SECTION SIX

PATIENT AND PUBLIC INVOLVEMENT

This section considers:

- the statutory duty to promote a more active and effective voice for patients and the public
- current arrangements to secure active patient and public involvement in all aspects of the PCTs activities
- the challenges posed by the new structures for patient and public involvement.

The PCT's duty to involve patients

Individual patients (and their informal carers) must be involved in every aspect of their own care. However, this micro-level of active partnership with patients is only one element in the sea change which clinical governance represents.

Section 11 of the Health and Social Care Act 2001 makes it a duty to involve local communities in:

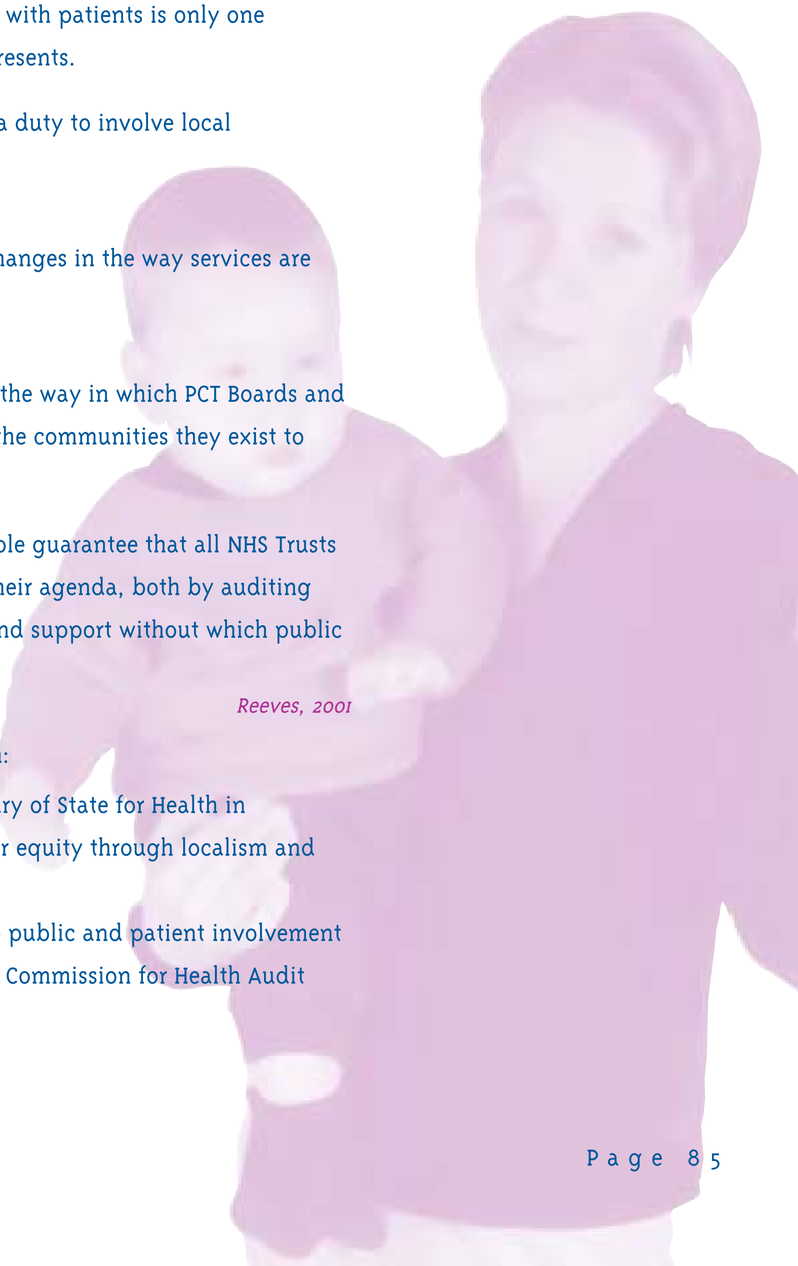
- the planning of the provision of services
- the development and consideration of proposals for changes in the way services are provided
- the decisions that affect the operations of services.

This legislation should have a fundamental impact upon the way in which PCT Boards and PECs will be required to conduct their relationships with the communities they exist to serve.

> 'These new structures provide for the first time a believable guarantee that all NHS Trusts will have to deliver on this critically important part of their agenda, both by auditing the work that is done, and by developing the training and support without which public and patient involvement will never be effective.'
>
> *Reeves, 2001*

Boards and PECs should ensure that they are familiar with:

- the thrust of Government policy set out by the Secretary of State for Health in 'Localising the National Health Service: gaining greater equity through localism and diversity'
- the Commission for Health Improvement's approach to public and patient involvement and the approach that is likely to be taken by the new Commission for Health Audit and Inspection.



