SECTION FIVE
THE PATIENT EXPERIENCE

This section considers:

- strategies and actions designed to measure the quality of the patient experience
- how actively these issues are addressed by the Board/PEC
- the need to build the quality of the patient experience into the PCT's commissioning arrangements
- the overall co-ordination of care as a key determinant of the quality of the patient experience.

Value and the patient experience

The values of humanity, respect, justice and partnership that underpin clinical governance should be reflected in every aspect of the patient experience. So far as the services provided by the PCT community are concerned, Boards and PECs must ensure that these values are given concrete expression in all aspects of care – so that it is routinely timely, collaborative, effective, compassionate and empowering.

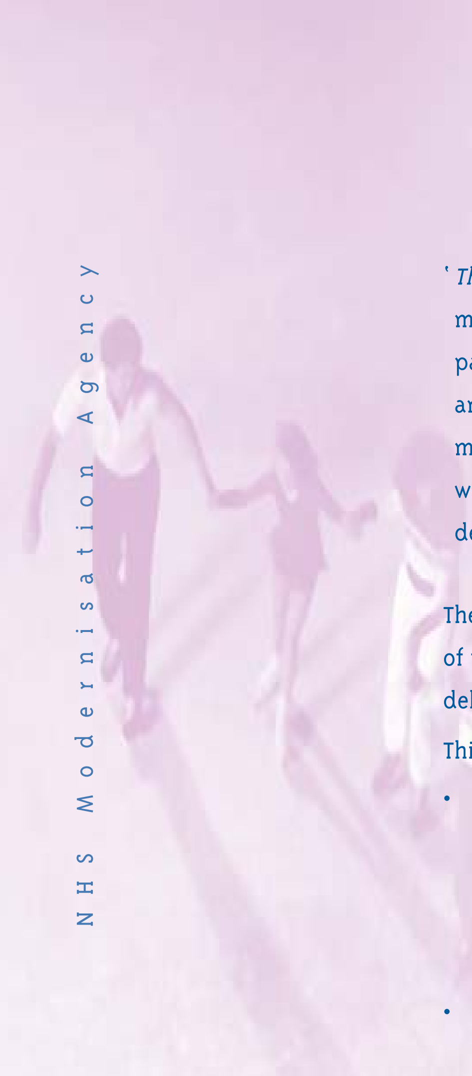
> 'Users and their carers should have choice, voice and control over what happens to them at each step in their care.'
>
> *Department of Health, 2000*

The key driving precept of clinical governance is to put the patient first. This will happen partly by transforming patterns of care so that they are determined by patient need rather than by historical precedent or organisational convenience.

> 'Each patient will need the pathway of care that is right for them.'
>
> *Department of Health, 2000*

If this fundamental human aspect of clinical governance has sometimes been overlooked in the face of the need to generate policies, structures and organisational processes, the balance has now shifted decisively. The new Commission for Health Audit and Inspection intends to put the patient experience at the heart of their inspection regime and to focus their judgements upon the impact that clinical governance has on its evidenced quality.

Clinical governance seeks to replace a long-standing culture of paternalism with one characterised by dialogue, innovation and participation.



> '*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 Our vision is to move away from an outdated system, towards a new model where the voice of the patient is heard through every level of the service, acting as a powerful lever for change and improvement.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*

The underpinning values of respect, justice and partnership should permeate every aspect of the individual patient's experience of care, wherever in the health system that care is delivered.

This means that the Board and PEC must:

- be prepared to investigate closely and imaginatively the reality of the experiences encountered by their patient populations in relation to
  - the services they receive from the PCT itself and
  - the services they receive from constituent GP and other practices (dentistry, pharmacy, optometry).
- take co-ordinated and persistent action to ensure that the basic safety and quality is assured in the present and continuously improved in the future.
- have equal regard for the quality of the patient experience in those services that they commission from other organisations.

