

Commission for
Health Improvement

Sharing the learning on
patient and public involvement
from CHI's work

i2i - Involvement to Improvement

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Summary	2
Background	4
1. The patient's experience	5
2. Patient and public involvement	7
3. What we found	10
4. Local work on PPI	14
5. A new era for PPI	16
6. Lessons for national agencies	18

¹ PPI includes the involvement of patients, service users, carers and the public

Summary

This report outlines what the Commission for Health Improvement (CHI) has found out about the involvement of patients and the public from more than 300 inspections and from its own research into the topic. We discuss what CHI looks for when assessing patient, service user, carer and public involvement (PPI)¹, what we have found, examples of how organisations are tackling this agenda and messages for the NHS in taking this work forward.

The main findings are that PPI activity is on the rise, and:

■ organisations are getting better at some aspects of PPI

The NHS is, on the whole, improving in some aspects of PPI, such as providing information for patients and undertaking qualitative and quantitative exercises in getting feedback from patients. But it is not doing as much to ensure that patients, carers, service users and the public influence decision making.

■ PPI is not part of everyday practice

Pockets of good practice are not being shared across organisations or being picked up at strategic level. Organisations are failing to integrate PPI activities with other efforts to improve services and are not making PPI central to core activities.

■ involvement is not leading to improvement

PPI is not yet having a major impact on policy and practice. This is despite a plethora of PPI initiatives. It is almost as if there is a brick wall between the activities going on and any changes on the ground that happen as a result.

The reasons for these findings include:

Strategies and plans

Many organisations are running before they can walk: CHI has found examples of impressive sounding strategies and plans, but often these are not rooted in reality nor linked to operational priorities. Or, there may be good work going on in parts of a trust, for example around getting patient and carer feedback in parts of the service, but these initiatives are not built upon, shared across the organisation, or linked with other improvement initiatives such as clinical audit. Organisations that succeed in PPI develop strategies linking PPI to existing groups, management initiatives and ways of working.

Organisational commitment

It is not enough just to have idealistic leaders. Where organisations seemed to be getting it right, they had a commitment to the work that came from the top. Senior management not only believed that PPI was the right thing to do, but could see what it could contribute to improving services. They also have a rationale and a business case for PPI. Those doing PPI know that it should be developed in conjunction with processes for involving staff and they provide tangible goals which mean something to staff. In these organisations, PPI is built into planning and policy formulation from the start.

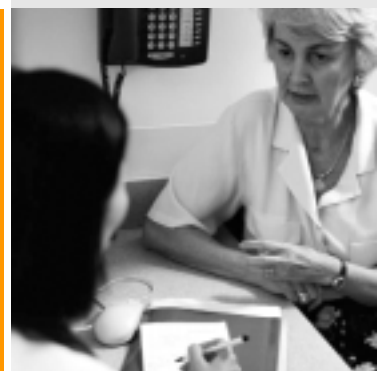
Mainstreaming

CHI saw few successful examples of where PPI had entered the corporate bloodstream. Where it did, this was exemplified by central support and performance management arrangements. It is rare to find places where directorates and staff have built in responsibilities for PPI, where reporting and monitoring arrangements are consistent, for example where there is integrated reporting on patient advice and liaison services (PALS), complaints and PPI work. In successful organisations, patient or user councils are sitting close to corporate decision making bodies and representatives are on those bodies helping to oversee PPI strategies and plans.

Feedback to influence

CHI has often found good operational work that does not influence decisions. There are also numerous examples of PPI going on in what may be termed 'safe' areas, such as having reader panels for patient information leaflets or focus groups on aspects of the ward environment. There are also plenty of examples of patient representatives sitting on steering groups for particular service areas or on projects. But often these project groups sit at the periphery of corporate decision making and the people involved may be marginalised and unsupported. The NHS seems to be getting better at finding out what matters to patients, carers and the public – less good at doing things about it. It is having a hard time shifting from 'feedback' mode (gathering information about the patient experience) to 'influence' mode (sharing a seat at the decision making table with patients, carers, service users and the public).

