, so that listening to and acting upon the views of the people who it is there for, becomes the norm and people are helped and encouraged to make their views known.

Making it easier to hear and strengthen citizens’ voices

People want to be involved, not just as patients or users of the NHS, but as citizens who fund the NHS for the benefit of themselves, their families and the wider community. There are examples of good citizen involvement around the country, but current structures do not always ensure that communities have a direct say in local NHS planning and the decisions that affect their health. We want to change this so that everyone has the opportunity to have a say.

The Government wants to empower citizens as well as providing first class public services. We are determined to increase public involvement as much as public investment; to reform the way we engage the public as much as to reforming the way we deliver public services; and to decentralise as a key part of delivery.

We recognise that to achieve this we need to build capacity by providing support for local communities – particularly minority and hard to reach groups. We need to reach out and help them become involved, so that they can put forward people who can fully and actively engage in the decision making process.

4. How we will achieve our aims

Progress so far

The NHS Plan, published just over a year ago, set out the route map for every aspect of the NHS. That programme of reform is well underway and already the Government has set in train its plans for restructuring the way the public can have greater control and influence over the NHS.

The Health and Social Care Act 2001 puts in place the building blocks for our patient empowerment agenda. It enshrines in law:

• new powers for local government Overview and Scrutiny Committees to scrutinise the NHS;
• a new duty on the NHS to involve the public in the planning and development of services, and in major decisions;
• a new duty on the Secretary of State to make independent advocacy services available to people wishing to make a complaint against the NHS.

These and a number of other initiatives are discussed in more detail below.

Scrutiny – independent, democratically elected bodies holding the local NHS to account

The Act extends local authority Overview and Scrutiny Committees’ (OSC) role into the NHS. This means that democratically elected bodies will now be able to scrutinise the NHS, and call local NHS Chief Executives and other NHS managers to account. This power will not come into force until the necessary regulations have been made; we anticipate this new role coming into effect next year. There will be a formal consultation process on the nature of the regulations and the guidance necessary.
Public Involvement – a duty on the NHS to involve and consult the communities it serves

4.5 The Act places a new duty on the NHS to involve the public in the decisions it makes. We do not intend prescribing to the NHS how to do this – we envisage producing a tool kit and/or best practice guidance. We will do this in tandem with the implementation of the wider arrangements for patient and public involvement in the NHS.

Information and on the spot help – solving problems and securing improvements for patients and carers

4.6 By April 2002 Patient Advocacy and Liaison Services (PALS) will be in place in every NHS trust and Primary Care Trust (PCT) in England, to provide information to patients, their carers and families and to help them to resolve problems and concerns quickly before they become more serious. PALS will also provide help by putting people in touch with specialist advocacy services, including independent advocacy and support to make a complaint.

4.7 The PALS must not work in isolation, but must work across organisational boundaries. We know that patients will often use many organisations as they progress through the patient journey. PALS will operate within a local network to provide support to patients and their carers as they pass from one organisation to another to ensure that patients’ concerns are picked up and dealt with in the most appropriate way for the patient concerned.

4.8 The PALS will be a key source of information and feedback for the trust and the local Patients’ Forum and will act as an early warning system, detecting, reporting and, where possible, resolving potential major problems before they escalate. The PALS will send anonymised reports to the local Patients’ Forum and to the trust about their work and action taken, identifying gaps in the system and areas for NHS staff training and development. The annual Patients’ Prospectus will include information about changes that have been made as a result of PALS’ work.

Example of how two PALS are already making a difference in two trusts

• As a result of a patient who contacted the PALS service a letter for a one-stop clinic has been changed. Patients were advised with a first appointment that, due to the nature of the clinic, they could be there all afternoon. Unfortunately, if an appointment was cancelled or re-arranged for any reason, this information was missed off the re-arranged appointment letter. This was brought to the attention of the PALS by a patient who had been inconvenienced. As a result, information telling patients what to expect is now sent out with all appointment letters, including re-arrangement letters. Although this seems like a small change, it is one that will reduce the risk of confusion, reduce frustration and enhance the experience of patients who use this particular service.