> 'The notion of partnership between the healthcare professional and the patient, whereby the patient and the professional meet as equals with different expertise, must be adopted by health care professionals in all parts of the NHS.'
>
> *Department of Health, 2001*

One expression of this notion of greater equality is the extension of the choice agenda in health – the fourth of the Prime Minister's principles of public service reform.

Clearly, choice poses major challenges for all NHS organisations and, given their commissioning and future contracting responsibilities, particularly for PCT's. However, if the current mechanisms and processes cannot deliver choice, it is the mechanisms themselves that must change.

Within the current NHS choice is exercised already by people with H.I.V. Far from having collapsed under the strain, these services provide some of the leading examples of patient-led transformational changes to models, locations and the ideology of care.

In the future, a powerful determinant of the equity and quality of the patient experience will be the extent to which all patients, irrespective of class, gender, age or ethnicity, are able to exercise real (i.e. informed) choice.

> 'The main cultural reason for this lack of fairness is the ability of some people to work the existing system better than others. Information, confidence and support are differentially distributed.'
>
> *Reid, 2003*

Key learning from the pilot programme

In the face of the very real pressures that are attendant upon the creation of any new organisation, and in the light of the exponential increase in their overall duties and responsibilities, few PCT Boards and PECs in the sample had explicitly identified, measured and kept under active review the key determinants of the quality of the primary care patient experience.

All recognised the underlying importance of the issue - that it is indeed their core business. However, many felt that its importance was obscured rather than highlighted by many of the targets set for them, and that it received scant attention from some (though by no means all) SHAs when compared with financial concerns.

Finding robust and sensitive ways to track the quality of experience of the diverse primary care patient population demands imagination, creativity and persistent attention. Gathering robust ‘intelligent information’ about the patient experience and acting upon it must be a major priority for PCTs as they prepare for the new CHAI inspection regime.

Significantly, across all the PCTs in the pilot programme, the section on Patient Experience was the fourth lowest scoring at 4.6 on the progress scale (range 3.1 to 6.3). The highest recorded score was the third lowest for any section.

Predictably, in the face of the other pressures upon them, the more recently formed PCTs were likely to find this an even more challenging issue than those that had had longer to begin to wrestle with it. The 25 PCTs that were under a year old when they completed the questions scored an average of 4.3 whilst the remainder scored an average of 4.8.

All Boards and PECs recognised the importance of this issue. It was the one upon which they were most likely to focus their scrutiny and their energy during the feedback process, although in many cases this was the first time that the Board and PEC had talked explicitly together as one community about this crucial goal of their quality and assurance processes.

Most felt that this reflected the pre-occupation with finance and quantitative targets that they believe characterises the performance culture within which they are required to operate. Although many Boards and PECs had not been previously aware of the ‘Vision for the New CHAI’ they welcomed its explicit emphasis upon the patient and the patient experience of care, whilst recognising the challenge that this presented to them.

No PCT in the sample had derived a specific and comprehensive strategy for defining and then tracking the component elements of quality as they map against the experience of the patients of PCTs, but most were keen to embark upon this process. All recognised that their commissioning duties required them to consider the quality of the patient ‘journey’ and not just those episodes of care that were delivered by their own staff or their independent contractors. A number were able to highlight excellent concrete examples of managed change processes in relation to a specific clinical condition (e.g. diabetes) that had actively engaged their patients with their staff, and those of partner organisations, in the fundamental redesign and improvement of models, patterns and outcomes of care.

Many Boards and PECs worked collaboratively on a Checklist of the 'key building blocks of quality of the patient experience'. The Checklist is presented at the end of this section. They reflect a high degree of consensus between Board and PEC members from PCTs serving very different communities. The final building block was always added to ensure that there is a reality check with local communities and with local patients.

The elements of the patient experience

The public rightly holds primary care in high regard – and they make frequent use of the services that it provides.

> 'Four-fifths of the population visited a GP in the last 12 months: 86% of women and 75% of men.
>
> Views of their GP's skills, knowledge, attitude and ability to communicate were generally very favourable.
>
> Half of the population had visited a practice nurse in the last 12 months: 61% of women and 42% of men.
>
> Patient's views of the nurse's skills, knowledge, etc were even more favourable than their views of the GP's skills and knowledge.'

