



**Transition Advisory Board –
Patient and Public Involvement in Health**

**Progress report on the work of the Transition Advisory Board
Prepared for the regional events October 2002**

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INTRODUCTION

The Transitional Advisory Board (TAB) was appointed by Hazel Blears to advise the Department of Health on the implementation of the legislation. The TAB as a group cannot influence the policy, but it can influence how the policy is interpreted on the ground. This is an important role with regulations yet to be drafted.

The TAB brings together 15 stakeholders from CHCs, the voluntary sector and the NHS. We began work in February and will complete our work in December, at which point we will hand over to the new Commission for Patient and Public Involvement in Health. The Chair Designate of the Commission, Mrs Sharon Grant, has now been appointed and we are working with her to help inform initial thinking on the shape of the Commission and its work.

The purpose of the regional events is to:

- To outline the Department of Health's proposals for implementation
- To outline the TAB's views on how the new arrangements might work and obtain feedback
- To enable participants to share experiences on what can be done at local level to prepare for the new arrangements

The focus of the day will be on local transition, which is why we are pleased to have a short presentation at each event from people who have made some progress towards seeing how the transition might be made. Information on the schemes presented at the events and many others will be posted on the TAB website (www.doh.gov.uk/involvingpatients/tab.htm)

Four briefing papers are attached:

- Paper 1 was prepared by the Department of Health and covers the arrangements as outlined in the NHS Reform and Health Care Professions Act and proposals for managing the transition.
- Paper 2 covers the key recommendations agreed by the TAB to date, which we will test with you during the day.
- Paper 3 Provides a summary of the local scheme.
- Paper 4 covers the main issues we wish to consult you on. Further details of these will be given on the day.

Paul Streets
Chair of the Transitional Advisory Board
Chief Executive of Diabetes UK

PAPER 1 –THE NEW ARRANGEMENTS FOR PATIENT AND PUBLIC INVOLVEMENT AND IMPLEMENTATING THE TRANSITION

Implementing the transition

The Department of Health has agreed to go forward by setting up 'Change Assessment Groups' comprising of a small board of key stakeholders for each strategic health authority (StHA). These groups will work for a six month period to enable the Commission for Patient and Public Involvement in Health to make decisions on transfer arrangements as quickly as possible. Guidance will be given shortly by the Department of Health to StHAs on their role in facilitating this process and setting up change assessment groups.

The new arrangements

All Patients' Forums

In every Primary Care Trust and NHS trust there will be a Patients' Forum that will:

- monitor and review the operation and range of services arranged and/or provided by the trust from the perspective of the patient;
- seek the views of patients receiving services provided or arranged by the trust;
- inspect premises where NHS services are provided or arranged by the trust;
- make reports and recommendations to the management of the trusts;
- refer matters of concern to OSCs, StHAs, CPPIH, CHI and NPSA etc – and any other person or body the forums deem appropriate, including the media;
- be represented on the Board at Non-Executive Director level;
- co-operate with each other in the exercise of their functions and exercise functions jointly.

PCT Patients' Forums

Staff will be based with PCT Patients' Forums and accountable to the forum. PCT Patients' Forums will help forums work together across boundaries; and take account of their views when setting priorities for their work.

In addition PCT Patients' Forums will:

- promote the involvement of the public in decisions and consultations on matters affecting their health;
- ensure that Independent Complaints Advocacy Services (ICAS) are

provided. It is expected that most PCT Patients' Forums will provide ICAS using their own staff but they can commission services through other local providers, where appropriate;

- collect information about the experiences of patients and the public, identify trends and make reports to decision-makers;
- provide advice and information to the public about complaints and public involvement;
- advise the NHS on meeting its duty to involve and consult the public and monitor how it does this.