Key learning from the pilot programme

PCTs in the pilot demonstrated a commitment to engage actively with patients and the wider community, but most had not yet developed the systems and processes to secure an effective local representative voice in all aspects of the planning, delivering and monitoring of their provided or of their commissioned services.

Across all the PCTs in the pilot programme, the section on Patient and Public Involvement was scored at 5.3 on the progress scale (range 3.9 to 7.2).

Predictably, the more recently formed PCTs were likely to find this a more challenging issue than those that had a longer time to address it. The 25 PCTs that were less than a year old when they completed the questions scored an average of 5 whilst the remainder scored an average of 5.6.

A number of factors beyond the control of PCTs themselves compounded the difficulty of promoting patient and public involvement. Foremost amongst these was the delay in establishing the new Patient Forums and the protracted uncertainty that this generated for CHCs and other local mechanisms of participation.

Despite this, a number of PCTs were proactive in establishing 'shadow' forums and in taking imaginative initiatives to consult with and involve their local communities. Those that had done so were confident that their efforts had reaped significant benefits.

The challenge of systematic patient and public involvement

Involving patient groups and local communities in all aspects of care planning, provision, monitoring and evaluation is one of the key underpinning principles of *The NHS Plan* and of clinical governance.

> 'The NHS Plan sets out our ambitions to create a patient-centred NHS. Our vision is to move away from an outdated system, towards a new model where the voice of the patient is heard through every level of the service, acting as a powerful lever for change and improvement. Our goal is to move away from a paternalistic model of decision making, towards a model of partnership, whereby citizens have a greater connection with their local services, and have a say in how they are designed, developed and delivered.'

Department of Health, 2001

This represents a fundamental cultural and structural shift that has particular relevance for PCTs.

> 'PCTs will be the cornerstone of the local NHS. Devolving power and responsibility to PCTs offers real opportunities to engage local communities in the decisions that affect their local health services.'

Department of Health, 2001

All change brings a series of challenges, dilemmas and questions. There are, unfortunately, no ready-made solutions. These need to be created through collaborative engagement between a PCT and its local community, its patient and service user population and the local health economy.

> 'The public's involvement in the NHS should particularly be focussed on the development and planning of health care services and on the operation and delivery.'
>
> *Bristol Royal Infirmary Inquiry, 2001*

Developmental work by NatPaCT has identified the elements of competence that will be necessary to respond to these challenges.

'1 The competency framework for patient and public involvement should address five key principles:

2 engage all people as **citizens** (rather than just as consumers) across the whole Partnership system.

3 accessibility and responsiveness to all local citizens in their **diversity** (including those who are most often excluded or marginalised).

4 optimal balance of **control** between citizens and organisations, with clear and transparent **accountability**.

5 an integrated and **coherent** system that engages effectively with all community and organisational structures.

6 **effectiveness** both in reflecting the voices of citizens and communities and in influencing policies, decisions and service provision that affect their lives.'

Chris Dabbs, Chief Officer, Salford CHC. November, 2002

REFLECTION

To what extent do you regard these requirements as an opportunity for the PCT – and to what extent do you see them as a distraction or potential threat?

Structural changes and their implications for PCTs

As well as demanding new competences, this will fundamentally influence and shape the composition and the nature of the groups within PCTs that routinely plan, commission and evaluate services. In the future PCTs should

> '…include user representatives on clinical governance committees or groups; involve users in quality improvement programmes (e.g. in all stages of the clinical audit process); provide training for both NHS professionals and users on effective patient and public involvement.'

Clinical Governance Bulletin, July 2000

Welcome as these changes are, they bring significant additional duties and responsibilities for the Boards and PECs as well as the management and liaison structures of PCTs.

> 'With the new emphasis on individual patient choice, commissioning decisions will also require the input and ownership of local people and patients – 35% of clinicians felt that their PCT commissioning system did not take account of the views of local people and the public yet.'

NHS Alliance, 2003

The Patient Survey

Each NHS organisation is required to undertake an annual structured survey of a proportion of their patient population. The information from the primary care survey will help each PCT (on behalf of local health services) to provide independently validated information to the public about the availability, the quality and the performance of local health services.

