Involving Patients and the Public in Healthcare: Response to the Listening Exercise
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1. Introduction

1.1 On 3 September 2001, the Department of Health published Involving Patients and the Public in Healthcare: A Discussion Document. In that document, we set out our proposals for implementing the vision of a patient-centred NHS outlined in the NHS Plan.

1.2 We want to 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.

1.3 Our proposals are also designed to respond to the recommendations made in the Kennedy report following the Bristol Royal Infirmary Inquiry. That report focused on the entitlement of patients and the public to be involved in every aspect of healthcare and that this principle should be embedded in all NHS structures.

1.4 In addition, the proposals ensure that new methods of involving patients and the public are introduced which match both the changed structures of the reformed NHS and the new culture of devolved resources and power set out in Shifting the Balance of Power within the NHS.

1.5 Finally, and importantly, the proposals introduce a more penetrative and more powerful system for involving patients and the public in health. Although new structures are described to align with the changing NHS, they do not start from scratch, but build on the best of existing work on patient and public involvement – notably by Community Health Councils (CHCs) and the voluntary sector. In particular, we want to ensure that the skills and expertise built up over many years amongst lay volunteers and professional staff in CHCs are not lost to the Health Service.

1.6 With these points in mind, the publication of Involving Patients and the Public in Healthcare: A Discussion Document set out the following main elements building on the provisions in the Health and Social Care Act 2001:

- To introduce Patient Advocacy and Liaison Services (PALS) - providing information and on the spot help – in every Trust;
- Provide locally based Independent Complaints Advocacy Service (ICAS) in England, operating to core standards;
- To introduce Patients’ Forums in every Trust, to bring the patient’s perspective in Trust management decision-making. These Forums would also be able to elect one of their members to sit on the Trust Board as a Non-Executive Director;
- To extend Local Authority Overview and Scrutiny Committees (OSCs) powers to scrutinise local health services and to call NHS managers to account;
- To set up a “Voice” in every Strategic Health Authority area, a professional group acting as a local resource for helping communities;
To set up a new national patients body to set standards and provide training, and to monitor the new arrangements.

1.7 The launch of the discussion document marked the beginning of a listening exercise spanning six weeks. In the course of that period, we took soundings from as wide a range of individuals and organisations as possible.

1.8 The listening exercise proved very constructive, with a great deal of support for the principles underpinning our proposals. All feedback we obtained was analysed and used to develop our proposals further and to create a robust, comprehensive package of measures.

1.9 This document sets out that comprehensive package of measures. Much of this will require legislation, and we are launching this document to present a clear picture of the new arrangements to complement the proposals for legislation that are now before Parliament. If and when that legislation is passed, we will introduce the new package in a way which makes the transition as smooth as possible. This is both in terms of the public interest in continued scrutiny of the NHS, and in the interests of the staff and members of CHCs to ensure that their skills and experience are not lost to the NHS. We will therefore be setting up very shortly a Transition Advisory Board, to advise on managing that process. This is described briefly in section 5 of this document.

1.10 In parallel with Involving Patients and the Public in Healthcare, the Department of Health also launched a listening exercise on potential reform of the NHS complaints procedure. The options for reform were published on 3 September 2001 in Reforming the NHS Complaints Procedure: a listening document, which can be accessed for information at www.doh.gov.uk/nhscomplaintsreform.

1.11 On 10 July 2001, the Secretary of State for Health also announced plans to produce early in 2002, a White Paper setting out reforms to the system for dealing with clinical negligence claims. The Chief Medical Officer, Professor Liam Donaldson, is chairing a committee to look at suggestions to make the system faster and fairer for patients, as well as doctors, nurses and other healthcare professionals. The Department of Health issued on 29th August 2001, a “call for ideas” on possible options for reform to the system for dealing with clinical negligence claims, which sought views on the present system, and in relation to potential options for consideration by the Chief Medical Officer’s advisory group.

1.12 The outcome of these two exercises, which we aim to announce early next year will clearly have an impact on the operation of the new arrangements for patient and public involvement – not least in terms of delivering ICAS and PALS. We will continue to ensure that the feedback we obtain from them is used to inform the further development of this work as well as of the complaints process itself.
2. The Listening Exercise

2.1 The listening exercise lasted from 3 September to 12 October. Wherever possible, we also included any final feedback which arrived after the closing date. During that period, we held nine major local events, in every region of the country. In the end, over 1,000 people across the country attended the events - and in fact some of these were over-subscribed.

2.2 Separately, the discussion document was made available electronically, both on the Department of Health’s central website, and by e-mail cascade to local CHCs, voluntary groups, local authorities and the NHS. 40,000 printed copies of the document were also distributed. A copy of the discussion document can be accessed here, for reference: http://www.doh.gov.uk/involvingpatients.

2.3 Besides input obtained in the course of the nine regional events, we received over 1,000 written responses, a record number. Furthermore, we also made sure that particularly hard to reach population groups were canvassed for their views by means of a research project commissioned from Opinion Leader Research. This focused on children in need, children in care, teenage parents, young runaways, homeless and rough sleepers, drug/alcohol misusers, people with mental health problems, people with disabilities, hearing or visual impairment, people with learning disabilities, elderly people, carers, volunteers, ex-prisoners, young offenders, travellers and refugees. A copy is available on the Department of Health’s website at http://www.doh.gov.uk/involvingpatients.

2.4 The vast majority of feedback was constructive, supporting many of the elements of our proposals, and suggesting improvements. We sincerely wish to thank all those who contributed both in writing and at the regional events. We will separately be writing to all contributors with our thanks.