• In another trust, a patient was unhappy about apparently conflicting advice about her condition and treatment. The PALS arranged for a Senior House Officer to call her at home and talk through the advice she had been given so that she was clear about her situation and confident in her treatment.
Advocacy and Complaints – Independent Complaints

Advocacy Service for people who want to complain about the NHS

4.9 The Act also places a new duty on the Secretary of State to make arrangements for independent support to be available for people wishing to make a complaint against the NHS. Patients or carers will be able to access this service directly to assist them in making a complaint about NHS services – if this is what the patient or carer wants. We will need to ensure that this support is provided in a way that delivers a consistent and high quality service across the country and between organisations. We are looking at this in conjunction with the review of the NHS complaints procedure and we are publishing the results of a national evaluation study.

4.10 We will be asking patients, the public and NHS staff how we can make the current arrangements better to ensure a robust, high quality service that addresses the concerns of people who want to complain about NHS services. New guidance will be issued to the NHS in 2002 with a view to the reformed NHS complaints procedure being implemented in early 2003.

Patient surveys – making the NHS publicly accountable

4.11 The new patient survey programme is an important tool for making the NHS more responsive to patients, and provides a formal mechanism for collecting patient views on the services they receive. Starting this year, every acute hospital trust will undertake a new patient survey programme to use local patient views to improve the quality of patients’ experiences.

4.12 To demonstrate clearly that the NHS is acting on information gained from patients and responding to patients’ priorities, from April 2002, every NHS organisation will be required to publish, in a new Patient Prospectus, an annual account of the views received from patients and the action taken as a result.

National Institute for Clinical Excellence (NICE) and the Citizens Council – informing guidance for clinicians

4.13 The NHS Plan set out our commitment to create a Citizens Council to advise NICE on the values inherent in its decisions and guidance on treatments. The Department of Health is currently working with NICE to develop a Council that is broadly representative of the English and Welsh populations. We will draw on the lessons learned by Citizens’ Juries and other deliberative methods to ensure that members of the Council have enough time and information to deliberate on the questions and give their advice to NICE.

5. Proposed changes to complete the picture

Summary of proposals

5.1 A substantial amount of progress has been made – but the picture is not yet complete. More needs to be done to ensure that:

- the perspectives of both patients and the public are embedded into the scrutiny of the whole of the NHS;
• the new structures operate according to national standards and arrangements are in place for support and training;
• that the new structures work together in the interests of patients and citizens;
• mechanisms are in place to build capacity in the community for effective patient and public participation.

5.2 To achieve this we will introduce legislation to replace Community Health Councils and the Association for Community Health Councils in England and Wales with:
• Patients’ Forums in every PCT and NHS trust in England;
• local bodies to be called Voice, for every strategic health authority area in England.
• a new national patients body Voice: the Commission for Patient and Public Involvement in Health;

These are discussed below.

Patients’ Forums – Putting the public ‘on the inside’

5.3 We will introduce legislation to set up independent Patients’ Forums for every NHS trust and PCT in England. They will be statutory independent bodies made up of patients and others from the local community, with extensive powers to inspect all aspects of the work of trusts. They will elect one of their members on to the trust board, so allowing patients to elect a representative of the key decision making body of every local NHS organisation for the first time. They will be the pivotal way for people who use the services to get involved and have a real say in the way their local NHS is run. They will directly influence the quality and shape of services, with the net result of making the local NHS more responsive to what local patients actually want.

5.4 Patients’ Forums core remit will be to find out what patients and their carers think about the services they use, to monitor the quality of local services from the patient perspective, and to work with the local NHS trust to bring about improvements. In particular, the Patients’ Forum will develop close links with the PALS and the trust board.

5.5 So that Patients’ Forums can carry out their job effectively, they will need administrative and secretarial support. We do not want to be prescriptive about where this should come from. Members will also need support and training. We propose that Voice: the Commission for Patient and Public Involvement in the Health, takes on the role of developing and accrediting training for Patients’ Forum members. The local Voice will also play a key role in providing this support function.