> 'Patient surveys will be used to monitor patient experience and will form part of the performance management …. Every Trust will publish an annual Patient Prospectus to bring together information on its services, patient views and how the Trust is responding to patients' concerns.'

Department of Health, 2001

The Patient Prospectus

Information gleaned from the primary care survey – and from those of other providers within the local health economy – will be a useful starting point for the Patient Prospectus which every PCT is required to produce. The Patient Prospectus will provide an annual account of patients' views and of the local standards set to address shortfalls identified through the survey and through other forms of consultation with patient and community groups and with the wider community.

> 'Prospectuses will form part of the information flow outwards as well as inwards. But I don't want them to be glossy spin. They need to show what the PCT has done, what its targets are and how it is spending the money.'

Harry Cayton, the new director of Patient Experience and Public Involvement at the Department of Health, 2002

The prospectus will also contain details about the choice of services available in primary care, such as female GPs, or specialist services.

> 'A central tenet of *The NHS Plan* was that services should be shaped around patients, so we need to find out what they think. Having established that, trusts need to act on it. Patient prospectuses will say 'this is what we have done on the basis of what you have told us'. They will also cover how organisations respond to complaints and what the Commission for Health Improvement (CHI) has said about them. This will allow patients to be more informed about the services they receive and eventually allow them to make choices about where they have their care.'

Sarah Mullally, Chief Nursing Officer and lead director for Patient Experience and Public Involvement at the Department of Health, 2002

Patient Advisory and Liaison Services

All NHS organisations are required to have in place a Patient Advisory and Liaison Service (PALS).

> 'Patient Advocacy and Liaison Services (PALS) ... [will] deal with patients and carers concerns on the spot, resolving issues before they escalate into problems'

Department of Health, 2001

However, recent research by the Health and Social Care Quality Centre suggests that almost 50% of organisations do not yet have the service up and running. The performance and impact of the PALS service will be specifically monitored by the SHA.

> 'Primary Care Trusts must have systems which ensure that patients know where and to whom to go when they need further information or explanation.'

Department of Health, 2001

In addition to responding to the issues raised in relation to their own services, PCT PALS need to be engaged in active dialogue with those of their provider organisations and to initiate and monitor co-ordinated responses to patient concerns.

REFLECTION

How prepared is the local PALS service to take on this co-ordination role? What evidence is there to support your view?

> 'PCT PALS will be expected to act as lead PALS, co-ordinating effective collaboration across their area.'

Department of Health, 2001

The Patient Forum

As a result of the NHS Reform and Health Care Professions Act, which became law in June 2002, a new Commission for Patient and Public Involvement in Health will fund, set up and oversee patients' forums in each PCT and NHS trust. These bodies will replace (and have a broader and more formal remit than) Community Health Councils. These were finally abolished on 1st December 2003 and took effect from January, 2003.

> 'A new, independent national organisation — the Commission for Patient and Public Involvement in Health (CPPH) — will be given responsibility for ensuring the effective delivery of patient and public involvement. [It] will develop explicit quality standards for patient and public involvement, initiate training and support to enable those standards to be achieved.'

Reeves, 2001

Each patient forum will be drawn from a mix of actual service users and local representatives of patient and voluntary organisations. In the first instance, eight members will be appointed to each local forum by the CPPH. They will be charged, in the first instance, with initiating a dialogue with their PCT and with developing locally relevant structures, processes and membership arrangements. There are likely to be approximately 20 members of each new forum with up to a third of members drawn from the former CHCs. The new forum will then monitor and review the range of local services provided and how well they operate.

Forums will differ from CHCs in a number of ways. They will have greater inspection rights, which will include access to GP surgeries and to the independent sector.

> ‘Patient Forums … … [will have] the power to visit and inspect any aspect of the care process. Made up of local patients and carers, these bodies will be a … … focus for reform and improvement in the provision and commissioning of services in both primary and secondary care.’

Department of Health, 2001

They will have the freedom to report their recommendations to the PCT but also to the Commission for Patient and Public Involvement in Health and to any other person or body they think is appropriate. The onus will be on forums to gather a broad and representative cross section of local views and opinions and to involve people who have not traditionally been given a voice in shaping or commenting upon services.

Eventually each Patients’ Forum will have the right to identify a member (other than the Chair) who will sit on the Board of the PCT as a non-executive director – a fundamental change intended to put the service user’s voice at the heart of the decision-making process.