The National Primary Care Development Team, 2002

Boards and PECs must also guard against complacency.

> 'Eleven percent of respondents said that they had felt like making a complaint about someone at the surgery in the past 12 months but had not actually done so.'

NHS Executive, 1999

The CHI assessment framework rightly places considerable emphasis upon the reality of the patient experience and the perception of care.

> 'The flow of care and treatment, waiting times, humanity, and environmental issues are the aspects of patients' experience where CHI is most likely to call for action.'

Commission for Health Improvement, 2002a

This emphasis will be further strengthened by the new Commission for Health Audit and Inspection (an issue covered in greater depth in Section 7).

> 'CHAI will put patients' experiences, including clinical outcomes of care, at the centre of its concerns and analyses'

CHI, 2003

CHAI will place particular emphasis on equity and upon the quality of the care that is provided to vulnerable and marginalized groups. It will:

> 'promote equal citizenship by ensuring that the well-being and healthcare of vulnerable groups, including children, older people, people with learning disabilities and people with mental illnesses (particularly those detained under the Mental Health Act 1983), are fully reflected in our assessments and that their rights are safeguarded'

CHI, 2003

The new Commission will also place greater emphasis upon the overall co-ordination and seamlessness of care, rather than looking only at those episodes of care that occur within the boundary of the organisation that is being inspected.

> 'the assessment should be addressed from the perspective of patients, based on an understanding of what they experience along the whole pathway of care along which they may travel'

CHI, 2003

Most patients' experience of care begins before they ever come face to face with a health professional. Telephone contacts are a common starting point. The quality of the response, in terms of its humanity as well as its efficiency, provides an early and significant indicator of the commitment of a health care organisation to its users.

> 'One in five (19%) respondents said a surgery receptionist had made it difficult for them to see or talk to a GP at least once in the last 12 months.'

NHS Executive, 1999

Although the following findings from CHI relate to hospital admissions and waiting lists, it would be as well to heed the warning. Some of the underlying factors may also affect the services offered by the PCT.

> 'Factors underlying waits and waiting lists include:
>
> - unclear access/admission policies
> - poor organisation of access/admission
> - lack of collaboration within an organisation
> - lack of collaboration between acute and community services
> - staff shortages.'

Commission for Health Improvement, 2002b

Delays in access to health care are a major source of concern, and can have consequences for patients that range from inconvenience to unmanaged risk.

> 'Overall, 15% of respondents put off going to the surgery because of inconvenient surgery hours. This varied between Health Authorities from 10% to 23%.'

The National Primary Care Development Team, 2002

REFLECTION
What evidence is there to show that the Board and PEC actively review issues of access to services?

Levels and flow of demand may make it impossible to guarantee instant access. Exemplary work undertaken by PCTs involved in the Primary Care Collaboratives provides powerful evidence of what can be achieved by:

- purposeful and sustained attention to the component elements in the appointments and access process
- making more flexible and focussed use of the range of expertise within the clinical team.

Boards and PECs needs to scrutinise the access process – patterns of demand and the appropriateness of existing methods of responding to this demand and take appropriate action to ensure the timeliness of care.

> 'To date, the average waiting time to see a GP in Collaborative practices has reduced by 62% … and Wave 4 practices have been achieved a 64% reduction in waiting times in just 10 month… Practices that have implemented advanced access have demonstrated that the system is sustainable but that this can only be achieved by proactive, ongoing management. The key is in recognising that advanced access is not an endpoint but a dynamic process.'

The National Primary Care Development Team, 2002

'Nothing about me without me'

A key transaction in the process of care is the initial diagnostic appointment with a general practitioner, community nurse or AHP. Extensive literature exists on the characteristics of professional/patient transactions that promote accurate diagnosis and appropriate treatment and satisfy the legitimate expectations of patients.