5.6 Examples of how we intend them to discharge this function are described below – we would welcome your ideas on how Patients’ Forums could fulfil their role most effectively.
Patients’ Forums should be able to:

• elect one of their members to be a non-executive director of the local trust board;
• inspect every service that NHS patients use, including primary care services, and go behind the scenes, too;
• make their reports available to key decision makers in the community including the local Overview and Scrutiny Committees (OSC), and Local Strategic Partnerships about the views and concerns of patients;
• monitor Patient Advocacy and Liaison Services (PALS) and bring to the attention of the trust cases where this service is under-performing. Where the service does not improve they should be able to recommend that it is replaced;
• report adverse incidents to the National Patients Safety Agency;
• make reports and recommendations for improvement of services to the trust board based on the experiences, ideas and needs of patients and the wider public;
• contribute evidence to inform the Commission for Health Improvement (CHI) inspections and Health Select Committee enquiries.

5.7 To maintain their independence we think it would be appropriate for members of the Patients’ Forums to be appointed by the new independent NHS Appointments Commission. Members will not be paid a wage, but out of pocket expenses will be covered including loss of earnings and expenses associated with caring responsibilities.

5.8 Patients’ Forums must look wider than their own trust. Just as patient care is not always confined to one trust, so Patients’ Forums should not work in isolation from the Forums for other trusts that make up a typical patient journey. In carrying out their role, Patients’ Forums should be able to work together and across boundaries where they think it is appropriate, and feed into the work of the local authority OSC. For example, a group of Forums may decide that they want to carry out a piece of work about services for the elderly in a particular area, feeding their findings into the strategic planning bodies and the OSC. As outlined below, we also intend that the work of Patients’ Forums is co-ordinated by the local Voice.

5.9 The Patients’ Forums for PCTs will have an important additional role. In addition to inspecting and reporting on the services provided by the PCT, they will also inspect and report on services commissioned by the PCT. This may involve them in reporting on services provided by trusts outside their normal area, and on the private sector services being provided under contract to NHS patients.

Voice – representing communities to improve health as well as healthcare

5.10 The NHS Plan recognised that a mechanism for engaging with citizens as well as patients on the strategic development of health services was important. The Plan outlined the idea of Independent Local Advisory Forums (ILAFs) to fulfil this role. We are now proposing a new model instead, Voice, which develops and extends the original concept of ILAFs. We realise that this is breaking new ground, and we are asking for your help to complete the picture.

5.11 Underpinning the establishment of Voices is the aim that every member of the local population is entitled to be heard, and that citizens who have tended to be excluded by poverty, disability and ethnicity, deserve particular support in this respect.
5.12 *Voices* will provide this much needed support. They will be there to help all parts of the NHS improve public involvement: helping communities have an effective say in their local NHS, and ensuring that the new system we introduce works in the best interest of patients and the public.

5.13 As such, we do not see *Voices* as isolated organisations in their own right, that act purely as a proxy representative for local communities. Rather, we are proposing a group of specialist staff, who have the skills and experience to support individuals and build capacity in communities enabling them to assert their own views and influence change.

5.14 *Voices* will also provide a focus for supporting and pulling together the valuable community involvement work that may be going on across an area. *Voices* are therefore not meant as a replacement for what already exists by way of community involvement. They are intended to be a means of promoting it, and where good community involvement already exists, one of their jobs will be to spread good practice. They will work with Local Strategic Partnerships (LSPs) and with partners involved in the Health Improvement Modernisation Plan (HIMP) process.

5.15 In this respect, the role of *Voice* will also include co-ordinating the work of *Patients’ Forums*, and ensuring consistency between health and social services approaches.

5.16 By supporting and co-ordinating this work, the *Voices* will provide both a means of empowering local communities to get involved, and of ensuring that consistent messages are identified and relayed.

5.17 Our proposals for *Patients’ Forums* empower patients, their carers and representative organisations. *Voice* takes this a step further and put in place a means of:

* developing the ability of patients and citizens to take greater control of their own health and over the organisations and services that affect their health;

* co-ordinating the views of patients and citizens from across an area, in particular by regularly bringing together the *Patients’ Forums* from the NHS trusts in that area to share feedback and information;

* ensuring that the experiences and views of patients and citizens from diverse backgrounds are built into the planning and decision-making of all local services that impact on the health of the local population;

* assuring the quality of citizen involvement in services and developments affecting the health of the population ensuring it is inclusive, consistent, rigorous and sustained.

5.18 There will be one *Voice* per strategic health authority (StHA), but they will need to work closely with other StHAs on key health service and wider health issues.

