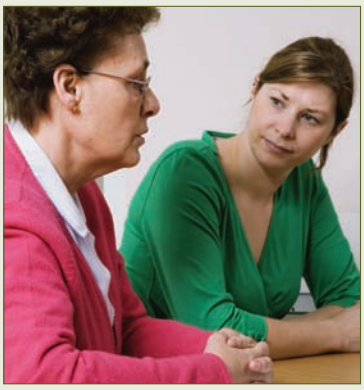
Inspecting Informing Improving

Healthcare Commission

Listening, learning, working together?

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



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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.

Summary

Background

This report describes the findings from a study of how healthcare organisations in England engage people when they plan and improve health services. It also looks at the extent to which people can influence decisions by health services.

We define 'patient and public engagement' as a process through which patients, users of services and communities share their views and experiences with trusts, and work together to plan and improve services. It covers how health services consult with, involve and participate with patients, users and the public and how they take account of people's views. It also covers how trusts communicate with people, about how they can engage with them, what people can influence, and what is done with their views and experiences.

We currently assess how well NHS organisations perform against standards set by the Government in our annual health check of the NHS. 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".[1] This requirement is underpinned by a legal duty on all NHS trusts to consult and involve patients, users of services and the public about how they plan and operate their services and when they develop proposals for change.[2]

We carried out our study because we identified mixed evidence about the standards of patient and public engagement across the country through the annual health check in 2006 and 2007 (see below). The Government has also strengthened the legislation related to engagement with patients and the public and has created new local arrangements for engagement through local involvement networks (LINks).[3, 4] It has also set out the role of the new regulator for health, mental health and adult social care, the Care Quality Commission (CQC). From 1 April 2009, CQC will regulate how local health and adult social care organisations engage with people. Also, importantly, the National Institute for Health and Clinical Excellence (NICE) published its first guidance on engaging with the community to improve healthcare in early 2008, which set down a level of quality for all trusts to meet.[5]

In our annual health check of NHS performance in 2007/08, 98% of healthcare organisations stated that they met core standard 17. As part of our assessment, patient and public involvement forums commented on three-quarters of healthcare organisations in relation to the standard, and overview and scrutiny committees (OSCs) commented on almost two-thirds. Boards of governors commented on engagement in just over a third of foundation trusts. Engagement is an area that is of particular interest to all these groups, and one that they have direct experience of.

In 2007/08, around 25% of all comments about core standard 17 received from patients' forums and OSCs were negative. More than 80% of these were about trusts failing to seek the views of patients and the public. And around 50% were about how far, if at all, their views were taken into account. The negative comments focused on trusts:

- Providing poor information, on how to engage and about proposed changes to services.
- Failing to involve forums and OSCs in important issues.
- Failing to act on comments made by the forums and OSCs.

We have also identified other evidence that has raised questions about the current level of performance across the country.[6-9] National voluntary organisations have raised concerns with us about the level of compliance with core standard 17. Local community groups in the most vulnerable situations, have told us of the problems they have faced in raising issues with health services. There is no national data about engaging people in planning and improving services to provide a benchmark or comparison. Other recent Healthcare Commission studies have also identified the need for certain groups of people in vulnerable circumstances to be more involved in health services.[10-15]

Evidence from other research, including two national censuses of involvement with patients and the public by the National Centre for Involvement, also set the scene for this study. The evidence shows that health services are putting systems in place to involve people in planning and improving services, and some progress has been made – but there is still much to do.[16,17] The main barriers identified by this research were a lack of commitment by senior managers or clinicians in some services,[17,18] inadequate resources and lack of incentives.[18,19] Health and social care services should make involving groups who have particular health needs, or who are in particularly vulnerable circumstances, a priority.[20, 21]

Scope of the study

This study has explored the range of approaches that all types of healthcare organisations are using to engage with patients and the public, including some in the independent sector. It also looks at the impact this engagement has on health services and the people using them. We have asked patients and the public what they think about the approaches used to engage them, and whether trusts are enabling all sections of society to be part of decisions about healthcare. We have also explored how trusts are working with the new representative bodies for patients and the public, LINks. The study does not include how people are engaged in their individual care, but we recommend that a further study should explore this issue.

To explore these issues, we have reviewed the current policies and best practice guidance about engaging people in healthcare settings, and have included some evidence of best practice from social care. We have brought together evidence from our annual health check and some of our other studies, and have looked at relevant national studies by other agencies. We consulted with national and local voluntary organisations, academic experts, some trusts and a citizens' panel to agree the scope of the study.