The NHS seems to be getting better at finding out what matters to patients, carers and the public – less good at doing things about it



Roles and responsibilities

There are numerous champions of PPI who are enthusiastic, dedicated, knowledgeable leaders at different levels of the NHS. But too often they are isolated and overwhelmed by the agenda and the number of operational and strategic tasks facing them. The work can be lonely, take immense courage and require supportive networks. A PPI coordinator needs appropriate expertise as a facilitator, change agent and finder of resources, in addition to being able to write strategies. They also need to be at a relatively senior level; at the third tier of management at least. Where PPI is done well, there are clear roles and responsibilities for other professionals as well. Organisations were sometimes able to point to the key roles played by, for example doctors, modern matrons, PALS, complaints services, strategic management teams and service teams.

CHI saw few successful examples of where PPI had entered the corporate bloodstream

Influencing change, supporting staff

PPI can challenge traditional practice. PPI is often seen by staff as something for 'other people', for instance, for nurses, but not for doctors. Professionals are sometimes not used to listening to patients. But it is sometimes the practical side of things where people are stuck – professionals may not understand the mechanics of how to do PPI well. Where organisations have been successful at bringing about change through PPI, this has meant tackling real (and imagined) concerns about the consequences of PPI, demonstrating benefits, celebrating success, sharing good local practice, creating new 'champions' and using professional connections.

Working together

CHI found a few good examples of cross community working, but too often organisations were working alone and risking repeating fruitless consultation exercises or duplicating work. The successful organisations demonstrated how they shared expertise through joint appointments, had developed cross boundary consultations with primary care trusts (PCTs), made use of consultation mechanisms set up by local authorities, or had good relationships with the local voluntary sector.

The challenge now is that PPI needs to be made part of everyday practice, or 'mainstreamed'. Unless this happens, PPI will be a passing fad, and a unique opportunity to ensure better quality care, treatment and decision making would be missed.

Background

Do people who use the NHS have a say in it? This report outlines what CHI has found out about the involvement of patients, service users, carers and the public from more than 300 inspections in England and Wales.

Our learning from these inspections has been augmented by additional research:

- literature review concerning the evidence about the degree to which PPI has had an impact on policy and practice in the UK health service;
- research into best practice in how organisations (in the public and private sector) can share learning;
- in depth case studies in two health communities concerning PPI and the factors that help or get in the way of embedding the work;
- group discussions in four regions with leaders of PPI work;
- a national stakeholder consultation event with representatives of patient and public interest organisations and representatives of trusts, Strategic Health Authorities and national agencies.

The work has been led by David Gilbert, head of patient and public involvement, and Jose King, project officer, and was carried out between January and September 2003. It is one project being carried out as part of CHI's patient and public strategy (*Nothing about us without us*. CHI's Patient and Public Strategy www.chi.nhs.uk). We would like to acknowledge the contributions of all those who took part in the group discussions, case studies and stakeholder event as well as those who carried out specific research (The Office for Public Management, Health Link and Ann Richardson).

The patient's experience – what matters to patients

1

PPI has to lead to change and improvement. But what sort of improvements are we looking for? And what exactly is PPI anyway? To answer both these questions, it is first necessary to understand what we mean by the patient's experience and to draw a distinction between the notion of PPI and the patient's experience.



The most important thing to patients and carers, regardless of circumstances, must be to get and feel better – the 'outcomes' of care, which may be physical, psychological or social. They can be clinical outcomes, such as the reduction of symptoms. But these outcomes can be as much to do with a better quality of life, such as getting back to work, healthy relationships with loved ones, or being better able to manage the symptoms of a long term condition.

These outcomes are dependent on the quality of care and treatment and the patient's experience of care, which includes:

- **getting the best treatment (clinical quality):**
high quality, safe and effective treatments delivered by competent professionals
- **being treated as a person (humanity):**
respect, dignity, empathy, attitudes
- **being safe and comfortable (environment):**
food, hygiene, safety, privacy
- **being informed and having a say (information and choice):**
information, opportunities to air concerns and complaints, influence over treatment decisions. Having a say in one's own care and treatment can be seen as both a part of the 'patient's experience' and PPI (see section 2).