5.19 Requiring *Voices* to work with StHAs means that they can pull together an overview of trends and themes, and take account of broader community issues and wider determinants of health. Armed with this information, *Voices* would make reports and recommendations to their StHA about the strategic planning of health services in their area, which the StHA would have a duty to take account of.

5.20 However, *Voices’* routine activities will be inside local communities and involvement systems. For example, the local agencies will perform an essential role of helping *Patients’ Forums* to actively seek the views of patients and the public, particularly from marginalised or minority groups. *Voices* might also help to co-ordinate formal consultation exercises, or set up Citizens’ Juries to investigate specific questions facing the health service.
5.21 *Voices* will also need to work closely with the local authority partners in their area to ensure coherence and consistency between health and social services work.

5.22 Because of the need to link with local authorities as well as StHAs, we propose that staff working for each *Voice* be employed by, and located with, a host local authority within that area. The local authority would be responsible for appointing staff, according to standard criteria set down by *Voice: the National Commission for Patient and Public Involvement in Health* (see below).

5.23 This arrangement would also reinforce the principle that *Voices* should be fully independent of the NHS.

5.24 We believe that these local agencies will be able to make the critical connection between patient experience of the NHS with the views of citizens and communities on matters that affect their health. There are a number of ways in which they might do this, and some of our proposals are listed below. **We would welcome your views both on the precise remit of Voices, and how they could fulfil that role most effectively.**

Examples of *Voice* functions:

- encouraging and facilitating public and patient involvement in and consultation on decisions, plans or proposals affecting the health of local communities and work alongside Local Strategic Partnerships (LSPs);
- arranging opportunities for members of the public to comment on health-related matters. For example, arranging public meetings or events, conducting surveys and interviews;
- encouraging public bodies, and voluntary organisations and other private bodies, to seek views of local communities on health-related issues;
- advising and assisting any public body, or private provider of services of facilities to the public, on arrangements for involving the public on proposals that affect the health of individuals;
- participating in the planning and development of services that relate to or have an impact on health, by feeding in the co-ordinated views of the local communities affected;
- co-ordinating the activities of *Patients’ Forums* within their area;
- making reports and recommendations to Overview and Scrutiny Committees (OSC) about the views, concerns and interests of communities about matters affecting their health;
- commissioning local independent complaints advocacy services.

**Voice: the Commission for Patient and Public Involvement in Health (VCPPIH) – setting standards, ensuring consistency**

5.25 In the course of the last 12 months, we have held on-going discussions with key patient groups and with other interested individuals and organisations. What became clear was that there is a need for a national means of ensuring the consistency and effectiveness of patient and public involvement across the country. As a result, the Secretary of State gave an undertaking to conduct a scoping study on the idea of a national body. We, therefore, commissioned a report from a study group, that comprised the Long-term Medical Conditions Alliance, the Patients’ Forum and the College of Health.
5.26 Taking on board the report’s findings we have identified the central purpose of the national body as being to facilitate the effective operation of patient and public involvement and representation systems at local, regional and national level.

5.27 The intention is that the body will have a formal role in relation to the NHS patient and public involvement mechanisms. It is also envisaged that it will maintain a full and mutually beneficial dialogue with the patient and public involvement bodies in the voluntary sector on these arrangements where appropriate.

5.28 The Government believes that an independent non-departmental public body is required. We have described below what its key functions should be, but we would appreciate your views on how it should operate.

Proposed functions for VCPPIH:

- represent to the Secretary of State and Parliament the views that “patients organisations” have about the arrangements for involving patients, public and carers in the running and planning of the NHS;
- identify and disseminate quality standards for the establishment, operation and evaluation of the public and patient involvement system;
- develop quality standards for independent advocacy services in support of people who have complaints against the NHS;
- inform, advise and support local public and patient involvement bodies – on recruitment, training, involvement and engagement processes;
- act as a resource to patient and voluntary groups on building the capacity of patients and citizens to voice their needs and concerns about matters that affect their health;
- provide a national assessment of the performance of the patient and public involvement system – reporting to the Secretary of State and Parliament on how well it is working and recommending ways of improving it;
- undertake and/or commission research on relevant subjects, e.g. tracking a sample of vulnerable people through the system;
- design and licence basic training in being a patient/public representative on the new NHS patient and public involvement bodies;
- report to other independent bodies, such as the Commission for Health Improvement (CHI), data on matters relating to patient safety and welfare that emerges through the whole system of patient and public involvement.