2.5 Our analysis of the responses revealed that our proposals contained all the elements essential for successful patient and public involvement, and highlighted the seven areas for further development:

- The need for a clear separation between PALS and ICAS, to focus PALS on internal championing of patient interests, and ICAS as a demonstrably independent source of advocacy;

- The need to ensure membership of Patients’ Forums is truly representative of a broad sweep of the community, with full support in their work;

- The need to show how Voices will be grounded locally, to act as an accessible resource for local communities;

- The need to demonstrate independence and clear lines of accountability for Voices, supported by lay input both for Voices and Strategic Health Authorities;

- The need to demonstrate how these new arrangements will be co-ordinated and work consistently across the country;

- The need to confirm the new national body as a lay body - appointed from local communities, with the ability to monitor services from the perspective of the patient’s welfare, safety and overall experience as well as the effectiveness of the new arrangements;
• The need to simplify the structures, to make working relations easier and more effective.

2.6 We have now developed a package that builds on the best work from the past, but is consistent with the reformed NHS of today. It has benefited from the input of many of the stakeholders locally who have a wealth of experience in this work. Our response clearly shows that we have truly listened to people during the course of the listening exercise and that we have taken account of the seven key messages. In summary, we will:

• Give the new Commission, the power to set up local networks, to provide local as well as national support. The Commission will be able to operate some of its functions at PCT level; and for each local network to use a number of community-based premises from which outreach teams can work for the benefit of local people and build on existing local work.

• Make the Commission an independent statutory body. Local network staff will be directly accountable to the Commission centrally, but will also have local lay reference panels to steer their work programme. To increase lay input, we will also give PCT Patients’ Forums collectively the power to attend Strategic Health Authority Board meetings.

• Ensure co-ordination through the Commission’s local networks. Given the independent status of the Commission’s local networks, with responsibility for commissioning ICAS, supporting Patients Forums and informing OSCs across the area, they are ideally placed to act as the “glue” which binds together all the other elements of the new arrangements.

• Simplify the system under the umbrella of the Commission, which, as well as fulfilling national functions, will now employ local teams which will promote and facilitate involving the public in local decisions that affect their health.

• Draw membership for the Commission from Patients’ Forums and Local Strategic Partnership lay members and others, in particular from the voluntary sector. In addition to original responsibilities around standard-setting, training and evaluation, it will be given a strengthened role to report matters of concern on issues of patients’ safety and welfare to bodies in a position to take action, for example CHI and the National Patients Safety Agency.

• The Commission will also produce an annual report highlighting its findings for the benefit of Parliament and the Secretary of State for Health.

• Use the NHS Appointments Commission to set the criteria and process for appointment to Patients’ Forums, to ensure transparency, but to make membership subject to very broad and inclusive criteria. Lay reference panels for local networks of the Commission will be charged with making the appointments to Patients’ Forums. The local network staff will then provide support for Patients’ Forums in their work.

• We will also rename PALS as Patient Advice and Liaison Services, and to make the Commission responsible, through its local networks, for commissioning ICAS.

2.7 From the patient’s perspective, the new arrangements will work as follows:

2.8 In each Trust there will be a PALS service providing on the spot help and information about ICAS where people need to pursue formal complaints. Patients’ Forums will work to influence the day to day management of health services by the Trust, and will monitor the effectiveness of the PALS and ICAS in their area. The Commission, through its local networks will support Patients’ Forums and will be the commissioner of ICAS.
2.9 **In each community** - local networks will have a key role as a resource for local citizens, helping and supporting community groups and promoting better public involvement. They will do this through outreach teams, working from local, community-based premises. These teams will also help to integrate the work of Patients' Forums and PALS by bringing them together regularly to share lessons and identify trends. To ensure that the outreach teams respond to local priorities, they will have a standing lay reference panel, which will guide their local work programme.

2.10 **At the centre** - the Commission for Patient and Public Involvement in Health will be a powerful means of aggregating and promoting information picked up by its local networks, and by Patients' Forums and PALS. It will publish annual reports on the system of patient and public involvement and also to highlight trends and concerns from the patient's perspective.
3. **Final Package of Measures for Involving Patients and the Public in Healthcare**

3.1 First and foremost, we want to set out the principles which underpin all our proposals. The system we introduce must fulfil six criteria for successful patient and public involvement. It must be:

- **Effective**, in representing and strengthening the voice of patients and communities;
- **Accessible** at a local level to people using health services;
- **Accountable** in a clear and transparent way;
- **Integrated** to match the structures of the NHS;
- **Independent**, to be able to scrutinise Health Services;
- **Adaptable**, building on the best of existing local practice and ensuring high quality.

3.2 Our final package, as outlined below, fulfils these criteria. It is backed up by legislation. It will be accessible both through every part of the NHS, and within communities, and will be accountable at all levels to and influenced by lay people.

3.3 To achieve an integrated system, we have embedded systems of involvement and representation at every level within the Health Service. But we need to make sure that effective, external scrutiny and representation is not lost, so we have also made sure that other bodies, independent of the NHS, exist to fulfil this function.

3.4 We believe that this system can be described very simply, as a partnership between three key groups – patients and the public; their elected representatives; and the NHS itself:

![Diagram](image.png)

3.5 This partnership exists at every level of the NHS – local, strategic and national. The arrangements for each of these levels are described on the next page.
Arrangements for Patient and Public Involvement Locally

3.6 At a local level, we see the partnership described above incorporating the four main components from the new system. These are as follows, and are described in more detail below:

- Local NHS organisations, incorporating Patient Advice and Liaison Services (PALS);
- Patients' Forums;
- The Commission for Patient and Public Involvement in Health, which will have local networks with community outreach workers responsible for commissioning Independent Complaints Advocacy Service (ICAS);
- Overview and Scrutiny Committees (OSCs).

