

## Essential quality updates

# Nothing about us without us: what patient and public involvement means to CHI

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### Guiding principles

The Bristol Royal Infirmary Inquiry and *The NHS Plan* commit the NHS to provide services that are 'patient-centred'.<sup>1,2</sup> New patient and public involvement structures include patient forums and the Independent Complaints Advocacy Services (ICAS) under the auspices of the Commission for Patient and Public Involvement in Health. Patient forums will monitor healthcare from the perspective of the patient. There is now a Director for Patient Experience and Public Involvement at the Department of Health and there will be a mandatory duty on the NHS to involve and consult with patients and the public.<sup>3</sup>

However, amidst the plethora of policy initiatives and patient-centric phrases, it is hard to identify common definitions and conceptual models that underpin notions of patient-centredness. There is an urgent need for the health service to adopt a congruent approach.<sup>4</sup> Without this, providers will be in danger of receiving mixed messages and confused lines of accountability as to what they are required to undertake in this field and concerning how best to do it.

The Commission for Health Improvement (CHI) has defined what patient-centredness means in the context of its own work and thereby offers some degree of conceptual clarity to this contested area. It has also undertaken some 200 clinical governance reviews that provide unique insight into the current state of patient and public involvement in the health service.

CHI's first principle is that the patient's experience is at the heart of its work. The CHI Patient and Public Strategy – 'nothing about us without us' – now at implementation stage and part of mainstream business, has been commended as a model of good practice.<sup>5,6</sup>

CHI looks for, and promotes, patient-centredness in the NHS through the measures it adopts and the

methods it uses. It also seeks to become a centre for excellence in terms of itself being patient-centred. In both these areas, when CHI talks about work on patients and the public, being patient-centred means two things:

- working for patients, carers and the public (the patient experience); this means that all the actions of an organisation are directed at doing things well for, and on behalf of, patients, carers and the public
- working with patients, carers and the public (patient and public involvement); this means that an organisation involves patients, carers and the public in the way it functions and in policy and planning.

The above definitions reveal a crucial distinction between the notion of involvement and issues concerning the patient experience. Much of this article focuses on the latter. First it is important to understand how CHI approaches the patient experience.

### The patient experience

As part of its clinical governance reviews, CHI assesses NHS organisations on different components of clinical governance. One of these is the patient experience, which is defined as the clinical and non-clinical factors characterising users' (patients and carers) contact with health services. The five dimensions of patient experience are: clinical effectiveness and outcomes, access to services, organisation of care, humanity of care and the environment.

Patients' views and users' assessment of health services are an essential information source about the quality of healthcare provided. However, at CHI patient experience is not solely equated to patients' views.

CHI gathers information about patients' experience from a range of information sources, including:

- the views of patients, users and carers (e.g. patient surveys)
- standardised indicators (e.g. mortality, waiting times)
- site observations (e.g. observation of interactions between patients and health service staff in clinical settings)
- interviews with a range of stakeholders including statutory partners, community and voluntary organisations (e.g. patient representatives), staff, and members of the public
- trust-based information (e.g. complaints records).

The *Priorities and Planning Framework 2003–2006* published by the Department of Health identifies national priorities and targets that organisations need to build into their local plans.<sup>7</sup> Improving the overall experience of patients in five specific dimensions is identified as a key priority.

The Department of Health dimensions are in line with the five dimensions of patient experience that CHI looks at in making assessments of NHS organisations and are shown in Table 1.

CHI gathers the views of patients, services users, carers and the public using methods appropriate to different client groups and healthcare sectors.

## Acute care

CHI makes use of the national inpatient survey results published with the 2001 performance indicators, as well as the results of previous Department of Health national patient surveys.<sup>8,9</sup>

## Primary care

CHI is currently piloting a new approach. It involves writing to patients who have used community health services to invite them and their carers to their stakeholder meetings.

## Mental health services for adults and older people

Service user reviewers interview a small sample of inpatients and community service users, using a semi-structured interview schedule.<sup>10</sup>

## Child and adolescent mental health services

CHI conducts a brief survey using a short questionnaire which is completed onsite by parents, carers and young people aged nine to 18.<sup>10</sup> This tool was specifically developed for young people and tested and validated by and with them.

## Patient and public involvement

CHI also assesses patient and public involvement (PPI) as part of its clinical governance reviews. The focus here is on a set of review issues built around a conceptual model of PPI. The model draws heavily upon the Wales Assembly Government Signposts document.<sup>11</sup> This document distinguishes between involvement at two levels:

- the 'individual' level – how patients and carers can have a say in their own care and treatment and the extent to which they share in decision making about options
- the 'collective' level – how patients, carers and the public can have a say in service delivery and policy and planning.