5.29 The VCPPIH will provide PALS, Patients’ Forums and providers of independent complaints and advocacy with the tools needed to make the involvement of patients and the public really count.
6. Opportunities in the new system

6.1 The new system for patient and public involvement will create a spectrum of opportunities for people wishing to be involved – both on a paid and voluntary basis.

6.2 Already PALS across the country are recruiting staff – as the programme is rolled out more opportunities will become available for people who would like to be involved in the delivery of customer service to patients. There will be roles for people with only a few hours to spare in a voluntary capacity, and for people looking for paid full – and part-time work – these will range from support functions to opportunities for staffing and managing the frontline service they provide.

6.3 The Patients’ Forum itself will be made up exclusively of volunteers – although it is likely that the secretarial and administrative support will be provided by paid staff. As the pivotal body in the new arrangements they will be the key method for influencing local decision making processes and the quality of services delivered. They will be a unique opportunity to drive forward the public and patient involvement agenda in local communities. The VCPPIH will open up opportunities at a national level.

7. CHC staff

7.1 Since the NHS Plan was published and the Government’s intention to replace CHCs was first announced, CHC staff have understandably been concerned for their future. As a minimum, we will guarantee that CHC staff are treated in a way that is fair and equal to all other NHS staff who will be moving as a result of Shifting the Balance of Power within the NHS. In fact, the new arrangements we are proposing provide a wide range of opportunities for CHC staff who have the key skills and experience needed in this area. We will be working with CHC staff representatives and unions to ensure that staff continue to have the support they need to take full advantage of these opportunities and will publish a separate human resources document soon.

8. What is in it for Patients and the Public?

8.1 Patients’ Forums, Voices and PALS, all create new opportunities for people to get more involved in their local NHS and to influence its decisions and the shape of services.

8.2 In addition, there are more personal benefits for people who decide to get involved:

- all out of pocket expenses, including those associated with caring responsibilities, will be met;
- everyone involved in the new patient and public involvement mechanisms will receive training and guidance to acquire the necessary skills to make a significant contribution;
- getting involved in Patients’ Forums, PALS and Voices will be a way to build networks and a way of finding other areas of public involvement that they are also interested in;
- there will also be opportunities to learn new skills that can be transferred to other volunteering and paid positions;
- increased awareness of the importance of community involvement in health improvement;
- reduced isolation of a range of vulnerable groups.
9. How to comment on the ideas we have described

9.1 Throughout September, there will be a series of seminars to discuss the proposals in this document, co-ordinated by the NHS Regional Offices. It will be an opportunity for you to feedback your views, and to ask questions and to get answers to them.

9.2 If you would like to attend one of these events please contact your nearest NHS Regional Office. The contact details are in Annex D.

9.3 We would particularly welcome participation in these events from CHCs and patient and voluntary sector groups, as well as representatives from the NHS and local government.

9.4 In addition you can feedback your ideas to our mailbox MBHazelBlears@doh.gsi.gov.uk

9.5 If you want to write to us with your comments please send them to

Hazel Blears MP
Parliamentary under Secretary of State
Department of Health
Room 402
Richmond House
79 Whitehall
London
SW1A 2NS

Or fax them to her on 0207 210 4902.

9.6 We are particularly interested in your thoughts on the functions of the new bodies we are proposing and the questions attached at Annex C. If you want to reply to a particular question please indicate, which question you are commenting on. **We would be grateful if you could reply by Friday, 12 October.**

10. Conclusion

10.1 We want to put in place mechanisms that best serve patients, carers, the public and the NHS. As the NHS is reformed there can be no vested interests but the interest of the patient. And it is this approach which will help us recast the relationship between the health service and the people it serves. While this will take time, we believe that this is the right agenda for the NHS.