3.7 These components fit together as follows:

3.8 We have set out below what each of these components involves, including the concerns that were raised about our original proposals, how we have responded to those, and the final set of responsibilities emerging as a result.

Patient Advice and Liaison Service (PALS)

3.9 PALS is designed as a means of providing on the spot help for patients within Trusts. PALS will be visible and accessible through a number of means. For example, they will be situated in main hospital reception areas and primary care settings. The service will be advertised locally and will be accessed through free-phone numbers. In the course of the listening exercise, this idea was widely accepted, but we saw a clear need to separate internal liaison for patients with NHS providers from ICAS. To clarify this, we have amended the title of PALS to Patient Advice and Liaison Service. We have also embedded ICAS in the community, through the Commission's local networks (described below).

3.10 PALS will be employed by and responsible to Trusts. However, Patients' Forums will have a role in monitoring the quality and effectiveness of PALS, and will bring any concerns to the attention of the Trust Board.
3.11 Our proposals are that PALS will now:

- Provide information to patients, carers and families, about health and health services locally and put patients in contact with relevant voluntary organisations and support groups;
- Where possible, to resolve problems and concerns quickly, before they become more serious;
- Inform people of the complaints procedure, and put them in touch with specialist, independent advocacy services when they wish to complain formally;
- To act as an early warning system for Trusts and Patients’ Forums, by monitoring problems arising, highlighting gaps in services and staff training, and submitting anonymised reports for action by Trusts and Patients’ Forums;
- Operate in a network with other PALS in their area, to ensure a seamless service for patients who move between and use many different parts of the care system for the care they need.

3.12 We are already well advanced in setting up PALS around the country, and the service will become available in all Trusts nationally from April 2002.

**Portsmouth Hospitals NHS Trust** started to operate their PALS earlier this year. Already they are making a difference for patients. For example, one patient who needed regular MRI scans told the PALS officer how claustrophobic they felt at having to enter the scanner head first. The PALS officer was able to facilitate a change in practice for that individual. In addition to providing information and help to individuals, the PALS staff arrange regular focus group meetings to enable patients to voice their views. Not only do patients value this as a way of influencing change, the trust values the patients’ experiences, using them to improve services to better meet the needs of its patients.

**Independent Complaints Advocacy Services (ICAS)**

3.13 The Health and Social Care Act 2001, Section 12 of which states: “It is the duty of the Secretary of State to arrange, to such extent as he considers necessary to meet all reasonable requirements, for the provision of independent advocacy services.”

3.14 ICAS are intended to give people who want to complain the support they need to do so. People will be able to get support from ICAS providers direct, through the Commission’s local networks, as well as via PALS. The Commission will be responsible for commissioning ICAS flexibly and promoting its availability. ICAS will complement existing advocacy services, and so are not intended to replace, for example, current mental health advocacy services.

3.15 The listening exercise gave us the opportunity to develop this proposal further, to show that ICAS will be a service truly independent of the NHS, and accessible directly within communities. We will now:

- make the commissioning of ICAS the responsibility of the Commission for Patient and Public Involvement in Health (the Commission), through its local networks – which are a development from the original proposal for local Voices, to be fully independent and lay-led, as described in more detail below;
• Ensure ICAS are accessible both by referral from PALS, and directly through the Commission’s local networks, which will work from independent, community-based premises, for example, local voluntary settings.

3.16 The development of ICAS is not only an integral part of our proposals to promote public and patient involvement in the NHS, but will form a key part of reforms to the system for dealing with complaints against the NHS. ICAS will be vital to ensure that complainants have access to the support they need to articulate their concerns and navigate the complaints system, thereby maximising the chances of their complaint being resolved more quickly and effectively.

A Citizens Advice Bureau (CAB) established within Arrowe Park Hospital in Heswall, has been asked to provide a pilot ICAS service. The CAB currently provides advice to patients on a range of issues, such as welfare benefits and consumer protection law, which they access during outpatient appointments. This already has a proven track record and, when surveyed, all respondents who were given advice said that they had followed the advice given. This will be built upon by extending the remit of the CAB to include two complaints advisers, who will offer ICAS.

Overview and Scrutiny Committees (OSCs)

3.17 Modernisation of local government through the Local Government Act 2000 creates a formal separation between executive and non-executive councillor’s roles with overview and scrutiny functions carried out by non-executive councillors.

3.18 The Health and Social Care Act 2001 provides specific powers for Overview and Scrutiny Committees to look at local NHS provision as part of their wider role in health improvement and in reducing health inequalities for their area and its inhabitants.

3.19 OSCs will also have formal powers to refer public concerns over major changes to health services or poorly consulted processes to the Secretary of State. In this respect, the power of referral to the Secretary of State will be no less than the current powers held by Community Health Councils.

3.20 They will be able to make routine reports and recommendations to their NHS counterparts, and they will be assisted in their work by the Commission’s local networks, which will act as a key source of local information on the health needs of the local population.

3.21 Finally, local MPs have a role to play in the shape of health services in their area, as they have an important role in raising issues in Parliament. For this reason, we will ensure they receive copies of Patients’ Forum reports from their constituency, so that they are kept aware of important local issues.

Patients’ Forums

3.22 We have introduced legislation to set up Patients’ Forums in every NHS Trust and Primary Care Trust (PCTs) as independent statutory bodies. They will have the key role of monitoring and reviewing services and influencing and informing management decision-making in their Trust.