These elements should be present at each stage – from the moment people feel unwell (and perhaps before, if one considers health promotion and public health) to when people are better or able to manage their own condition.

The 'patient's journey' itself includes:


- **getting care when and where I need it (access):**
responsiveness, waiting, convenience, location;
- **making the journey as smooth as possible (continuity):**
from initial contact through to coming home; consistency and continuity of care; support for carers.

Equity, diversity and choice

CHI sees equity and diversity as cross cutting issues rather than an additional dimension of a patient's experience. This is because different people and groups from different parts of society often face additional barriers to getting the things that matter. For example, homeless people may face specific barriers when registering with a GP (access) and people whose first language is not English may find it hard to understand what is being said to them (information and choice).

Different people may have different concerns across the elements of the patient's experience and make choices about or trade offs between them. For example, some may value quality over access and be willing to travel further to get particular specialist treatment. People may choose between treatments or

between GPs. People dying of cancer may wish to be at home with their loved ones (a patient centred outcome), rather than spending their final days in a hospital on treatments that give them a few extra days of life (clinical outcome). The national consultation on choice will identify some of these crucial issues of choice.



CHI sees equity and diversity as cross cutting issues rather than an additional dimension of a patient's experience

Patient, service user, carer and public involvement

2

PPI should lead to improvements in all aspects of the patient's experience. However, PPI is not only about improving the quality of services. It is also about improving the quality of decision making. It can improve relationships between individuals and professionals – something highly prized and a major cause of dissatisfaction in the NHS – and between organisations and communities.



Improved accountability, transparency and openness are also key goals of PPI. Overall, PPI should have an impact on policy, practice and outcomes.

PPI is one of seven components that CHI looks at within its routine inspections (clinical governance reviews) that look at how an organisation ensures high standards of care. The other six components are: risk management, use of information, clinical effectiveness, staffing and staff management, clinical audit, and education and training.

In each of these components a score of i-iv is given. A score of 'i' means that there has been little evidence of progress at strategic, planning or operational levels, while a score of 'iv' means coordinated activity across all these areas plus partnership working, clarity about the future and evidence of improvements resulting from the work. These scores contribute to an organisations' star ratings.

There are different degrees of involvement: information, feedback and influence

CHI's model for PPI draws upon the Welsh Assembly Government's Signposts document *Signposts: a practical guide to public and patient involvement in Wales* (www.wales.gov.uk/subihealth/content/nhs/signposts/index.htm) and now takes account of Section 11 of the *Health and Social Care Act (2003) – Strengthening accountability: Involving patients and the public*. Policy and Practice Guidance, Section 11 duty on organisations to consult and involve patients and the public. Its model for PPI is consistent with others, such as that used by the community engagement team of the National Primary and Care Trust Development Programme (NatPaCT). PPI can take place 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 both levels, there are different degrees of involvement: information, feedback and influence.

At the individual level, people can:

- be informed about treatments available to them;
- provide feedback about their care and treatment, for example, through the patient advice and liaison services (PALS) or complaints procedures;
- influence things through shared decision making about treatment options or taking control over their own treatments, for example by becoming 'expert patients' able to manage their own condition.