Patients Advice and Liaison Services

And in every NHS trust and PCT there will be a Patient Advice and Liaison Service (PALS) that will:

- resolve problems on the spot;
- provide information to patients, carers and their families about local health services and put people in contact with local support groups;
- tell people about the complaints procedure and signpost them to independent complaints advocacy services;
- act as an early warning system for trusts and Patients' Forums by monitoring trends and highlighting gaps in services, and making reports for action to trust management.

Overview and Scrutiny Committees

All local authorities with social services responsibilities will have new powers to scrutinise NHS services through Overview and Scrutiny Committee. They will

- take on the role of scrutiny of health services including the NHS;
- be able to call NHS managers to give information about services and decisions;
- report their recommendations to the NHS bodies concerned;
- have to be consulted by the NHS where there are to be major changes to health services;
- be able to refer contested service changes to the Secretary of State.

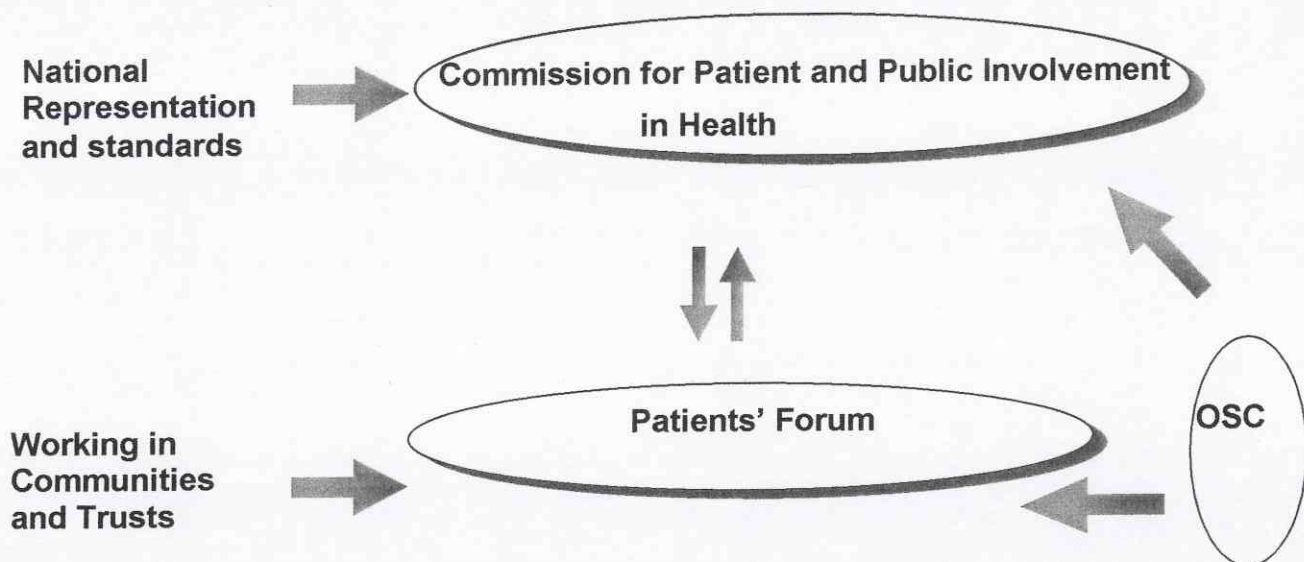
Commission for Patient and Public Involvement in Health

The Commission for Patient and Public Involvement in Health (CPPIH) will be established from January 2003, with a head office in Birmingham. It will:

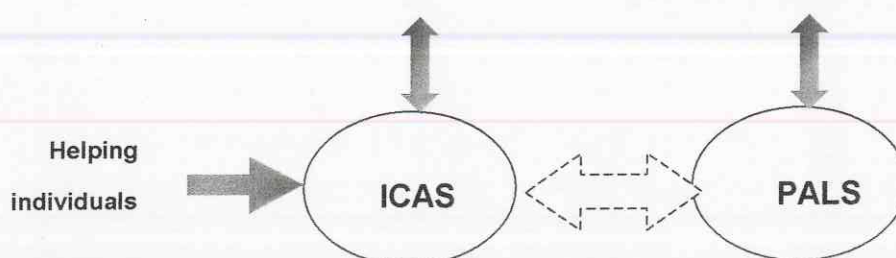
- employ staff who will provide support and be accountable to Patients' Forums;