3.23 We have proposed also that Patients’ Forums should have the power to elect one of their members to become a Non-Executive Director (NED) on the Trust Board. These elected representatives will fill existing NED posts as vacancies arise.
3.24 Concerns were raised as part of the listening exercise that this may create conflicts of interest. However, there is a strong case for introducing this new element for patient and public involvement. It will in no way prevent Patients' Forums attending and speaking at Trust Board meetings as Trust Board meetings are public meetings. The election of a NED will instead be a valuable supplement to observer status, creating a platform to affect board decisions directly. We will ensure that NEDs have the support that they need to deal with any conflicts of interest and to discharge their functions effectively. The listening exercise highlighted implications for payment of Patients' Forum NED members. We are looking into this before making further decisions.

3.25 In the course of the listening exercise, what became clear was the fact that Patients' Forums in PCTs will have an increased role. PCTs will be responsible both for commissioning and providing services, particularly in the light of Shifting the Balance of Power within the NHS. PCT Patients' Forums will therefore also need to consider a broader range of issues. This will include linking into wider health debates, with Local Strategic Partnerships, Health and Social Care partnership boards and the development of Health Improvement Modernisation Plans. We will make sure that PCT Patients' Forums get the training and support they need to fulfil this extended role.

3.26 We will also make sure that Patients' Forum membership is widely representative. To ensure transparency, the criteria and process for appointments will be advised on by the Appointments Commission. The Commission for Patient and Public Involvement in Health will conduct the appointments process. The criteria for membership will need to be open and clear enough to help identify people with the skills needed to do the job. However, this must be balanced against the need to ensure that they are not exclusive or restrictive, so that others, particularly from vulnerable community groups, can be given the training they need to get involved. We will be seeking the views of the Transition Advisory Board (described in section 5 below) about how this balance can best be achieved.

3.27 We also recognise that it is important to develop a comprehensive strategy to get full and inclusive membership. Part of this strategy will involve a national publicity campaign to ensure wide cross-sections of people are aware of the opportunities and benefits of the new system. The Transition Advisory Board will also be able to provide advice on how we can create incentives and encourage greater patient and public involvement.

3.28 The final list of responsibilities and powers for Patients' Forums is therefore:

- To represent the views of local communities to Trusts, about the quality and configuration of health services. This representation will not be by proxy, but by actively engaging in the community to find out what patients, carers and families think;

- To monitor service delivery from the patient's perspective, drawing on sources from PALS and the Commission's local networks as well as the formal complaints system, and to examine delivery of change following complaints and work with the Trust to bring about improvements;

- To inspect every aspect of care used by NHS patients from the perspective of the patient's experience of services. This will include new powers to inspect primary care and GP premises and NHS care provided by the independent sector;

- To produce an annual report of its work and make its findings and reports available not only to Trusts, but also:
  - Overview and Scrutiny Committees;
  - Local MPs;
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- Strategic Health Authorities;
- The Commission for Patient and Public Involvement in Health (described below);
- The Commission for Health Improvement;
- The National Patient Safety Agency, where adverse incidents are concerned.

These reports may be published as part of the Trust’s annual Patient Prospectus;

- To elect one of their members to sit as Non-Executive Director on the Trust Board. We would also wish OSCs to invite a Patients’ Forum member to join their health scrutiny panels;
- To monitor the quality of the PALS in the area, and to bring problems to the attention of the Trust and the Commission for Patient and Public Involvement in Health against nationally agreed criteria;
- In the case of PCT Patients’ Forums, to monitor the quality of the ICAS in the area, and to bring problems to the attention of the Commission for Patient and Public Involvement in Health.

The Royal Liverpool and Broadgreen University Hospitals NHS Trust established a Patients’ Forum in 1999 at the request of the Trust Board, as it wanted to know how patients really perceived the hospitals managed by the trust. The Forum has 20 members all of whom use, or have used the trust services, or have been a long-term visitor of patients of the trust. The Forum sets its own agenda and has access to the Board, making a direct contribution to service planning and improving quality. For example, they review and comment on anonymised complaints data and were instrumental in making changes to the trusts catering, no-smoking and security policies.

Roger James, Trust Chairman says “In short, because it is both independent and recognised by the Trust Board, it has teeth, and I believe our trust provides a better service as a consequence of it being in place.”

The Commission for Patient and Public Involvement in Health – at the local level

3.29 Our proposals for the Commission will complement and support the work and expertise of existing patient organisations. The Commission nationally will set standards, provide training, and monitor PALS, Patients’ Forums and ICAS. These functions are described in more detail in a separate section on the Commission itself later in this document.

3.30 However, equally important is the need for a local resource. This local resource within communities, is needed in order to:

- Help build capacity within communities for engagement and involvement, helping existing networks and community help groups to maximise their effectiveness;
- Work with Patients’ Forums in an area to provide them with a means of networking and sharing local experiences and conclusions.

3.31 In addition, this local resource is ideally placed to be able to channel the feedback obtained from its core local work described above into decision-making by Strategic Health Authorities (STH As) on more long-term, strategic issues and to inform the work of local authority OSC’s and Patients’ Forums.
In Involving Patients and the Public in Healthcare: A Discussion Document, this idea was described as a separate organisation, called "Voice". During the listening exercise the aims and functions proposed were very well supported, but there was concern about the independence and accountability of the professional staff fulfilling these functions. We believe the concept can be improved, by ensuring the work is the responsibility of an independent body, with lay input, and grounded in local communities.