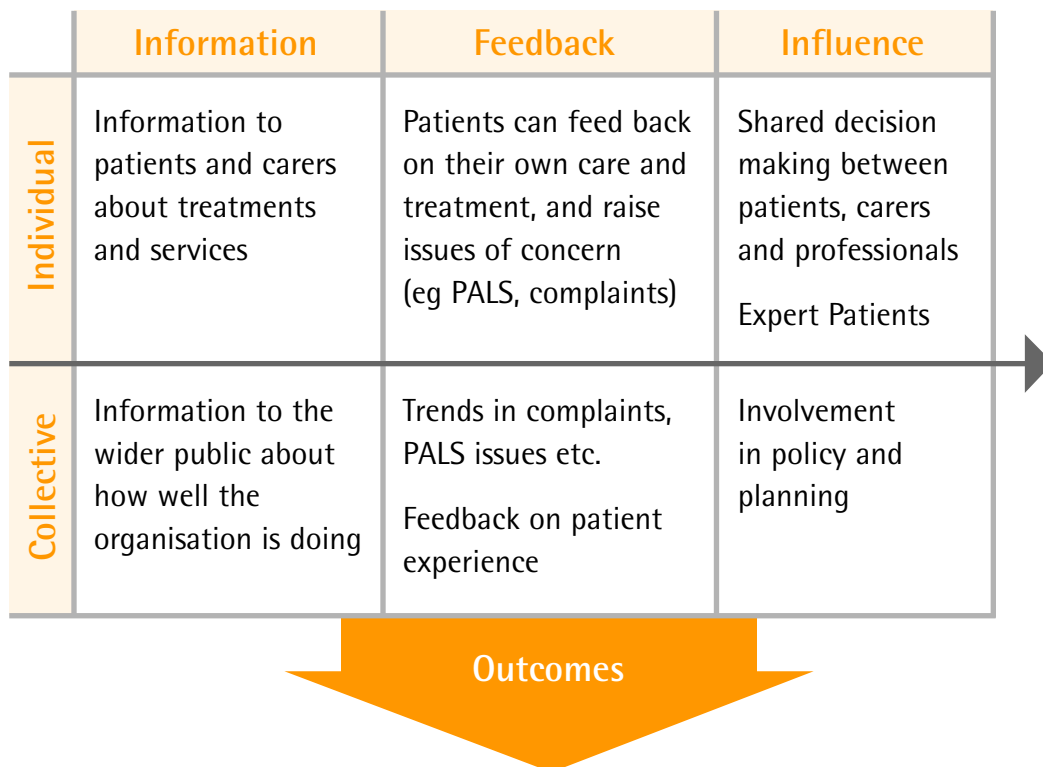
At a collective level, people can be:

- informed about the type of services that are available and how well they are performing
- provide feedback on their own experience, for example through focus groups, other qualitative methods and surveys, to provide a picture of what matters to local patients and carers and what needs improving
- influence a service or organisation by being part of policy and planning, for example through lay representation on reference groups, committees or boards; in service reconfiguration or priority setting. This is where Section 11 duties are most pertinent in England.

This model can be viewed as a PPI grid (see figure 2.1).

Figure 2.1

A model for effective PPI



CHI seeks evidence of meaningful involvement leading to improvements in planning and service delivery. It looks at the range and nature of involvement initiatives (across the levels and dimensions above), and the organisation's strategic approach to PPI. This includes whether there are plans implemented which are based on a baseline assessment of needs and organisational priorities.

CHI also looks at whether there is senior leadership and clear performance management processes for the work (accountabilities, clear roles and responsibilities, reporting and monitoring); that there is organisational support for the work (for example resources, staffing, training and development); that there is integration of PPI with other clinical governance work, such as clinical audit; that it links with overall clinical governance arrangements, wider improvement work and partnership working; and whether people and groups from diverse communities have been involved.

Information about PPI is gathered from a range of sources including documentation (for example trust questionnaires, data and information requests); site visits; interviews with stakeholders (for example patients, carers and the public, community and voluntary organisations, statutory partners and staff).