- fund Patients' Forums and ICAS;
- appoint members to Patients' Forums;
- set standards for Patients' Forums and ICAS;
- monitor the performance of Patients' Forums and providers of independent complaints advocacy services;
- submit reports to the Secretary of State on how the whole system of patient and public involvement is working and advise him about it;
- make reports as it sees fit to other national bodies such as the Commission for Health Improvement, the National Care Standards Commission and the National Patient Safety Agency on patient and public involvement issues and issues that in its opinion give rise to concern about the safety or welfare of patients that have not or are not being dealt with properly;
- carry out national reviews of services from the patients' perspective – collating data from forums and making recommendations to the Secretary of State, and to other bodies and persons it considers appropriate.

How does it all fit together?



Staff employed by the CPPIH based with PCT Patients' Forums providing support to Patients' Forums



PAPER 2 PRELIMINARY RECOMMENDATIONS

The full report is available on www.doh.gov.uk/involvingpatients/tab.htm

The Commission for Patient and Public Involvement in Health

- 1) The Commission should be an example to the NHS in the transparent and inclusive way it works, in particular with people involved at local level and from disadvantaged groups.
- 2) As a national body, mainly working at local level, there will need to be arrangements to enable members of Patients' Forums, voluntary organisations, and others to communicate with the Commissioners at national level. There may need to be arrangements, based on the nine regional government offices or the four NHS Directorates of Health and Social Care, to bring forum members together regularly in order to:
 - Share experiences and good practice, and possibly training;
 - Advise CPPIH on how it is performing its own functions and report on patients' experiences of services;
 - Contribute to decision-making in public health strategies, managed clinical networks, specialised commissioning and regional scrutiny.
- 3) Selection and appointment of members and performance management of Patients' Forums as well as some human resource functions will need to be carried out by staff who are accountable to CPPIH centrally. There may need to be an intermediate level, linking staff working centrally and those within PCT forums.
- 4) The Commission will be a significant national player and at an early stage should consult stakeholders on how it will liaise with them. Options could be an advisory council, reference group or college for consultation.
- 5) Commissioners need to have the skills to contribute to the strategy of the Commission but also be credible with people working at local level. Innovative ways of selecting Commissioners should be considered for the second term, including the election of a proportion of Commissioners. Individuals could be screened before election to ensure that they had the necessary skills and experience to contribute to the Commission.
- 6) It will be important that people who would not normally be appointed to national bodies have the opportunity to develop the skills to become Commissioners in the future. Training programmes may need to be developed to assist applicants to gain the relevant skills.

Patients' Forums

- 1) The name, PCT Patients' Forum, does not reflect the role it will have or its independence. A different national 'branding' should be considered.
- 2) Patients' Forums need to be involved with advising trusts on their arrangements for providing information and advice rather than providing this themselves.