There was strong support at the regional listening events for employment of the local staff fulfilling these duties to be the responsibility of the Commission. It will be a statutory independent body and provide a clear and direct line of accountability to a national lay group. It also simplifies the system we are proposing.

The work of bringing together Patients' Forums, and helping to build capacity for involvement within the community will now therefore be discharged by the Commission, through a series of local networks. The Commission will be given the responsibility of making the necessary arrangements to carry this work out.

Our legislative proposals set out a clear statutory duty to ensure that the work of the Commission is properly grounded within communities. Each local network will have outreach workers across every PCT area, working from readily accessible community-based premises.

It will be important to ensure that the support the Commission provides through its local networks is appropriate for local needs and circumstances. Therefore each network will have a lay reference panel, to act as a means of guiding work priorities. To ensure health as well as healthcare is considered, reference panels will include representatives of the PCT Patients' Forums in the StHA area, and lay representatives elected by each of the Local Strategic Partnerships in the area. This will ensure a direct link into the wider health agenda and local authority work. It will also provide a further means of linking together the work of PCTs in the area.

It is important to stress that the work of the Commission's local networks must feed into local authorities' community leadership responsibilities for ensuring the economic, environmental and social well-being of the local population. To this end, we intend the Commission at a local level to develop effective partnership arrangements with other community development activities.

Ensuring that the Commission's local networks have accessible bases and can operate effectively within communities means that they are ideally placed to fulfil a number of additional duties: commissioning ICAS, providing administrative support for Patients' Forums locally and providing a link to OSCs.

This model therefore takes and builds on the concept of Patients' Councils, which was proposed in Parliament in the course of debate on the Health and Social Care Act 2001. Patients' Councils provided a sensible option for facilitating the co-ordination of patient and public involvement mechanisms and drawing together information from all the new arrangements across a PCT area. The Commission's local networks will be able to fulfil these functions, but with some important additions:

- They will be there to help build capacity amongst communities, so that patient and public involvement is constantly improved and strengthened;

- They will, with their links into local authority work, be able to have real input into the wider determinants of health, and promote synergy with other activity in the community;

- With their work in communities and across health as well as health care, they will be able to promote and support involvement by everyone in the community, not just existing patients.
With these important building blocks in mind, the final set of responsibilities for the Commission's local networks will therefore be:

- Helping to develop the ability of citizens and communities to take greater control of decisions that affect their health and the organisations and services that affect their health;
- Commissioning ICAS for patients, carers or families who need independent support in making a complaint;
- Monitoring the quality of complaints handling from the patient's perspective, drawing on information provided by Patients' Forums, as well as their experience of the system through commissioning ICAS, to inform them in influencing the development of healthcare locally;
- Providing administrative and secretarial support for Patients' Forums in their area;
- Networking Patients' Forums and supporting them in their activities to seek community views on health care services;
- Providing a means of linking healthcare strategies into wider health agendas, both through panel membership from Local Strategic Partnerships and by providing a link between the role of patient and public involvement and the local scrutiny function by facilitating the sharing of information on critical and strategic issues to OSCs to inform the scrutiny agenda;
- Supporting the partners at strategic level; and providing a means of channelling information to STHAS to influence wider decisions of long term configuration and provision of services across the STHA area;
- Channelling information to the Commission centrally, to inform its reports and recommendations on nation-wide trends and concerns about patient safety and welfare.

The Commission's local networks are therefore the “glue” which binds together all the arrangements at a local level, acting as a resource both for each new representative body, and for individual patients and communities.

In this respect, the local networks and their outreach workers build on the best elements of CHC work on complaints advocacy and on action within communities. The new arrangements go further, being supplemented by all the other complementary components that the networks bring together.

In Newcastle and North Tyneside, the North of Tyne Voice initiative has shown how these arrangements can be brought together in a positive and cohesive way. Sixteen local public sector organisations spanning Newcastle, North Tyneside and Northumberland, have worked together to develop this initiative. They include the PCTs, Local Authorities, NHS and Community Trusts, and CHCs. These organisations will be forming a consortium, which will bring together health and health care services and provide a single source for the delivery of co-ordinated PALS for all the Trusts in the area.
Strategic Level Arrangements

3.43 At a SH A level, we envisage 3 key players in the partnership: OSCs working jointly, the SH A, and PCT Patients' Forum representatives – all of these being informed by the activities of the Commission's local networks. The picture therefore looks like this:

- **PCT Patients' Forums**
- **CPPIH Local Network**
- **Strategic Health Authority**
- **Joint Overview and Scrutiny Committees**

3.44 We have made clear above that the Commission's local networks will on a day to day basis be occupied with local work, from local community bases. Nevertheless, there is a clear need for periodic liaison with SHAs to collect and pass on information and concerns that are picked up across the SH A's area. The local network teams will therefore have responsibilities extending into this area which reflect that need. We believe it is a natural role for the local networks to fulfil. They are placed at local level, but have clear capacity, as local parts of the national Commission, to aggregate information and channel it both to SHAs and to the Commission centrally.

3.45 Following the listening exercise, we believe that the input of the local networks at this level should be backed up by lay input more generally.

3.46 There will be lay input to the work of the Commission's local networks, both through the Commission itself and the local lay reference panels described above. However, we believe that arrangements at this level should include an opportunity for lay input to SH A boards: in other words there should be lay observers with speaking rights attending SH A Board meetings.

3.47 The natural source of input to SH A Boards is PCT Patients' Forums collectively. In the same way as PCTs will work together in “federations” within each SH A, PCT Patients' Forums will be linked together, supported by the Commission's local networks. In their capacity of overseers of both health and health care commissioning and delivery, PCT Patients' Forums will be able to put forward representatives with the relevant knowledge and experience to influence SH A Boards.