Department of Health
September 2001
How current Community Health Council (CHC) functions will be picked up and strengthened by our proposals

1. Scrutiny of NHS services

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<tr>
<th>Current system</th>
<th>Proposed system</th>
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<tr>
<td>• Heath Authority (HA) duty to meet the CHC formally once a year.</td>
<td>• Locally elected Councillors will undertake scrutiny role through the local authority’s overview and scrutiny committee (OSC).</td>
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<td>• CHC power to inspect premises controlled by the HA.</td>
<td>• OSCs will be able to call NHS executives to account in a face to face meeting twice a year.</td>
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<td>• Patients’ Forums to be given extended powers to be able to conduct inspections of every aspect of NHS patient care, and everywhere the NHS patient goes – including primary care and private sector facilities contracted to the NHS.</td>
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Advantages of the new system

• Complete coverage of NHS services.

• Gives patients/carers and patient organisations the opportunity to have a direct input into NHS scrutiny.

• Scrutiny by democratically elected OSCs brings a broader community perspective to NHS scrutiny and strengthening links within local government.

• Wider powers of local inspection, including GP premises.
2. Public representation

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<th>Current system</th>
<th>New and proposed system</th>
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<tr>
<td>• CHC duty to represent the local public within its district.</td>
<td>• New duty in the Health and Social Care Act 2001 on the NHS to consult and involve</td>
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<tr>
<td>• CHC right to be consulted on proposed substantial service changes.</td>
<td>patients and the public in decision-making.</td>
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<td>• CHC observer status at certain Trust meetings.</td>
<td>• New powers for local authorities in the Health and Social Care Act 2001 to scrutinise</td>
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<td>health through the OSC with right to refer any contested service changes or concern</td>
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<td>about the consultation process to SoS.</td>
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<td></td>
<td>• Elected representatives of Patients’ Forums to sit on trust boards.</td>
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<td></td>
<td>• Voices, located with local authorities will ensure that the views of patients and the</td>
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<tr>
<td></td>
<td>public are built into local planning decisions that affect people’s health e.g.</td>
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<td></td>
<td>through Health Improvement Modernisation Plans (HIMPs), Local Strategic Partnerships</td>
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<td>(LSPs) and social services.</td>
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</table>

**Advantages of the new system**

• Democratic scrutiny of health service plans and public involvement process by Local Authority OSC.

• Independent advice to SoS on contested service changes from the Independent Reconfiguration Panel.

• Greater independence, with Voice staff recruited to national criteria and employed outside the NHS.

• Greater representation, at a higher level, with patients sitting on trust boards.

• Wider NHS duties of consultation.

• NHS cannot ignore views of patients/public: they are integrated at every level, even nationally, and they will influence all determinants of health, not just health services.
3. Monitoring NHS services

<table>
<thead>
<tr>
<th>Current system</th>
<th>Proposed system</th>
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</thead>
<tbody>
<tr>
<td>• CHC duty to advise the HA on health service matters, to make recommendations and produce an annual report.</td>
<td>• OSCs will monitor the full range of local NHS services including primary care.</td>
</tr>
<tr>
<td>• Each Patients' Forum will monitor services provided by the trust to which they relate.</td>
<td>• Duty on NHS bodies to publish details in a patient prospectus about how they have involved service users and their local community.</td>
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<tr>
<td>• Patient Advocacy Liaison Service (PALS), in giving complaints advice and support.</td>
<td>• Patients' Forums will collect data on trust performance and will be able to work across trust boundaries for services that span more than one area.</td>
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</tbody>
</table>

Advantages of the new system

• Independent monitoring by democratically elected body.

• Closer monitoring and scrutiny of each trust by the people who use the services.

• Patient views feeding directly into service and organisational development.

• Trusts will be more responsive to feedback and this process will assist the culture change to see feedback as a positive force for local NHS change, not simply criticism.

4. Support in making a complaint

<table>
<thead>
<tr>
<th>Current system</th>
<th>New and proposed system</th>
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</thead>
<tbody>
<tr>
<td>• Conventional role, fulfilled by many CHCs, in giving complaints advice and support.</td>
<td>• Patient Advocacy Liaison Service (PALS), currently being established for every trust and PCT, will provide on the spot support to resolve concerns raised about services within their trust.</td>
</tr>
<tr>
<td>• Duty on NHS bodies to publish details in a patient prospectus about how they have involved service users and their local community.</td>
<td>• New statutory duty on the SofS to make Independent Complaints Advocacy Services available throughout England to provide support to patients.</td>
</tr>
</tbody>
</table>

Advantages of the new system

• Accessible and visible services for patients/carers/family which will deal with complaints on the spot.