> 'Surveys of cancer patients have shown that they give a very high priority to:
>
> - Being treated with humanity
> - Good communication with health professionals
> - Being given clear information about their condition
> - Receiving the best possible symptom control
> - Receiving psychological support when they need it.'

Department of Health, 2000

The quality of the patient experience can be improved by ensuring that patients (and their own carers):

- are actively involved in the process of diagnosis
- are full and active partners in the identification and management of risks
- make informed decisions about treatment options
- see themselves as active and key partners in their own care.

'Patients should:

- be involved in the management of their condition;
- be helped to understand clinical risks;
- be able to give genuinely informed consent.'

Clinical Governance Bulletin, December 2001

Some patients welcome written as well as verbal explanation. This may aid understanding and increase the possibility of compliance with treatment regimes. The Department of Health has developed a toolkit that includes guidance for written patient information together with a series of templates – this is available from www.doh.gov.uk/nhsidentity/toolkit-patientinfo.htm

'Improving Patient Information in The NHS is an important part of the patient journey.'

CEO Bulletin 140

It is important to take into account issues of language and culture and attempt to find the best means of communicating the necessary information.

'Information should be given in a variety of forms... and should be tailored to the needs, circumstances and wishes of the individual.'

Department of Health, 2001

Professional staff are generally familiar with most of these issues and characteristics. Faced with time pressures and co-incident demand, however, such issues may be neglected.

REFLECTION

What evidence is there to suggest that appropriate steps are being taken to address issues of language and culture when communicating with patients?

'In a third of all organisations reviewed, CHI called for action because patients expressed concerns about lack of involvement in their own care and called for better use to be made of verbal and written information.'

Commission for Health Improvement, 2002a

Inevitably this has consequences not only for the quality of the patient experience, but also for the sense of pride and satisfaction that staff take in their work. Individual mistakes are most likely to occur when one of the most basic building blocks of care (attentive listening) is absent. PCT Boards and PECs have an obligation to monitor the level of demand upon all of their staff to ensure that it is maintained at a level where sustained quality can be routinely achieved.

'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 quality of the patient experience and the co-ordination of care

The PCT delivers and commissions care for its patient population. Where the initial contact is the starting point for a more extended process of treatment, the PCT has a unique responsibility for managing the co-ordination of all of the different responses from the necessary parts of the health (and social care) system. Integrated Care Pathways should be generated and implemented at local level to ensure delivery of the most effective care.

> 'Development and implementation of integrated care pathways (ICPs) offers the prospect of both better quality multi-disciplinary care and better deployment of resources.'

Commission for Health Improvement, 2002

As patients move into and out of contact with different providers of care – often over a period of years – the GP practice and the PCT provide continuous management of the total process. It is this continuity which can generate sustained excellence. Access to patients' own experiences can provide the Board and PEC with vital information about the quality of the patient experience.

> 'A patient is invited to document in the form of a diary all events throughout their health care experience. This comprises a record of the events, times and actions, together with comments about feelings relating to the experience (what went well/could have been better). They can also include emotions, the attitude of staff, the environment and critical incidents associated with their journey.'

Learning Through Partnership, 2000

To aid learning from this process, the Government has established the Expert Patient Programme. This programme enables people with long experience of the NHS as consumers to put their experience and wisdom at the disposal of other service users, PCTs and other providers of care. In the same way, a member of staff acting as a 'Patient Tracker' can provide insights that may otherwise remain beyond the immediate grasp of Boards, PECs and key professional staff.

> 'A patient ..[is] accompanied by a member of staff. It is preferable that the tracker does not have knowledge of the process and is comfortable asking the 'why' questions...... The movement of the patient as well as the actions is recorded. A comprehensive picture is built up of the movement combined with a flow diagram of actions. This can be invaluable when trying to map what happens currently in a service.'