3.48 In terms of elected scrutiny, section 8 of the Health and Social Care Act 2001 provides for OSCs to come together jointly to scrutinise the health service on cross-boundary issues such as would be dealt with by Strategic Health Authorities.
National Level Arrangements

3.49 Until now, the role of national co-ordinator of patient and public involvement interests has fallen to the Association of CHCs for England and Wales (ACHCEW). However, its remit has been formally limited in statute to supporting CHCs. In addition, whilst ACHCEW has been able to develop some excellent training and support for CHC members, there has been no means of instituting minimum standards of performance and service nationally.

3.50 It was with this in mind that “Voice: The Commission for Patient and Public Involvement in Health” was proposed. We have now shortened this title to call it the Commission for Patient and Public Involvement in Health (CPPIH).

3.51 This completes the three-way partnership at the national level, with the Department of Health, and Elected Scrutiny through the Health Select Committee and Parliament:

![Diagram of three-way partnership]

CPPIH

Department of Health

Health Select Committee

3.52 Our proposals for the Commission focus on the need for minimum standards to be set; for training to ensure local patient representative bodies are in a position to meet those standards; and for evaluation of the system to keep it updated and responsive.

3.53 These are extremely important objectives, but we think they can be strengthened yet further by ensuring that the Commission is driven by a lay agenda and can monitor and report publicly on the patient and public involvement system.

3.54 On the first of these points, membership of the board will be drawn from a range of constituencies, including Patients’ Forums, local voluntary organisations and national patient organisations. We see membership being drawn in the main from lay people involved at a local level with relevant expertise. This would be through nominations from the lay panels of the Commission’s local networks and from Patients’ Forums. Membership will also comprise key representatives from national stakeholder groups, bringing with them the necessary skills, experience and expertise to ensure that the Commission’s work is informed by this knowledge base. We also think that it is important to make honoraria available for Board members to appropriately recompense the high level of input that the role will require.

3.55 However, for the first year only, to ensure that the Commission is operational immediately, we would draw membership both from nominations made by voluntary organisations and CHC members. We will ensure that the process for nominations for membership of the Commission is fully inclusive for all groups in local communities and the NHS Appointments Commission will have a role in making the appointments.
Secondly, the responsibilities of the Commission for Patient and Public Involvement in Health will be extended. The Commission will be a clear means of focusing publicly on representing the interests of patients and the public in the delivery of NHS services. Its findings will be used by the Health Select Committee and by Parliament nationally to hold the Department of Health to account.

The Commission will therefore be set up with a remit not only to evaluate the operation and effectiveness of the new arrangements, but also to analyse and report on key trends emerging from them.

The functions of the Commission for Patient and Public Involvement in Health will therefore be:

- To identify and disseminate quality standards for the establishment, operation and evaluation of the patient and public involvement system;
- To develop quality standards for the delivery of PALS and ICAS;
- To provide best practice advice to patient and public involvement bodies on recruitment, training, and involvement and engagement processes;
- To develop best practice guidance on the means of developing capacity within communities to voice their needs and concerns about matters affecting their health;
- To set out accountability arrangements and minimum professional standards for the services provided by its local network staff;
- To develop and license training and induction materials for being a patient/public representative in the new system;
- To undertake and/or commission research on relevant subjects. For example, innovative approaches for involving people from hard-to-reach groups, learning from international experience of patient and public involvement;
- Drawing on sources from its local networks and outreach teams, PALS, OSCs and Patients' Forums, to monitor services nationally from the perspective of patient safety and welfare, and to publish an annual report of its findings, bringing them to the attention of the Secretary of State, the Commission for Health Improvement (CHI), the Professional Regulatory Bodies, the NPSA and the Health Select Committee;
- Drawing on views taken from patients and patient organisations, to evaluate the effectiveness of the new arrangements for patient and public involvement and to recommend improvements.

It is important to emphasise that the role of the Commission is primarily to support and facilitate effective patient and public involvement through the system described in this document. It will also be well placed to assist other organisations undertaking health related involvement activity. We are very clear that the Commission will not replace existing expertise within national or local patient bodies. Furthermore, the Commission will not function to provide a homogeneous patient voice to Government.
Other measures to underpin patient and public involvement in health and healthcare

A duty to consult and involve

3.60 Underpinning all the new structures we are introducing, will be a statutory duty placed on the NHS to ensure that these arrangements are implemented effectively. Every NHS body is now, as a result of the Health and Social Care Act 2001, under an obligation to consult and involve the public.

3.61 How that duty will be discharged will be fleshed out in guidance, which we will develop over the next few months, to issue in April 2002. We shall be discussing this work in depth with a number of key stakeholder groups, including patients and carers, before putting out to tender the task of developing a user-friendly toolkit on consultation.

Recognition for voluntary work

3.62 This is a challenging agenda. It will not work without the continued support of dedicated lay volunteers. We believe this support should not go unrecognised. A clear message emerged from the listening exercise that remuneration was not appropriate here. However, there are other ways that we can show how valued the input of lay volunteers is. In addition to standard reimbursement for expenses and childcare/caring responsibilities we shall also:

• Explore the practicalities of granting lay members of Patients' Forums statutory time off from employment to carry out voluntary work;

• Develop the availability of accredited training for lay people so that they can obtain qualifications from the work they do.