We held interviews with nearly 50 trusts and 31 independent healthcare organisations, and we surveyed the views of over 40 local user and community groups. Finally, we held 20 workshops around the country, involving around 500 people from healthcare organisations, users' and community groups, LINks and patients' representatives, and others to explore together how well people are engaged in health services and their priorities for improvement. In total, 139 healthcare organisations and 170 user and community groups and their representative bodies from across England took part in the study.

We selected healthcare organisations to interview to reflect a range of performance across the country, a mix of types of organisations, and from different parts of the

country. They included a random sample, and a number of organisations that had either won awards for engaging with patients and the public or that had declared some problems with meeting core standard 17. We randomly selected healthcare organisations to attend the 20 workshops, which resulted in a mix of different types of trusts from different parts of the country being included. More details on our approach to sampling for the study are set out later in the report.

We did not assess the performance of individual trusts in this study.

Main findings

Our overall findings reinforce those of previous studies and provide further evidence of the need for improvement. The people we involved in this study generally did not feel that they had enough say in the health services that are provided in their area, or the way they are delivered. Those in the poorest health, in vulnerable circumstances or experiencing discrimination, often found it more difficult than others to engage with health services. Many groups of patients and users and community groups still needed to be convinced that health services wanted their views or would act on them. We heard this consistently from all groups of patients and the public in the study, from those already well engaged to those who had no experience of contributing their views to health services.

It is also clear from this, and other studies, what poor engagement practices look like from the perspective of patients and the public. We have heard the same problems raised by patients' and users' groups at a national and local level, across different parts of the country, and from evidence provided by patients' forums and OSCs for the annual health check. These problems included health services failing to:

- Provide people with adequate information about getting involved or about service performance.
- Ensure that people could attend key meetings.
- Provide consistent and adequate information.
- Respond to local reports by patients' groups.
- Involve the voluntary sector effectively.
- Involve people early enough in planning service reconfigurations.
- Organise engagement activities sufficiently – for example, not ensuring adequate publicity or access to venues.
- Support people with communication needs or sensory disabilities.
- Ensure that staff understood the procedures for involving health scrutiny committees.
- Provide evidence that action has been taken to respond to the issues people have raised.
- Feed back to patients and public on their concerns.

Few trusts could demonstrate that people's views routinely influence their decision-making. When views and experiences are used, organisations often found it difficult to provide evidence of what difference these views have made to plans or services. Few healthcare organisations in the study described any evaluation of their engagement with patients and the public to find out whether it did make a difference to people, to the services, the way the organisation works or whether services now deliver better care.

Despite these problems, we have found that patients, users of services and the public have been able to influence health services in some important ways. Patients and users of services have had the most influence on improving the care environment, the quality of information provided to patients, appointment systems and opening hours. Patients and users, along with the wider public, have also had some influence on service plans and designs. They have been least able to influence how health services allocate funds or make priorities, or on the quality of care or safety issues. When people's needs have not been met, or mistakes have been made, it can be particularly difficult for those individuals to engage with services to find solutions.

Healthcare organisations recognised these problems and have been working to engage more people, more effectively, and make better use of the views and experiences they hear. The majority of organisations had strategies and plans for improvement. All of them were giving a higher priority than before 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 vary across the country, but most commonly they included 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 organisations, a priority was to find ways to talk to the working population as a way of reaching the wider public.

There was a remarkable consensus among patients, the public and trusts on the benefits of effective engagement – people and communities feel valued and health services provide better care. Most importantly, services can better meet the needs of those in poorest health. There is also agreement that services will better adapt to emerging health needs and community aspirations if they engage the public and those who use services occasionally, as well as regular patients and users of services.

Trusts have also been encouraged to engage with patients, users and the public better through a set of important policy influences. The framework for World Class Commissioning[22] has encouraged primary care trusts (PCTs) to increase the influence people have on the services they commission. The move to foundation trust status has required some healthcare organisations providing services to build a membership of patients and users of services (see below). Providers of health services have also been increasing their efforts to capture patients' experiences and to understand them better. This is in response to the Government's requirements for services to publish information about patients' experiences as a key measure of the quality of care, such as in the new Quality Accounts[23] that healthcare providers will publish.