> ‘Rather than relying on the usual groups of people who turn up at council meetings and respond to public consultations, there may be more capacity in the system to do outreach work, to get out on to housing estates and involve single parents and asylum seekers – people with whom historically the NHS doesn’t engage.’

Peter Walsh, the director of ACHCEW, 2002

The PCT’s own Patient Forum (in collaboration with the Patient Forum of another PCT/PCTs where appropriate) will be required to take a lead role in co-ordinating action across a local health economy.

REFLECTION

What do you see as the major challenge in working effectively with the new Patient Forum?

The Local Authority Health and Social Services Oversight Committee

The Local Authority's newly created (January 2003) Health and Social Services Oversight Committee has a key role in monitoring and regulating service integration across the health and social care interface. This is intended to ensure effective and timely collaboration and co-ordination across the frontier that has historically divided the health and social care communities.

To assist Local Authorities in the discharge of these functions, the Department of Health website carries guidance and advice at:
www.doh.gov.uk/involvingpatients/guidance.htm

It is likely that these LA committees will adopt a themed approach – with scrutiny (not least as a result of the outcomes of the Inquiry into the Death of Victoria Climbié) directed at co-ordinating all the services that exist to protect and support local children and other vulnerable groups. The committee will meet not less than twice a year with the Chief Executive of the PCT and will review other issues of mutual interest or concern. The PCT will be required to consult with the committee with respect to any proposed and significant changes to the pattern or location of local services (e.g. the closure of a community hospital or health clinic).

REFLECTION

What do you see as the major challenge in working effectively with the Local Authority Oversight and Scrutiny Committee?

Future developments

The Secretary of State has placed significant emphasis upon local accountability for NHS services.

> 'PCTs are local organisations whose sense of direction is looking outwards to their locality, not upwards to Whitehall.'
>
> *Reid, 2003*

In addition to the changes set out above, the Government and the Department of Health are keen to develop 'health communities' and foster further active engagement between NHS bodies and all of the organisations that can influence and promote public well being at a local or regional level.

> 'The DoH is determined to see all NHS organisations signed up to a geographically relevant 'local compact' by March 2004. A local compact should be part of the ongoing consultation and involvement process of monitoring, reviewing and implementing service changes. It involves local voluntary and community organisations, local authority councillors and officials, NHS boards and staff all working together.'
>
> *CEO Bulletin September 2002*

Responding to the challenge

All these initiatives pose a significant challenge for PCTs and other NHS Trusts. CHI reviews to the end of December 2002 indicate that concerns still exist in the overwhelming majority of organisations about the nature and extent of consultation and patient involvement.

CHI has found that real involvement is sometimes obstructed by failure to take pro-active steps to involve service users and communities, particularly in the planning and development of services. Public involvement may be further hampered by lack of (or inaccessible) information. CHI has also noted that barriers to complaints still exist — especially for vulnerable groups.

As a result of the pilot reviews in primary care, CHI encourages all service providers within PCTs, including general practices, pharmacists, dentists and optometrists, to consider how patients can be more fully involved in all aspects of service delivery.PCTs must, therefore, respond positively to the challenge of adopting a more open and participative approach.

> ‘Those who have taken the step, and properly opened up their service to public scrutiny through lay involvement, have found that members of the public are often more supportive and more constructive than expected.’
>
> *Clinical Governance Bulletin, December 2001*

PCTs must put in place structures and processes to ensure effective liaison with each constituent organisation and function designed to promote patient involvement. Boards must also ensure that they openly co-ordinate and, where necessary, justly balance the different expectations and aspirations of each of these bodies.

> ‘Finally, a huge amount of work remains to be done to put flesh on the bones of these proposals.’
>
> *Reeves, 2002*

Priorities for action

Now that you have finished reading through this section, please identify three key priorities for action that would help to promote patient and public involvement and compare them with the checklist below.

1

2

3

Checklist: Promoting Patient and Public Involvement

Please highlight or tick each issue when it has been considered.

Is the Board and PEC familiar with the priority that Government and the NHS attaches to a proactive approach to the PPI agenda?

Is the Board and PEC familiar with the duties and responsibilities of the Commission for Patient and Public Involvement in Health?

Do the Board and PEC keep under active review the way that CHI and the new Commission for Health Audit and Inspection approach this issue?

Is there a clear strategy for fostering Patient and Public Involvement in Health?

  Does the strategy address the services that are commissioned as well as those that are provided by the PCT?
  Do all members of the Board and PEC know about it?

Is the process of implementing this strategy 'project managed'?