Patient Surveys to obtain direct feedback

3.63 As described in this document, we are introducing new representative bodies in Trusts, together with systems for building capacity within communities for people to assert their own views. However, there are other ways of obtaining feedback from patients and the communities that NHS bodies serve. We will therefore be introducing a complementary system of annual local patient surveys, whereby NHS Trusts will seek direct feedback on specific issues relating to the quality and diversity of health services provided.

3.64 Trusts will be provided with a core questionnaire, to seek feedback on certain issues which we will be measuring and comparing nationally. However, there will be flexibility for other questions to be added, to measure performance against local priorities. Trusts will be given help and support centrally as to how to manage and conduct these surveys.

3.65 Trusts will also be working with their Patients' Forum and with other community representatives identified through the Commission's local networks to pinpoint what priorities need to be measured locally. Trusts will likewise discuss the outcomes of the surveys with these groups, and agree action to improve weaker areas. All these elements – the priorities, the survey results, and the agreed forward action plan – will be published by the Trust each year in its annual Patient Prospectus.
Other National Initiatives

3.66 We will be ensuring that not just the NHS locally and regionally is fulfilling its obligations to consult and involve communities in its work. The discussion document, Involving Patients and the Public in Healthcare referred to the introduction of lay input in the work of national bodies. We will continue with this drive to involve lay representatives nationally, notably:

- The Commission for Health Improvement activities will include a lay component;
- The National Institute for Clinical Excellence will be setting up a Citizens’ Council, to ensure that its work programme is influenced not only by clinical factors, but also the patient’s experience;
- Supporting the system for managing and monitoring complaints about NHS services, and improving services by learning from complaints;
- The GMC and other professional bodies are increasing their proportion of lay members, and the new Council for the Regulation of Healthcare Professionals to which our current legislative proposals would make these bodies accountable, will have a lay majority;
- Patients, users and carers are being directly involved in the redesign of services through programmes run by the NHS Modernisation Agency. For example, several hundred ‘discovery’ interviews were conducted with patients suffering from heart disease and their families to help inform the redesign of CHD services;
- The work carried out by Opinion Leader Research to target hard-to-reach groups for this listening exercise, will be used as a good practice standard for policy development. It provides the starting point for ensuring policy in the future is informed by all views, including historically excluded groups such as children and ethnic minority communities;
- We will continue to work towards encouraging patient and public involvement in mental health advocacy initiatives and the developing Expert Patients Programme.

Developing the new system further

3.67 We have made provision for the new arrangements described in this document in legislation now before Parliament. However, those provisions, if and when passed, set the framework for our proposals. Much will be left to finalise in the form of regulations and guidance, covering how the new bodies, particularly the Commission will discharge their functions. We are committed to consulting openly and iteratively when we begin to develop guidance and regulations, and will continue to invite feedback on these points from as many sources as possible.

3.68 Furthermore, once the new arrangements have been given time to bed down, we will also make sure that we undertake a review of the system, taking into account the evaluation and recommendations of the Commission and making improvements where necessary.

3.69 The Government is committed to the principles underlying patient and public involvement, and equally committed to making the new arrangements work. People are the most important resource in the system, and through the Commission for Patient and Public Involvement in Health, we will make sure that the training and support is there for patients and the public to achieve real influence.

3.70 We are working to secure funding to maximise these proposals as part of the current government spending review.
4. What it means for Patients, Carers and Communities

4.1 The NHS is a complex and multi-layered organisation. To make sure we embed effective systems of patient and public involvement in every NHS organisation means new structures, and more of them. We are sure that we have achieved the right balance and with the guiding hand of the Commission for Patient and Public Involvement in Health, we can provide seamless and co-ordinated services.

4.2 This seamless and co-ordinated service is what is most important. When a patient, a carer, a member of the public wants to make their voice heard, they just want to know who to ask and how they can do it. In short, people need to know how the system works for them. We believe that our new arrangements build an easy platform for conveying this message:

- Patients, carers and their families can get advice and information about health and healthcare from PALS wherever they use the NHS - whether that be GP practices, hospitals or clinics. If they are not using NHS services, they can contact NHS Direct for advice and guidance;

- If people have concerns about the services they are getting, they can raise this with the PALS, which will be there on the spot to help. The PALS may be able to resolve the problem there and then. Otherwise, they will be able to offer information about how the complaints system works, and if required, where to get independent advice and support;

- If someone wants to go directly for independent help, rather than through PALS, they will be able to go to ICAS. ICAS will be based in their community, and working from easily accessible premises;

- People will be able to get involved in shaping their local health service by approaching a Patients’ Forum, and there will be one of these for every NHS trust and PCT. If they want a direct say, they can apply to join the Forum;

- Information on all these services, and trained support on having a say, will be available in all communities through their local networks;

- People can be sure that the service they get will be the same throughout the country, and provided to a minimum standard, because there will be a new national Commission to oversee the system.
5. Managing the Transition

5.1 We will be aiming to ensure that the new arrangements are in place, in full, by April 2003. However, for the final package of measures to be genuinely successful, we will need to evaluate our progress in the intervening period and make adjustments accordingly.

5.2 The Commission for Patient and Public Involvement in Health will also take time to set up and start its programme of work. As a result, we will also need to begin to set some initial criteria and standards for the work that the new patient and public involvement bodies will be undertaking. The Commission for Patient and Public Involvement in Health, once up and running, will then have a platform from which to work, and will be able to review and refine standards on a rolling basis.

5.3 Finally, we will ensure that the skills and experience of CHC members and staff are not lost to the NHS. They need to be translated into the new system in a way that both benefits the NHS and motivates the individuals concerned to stay involved.

5.4 We will therefore be setting up a Transition Advisory Board, to advise on the implementation of the new arrangements for Patient and Public Involvement.