We have found, however, that the staff who work in health services are often the most important drivers for change. Usually, trusts have very few staff with specific responsibilities for engaging patients and the public. We have repeatedly heard from many different sources how committed senior managers and clinicians play a vital role in creating 'responsive' healthcare organisations in the NHS and in the independent sector. However, many clinicians were still not engaging directly with patients and carers to explore ways of improving the quality of care or clinical practice. Yet when they had taken the lead in such activities with patients, the changes that patients said they

wanted were often made much more quickly. We found examples from different services of how health service staff feel more satisfied at work if they understand people's needs and feel they are able to respond to them.

There are other influences and pressures that affect the ability of trusts to engage effectively. These included negative media reporting, managing particularly high-profile complaints about services, or handling poor results identified by national or local surveys of patients' views. It has been a priority for many PCTs, in particular, to improve the public's understanding of healthcare and of the difficult decisions they need to make when planning local services.

The capacity of the community to engage with health services, including the resources and skills of users' groups and their community leaders, were also significant in local areas. The mix of rural and urban populations, the range and size of different communities and the changing patterns of communities were all important here, as was the history of sharing resources and decision-making between health services and local user and community groups.

The most developed LINks demonstrated how they can open new channels of communication with trusts and strengthen community networks to influence health services. One particular advantage of LINks is seen to be that they can bring together patients' and users' groups both across a local area, and across health and social care. Trusts were mainly positive about the influence that LINks will have on their organisations. LINks were in early stages of development during this study, but there were some promising signs that they were starting to work with health services, and building relationships with the many different services in their areas. Their relationships with OSCs and other local community networks will be critical to their success, as will the support they receive from trusts.

We found some excellent practice in PCTs, but much progress needs to be made if people are to influence the development of the services that PCTs purchase on their behalf. People are most likely to be consulted on major reorganisations of services. We found, however, that patients, users and the public are gradually being brought into the different stages of reviewing and planning new services, including service reviews, developing specifications and procuring new services from providers. People have less influence over their GP practices in many areas, though, and PCTs are making slower progress in driving improvements here.

There were few examples of PCTs requiring services to engage with local people in their contracts, and this is seen as a key area for improvement by all types of healthcare organisations and voluntary organisations in this study. We found some evidence of joint work with local authorities to involve people in assessing their health needs, but many PCTs recognise the need to improve this aspect of their work.

Many service providers were working to understand their patients' experiences better. We found good examples from acute and ambulance trusts of how people's experiences can be used to change the way services are delivered. Some service providers have been trying to build stronger links with their local community and voluntary groups to create other routes to gather views and experiences. Mental health and learning disability trusts in particular, demonstrated how users of services could participate more actively in their services and form partnerships with service providers.

For example, some were employing voluntary organisations to help gather the views of users of services, and involving users routinely on panels for recruiting staff. There was a strong focus on users' rights to a say in these services.

A health service membership culture is developing, led by foundation trusts, which is intended to give more people a stake in their local services. PCTs and some service providers have also been using this model to develop registers and 'user banks'. 'Membership' is driving health services to make contact with communities they have not reached before. However, it was unclear whether more people were becoming more engaged and, if so, whether they adequately represent the different voices of local communities. The initial focus by foundation trusts has been to provide information for members about services, and it was not clear from this study that members were better supported to influence decisions or if trusts are more accountable to the wider public or local communities as a result.

There are some different pressures and influences on patient and public engagement for providers in the independent sector. They measure and improve patients' satisfaction for commercial and publicity reasons, as well as for service improvement. We found some coordinated approaches to preparing and using surveys as an improvement tool, and as part of routine performance management. However, this study did not itself provide evidence about the quality and response rates of these surveys, or how far they take account of patients' experiences. Independent providers felt there was an opportunity to share good practice with NHS colleagues.

However, the independent sector was less likely to capture qualitative information about patients' experiences, or to discuss or share ideas with patients in discussion groups. We also found fewer examples of organisations in this sector working closely to engage carers or the wider public, except in publicity or fundraising activities. The exception is some excellent practice in hospices, where a wide range of approaches were being used to engage with users of services, carers and the wider public.

Healthcare organisations, particularly PCTs, have been working to find new ways of engaging people, by using, for example, electronic surveys, websites, direct contact with households, citizens' panels and text messaging. Many trusts continued to rely predominantly on national and local surveys, feedback from Patient Advice and Liaison Services (PALS) and data on complaints. While these are important sources of data, organisations were not making the most of patient interviews, focus groups and other more informal feedback from local people. Some large-scale consultations bring these different approaches together and also include open days, public events and roadshows. People have told us that they generally prefer to tell their stories of their health and care in their own words, and in environments where they feel comfortable to discuss issues.