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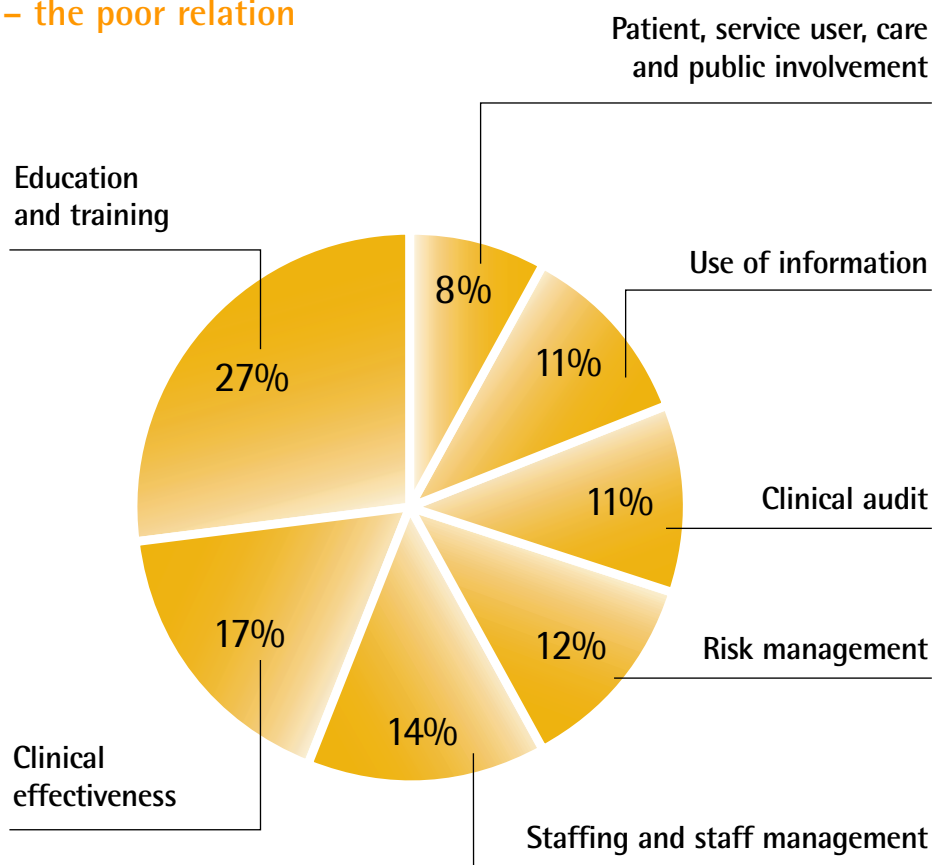


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What CHI has found

Figure 3.1 sets out the percentage of 292 trusts reviewed (trusts with reports published by beginning of December 2003), scoring iii or iv for each of the seven clinical governance components. PPI scores lowest compared with the other components. CHI has not given the score 'iv' in PPI at any of the organisations assessed in this time.

Figure 3.1
PPI – the poor relation



When we looked in more detail at the state of PPI across the NHS, both through looking at CGR reports and through our research, the main findings were:

■ **organisations are getting better at some aspects of PPI**

The NHS is, on the whole, improving in some aspects of PPI, such as providing information for patients and undertaking qualitative and quantitative exercises in getting feedback from patients. But it is not doing as much to ensure that patients, carers and the public influence decision making.

■ **PPI is not part of everyday practice**

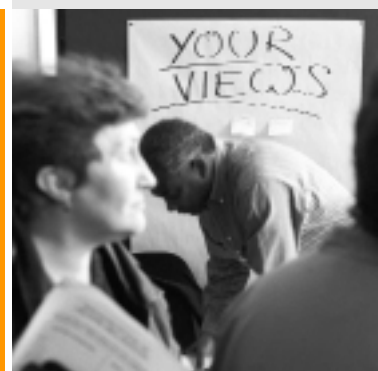
Pockets of good practice are not being shared across organisations or being picked up at strategic level. Organisations are failing to integrate PPI activities with other efforts to improve services and are not making PPI central to core activities.

■ **involvement is not leading to improvement**

PPI is not yet having a major impact on policy and practice. This is despite a plethora of PPI initiatives. It is almost as if there is a brick wall between the activities going on and any changes on the ground that happen as a result.

These findings are supported by the National Audit Office (NAO), which examined progress on the implementation of clinical governance. The NAO found that those functions which serve some statutory or external requirement such as risk management, claims and complaints, appear to be more robust while 'those which are newer, and which though clearly desirable may not yet be consistently seen as essential (such as patient and public involvement, and knowledge management, including sharing of good practice) are less well developed in many trusts' (National Audit Office, 2003. Achieving Improvements through Clinical Governance).