At the collective level, one can differentiate between different degrees of involvement:

- information – where an organisation informs patients, carers and the public, for example about the type of services that are available and how well

**Table 1** The dimensions of patient experience

CHI dimensions	Department of Health dimensions
Access to services	Improving access and waiting
Organisation of care	Safe, high-quality, co-ordinated care
Clinical effectiveness and outcomes	More information, more choice
Humanity of care	Building closer relationships
Environment	A clean, comfortable, friendly environment

- they are performing. The purpose here is to promote informed use of services and choice
- feedback – where an organisation seeks feedback on the patient experience, through qualitative and quantitative methods. The purpose here is to improve the quality of service delivery and the patient experience
- influence – where an organisation involves patients, carers and the public in policy and planning, for example through lay representation on committees or boards (e.g. NEDs – non-executive directors) or in decisions concerning resources, planning and reconfiguration. The purpose here is to improve the quality of decision making and promote accountability.

When assessing patient and public involvement, CHI is seeking evidence of meaningful involvement leading to improvements in planning and service delivery. CHI looks at the range and nature of involvement initiatives (across the dimensions above), and the organisation's strategic approach to PPI. This includes whether the organisation has a strategy and implementation plans, senior leadership, clear accountability arrangements and adequate reporting and monitoring structures. CHI will also wish to see links to wider improvement work and joint working, integration of PPI with clinical governance arrangements, and organisational support for the work (e.g. resources and staffing).

Information is gathered about these systems and processes from a range of sources, including a trust questionnaire, a data and information request, and interviews with stakeholders, such as statutory partners, community and voluntary organisations, staff, patient representatives, and patients, carers and the public.

## Patient and public involvement in the NHS: emerging themes

CHI has assessed over 200 NHS organisations. As with other components of clinical governance, a trust's record on involving patients and the public is graded from one to four. One represents 'little or no progress at an operational planning or strategic level', with four being excellence. CHI has not found excellence concerning PPI at any trust to date. CHI has asked organisations to take action about patient and public involvement in all but 9 of 193 NHS organisations reviewed to November 2002.

The following are notable practice examples (accurate at the time of the review).

- There is a wide range of mechanisms in maternity services at the Whittington Hospital NHS Trust to involve patients and their representatives in the planning of care. These include user representatives on the maternity services liaison committees.
- Newham Healthcare NHS Trust has a good strategic grasp with an enormous amount of work having been carried out given the diversity of the population. Of notable practice is the trust's health advocacy service which aims to involve patients in their care and treatment, not least by providing an interpretation service.
- The Royal National Orthopaedic Hospital NHS Trust has a written strategy on user and patient involvement and there has been considerable senior management effort to address patient involvement.
- Doncaster and Bassetlaw Hospitals NHS Trust has developed a number of methods for consulting with patients including departmental questionnaires, a trustwide questionnaire that has been adapted for children to complete, patient focus groups, and a patient conference.

From the sixteen mental health trusts CHI has reviewed, there are many good examples of user involvement in recruitment and training, service planning and monitoring. However, this activity is often inconsistent. Trusts recognise their reliance on a small group of users at a strategic level and the need to involve carers more systematically as well as groups and communities who are under-represented, such as users from black and minority ethnic communities.

The following are notable practice examples (accurate at the time of the review).

- North Cumbria Mental Health and Learning Disabilities NHS Trust offers a case study of change management to improve the service user experience. On a ward where a CHI investigation took place, the team has changed its models of care, approach to care planning, teamworking and the physical environment.
- Service users at the South London and Maudsley NHS Trust were actively involved in the development and provision of the Lambeth Early Onset (LEO) Unit. The Mosaic Clubhouse provides training to other service users and clinicians who want to establish their own clubhouse.
- The service evaluation scheme in Community Health Sheffield NHS Trust is notable for its maturity and thoroughness and the way it involves service users, external organisations and board directors in evaluating the quality of care in many areas of the trust.

In primary care, CHI's full programme of PCT inspections is just getting underway and more data will soon become available.

Across the NHS, some general themes emerge with respect to patient and public involvement.