- 3) The number of members for Patients' Forums might be determined locally based on national guidelines and in agreement with CPPIH, but may be expected to be between 9 and 15. Patients' Forums will need to have a majority of users and carers of local services as members.
- 4) PCT Patients' Forums may need additional members as membership will include people nominated by forums in NHS trusts in each locality.
- 5) PCT forums have an additional and separate remit to monitor primary care and PCT commissioning. They will need to consider separating arrangements for:
 - Strategic decisions about the work programme and the deployment of CPPIH staff between trust forums that must involve all PCT forum members;
 - Monitoring primary care and the PCT that involves members who are not nominated by trust forums.
- 6) There are some concerns about the election of a non-executive Director to the Trust Board from the Patients' Forums. In the first instance. Regulations should require that each forum can elect a member to have observer status with speaking rights on the Board. Once Patients' Forums are established locally, the Commission should consider the best ways of enabling Patients' Forum members to take part in decisions of the trust.
- 7) Forums need to develop new ways of working to enable people who find committees and formal structures off-putting, though they will need to work in a transparent way, record actions and decisions and provide access to the public to reports and papers.
- 8) Forums should work with other community development agencies responsible for area-based or other initiatives who are working with different communities to raise their awareness and interest in health, rather than setting up their own arrangements.
- 9) The CPPIH should consider inclusive ways of selecting forum members in future, including elections.
- 10) Regulations will need to recommend what expenses can be claimed by Patients' Forum members (and others co-opted or working with members on forum business). These should include:
 - Payment of travelling expenses
 - Dependant care allowances (including child care)
- 11) Recognition for volunteer work is important and incentives will be needed in order to involve people from disadvantaged communities. The following points in particular should be considered.
 - It is essential that voluntary work does not affect benefits that people receive;
 - Granting members statutory time off from employment to carry out voluntary work;

- Training for members to help develop skills that may be transferable.
- 12) It will be essential that PCT forums work closely together, where appropriate sharing facilities and exercising functions jointly. PCT forums need to decide the best ways of working together within an OSC or strategic health authority area, to deliver their functions in consultation with all local stakeholders
 - 13) Staff may need to work with a number of PCT forums to enable specialisation and co-ordination across forums. The level at which the office is based will depend on local circumstances.
 - 14) PCT Patients' Forums will need, in conjunction with CPPIH nationally and regionally, to develop explicit working arrangements with staff. These should be monitored by the Commission centrally to ensure accountability to each forum is delivered.

Independent complaints advocacy

- 1) Consideration might be given to changing the name to reflect that the service will provide independent support for NHS complaints rather than an advocacy service.
- 2) ICAS needs to be clearly seen as separate from the other activities of the PCT Patients' Forums and resources should be protected.
- 3) ICAS needs to be accessible and widely publicised nationally and locally, using a national logo. A website providing interactive information and a national phone number might be provided as a first point of contact for complainants and phone calls routed to the local ICAS.
- 4) The standards provided by the Community Legal Service should be used as the framework for ICAS.
- 5) The decision about how ICAS is organised in each area should be made by PCT forums in consultation with other local stakeholders to meet the needs of that locality. The decision at which level to provide the service will need to take account of the following:
 - the needs of the local area and its communities;
 - that the volume of complaints is sufficient to enable staff to develop the necessary expertise, provide relevant cover for sickness and develop specialist representation.
 - the service is sufficiently distanced from NHS and Primary Care Trusts that clients will see it as independent.
 - any likely future reconfiguration of PCT boundaries or mergers.
- 6) ICAS needs to support the development of specialist independent advocacy services and, where appropriate, commission services to supplement the generic ICAS.
- 7) Where PCT forums decide to commission ICAS, a business case should be submitted to the CPPIH to enable it to allocate the resources and hold the contract.

- 8) There needs to be a robust and independent evaluation of ICAS pathfinders funded 2002-2003.
- 9) An audit of the skills and competencies required from staff to deliver different levels of advice and representation should be undertaken by the Department of Health and training should be developed to assist the development of ICAS.