We found that most healthcare organisations in the study have made it a priority to use a wider range of approaches to engaging people, beyond formal research, and in particular, 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 patient 'stories'.

- Improve the quality of local patient surveys and questionnaires and
- Work with other agencies to gather and use information together.

Consumer and market research activities to gather people's views and experiences were seen as only one set of tools required to engage with people properly. Trusts and community groups have emphasised how they need to be able to work together, so that local people can understand health services and engage with them better. Community development approaches, which take time, commitment and cooperation from local public services, were seen as the most effective in engaging those in the poorest health or with complex needs. People also highlighted to us how their health needs and care experiences cut across organisational boundaries. They therefore expect trusts and local authorities to pool their resources so that they can engage local communities and make the best use of what they say.

The approaches being used to support 'seldom heard' communities to share their views and experiences were in their infancy in some areas and more established in others. They included:

- Work to map local communities.
- Identifying and acting on communities' immediate health needs.
- Outreach services to work with local communities in particular areas.
- Using the existing centres and networks where people meet.
- Working in partnership with local voluntary organisations.
- Improving communication with groups.
- Recruiting members of the community to provide advice about their traditions.
- Workshops and focus groups for particular groups.
- 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, and to promote consultation events and services.
- Developing tailored information with communities themselves, about health services and how to engage with healthcare organisations.

No national data is gathered on how well people are engaged in health services. This made it very difficult to compare the performance of different trusts across the country. The Government's standard for engagement (core standard 17) is reported as being met by 98% of trusts in the annual health check, but the views of patients and the public were that the performance of trusts is more mixed.

People generally want more information about their local health services, how to give their views, and about what changes are made as a result of their contributions. They want an opportunity to share their experiences and have a say in all aspects of the health service, even if they choose not to use it. When people feel they have no influence, it can lead to a loss of trust and confidence in health services, and make future engagement more difficult.

There is particular interest 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 want to have a say about health service staffing and how money is spent, the facilities and the environment in hospitals, and in making healthcare safer. Again, these messages emerged consistently from all those

patients' and public groups and their representatives who took part in our study.

Those involved in our study were in agreement about what effective engagement should look like and how it could be assessed locally and nationally. This has been set out in our recommendations.

Recommendations

Our recommendations set out the actions needed to improve how people are engaged in health services, and to ensure that their views are better used to provide services that meet their needs. We have set out recommendations for national agencies that can support the NHS and independent sector to improve, including specific recommendations for the Department of Health. We encourage the Care Quality Commission to consider our proposals for the future assessment of how trusts engage patients and the public.

We also provide recommendations for local healthcare organisations. These include how trusts should assess themselves on how ready they are to engage with local people, what they need to do to achieve a minimum level of performance, how they should demonstrate improvements over time, and how they can work towards a higher level of performance using a new performance framework that we developed during our study.

Our recommendations for a national development programme for the NHS and independent sector

- An NHS development programme is needed to support improvements in how people are engaged and their views taken into account in health services, and to share good practice. The Care Quality Commission could take a lead in bringing together development agencies including:
  - The National Institute for Health and Clinical Excellence.
  - The National Centre for Involvement.
  - National Institute for Innovation and Improvement.
  - The Royal College of Nursing.
  - The General Medical Council.
  - Skills for Health.
  - Skills for Care.
  - The Foundation Trust Network.
  - The Improvement and Development Agency.
  - The Centre for Public Scrutiny
  - Strategic health authorities.
- The independent healthcare sector needs a development programme to address the issues identified in this report. Those bodies representing independent healthcare organisations should be invited to consider how they might formalise arrangements to support improvements and share practice between their members and the NHS.
- Further support will need to be provided to LINks, OSCs and boards of governors at foundation trusts to enable them to participate in local engagement checks and to provide evidence of performance for use in national assessments. Some of the organisations listed above will be well placed to provide such support.
- Health and social care staff need to be supported to develop engagement skills, and 'engagement champions' should be developed among medical and other clinical

staff, as well as senior managers. This includes the skills to gather and use people's stories about their health and their care, and knowledge of the approaches needed to develop and maintain dialogue and feedback with different local communities.

