

# Listening, learning, working together?

A briefing on a study of how well healthcare organisations engage local people in planning and improving their services



# The Healthcare Commission

The Healthcare Commission works to promote improvements in the quality of healthcare and public health in England and Wales.

In England, we assess and report on the performance of healthcare organisations in the NHS and independent sector, to ensure that they are providing a high standard of care. We also encourage them to continually improve their services and the way they work.

In Wales, the Healthcare Commission's role is more limited. It relates mainly to national reviews that include Wales and to our yearly report on the state of healthcare.

The Healthcare Commission aims to:

- Safeguard patients and promote continuous improvement in healthcare services for patients, carers and the public.
- Promote the rights of everyone to have access to healthcare services and the opportunity to improve their health.
- Be independent, fair and open in our decision making, and consultative about our processes.

On 1 April 2009, the Care Quality Commission, the new independent regulator of health, mental health and adult social care, will take over the Healthcare Commission's work in England. Healthcare Inspectorate Wales will become responsible for carrying out our activities relating to Wales.

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# About this briefing

This is a summary of the main findings and recommendations from our national study of how well trusts engage people when they plan and improve health services. It also looks at how much people can influence trusts' decisions.

The full report includes a performance framework and checklists that can be used locally. The report, and a separate practice briefing that gives examples of what trusts are doing in this area, are available at [www.healthcare.commission.gov.uk](http://www.healthcare.commission.gov.uk)



## What we mean by engagement with patients and the public

People are engaged with health services when they can share their views and experiences with trusts, and work with them to plan and improve services. This includes how patients, users and the public are consulted, involved and able to participate in healthcare work and how trusts take account of people's views. Engagement also covers how trusts tell people how they can be involved, what they can influence, and what is done with the views and experiences they contribute.

## Background to our study

We check how well trusts perform against standards set by the Government in our annual health check. Core standard 17 requires that "the views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving healthcare services".<sup>1</sup> In 2007/08, 98% of trusts reported that they met core standard 17. However, we have other evidence from patients' forums, overview and scrutiny committees (OSCs), and some national and local voluntary organisations that suggests the performance of trusts is more mixed.

We also check how well independent health services take account of National Minimum Standard C6, which requires that "Patients' views are obtained by the establishment and used to inform the provision of treatment and care and prospective patients".<sup>2</sup> Our knowledge of how well independent health services engage with patients and the public is limited to their performance against this minimum standard.



There is no national data on how well people are engaged in health services. This makes it very difficult to compare the performance of different trusts across the country.

In April 2008, the Government introduced new local arrangements for involving patients and the public, mainly through local involvement networks (LINks). It also introduced new legislation giving people a right to be involved in their health services and giving trusts a duty to involve people.<sup>3-5</sup> The National Institute for Health and Clinical Excellence published its first guidance on community engagement for health improvement in 2008. This set down a standard of quality for all trusts.<sup>6</sup>

Evidence from other regulators and national studies shows that health services are making progress in the ways they engage people, but they still have much more to do.<sup>7-11</sup> This includes the two annual censuses in 2007 and 2008 on patient and public involvement in the NHS, run by The National Centre for Involvement, which have informed this study.

## Study aims and methods

In the light of this evidence, we aimed to find out more about the different ways that people are engaged in health services, and how much influence they have over the ways that trusts plan and deliver services. We explored what helps and hinders trusts in engaging people, and how they are working with those in the poorest health or in the most vulnerable circumstances, and with the new LINks. We have set out recommendations for trusts and the Department of Health, and proposals for the Care Quality Commission, which is the new national regulator for health, mental health and adult social care services. We did not assess the performance of individual trusts in the study.

To help us to design the study and consider the findings, we held discussions with a wide range of national and local organisations and groups, including a citizens' panel with members of the public. We reviewed the Government's policies and guidance on

engaging with patients, users of services and the public, and gathered evidence from our annual health check and other studies. We carried out:

- Interviews with 47 NHS trusts and 31 organisations from the independent healthcare sector, selected from across the country. The NHS trusts we selected also reflected a range of levels of performance in how they engage people.
- A survey of 42 local users' groups, including members of LINKs, patient participation groups, community groups, patients' groups, and other groups representing, for example, users of mental health services.
- Twenty workshops across the country, bringing together nearly 500 people from NHS trusts, users' and community groups, members of LINKs and OSCs, practice participation groups and some individuals representing patients.

In total, 139 NHS trusts and representatives from over 170 community or voluntary sector groups, patients' forums, LINKs, OSCs and other groups took part in the study.

## What did we find?

### The main problems

People generally did not feel that they had enough say in the kinds of health services that were provided or how they were run. We found limited evidence that trusts used people's views as a matter of course to plan services, or that they routinely used them to improve the delivery of services.