The transition

- 1) Regulations governing Patients' Forums should be flexible to allow people to build on existing developments, local variations and learning within a national framework to ensure consistency.
- 2) In each area local stakeholders, including CHCs, trusts, strategic health authorities, local authorities, OSCs, local strategic partnerships and councils for voluntary service should meet to identify:
 - The functions that PCT Patients' Forums may wish to perform jointly and in which geographic areas;
 - How forums can be co-ordinated;
 - The most appropriate local base for staff teams that will support all Patients' Forums;
 - A lead agency to facilitate the transition.
- 3) While all stakeholders need to be involved in preparation, there needs to be a lead agency to facilitate the transition. While it is not appropriate that the implementation is seen to be led by the NHS, strategic health authorities may be in the best position to facilitate these discussions and report to the CPPIH.
- 4) The new arrangements might be phased by prioritising the most important parts of their role. Initially PCT forums might be set up, followed by forums in trusts. The PCT forum, once established, might then take over the duties of CHCs.
- 5) There are concerns about the continued uncertainty for CHC staff and members. A realistic date for the hand over from CHCs should be set to enable timetables for implementation to be drawn up.
- 6) Further work is urgently needed nationally to identify the skills needed at a local level and to develop, in advance, the training required:
 - to allow CHC staff who transfer or are recruited to these functions to fulfill them effectively;
 - for CHC members and others who may wish to offer their services to the new system.
- 7) It will be important to use the skills and experience of ACHCEW and the regional associations in helping with the transition and ensure that the experience, skills and resources within ACHCEW and the regional associations are available to the Commission.

PAPER 3: MAKING IT WORK

In each regional event a local scheme that has explored ways of making the new arrangements work will make a presentation. Information on all these schemes and others will be on the website: www.doh.gov.uk/involvingpatients/tab.htm

ESTABLISHING A SHADOW PATIENT FORUM FOR DONCASTER WEST PRIMARY CARE TRUST – AN OVERVIEW

1. BACKGROUND

Since August 2001 the Doncaster CHC and Doncaster West PCT have been working together on a pilot project to develop a shadow Patients' Forum. The forum has been operational since May 2002, and provides an independent body for local people in the West PCT area to input on health matters and inspect and monitor the PCT's services. It gives the PCT a forum to work in partnership with to improve its responsiveness and accountability to the community it serves.

There are 3 PCTs in Doncaster and experiences are being shared through the steering group for the Forum and with the wider community through the Doncaster Collaborative on the new measures for patient and public involvement.

2. USE OF CHC OPERATING FRAMEWORK

A key aim in establishing the patient forum was to build on the skills and experience of the CHC, and the initial approach taken by Basingstoke and N Hampshire CHC to set up a patient forum was utilised. This drew on aspects of the CHC operating framework, such as forum members being required to abide by the NHS Code of Conduct for CHC members. Terms of Reference and working arrangements for the Forum have been developed and agreed by the CHC and PCT.

3. MEMBERSHIP ELIGIBILITY CRITERIA

CHC members from the West PCT area were eligible to form the initial "core" membership, widened by a very broad recruitment process targeting local people resident or registered with a GP in the West PCT area. The following were not eligible for membership:

- Employees of the NHS;
- Current Non-Executive Directors of Trust Boards;
- People who would experience a conflict of interest through membership;
- Elected members of Local Authorities.

The exclusion of elected members was because of the role local Councillors will play in health scrutiny, and because the patient forum member's role was to give a lay perspective on health matters, as distinct to acting as lay representatives.

4. RECRUITMENT

The expectation was that it would be hard to recruit to a patient's forum; there are a number of forums already in existence in Doncaster and many people remain to be convinced that getting involved is worthwhile. We aimed to conduct as broad a recruitment campaign as time and resources allowed, to encourage people forward, and also to learn about the scale of the recruitment task. The approach taken was based on the previously successful model adopted by the CHC in conjunction with the Doncaster PCTs in hosting events for potential PCT Non-Executives.

Patient Forum recruitment involved:

- Distribution of 1500 information leaflets;
- Advertising on local radio and in the local press;
- Mail outs through many local networks, including Parish Councils, Tenants and Residents Associations, GP surgeries, and community and voluntary groups;
- 12 information sessions jointly hosted by the CHC and PCT at 4 events held at various times across the PCT area.

Attendance at the information events was low, with only 19 people attending the sessions – a response rate of under 2%. However, those who did attend were very interested, and 14 applications were received. More work is needed to engage with the hard to reach, and to ensure members are geographically linked into the PCT area.