Other research has reinforced concerns that serious barriers still exist concerning people's capacity to participate in decision-making



The main problem is the lack of a strategic approach to working with communities

Other research has reinforced concerns that serious barriers still exist concerning people's capacity to participate in decision making (eg having the skills, resources and confidence to access information and decision making), and the organisational opportunities to do so (Thompson AGH et al. 2002. Citizen involvement in healthcare: meanings, motivations and means. Report for the Health in Partnership Programme, Department of Health: London. www.healthinpartnership.org).

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 (eg concerning organisational ethos and culture, organisational skills and competencies; and community capacity to engage) Pickin C et al. 2002. Developing a model to enhance the capacity of statutory organisations to engage with lay communities. Kings Fund, (www.kingsfund.org.uk/WhatsToStop.pdf).



This project and our research has focused mainly on PPI from an NHS organisational point of view and the extent to which the NHS is responsive to the PPI agenda. With this in mind, we found that there are some important underlying reasons for our own findings. These need to be addressed as the next phase in local PPI work.

CHI has often found good operational work that does not influence decisions

Strategies and plans

Many organisations are running before they can walk: CHI has found examples of impressive sounding strategies and plans, but often these are not rooted in reality nor linked to operational priorities. Conversely, there may be good work going

on in parts of a trust, for example around getting patient and carer feedback in parts of the service, but these initiatives are not built upon, shared across the organisation, or linked with other improvement initiatives such as clinical audit. Organisations that succeed in PPI develop strategies linking PPI to existing groups, management initiatives and ways of working.

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Roles and responsibilities

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Working together

CHI found a few good examples of cross community working but too often organisations were working alone and risking repeating fruitless consultation exercises or duplicating work. The successful organisations demonstrated how they shared expertise through joint appointments, had developed cross boundary consultations with primary care trusts (or local health groups in Wales), made use of consultation mechanisms set up by local authorities or had good relationships with the local voluntary sector.

CHI found a few good examples of cross community working but too often organisations were working alone and risking repeating fruitless consultation exercises or duplicating work

Where PPI is done well, there are clear roles and responsibilities for other professionals as well



4

Local work on PPI

Below, we outline just a few of the many examples of PPI work that have come to our attention during our reviews. They have been chosen to illustrate the range of ways in which NHS organisations have undertaken PPI and tackled some of the issues above.

Barnet Primary Care Trust's user group in learning disabilities has developed a guide to being an inpatient called *The Hospital Book*. The book uses pictures to make information accessible to people with learning disabilities

Conwy & Denbighshire NHS Trust uses patients to assess consultants' communication skills.

At **Birmingham Children's Hospital NHS Trust** children are involved in training junior doctors by taking part in role play with them. They alternate roles so that children play the role of doctors and vice versa.

South Manchester University Hospitals NHS Trust undertook discovery interviews – semistructured, in depth interviews of patients and carers in which the interviewee is encouraged to share their experiences – to identify and address issues of concern. The results are to be used to focus future audit projects and to disseminate good practice.

At **South London & Maudsley NHS Trust**, there is clear involvement of service users in developing research projects.

The podiatry department at **Sheffield South West Primary Care Trust** set up a patients' panel in 2000, which meets regularly and enables patients to be consulted on service planning and delivery

South Gloucestershire Primary Care Trust has developed and implemented a scheme, called *No Worries*, to improve young people's access to sexual health services. The idea for this scheme followed discussions with young people using existing contraception clinics.



The Sloan Kettering project at **Christie Hospital NHS Trust** is based on a system used at the Memorial Sloan Kettering Hospital in New York, which has been modified to suit local needs. Discharged patients are phoned at home by trained volunteer staff and asked about their experience at hospital. The ward team discusses the issues raised, identifies the actions to be taken and where possible makes the necessary changes.