People who are in the poorest health, in vulnerable circumstances or experiencing discrimination often found it more difficult to engage with health services. Many users' groups and community groups did not believe that trusts wanted their views, or would act on them.

Patients' groups and users' groups, and their representatives, including patients' forums and OSCs, told us about their problems with engagement, which fall into four main groups. Some trusts were failing to:

- Involve patients, the public and the voluntary sector in decisions effectively. This included trusts not involving people early enough when they planned reconfigurations of services.
- Provide adequate and consistent information about local health services. This included patients' groups and OSCs being unable to find out about the performance of their health services, or trusts not responding to local reports from these groups about the quality of local health services.
- Organise engagement activities effectively. This included inadequate publicity material, problems with access to venues, a lack of support for people with communication needs or sensory disabilities, and staff not knowing the procedures for involving health scrutiny committees.
- Provide evidence and feedback to patients and the public that action had been taken to respond to the issues that they had raised.

### The progress being made

Trusts recognised these problems and were working to engage more people. They were using a wider range of approaches and were trying to make better use of the views and experiences they heard about. Although the majority of trusts had strategies in place and plans for improvement, progress in engagement was variable across the country.

All trusts were giving a higher priority to getting the 'right' people engaged –those who consider themselves excluded, whose voices have not been heard enough in the past, or who have greatest needs. These people varied across the country, but were most likely to include black and minority ethnic communities, older people, carers, travellers, people with learning disabilities, refugees and asylum seekers, disabled people, children and young people, communities that have recently arrived from Eastern Europe and lesbian, gay, transgender and bisexual communities in larger cities. For some trusts, a priority was to find ways to talk to the working population as a way of reaching the wider public.

Patients, users of services and the public have been able to influence health services in some important ways. They have had the most influence on improving the care environment, the quality

of information provided to patients, appointment systems and opening hours. Patients, along with the wider public, have also had some influence on service plans and designs. They have been least able to influence trusts on how they allocated funds or made priorities, or on their quality of care or safety issues. When people's needs have not been met, or mistakes have been made, it was particularly difficult for those individuals to engage with services to find solutions.



There was a remarkable consensus among patients, the public and trusts on the benefits of engaging with people to improve health services. People and communities felt valued and trusts provided better care. Most importantly, trusts were better able to meet the needs and aspirations of all local people, and especially those in poorest health.

## The influences on health services

The most important influences on trusts that affected how much they engaged with people were:

- New policies encouraging health services to improve, especially the requirements set out for primary care trusts (PCTs) in the World Class Commissioning framework.
- Health service staff, particularly senior managers and medical and clinical staff, taking a lead in gathering and using people's views in their day-to-day work.
- Negative reporting in the media, including high-profile complaints about services, or poor results from national or local surveys of patients' views.
- The size, strength and resources of local users' and community groups and their leaders.
- The changing patterns of communities in an area, and how effectively health services have shared resources and decision-making with local groups in the past.

## Working with LINKs

Some LINKs showed us how they could bring together patients' and users' groups, both across a local area and across health and social care, to influence services. Health services were mainly positive about the influence that LINKs would have on their organisations. We found that LINKs' relationships with OSCs and other local community networks were seen as critical to their success, as was the support health services give them as they develop.

## Engaging people in different types of health services

We found pockets of good practice in all types of NHS trusts and from the independent sector. For example, some PCTs were using a wide range of approaches to engage communities in reconfigurations of services, and starting to take account of people's views in the different stages of commissioning health services. However, we found few examples of PCTs building requirements for engaging people into their contracts with providers of services, or taking a lead to ensure people were being engaged in practice-based commissioning. There was also only limited joint working between local authorities and trusts, to allow them to use people's views about care spanning across different services.

We found that hospitals and ambulance services were committed to improve their understanding of their patients' experiences. However, their practice in taking account of the views of the public and local communities in their areas was much more variable. There were fewer examples of ongoing partnerships between patients and these services, apart from some good relationships with patients' groups. Some of these trusts were developing more outreach work with local communities to promote their services and build partnerships with them, but this was not widespread.

In mental health and learning disability services, we found a stronger focus on users actively participating in healthcare work. This included trusts recruiting users to talk to other users about their experiences. These services were also more likely to make greater use of advocacy services and to engage with carers, but again, practice varied across the country.



A health service membership culture was developing, led by foundation trusts, which was intended to give more people a stake in their local services. PCTs and some service providers were copying this model. The development of a membership was driving

health services to make contact with communities they had not reached before. However, it was unclear whether more people were becoming engaged as a result and, if so, whether they represented the different voices of local communities.

We found that independent providers were focused on measuring patients' satisfaction for commercial and publicity reasons, as well as for service improvement. There was a wide range of practice between different types of providers, such as acute hospitals, hospices and walk-in clinics, but a strong focus on using information from patients to address problems with services. Services used local surveys extensively, but we need to find out more about the quality and response rates of these. There were fewer examples of organisations seeking people's experiences of care, apart from in the independent hospice and mental health services. The public was less engaged in independent services compared to the NHS, although they did get involved more in fundraising and in awareness raising events. Hospices, in particular, were most likely to engage the public, carers and service users in their routine planning and service improvements.