Lessons from recruitment include:

- It's hard to get people involved – time and resources are needed;
- Try and meet people on their own ground - don't expect them to come to you;
- Consider targeted approaches;
- Merits of a District wide (ie Doncaster wide) approach. For example, developing a rolling programme of information, including going out to speak with local groups about the new public involvement arrangements. This would be a means of identifying a pool of people interested in getting involved in health matters; some of whom may be potential patient forum members; and would assist development of the community links so important for patient forums. Giving out common information to the public

would help reduce confusion about the different forums, and also maximise resources in the face of a considerable task.

5. APPOINTMENT

Applicants were invited to attend an informal group session and a short interview. 10 applicants, including 2 CHC members, were appointed in accordance with agreed criteria and person specification. While all the qualities on the person specification were important, the interview experience was that *"willingness to learn about health care issues"* and *"sensitivity to others"* were particularly important qualities for applicants to demonstrate.

6. ON-GOING ISSUES

- Patient forum members are on a steep learning curve - training is pivotal.
- Membership of the forum should be enjoyable with everyone feeling able to contribute – diary forms sent to an independent researcher have been devised to learn about members experiences and help the forum to develop to meet members needs.
- For membership to be inclusive, recompense is needed for loss of earnings as a result of patient forum involvement. Associate membership of the CHC is being explored in this respect.
- Links need to be forged at many levels – individual members have a range of community links, while work needs to take place on identifying and linking into the existing and new community structures.
- The name "PCT Patients' Forum" is not meaningful to the public and does not help the task of informing and engaging the local population in patient forums.

Lorraine Lawson

Research Officer/Deputy Chief Officer, Doncaster Community Health Council

September 2002

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PAPER 4 WHERE THE TAB WOULD LIKE YOUR HELP

Question 1- How will the success of Patients' Forums be measured?

The establishment of Patients' Forums provides an opportunity to develop new ways of working, in particular in involving people from disadvantaged communities. This requires a vision that sees the forum and its members as the core of much wider networks. In this (fried egg) model, members are the yolk or core, and will wish to consult and involve patients, carers, outside reference groups or communities in putting forward their views. Patients' Forum members will be independent but working more closely with trusts, including the right to elect one of their members to sit on the trust board. This will require negotiating skills and clarity about their 'insider-outside' role.

Members are not expected to 'represent' other members of the community served by the trust but will be expected to engage with their views and ensure that they are heard, either through their own networks or by networks set up by the forum or trust. 'The public' is made up of different communities of interest, identity and location, whose interests may not coincide. They will need to work with key local partners to ensure that patients and the public are involved in public health issues and in addressing social inclusion.

- **How can we make involvement effective in improving services?**
- **What criteria could be used to assess the success of forums?**

Question 2 - How do we recruit the first forum members, in particular people from hard to reach groups?

Consideration is now being given to how recruitment can be undertaken fairly and speedily, and to ways in which appropriate training can be provided. The Commission will formally appoint Patients' Forum members. CHCs, trusts and the voluntary sector all have an important role in recruiting and encouraging people to apply to become members. However recruitment is undertaken locally, it needs to be based on national guidelines and be endorsed by the main stakeholders, NHS and community, in each area.

The harder question is how the first forum members should be selected. The selection could be undertaken for CPPIH according to agreed national processes by:

- A local agency, such as a council for voluntary service or local consultancy;
- CPPIH staff or CHC staff working with local stakeholders.

While the role of members of Patients' Forums is different from CHCs, existing CHC members who want to have an important role in supporting the new members and ensuring that the local knowledge and contacts that CHCs have built up is not lost. CHC members will be encouraged to apply for membership of forums on the same basis as other applicants, and it is expected that there will be a mixture of "old" (CHC) and "new" members.

- **Should local councillors be eligible to serve on Patients' Forums?**
- **Who should be involved in selection and recruitment?**
- **What can be done in the next 6 months to start recruitment?**
- **How can people who are not part of traditional networks and from disadvantaged communities become involved from the start?**

Question 3 - How can the Commission for Patient and Public Involvement in Health link with those involved at local level?