- PCTs, in particular, need further support to engage people when they commission health services, and in ensuring both service providers and GP practices are engaging and responding to the needs and views of local people.
- The Care Quality Commission needs to build on work already underway in the Healthcare Commission to maximise response rates from minority communities and other under-served groups in the national patient survey programme. Alongside this, the programme could further encourage local healthcare organisations to improve the quality of their own surveys of patients and the public, in conjunction with local communities, again, building on previous work.
- A gap remains in our understanding of how well people are engaged in their individual care. In the light of the NHS Constitution, the Care Quality Commission could explore ways of measuring how health and social care organisations engage people in their own care, possibly using patients and carers as 'trackers' across a sample of health and social care pathways.

The Department of Health should:

- Incorporate the experiences of patients, users, carers and the public into the measurement of quality and clinical outcomes – for example, using the new Quality Accounts.[23]
- Encourage the development of local quality standards for engaging patients and users, carers and the wider public in contracts between commissioners and health and social care providers. These should focus on how people's views and experiences are used to improve the provision of services.
- Support LINks to ensure that they are equipped to fulfil their activities. The Department should also evaluate the impact of LINks over the longer term.
- Encourage PCTs to strengthen their local requirements for engaging patients, users, carers and the wider public in the independent sector. The Department could explore ways of aligning national standards for engagement between the NHS and independent sector.
- Consider how the strengthened duty to involve (section 242 1B) and the new duty to report on consultations are being used, and build further capacity in trusts to deliver this effectively and share best practice.
- Introduce further measures to strengthen the NHS's accountability to local people through means such as participatory budgeting, greater roles for community advocates and more formal arrangements from partnerships between staff and users of services.

Our recommendations for assessing patient and public engagement – for the Care Quality Commission and local healthcare organisations

This section sets out how engagement with patients, users and the public could be assessed in the NHS or the independent healthcare sector. In developing the performance framework and requirements below, we have taken account of:

- What matters most to patients and the public about being engaged in health services.
- How patients and the public think the Care Quality Commission should assess their engagement with health services.
- Legislative requirements as set out in Section 242 1B of the NHS Act and the Local Government and Public Involvement in Health Act 2007.
- Best practice guidance, particularly the Department of Health's statutory guidance Real Involvement[3] and NICE guidance on the evidence of effective community engagement to improve health.[5]
- The evidence available through the Audit Commission's Auditors Local Evaluation (ALE) and use of resources assessment.
- Evidence gathered by PCTs as part of the World Class Commissioning assurance system.

This builds on the current assessment of core standard 17 – "Healthcare organisations seek and take account of the views of patients, their carers and others in designing, planning, delivering and improving health services".[1]

The Care Quality Commission is encouraged to use these findings in developing its approach to regulation. Trusts are encouraged to act on the specific recommendations and work towards the level of performance described below.

We encourage the Care Quality Commission to:

- Put people's voices at the heart of all aspects of the regulation of health and social care organisations. When health and social care organisations are assessed about the quality of clinical care, the environment of care or the way care is provided, they need to demonstrate that they are listening to and acting on the needs and aspirations of patients, users, carers and the public, and working with them to develop or provide care.
- Continue to assess how health and social care organisations engage with patients, users, carers and the public, as a quality issue in its own right. This could link to the evidence gathered by PCTs as part of World Class Commissioning (competency 3). This would include the following four steps:
  - A **voluntary local engagement check** by health and social care organisations of how well placed they are to engage with people (to be conducted in partnership with local groups for patients, users and the public).
  - Introducing **minimum requirements** for engaging patients and users, carers and the wider public. These could be incorporated into registration requirements for all trusts.
  - **Measures of improving engagement** that health and social care organisations would demonstrate yearly progress on.
  - A **national assessment of people's engagement with health and social care organisations** to provide a baseline of performance. We have developed, with trusts and user and community groups, a performance framework that could be used as a starting point – see below.
- Ensure that any assessment of how well people are engaged in health services should find ways to collect evidence directly from a range of patients, local groups, LINks and OSCs, as well as clinicians, managers and front line staff. Evidence should also be compiled from minutes of meetings where

decisions are made about services, attendance records of engagement activities, databases of local patients' and users' groups and individuals, and evaluations of engagement activities. It will be essential to take account of information gathered by other regulators and from development work, including World Class Commissioning for PCTs. Groups representing patients and the public strongly believe that, whenever possible, the Care Quality Commission should bring trusts, patients and the public together to reflect on how effectively people's views influence services.

- Undertake further work to pool knowledge with the Audit Commission and other regulators, about how far local strategic partnerships, and trusts within them, are using community engagement to deliver health outcomes.