### **The different approaches to engaging people**

The majority of trusts in this study wanted to use a wider range of approaches to engage people, and to build on their use of national and local surveys and information from Patient Advice and Liaison Services and complaints. NHS trusts had a commitment to:

- Focus more on building relationships and creating partnerships with patients and the public.
- Tailor approaches for particular groups to make them more accessible.
- Increase the use of qualitative approaches and patients' stories.

- Improve the quality of surveys of local patients and to work more with other agencies to gather and use information.

Users' groups and community groups agree on these priorities.

### Working with 'seldom heard' communities

The approaches used to support 'seldom heard' communities to share their views and experiences were still in early development in some trusts, but were more established in others. They included:

- Work to map local communities.
- Outreach services to work with local communities in particular areas and local centres.
- Working in partnership with local voluntary organisations.
- Recruiting community members to provide advice about their traditions.
- Providing resources to communities to help them identify needs and develop services.
- Working with local councillors, community leaders and elders, and the community press to help build relationships.
- Developing tailored information about health services with communities themselves.

### What people want to influence in future



The people who took part in this study wanted more information about their local health services, about how to give their views, and about what changes were being made as a result of their contributions. They wanted an opportunity to share their experiences and have a say in all aspects of the health service, even if they chose not to use it. They generally preferred to tell the stories of their health and care in their own words, and in environments where they felt comfortable discussing issues. When people felt they had no influence, it led to a loss of trust and confidence in health services, and made future engagement more difficult.

People were particularly interested in influencing the services provided by GPs, the care of people with specific conditions and how people from different communities are treated. Some people also wanted to have a say about the staffing of health services and how money is spent, the facilities and the environment in hospitals, and in making healthcare safer.

## Recommendations

### Trusts should:

- Strengthen the culture of openness and responsiveness to local people, through strong management and clinical leadership.
- Increase the influence that under-served and seldom heard groups of patients, users and the public have on the decisions they make.
- Show how engaging with people is leading to improvements to services and to people's experiences of care.
- Undertake local engagement checks to assess whether they, and their local users' and community groups, have the knowledge, resources and skills to engage with each other, and take action where there are gaps.
- Show improvements over time in the extent to which people influence their decisions across all their services and departments.
- Work towards a higher level of performance using the performance checklists in the full report. These are based around five areas:
  - Promoting people's rights to a voice.
  - Keeping people engaged.
  - Using people's views to plan and improve services.
  - Engaging people in appropriate and accessible ways.
  - Learning how to engage people better.
- Work more closely with other local agencies, especially local authorities, to coordinate gathering people's views, needs and aspirations about services and act on them.

### **The Department of Health should:**

- Incorporate the experiences of patients, users and carers in the measurement of all aspects of the quality of health services.
- Encourage the development of local quality standards for engaging people in the contracts agreed between commissioners and providers of services.
- Encourage PCTs to strengthen the local requirements for engaging patients, users, carers and the public in the independent sector.
- Consider how the strengthened duty on all health services to involve people and the new duty on PCTs to report on consultations are being used, and support health services to meet these responsibilities.
- Strengthen the accountability of the NHS to local people, for example through the introduction of participatory budgeting – where local people are directly involved in making decisions on trusts' spending and priorities, greater roles for community advocates, and stronger partnerships between staff and users of services.
- Support LINKs to fulfil their activities and evaluate their impact.

### **The Care Quality Commission is encouraged to:**

- Require health services to demonstrate that they are listening to, and acting on, the needs and aspirations of people, and working with them to develop or provide care – in all aspects of their assessments.
- Undertake a national assessment of how health services engage with people, taking the performance framework developed in this study as a starting point. The approach to assessing engagement with patients, users and the public should reflect the new right of patients to be involved, and health services' duty to engage people. It should focus on how health services use the views and experiences of patients and the public to improve services, and how they can demonstrate over time that people are becoming genuine partners in improving health and social care.
- Support a national development programme for the NHS and independent sector, by bringing together agencies that represent their interests and support their development. The programme should include supporting PCTs to better engage with people when commissioning services, and in ensuring providers, GP practices and the independent sector are responding to the needs of their patients and the public. The programme should also include building the skills of staff to engage with people, including medical, clinical, social care staff and managers.
- The development programme should provide support to LINKs, OSCs and foundation trusts' boards of governors, to enable them to engage with their local health services and to check how well these services are engaging with local communities.
- Build on the Healthcare Commission's work to maximise the quality and use of national surveys of patients, and support the development of high-quality local surveys of patients and the public.
- Explore ways of measuring how well health and social care organisations engage patients, users and carers in their own care.

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