  Is there clear delegation of responsibility and authority for managing the interface with the Patient Forum and with the wider participation agenda?
  Is the strategy adequately resourced?
  Are there clear and realistic action plans?
  Is there an indicative timetable?

Is the extent of local patient and public involvement and its impact kept under regular and active review?

Are outcomes, emergent issues or major obstacles to implementation reported back to the Clinical Governance Committee and through them to the Board and PEC?

References

Bristol Royal Infirmary Inquiry 2001. *Learning from Bristol: The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984-1995*, BRI Inquiry Final Report, Bristol: BRI Inquiry

Harry Cayton, the new director of Patient Experience and Public Involvement at the Department of Health

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Reeves, N. 2001. *Involving patients and the public in healthcare*. Primary Care Network www.doh.gov.uk/publications

Reid, J. 2003. *Localising The National Health Service: gaining greater equity through localism and diversity.* London: New Local Government Network

Peter Walsh, the director of ACHCEW

Resources

Building a safer NHS for patients
www.doh.gov.uk/buildsafenhs

The College of Health
www.collegeofhealth.org

The College of Health has several publications of interest:

Kelson, M. 1997. *User Involvement: A Guide to Developing Effective User Involvement Strategies in the NHS*, London: College of Health

Kelson, M. 1998. *Promoting Patient Involvement in Clinical Audit: Practical guidance on Achieving Effective Involvement*, London: College of Health

Kelson, M. 1999. *National Sentinel Audits Involving Older People: A Guide to Involving Older People in Local Clinical Audit Activity*, London: College of Health; Oxford: RCN Institute

Commission for Health Improvement – CHI's aim is to improve the quality of patient care in the NHS.
www.chi.nhs.uk

CHI uses an approach to public and patient involvement to assess PPI progress. This can be accessed at
www.chi.gov.uk/patients/strategy.pdf

Department of Health – access all Department of Health information is through their website:
www.doh.gov.uk

Department of Health Public Involvement Bulletin
subscription@talking numbers.com

Commission for Patient and Public Involvement in Health and Patient Forums
An update report on the Commission for Patient and Public Involvement in Health, Patients Forums, independent complaints advocacy, overview and scrutiny committees and the imminent new duty on the NHS to involve and consult the public is available under the menu headings 'Status Report' and 'Policy Update' at: www.doh.gov.uk/involvingpatients and at www.cppih.org

Guidance on the proposed 'Local Compacts' is set out at:
www.doh.gov.uk/compact/index.htm
See also: Department of Health 1999. *Patient and Public Involvement in the New NHS*, Wetherby: Department of Health

The Essence of Care – provides best practice benchmarks on aspects of care that are central to the quality of the patient experience.
www.doh.gov.uk/essenceofcare

Involving Patients and the Public in Healthcare: the NHS Alliance response
www.nhsalliance.org

GPs with a Special Interest – a report shows that GPs with a special interest can help local health economies to meet some of the key NHS objectives such as improving patient access, reducing waiting times, improving the patient journey and promoting links between primary and secondary care.
www.doh.gov.uk/pricare/gp-specialinterests

For specific information about GPs with a special interest in ENT, visit www.gpwsi.org

Good practice in consent: achieving *The NHS Plan* commitment to patient-centred consent practice:
www.doh.gov.uk/consent

Involving Patients and the Public in Healthcare
www.doh.gov.uk/publications

Involving patients and the public in health care – response to the Listening Exercise, November 2001
www.doh.gov.uk/involvingpatients

Learning from Bristol: The Department of Health's Response to the Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995
www.doh.gov.uk/bristolinquiryresponse

Patient safety is featured on the website
www.qualityhealthcare.org

Strengthening Accountability: involving patients and public.
www.doh.gov.uk/involvingpatients/strengthaccountpolicy.pdf

Your guide to the NHS: the NHS's commitment to its patients January 2001
www.nhs.uk/nhsguide

Rating the PCT's current stage of development

Please rate the PCT's current stage of development in relation to the following questions. Remember to use the Response Sheet provided for your answers.

6.1 To what extent do the Board and PEC have a strategy for ensuring that the local communities become proactively involved in all aspects of the 'planning, delivery and evaluation of care'?

6.2 To what extent are the current arrangements to secure this level of community involvement effective?

6.3 To what extent do the Board and PEC have a strategy to ensure that patients and their carers develop 'choice, voice and control at every step in their treatment'? *(NHS Cancer Plan)*

6.4 To what extent are the current arrangements to secure this level of patient and carer involvement effective?