• Independent complaints advocacy services are available everywhere, and provided to common standards.
New areas covered in our proposals

5. National co-ordination & standard-setting

The proposed national body, Voice – the Commission for Patients and Public Involvement in Health (VCPPIH) – will facilitate and support the effective operation of patient and public involvement in the running and planning of the NHS at the local, regional and national levels. The Association of CHCs for England and Wales (ACHCEW) currently exists to represent the interests of CHCs nationally, provide certain training packages and a legal advice service for CHC members.

6. Information for patients

The Patients’ Prospectus will show how trusts make changes to the way they operate based on user feedback.

• New NHS trust-based patient survey will help to deliver a modern patient-focused service. Measuring the patient experience of local health services will form part of the overall performance management arrangements and so increases the influence patients have within the NHS.

• Patient Prospectus’ will expound the views received from patients and the action taken as a result. The annual Patient Prospectus publication will therefore act as a single vehicle for publishing local targets and local standards, how they were measured, progress made against them and new priorities for the next year.
Explanation of the diagram summarising the public and patient involvement mechanisms

We are putting patients and the public at the centre of our thinking. The structures we are proposing are designed to make sure that wherever they are involved or affected – whether as individual patients, or as groups and communities – there is a mechanism in place to support them and make their views heard.

For individual patients, in every primary care and hospital trust, the Patient Advisory and Liaison Service (PALS) will be there for on the spot help. It will also be able to refer more formal matters of complaint to the Independent Complaints Advocacy Service (ICAS). PALS will be able to make reports to independent Patients' Forums about their work and when they receive multiple queries about the same issue, they will act as an early warning system and will inform the Patients' Forum who will report their concerns to the trust board. Like PALS, Patients' Forums will be in every NHS trust and PCT. They will monitor trust activity and input into their decision-making and planning. The Patients' Forum will be able to elect a non-executive director to sit on the trust board. In addition the Patients' Forums will be responsible for monitoring the service the PALS provides and will be able to recommend they are replaced if they are under-performing. Patients' Forums and Overview and Scrutiny Committees will share their reports with each other ensuring that their scrutiny roles takes account of each others work.

At a community level, the local independent Voice - based in and working with local authorities - will act as a means of supporting and promoting community involvement activity locally. It will provide training and education skills for local people so they can influence decision making. It will consider all the determinants of health, not just health care, and make reports to OSCs, giving them the essential information to fulfil their role as scrutineers of the NHS locally. The local Voice will also be able to channel key messages from communities and Patients' Forums to the Strategic Health Authority, to influence change and improvement in the longer term. The Strategic Health Authority will have a duty to take account of the reports it receives from local Voices. They will work alongside Patients' Forums, as well as other community involvement mechanisms, facilitating patient and the wider public’s involvement in the NHS.

Overarching all this nationally will be Voice: the Commission for Patient and Public Involvement in Health. This independent body will be responsible for monitoring patient and public involvement across the health service, ensuring it is taken seriously and adds value. One of the ways it will do this is by setting and monitoring minimum standards against which the PALS, Patients' Forum and local Voice should work. It will also provide them with training and guidance. Both local Voices and Patients' Forums will submit annual reports to the national Voice, which will be able to report on the patient and public involvement systems to the Secretary of State for Health.
Involving Patients and the Public in Healthcare

VOICE
Commission for Patient and Public Involvement in Health

- **PALS**
  Patient advocacy and liaison services

- **PATIENTS' FORUMS**
  Monitoring trusts

- **ICAS**
  Independent Complaints Advocacy Service

**PATIENTS & PUBLIC**

**LOCAL VOICE**
Empowering local people

**StHA**
Strategic Health Authorities

**OSCs**
Local Authority Overview and Scrutiny Committees
Questions to help you make your comments

We would welcome any general comments, both on the overall content of this document, and on the general functions and operation of the new arrangements we are proposing. In addition, there a number of important areas where we are seeking your specific input. These are as follows:

**General**

1. How can we ensure that we involve people in the new system that are traditionally marginalised, for example through inequality?