Older patients in **St George's Healthcare NHS trust** are encouraged to take part in talk back sessions where they can discuss their experiences. Information gained from these patients is used to plan improvements to care.

Patients are routinely invited to join the weekly multidisciplinary team meetings to discuss their own care on the stroke unit at **Burnley Health Care NHS Trust** (now merged with Blackburn, Hyndburn & Ribble Valley Healthcare Trust to form East Lancashire Hospitals NHS Trust). This ensures that the patient's care plan is developed to include the patient's own goals as well as the medical and nursing goals.

Since 1999, a panel of over 50 users has been in place at **Avon & Wiltshire Mental Health Partnership NHS Trust**. This group provides input for the annual agenda setting process undertaken by the trust board. Members of the group are involved in initiatives such as the cleaning task force and the equal access group.

At **NHS Direct South Yorkshire and South Humber**, an expert user panel exists. Its members are people who have used NHS Direct services. All the members are recruited through the user call back survey, which included people with disabilities and from different ethnic backgrounds. Specific groups from the panel are targeted to attend each meeting once the agenda has been determined. This ensures that people attend relevant debates and remain engaged with the process.

Community Health Sheffield NHS Trust involves service users in the recruitment of staff. Service users are invited to suggest possible interview questions and sit on interview panels. Service users are also involved in the staff's induction training.

At **Southern Derbyshire Acute Hospitals NHS Trust** CHI found various examples of patient involvement including representation on a rehabilitation and therapy group and a maternity group. Several changes have resulted from involvement, for example consultation with patients led to revised pre clerking arrangements for day case patients.



5

The new era of PPI

These are exciting, if slightly confusing, times for PPI. New systems and structures are being developed at a local and national level.

From January 2003, Section 11 of the Health and Social Care Act (2001) in England has placed a mandatory duty on primary care trusts (PCTs), NHS trusts and strategic health authorities to involve and consult with patients, carers and the public – not just when a major change is proposed, but in the development of proposals and in ongoing service delivery. In Wales, there are robust performance management arrangements for public and patient involvement through the Signposts framework, with Signposts Two, providing advice on organisational change and a self-assessment framework (Welsh Assembly Government. 2003. Signposts Two – putting public and patient involvement into practice).

About 98% of NHS trusts now have a PALS to support people and resolve individuals' concerns. While Wales will retain community health councils (CHCs), in England, the Commission for Patient and Public Involvement in Health, an independent non departmental public body will oversee new structures to empower patients, carers and the public to have a say in local and national decision making.

At local trust level in England, there will be Patient and Public Involvement Forums (PPIFs) which, amongst other things will monitor the quality of services from a patient perspective. They will also and commission or provide Independent Complaints Advocacy Services (ICAS) to support complainants. Complainants will be able to access advice to help them articulate their concerns and navigate the complaints system. ICAS can also provide advocacy for those needing support with writing letters, or requiring someone to speak on their behalf at meetings. Information on ICAS is available at www.doh.gov.uk/complaints/advocacy.htm.

Local authorities with social services responsibilities have been given power (under 2001 Health and Social Care Act) to review the planning, provision and operation of health services through overview and scrutiny committees (OSCs). These committees will report to local NHS organisations, who must respond in writing within 28 days. NHS organisations have a duty to consult with their local OSC if they are considering any substantial development of health services, or any substantial variation in provision of services. Guidance on overview and scrutiny is available at www.doh.gov.uk/involvingpatients.