The Commission will provide the staff and support for Patients' Forums. It will set standards and monitor their work. In addition it will take up issues at national level that forums report in their annual reports, undertaking policy or service reviews if necessary. To do these things the Commission will need good dialogue between those involved at local level and those at national level.

How might it ensure that it is accountable and maintains credibility with the grass roots? The TAB has suggested some possible approaches. These include:

- National Commissioners with a responsibility for and accountability to different regions;
- Commissioners elected by Patients' Forums;
- Regional assemblies where members of forums and others can come together to share experiences and put forward issues to raise at national level.
- **What mechanisms are need to help forums communicate their views and experiences to CPPIH at national level?**
- **How can we make sure that patients' voices are heard at every level in the new system?**

Question 4 - What is the best way of managing the transition to the new arrangements?

It is important that there is a smooth transition from CHCs to Patients' Forums. Change Assessment Groups which will include CHC representatives, are being set up in each Strategic Health Authority to advise the Department of Health on the most appropriate configuration of the new system in their areas. This will be taken note of by the Commission when it comes into being in January 2003.

No abolition date has yet been fixed for CHCs. Many CHCs have indicated that they would find it helpful to have the eventual abolition date set to enable planning for the transition. CHC staff need to know the opportunities available as soon as possible in order to avoid experienced staff moving on and to give continuity. Staff issues are not a matter for the TAB, and are being negotiated between the Department of Health and their staff representatives.

TAB members

Paul Streets, Chair and Chief Executive Diabetes UK

Nik Barstow	Chair, UNISON CHCs Staff Forum
Sally Brearley	Vice Chair, Association for Community Health Councils of England and Wales
Cllr Kate Carr	Local Government Association
Rosemary Edwards	Deputy Chair, National Association of Citizens Advice Bureau
Gary Fereday	Policy Manager, NHS Confederation
David Gilbert	Head of Patient and Public Involvement, Commission for Health Improvement
Bill Hamilton	Assistant Chief Executive (Scrutiny) Bedfordshire County Council representing the Local Government Association
Alan Hartley	Chair, Association of Community Health Councils of England and Wales
Robert Johnstone	Trustee, Long term Medical Conditions Alliance
Marianne Rigge	Director, College of Health
Imelda Redmond	Deputy Chief Executive, Carers UK
Saranjit Sihota	Senior Policy Officer, National Consumers Council
Tony Tester	Chair, Society of CHC Staff
Rob Thompson	Head of Patient and Public Involvement. NHS Executive
Peter Walsh	Director, Association for Community Health Councils of England and Wales
Simon Williams	Director of Policy, Patients Association

Christine Hogg – Project Manager

Glossary

ACHCEW	Association of CHCs for England and Wales
CHC	Community health Council
CHI	Commission for Health Improvement, to be replaced by CHAI (Commission for Healthcare Audit and Inspection)
CPPIH	Commission for Patient and Public Involvement in Health
DHSC	Directorate of Health and Social Care – regional offices of the Department of Health – 4 for England
ICAS	Independent Complaints Advocacy – new service to support NHS complainants from April 2003
NED	Non-executive director on trust Board
NPSA	National Patients Safety Agency
OSC	Local government Overview and Scrutiny Committees from January 2003 will have the power to scrutinize the NHS. Some of the rights of CHCs on consultations will transfer to OSCs.
PALS	patients advice and liaison service – to give information and help to patients in each NHS trust
Patients' Forum	a group of patients and carers to be set up for each NHS and primary care trust to advise on services from a patient perspective
PCT	Primary Care Trust
RDA	Regional Development areas – planning areas for local government – 9 in England.
StHA	Strategic Health Authorities responsible for performance management and strategy for primary care trusts in their area. 28 in England
TAB	Transition Advisory Board