2. What incentives would be appropriate and relevant to encourage wide-ranging and active involvement in the new system?

3. What ideas do you have for measuring the effectiveness of the involvement mechanisms?

4. Can you see other ways by which the new system can be further strengthened to ensure the protection and safety of patients?

5. Do you think the system has sufficient powers for patients and citizens – is there scope for more influence?

6. Do you have views on how best to ensure clear, quick and comprehensive flow of information throughout the system?

7. We think it is essential that information from the various involvement mechanisms should be open to the public – do you agree? If not, which areas should be excluded?

**Patients’ Forums**

8. What criteria should the Independent Appointments Commission use when appointing members of Patients’ Forums?

9. What would be the most appropriate quorum for membership for Patients’ Forums?

10. What protocols should be in place for Patients’ Forum making unannounced visits to sensitive service areas e.g. maternity wards, intensive care units, secure units?

11. Should core members of the Patients’ Forum be formally required to undertake an induction process prior to taking up their membership?

12. What sort of issues or areas should be covered in a formal induction process for Patients’ Forum members?
13. Would it be helpful for there to be a “Code of Conduct” for Patients’ Forum members?

14. In the event of a Patients’ Forum producing a knowingly misleading report, what actions/sanctions should be taken or instigated and by who?

15. Where two or more Patients’ Forums, work collaboratively on NHS service issue affecting their trusts, should a single Patients’ Forum be nominated as the lead to co-ordinate the work or should the Patients’ Forums concerned be asked to set up a joint committee reporting back to each of the Patients’ Forums involved?

16. Where should the secretarial support for Patients’ Forums be best located?

**Voice**

17. What additional areas of community involvement do you envisage Voices being involved in?

18. What relationship should the Voice have with the Strategic Health Authority – other than the St HA having the ability to commission patient and public involvement work from the Voice and the Voice providing information to the St HA?

19. What sort of activities would it be reasonable for a Voice to demonstrate that they are encouraging public and patient involvement – particularly amongst hard to reach or “unseen” community groups and individuals?

20. What relationship should Voice have with local voluntary bodies involved in community involvement?

21. Should the Voice be able to accept commissions to undertake work from bodies outside the NHS or Local Authority? If so, are there basic criteria that should guide these local decisions i.e. complimentary to their core functions and bringing value to local communities and NHS?

22. Should protocols of engagement (similar to the Compact model for working with the voluntary sector) be developed to help Voices work across their communities?

23. What should the precise relationship between Voices and Patients’ Forums be?

24. Is a host local authority the best model for recruiting, employing and locating Voices?

25. To whom should Voices be ultimately accountable?

**Voice: the Commission for Patient and Public Involvement in Health (VCPPIH)**

26. One of the VCPPIH’s roles could be to provide a national assessment of the performance of the patient and public involvement system to the Secretary of State. Should this report specifically focus on SHA areas and look at each of the patient and public involvement components?

27. Should there be specific links and joint working between the VCPPIH and the National Council for Voluntary Organisations (NCVO)?
28. Where concerns are raised about local performance of either a Patients’ Forum or the Voice what, if any, role should VCPPIH have? Should it, for example, work with the relevant Strategic Health Authority to support and encourage the body concerned to raise their performance to meet the national standard?

29. Should the membership of VCPPIH be limited to national health related voluntary sector organisations? If so, how should they be selected? If not, which other stakeholders should be represented on the management board and how will they be selected?

30. Should there be a term of office for VCPPIH board members? If so, for how long?

31. Should members of VCPPIH be required to undertake a formal induction prior to taking up their post – with a clear commitment to time involved?

32. Would it be appropriate for VCPPIH to be the single national ‘gateway’ into public and patient involvement systems at any level, for example by a single telephone call which puts you in touch with your nearest PALS, Patients’ Forum or independent complaints advocacy provider?

PALS

33. We are proposing that PALS should provide feedback to Patients’ Forums. What kind of feedback would it be most useful for them to provide?

34. How should PALS network with other service providers locally e.g. voluntary groups and patient groups?

35. How should Patients’ Forums monitor the service provided by PALS?

36. What should be the extent of the relationship between PALS and Patients’ Forums?

37. To what extent will PALS influence the agenda for change in trusts and how will they do this?

38. What will be the role of volunteers in complementing the PALS service?
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