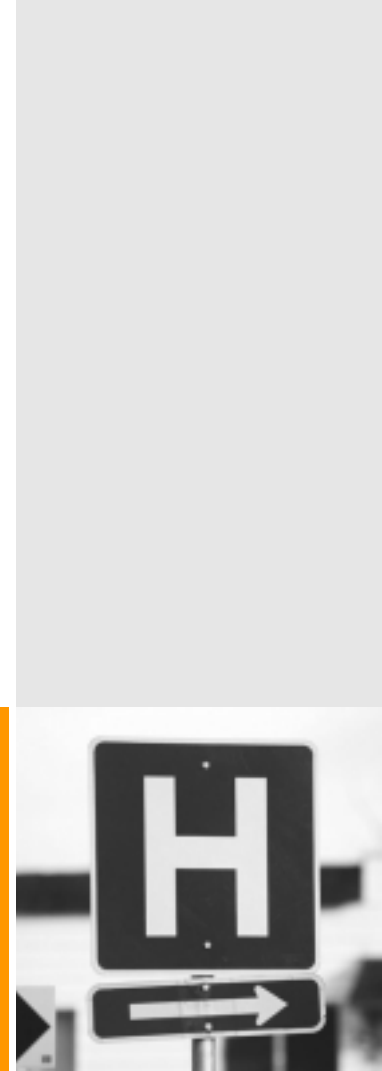
In April 2004, the new Commission for Healthcare Audit and Inspection (CHAI) will take over the responsibilities of the CHI, the healthcare value for money work of the Audit Commission, the National Care Standards Commission's work in private healthcare and later, subject to legislation, the work of the Mental Health Act Commission. In England, CHAI will also take over responsibility for the second stage of the complaints process. In Wales, the second stage in the complaints process will be the responsibility of lay people, independent of the NHS, appointed by the Welsh Assembly.

Instead of a rolling programme of local inspections across every trust, the vision for CHAI is that it will gather information from existing local and national sources and have a local presence. Information will be screened and there will be targeted in depth reviews. In terms of PPI, it will continue to assess the same things, such as the patient's experience and trusts' PPI arrangements, but in different ways. This provides the opportunity for different agencies, such as CHAI and CPPIH to work together, share data and coordinate inspections so as to reduce the burden of regulation on healthcare organisations.

The vision for CHAI is that it will gather information from existing local and national sources and have a local presence

These new systems and structures make this a crucial period for the evolution of PPI. Our research has highlighted that local PPI activity has been a response to a convergence of these pressures, as well as a reaction to the NHS Plan and the recommendations of the Bristol Inquiry (Learning from Bristol. 2001. The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984 – 1995. Command Paper CM 5207). People have reported that CHI's spotlight on PPI during a clinical governance review has also been a stimulus to work in this area.

However, many people during this project have expressed their confusion with the new PPI structures and systems. In response to this, CHI has produced an A-Z of recent PPI initiatives. This is available on the patients and public page at www.chi.ns.uk.



6

Lessons for national agencies

The research that we carried out, for example the group discussions, consultation conference and case studies, also revealed a number of issues to be tackled at a national level to maintain the PPI momentum. These apply to those agencies setting standards, for example the Department of Health; inspectorates, such as CHI, Audit Commission, CHAI; and those agencies responsible for supporting delivery, for example the Commission for Patient and Public Involvement, Modernisation Agency and NHS University. These organisations should:

- **help people resource the work**

For example, by ringfencing resources for PPI work to ensure that adequate resources are made available to support a meaningful level of PPI activity. Advocacy work, in particular, was identified as an area where improved resources – in the NHS and social services – would support the wider engagement and involvement of patients.

- **address training and development needs**

For example, training and development needs to be part of enhanced education and training for clinicians and needs to become part of continuous professional development for many staff.

- **standardise approaches and methods**

For example, develop common standards for PPI, a unified way for collecting monitoring data on PPI activities and performance and develop an evidence base about the impact of PPI work.

- **work with each other**

All the main agencies involved in PPI at national level should work more closely together at national level.

- **speak with one voice about PPI, and spread common messages**

They need to clarify links between consultation and involvement and the wider modernisation agenda and provide examples of good PPI strategies and approaches; why they are good, what they contain and what they will deliver. As one person in our case study report said: "If the secretary of state and CHI are committed to PPI – the thread needs to clearly follow through policy and have equal status to monetary and other targets."



This report has been produced under CHI's statutory function of providing advice and information on the arrangements made by NHS Trusts for monitoring and improving the quality of health care for which they have responsibility, as set out in section 20(1)(a) of the Health Act 1999.



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