5.5 The Transition Advisory Board will need a broad skills base and wide stakeholder representation, to reflect both local and national perspectives, and we will seek to appoint members by a transparent process of nominations from stakeholder groups. Overall responsibilities of the Board will be:

- Overall advice to DoH on the transitional process, including identifying any further work necessary as a result of the legislative process;

- Co-ordinating work to ensure a consistent approach to helping CHC lay members and staff to identify opportunities in the new arrangements – including ensuring new systems build on the best of CHCs, harnessing the skills and experience of lay members and staff;

- Advising on the process for setting up and recruiting for the new Commission for Patient and Public Involvement in Health (including developing interim standards in advance of advent of the Commission, and designing its own exit strategy to ensure a smooth hand-over to the new Commission).

5.6 The work will be separated principally between the support needed for lay volunteers and existing staff, and preparing for the new Commission. Sub-groups of the Transition Advisory Board will focus specifically on membership and staff issues, and the Commission for Patient and Public Involvement in Health. The board will comprise key stakeholders, including ACHCEW, the NHS, local government and the voluntary sector.
6. Conclusion

6.1 This document sets out our policy for the future of patient, carer and public involvement in the NHS. It builds from the initial vision described in the NHS Plan for a patient-centred NHS. It also shows how we will match the needs of the devolved NHS through Shifting the Balance of Power in the NHS, and how we will respond to the recommendation made by Professor Kennedy following the Bristol Royal Infirmary Inquiry that the views of patients and the public should permeate and be embedded in every part of the NHS.

6.2 Our proposals have been developed in detail over the course of the 15 month period since the launch of the NHS Plan. They have also benefited from a period of intensive discussion and feedback from key stakeholders which we concluded on 12 October this year.

6.3 We believe that this final set of proposals represents a comprehensive and cohesive package, put together on the basis of wide and inclusive discussions with a broad range of interested groups and individuals. We also see the system being simplified under the umbrella of the Commission for Patient and Public Involvement in Health, which will now have a clear remit locally, in communities, and nationally. Furthermore, we also believe that this package fulfils all the criteria necessary for successful patient and public involvement. It is namely:

- **Effective**
  There is now a means of representing the patient’s, carer’s and the public’s perspective across the NHS — it has been integrated and embedded in every NHS organisation. This is supported by a new national body to ensure uniform minimum standards, by a statutory duty on the NHS to consult and involve the communities it serves, and by including the patient’s perspective as a means of measuring the performance of the NHS.

- **Accessible**
  PALS will be providing on the spot help in every Trust. They will also be a source of information on all the other elements of the new arrangements. However, if people want independent support, they will be able to access directly ICAS. They will also, of course, be able to seek advice through NHS Direct, which will refer people to the appropriate source of help and assistance.

- **Accountable**
  There is now a system for ensuring that the NHS itself responds to the patient’s view at every level. Within the system, the effectiveness of PALS and ICAS will be monitored by Patients’ Forums. Staff working in the Commission’s local networks will be directly accountable to the Commission centrally, but will also have their local work programmes steered by a lay reference panel. Nationally, the system will be subject to uniform minimum standards set by the Commission, with core induction and training for all those involved.
• **Integrated**
  The Commission’s local networks, with their community outreach bases, and their wider links both to Overview and Scrutiny Committees and to Strategic Health Authorities, will provide the “glue” for bringing all these organisations together and ensuring information is uniformly available. They will promote public involvement across their area, and will likewise be the means of networking and supporting Patients’ Forum individually and collectively.

• **Independent**
  Patients’ Forums and the Commission for Patient and Public Involvement in Health will be independent statutory bodies, subject to legislation. Furthermore, the Commission’s local networks will be charged with commissioning ICAS to make sure advocacy services are also fully independent.

• **Adaptable: building on the best of current practice**
  These arrangements are intended to build on the best elements of CHCs and to complement and support the valuable work being done by local voluntary sector organisations. The Commission’s local networks will take forward the best of CHC work, particularly in terms of helping complainants and co-ordinating patient and public representation. Local networks will also be there to support the community and existing community groups, and the new system goes much, much further. It sets up on the spot help in every Trust, through PALS, it has direct representation in every Trust and Strategic Health Authority through Patients’ Forums and elected NEDs, and it introduces consistency through the standard setting and monitoring by the Commission for Patient and Public Involvement in Health.

6.4 Finally, we recognise the need to ensure that the transition from current arrangements under CHCs to full implementation of the new bodies will be as smooth and seamless as possible. This is necessary both in terms of the public interest in continued scrutiny of the NHS, and in the interests of the staff and members of CHCs to ensure that their skills and experience are not lost to the NHS. We will therefore be setting up very shortly a Transition Advisory Board to advise on managing that process.
Timetable for Implementation

The timetable for establishing Patients' Forums, the Commission for Public and Patient Involvement In Health and its local networks assumes the NHS Reform and Health Care Professions Bill receives Royal Assent next year.

Our intention would be to have a short transitional period when CHCs operate alongside Patients' Forums and local networks of the Commission. We will develop our proposals for the most practical transitional arrangements, with the Transition Advisory Board described in this document. However, we envisage establishing the Commission for Patient and Public Involvement in Health, its local networks, and Patients' Forums at the beginning of 2003 and CHCs and ACHCEW ceasing to operate in April 2003.

We also envisage commencing the provisions in the Health and Social Care Act 2001, with regard to Overview and Scrutiny Committees, their new powers at the beginning of 2003 so they too could work alongside CHCs in the transitional period.