- Many organisations are demonstrating an ability to elicit feedback on the patient experience, through qualitative and quantitative methods. But often these are in discrete clinical areas through dedicated 'champions'. What is often lacking are mechanisms of generalising processes in other areas or being able to share the outcomes at a strategic level in order to promote change. CHI has drawn attention to lack of sharing good practice in involvement within at least a third of organisations.
- Organisations seem to be struggling with how to involve patients and the public in policy and planning – in other words, how to move from 'feedback' mode to 'influence'. Often there is little attention to how people can be 'brought in and brought on' to strategic level decision making – how lay representatives, for example can be supported to make effective contributions in decision-making committees.
- Some organisations are developing strategies at board level on patient and public involvement but these can remain disconnected from operational work and staff accountabilities for delivering involvement initiatives. PPI is seldom integrated with other clinical governance activities or with clinical governance arrangements more generally.

Emerging themes reinforce recent research concerns that serious barriers still exist concerning people's capacity to participate in decision making (e.g. having the skills, resources and confidence to access information and decision making), and the organisational opportunities to do so.<sup>12</sup> In the field of community engagement, research has identified 24 barriers to effective relationships between statutory agencies and communities. The main problem is the lack of a strategic approach to working with communities (e.g. concerning system dynamics; organisational ethos and culture; professional service culture; organisational skills and competencies; and community capacity to engage).<sup>13</sup>

By assessing PPI as an integral part of clinical governance, CHI focuses attention on an issue that might once have been regarded as a secondary consideration. However, evidence from CHI reviews shows that there is still a long way to go.

## CHI's work on patient and public involvement

CHI is seeking to promote a common language and approach around patient and public involvement, and to foster a consistent approach to assessment of organisations in this area. But it is also undertaking a raft of associated initiatives in order to support patient-centredness in the health service.

### Supporting NHS organisations

CHI will share the learning from its clinical governance reviews (CGRs). Patient and public involvement is one of three themes (the others being use of information and risk management) where CHI will produce a consensus learning document at national level. This will distil the lessons of CHI's work to date on patient and public involvement and summarise the messages to the wider NHS as to how this work can be done better. CHI will work closely with local and national organisations, such as the Modernisation Agency (Clinical Governance Support Team, Leadership Centre, National Primary and Care Trust Development Programme (NatPaCT)) and the Commission for Patient and Public Involvement, in order to share best practice and useful learning via effective dissemination mechanisms. CHI is also working closely with the Department of Health on guidance for the NHS on its duty to involve and consult (Section 11).<sup>3</sup>

### Performance management of PPI

As well as congruence between national and local players about what PPI means, it is also vital that there is clarity about who does what with respect to performance management of PPI. For example at national level this concerns who sets standards for PPI (Department of Health), who supports delivery (e.g. Modernisation Agency) and who monitors and assesses PPI (CHI). The role of the Commission for Patient and Public Involvement in Health in each of these areas will also need to be clarified.

### Working with community and voluntary organisations

CHI is improving the methods it uses to identify, contact, engage with and utilise information from community and voluntary organisations (CVOs). These CVOs offer an expert perspective on the quality of care for patients within the local area, how well the local NHS is involving patients and the public (and their own organisation) and their view on joint working arrangements. CHI is developing a

national database of local CVOs as a foundation for this work that it intends to share with other organisations. It is also moving towards a cross-community approach to its stakeholder work. This will help to avoid consultation fatigue amongst CVOs and help focus CHI's assessments on the patient journey rather than on lone institutions. CHI is set to work closely with patient forums and aims to share data, avoid duplication in assessments and promote patient forum involvement in monitoring the action plans arising from a CHI review.

## Keeping CHI's work patient centred

A key CHI principle is that it applies the same principles and expectations to itself as it does to the organisations it assesses. When CHI assesses an organisation, there is a lay reviewer in the team. In mental health reviews, CHI has two service user reviewers (in addition to the lay reviewer) who are an integral part of the team and interview service users. When CHI develops new methods and measures of quality – be it in acute services, primary care or mental health – it seeks to fully involve patients, carers and patients' and carers' perspectives.

## The Commission for Healthcare Audit and Inspection

CHI is set to take on the development of new functions (inspection and improvement measures and the Office for Information on Healthcare Performance). Also, from April 2004, the Commission for Healthcare Audit and Inspection (CHAI) will assume the functions formerly conducted by CHI, the healthcare value for money functions of the Audit Commission and the independent sector health regulatory functions of the National Care Standards Committee (NCSC).

When Alan Milburn announced the creation of the new CHAI, he said that CHAI will be the judge of the NHS and the public will, importantly, be the jury. Professor Sir Ian Kennedy is clear that his starting point for CHAI is always what is in the interests of patients.<sup>14</sup> The forecast is clear: the inspections will continue to be patient-centred and patients will be at the heart of CHAI's work.

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