Learning Through Partnership, 2000

> 'The PCT should aim to learn from these experiences and ensure that the patient journey is managed to produce the seamless care offered by effective ICPs. Such care demands sustained collaboration and partnership not just with patients but also between many different professional staff in many different organisations. The Primary Care Collaboratives have provided compelling evidence of the improvements that can be achieved on behalf of patients through capacity and demand management strategies. In collaboration with local acute care providers these can improve access to routine secondary care services.'

The National Primary Care Development Team, 2002

As this experience demonstrates, these improvements come about only when a health care community acts in concert and regards organisational boundaries as soluble challenges to the smooth flow of treatment and care – rather than as territories to be defended in the pursuit of factional fiscal or competitive organisational advantage.

Priorities for action

Now that you have finished reading through this section, please identify three key priorities for action in relation to improving the patient experience, and compare them against the checklist below.

1

2

3

Checklist: Quality of the patient experience of care - key building blocks

All aspects of care should be:

1 Timely, accessible and delivered in an environment that conveys dignity.

2 Respectful, compassionate and sensitive to individual difference and preference.

3 Based upon equality and partnership with patients and their carers, so that people are able to make informed choices about their own care.

4 Managed so that transitions between health care providers and from health care providers back into the patient's own home are, from the patient point of view, safe, seamless and problem free.

5 Clinically effective and based upon the best available evidence so that the prospects for recovery are maximised, good health is prolonged and suffering and pain are minimised.

6 All of these criteria need to be fully debated with the Patient Forum, local communities and the PCT's own patients and staff so that they are added to and developed to reflect local needs and emergent 'wisdom'.

References

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Department of Health 2000. *The NHS Cancer Plan: a Plan for Investment, a Plan for Reform*, London: DH

Department of Health 2001. *Shifting the Balance of Power within the NHS: Securing delivery*, London: DH

Learning Through Partnership 2000. *Tools and Techniques for involving Patients, Users and Carers in Change Projects*, Aylesbury: Learning Through Partnership

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NHS Executive 1999. *National Surveys of NHS patients – General practice 1998 – Summary of key findings*, Leeds: NHS Executive

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

Resources

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

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

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

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

Expert Patient Programme: a new approach to clinical disease management for the 21st century
www.doh.gov.uk/cmo/progress/expertpatient/epp6.htm

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

Haines, Randa (director) 1991. *The Doctor* A video starring William Hurt as a heart surgeon who find out at first hand about the patient experience. Available from
www.amazon.co.uk

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

The Modernisation Agency – is a valuable source of information. You can access the different strands of the Agency through the website at:
www.modern.nhs.uk

National Clinical Governance Support Team – the CGST runs a series of programme to support the implementation of clinical governance 'on the ground'
www.cgsupport.org

National Institute of Clinical Excellence – the NICE site contains details on the Institute, its ongoing work programmes, the methodology and processes it uses, the guidance it has issued to date, copies of all press releases and the minutes and papers from its Board meetings.
www.nice.org.uk

The National Primary and Care Trust Development Programme – the NatPaCT team helps PCTs with organisational development.
www.natpact.nhs.uk

The National Primary Care Development Team – the NPCDT team helps to address access and service improvements for patients.
www.npdt.org.uk

National Primary Care Development Team 2002. *The National Primary Care Collaborative: The First Two Years, Manchester*: NPCDT.

New Health Network including *The next Phase: Localising the NHS, gaining greater equity through localism and diversity.*
www.newhealthnetwork.co.uk

Patient Information
The Department of Health has developed a toolkit that includes guidance for written patient information and a series of templates to accompany the guidance.
www.doh.gov.uk/nhsidentity/toolkit-patientinfo.htm

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

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.

5.1 To what extent has the Board and PEC identified key indicators of the quality of patient experiences of PCT-delivered care?

5.2 To what extent is attention given within the commissioning process to the quality of the patient experience?

5.3 To what extent do the Board and PEC keep the overall co-ordination and 'seamlessness ' of patient care under active review?

5.4 To what extent are mechanisms in place to gather evidence about the overall quality of the patient experience?