Trusts should:

- Strengthen the culture of being open and responsive to local people, through strong management and clinical leadership that ask people how their health services can serve them better, and act on their responses.
- Increase the influence that under-served groups of patients, users of services and the public have on the decisions they make. Trusts should also find ways of showing how engaging with people is supporting improvements to services and to people's experiences of care.
- Undertake local engagement checks to assess how well placed they are to engage with people and use their views (see details below). This includes considering how well they know the users of services and members of the public in their area; their community's capacity to engage; their organisation's ability to engage and respond; and their legal duties and responsibilities to engage with people and take account of their views. This could form part of the work PCTs are already undertaking to develop their capacity to meet the requirements for World Class Commissioning.
- Be able to demonstrate a minimum level of performance to show that people are influencing their major service and commissioning decisions. They should also be able to show how they have increased the extent to which patients, users and the public have influenced their decisions across all their services and departments – and what difference these decisions have made. Our proposed requirements are set out below.
- Work towards a higher level of performance, using the following performance framework and performance checklists for different types of organisations. This starts from the perspective of patients and the public and sets out what actions trusts should be able to demonstrate if they are engaging people effectively.
- PCTs, in particular, should work more closely with other local agencies, especially the local authority and other healthcare organisations, to coordinate efforts to gather and use information from people about services and to promote their direct participation in service improvements.

Our proposals for action by trusts

1. Undertake a local engagement check with local partners and communities

Trusts should have the necessary systems and processes to enable people to influence services, and a local infrastructure to enable them to develop long-term relationships with their communities. Where possible, information gathered for other purposes should be used to check local engagement – in particular, evidence gathered for World Class Commissioning by PCTs in relation to competency 3.

The basics	Trusts, with their partners, users of services and the public should:
Your local circumstances	Know about the people and communities in the area – who they are, where they are and how they live.
Your community's ability to engage	Know the voluntary, community and users' groups in their area, as well as their networks – including LINks. Support the development of these groups and networks to engage with health services.
Your organisation's capacity to engage and respond	Develop a culture of engagement in their organisation, through senior management and clinical leadership, making people accountable for it across the organisation. Identify the necessary resources to engage – for particular services and with the different groups and communities in their area. Develop the skills of staff, particularly clinicians and managers, to engage with people, using a range of approaches and tools. Ensure they have systems for gathering and reporting on information from engagement activities across the organisation. Build people's views into decision-making processes at corporate and service levels across the organisation.
Your legal duties and responsibilities	Comply with the duties: • Section 242 1B of the NHS Act 2006 • Real Involvement statutory guidance • Responsibilities in relation to LINks and overview and scrutiny committees.

2. Trusts should be able to demonstrate a minimum level of performance

Trusts should be able to demonstrate that:

- They have assured themselves that they are meeting statutory requirements and have put in place the necessary systems and processes (as set out above).
- The views and experiences of patients, users of services, carers and the public influence their corporate priorities.
- For PCTs, the views and experiences of patients, users of services, carers and the public influence the process of commissioning and designing services. PCTs should be able to demonstrate that they have engaged people in key stages of the commissioning process, for at least those services given priority in their strategic plan.
- For service providers, the experiences of patients and carers are continuously influencing service delivery and improvements across a range of services in the organisation, and at least those service developments prioritised in the business plan.
- They have learned lessons from their recent engagement activities and are acting on these to improve future engagement.

3. Trusts should also be able to demonstrate progress year-on-year

Engagement with patients and the public is a process that is continuously being developed, building on sharing information and ideas, with people working together to put these into practice. Trusts should be able to demonstrate year-on-year how they are:

- Improving the quality and range of the information they gather and use from patients and the public, in order to respond to their needs, aspirations and experiences.
- Increasing the contacts and relationships they have with individuals and groups from their communities, especially with groups experiencing the poorest health or whose needs are not being met.
- Increasing the influence that patients and users of services and the public have on their decision-making at both corporate and service levels, and in developing care pathways.
- Increasingly able to demonstrate how engagement has led to improvements to services and is having a positive impact on communities.

4. Trusts should work towards a higher level of performance

We have developed this performance framework using the views of healthcare organisations, patients and the public and community and voluntary organisations. It identifies five areas that were most commonly cited by these different stakeholders, as the most important in assessing how well a trust engages with patients and the public. Importantly, it provides descriptions of performance from the perspective of patients and the public. Trusts can use this framework to help improve their performance. We encourage the Care Quality Commission to use this framework in a national assessment of performance to establish a baseline.

Aspects of performance	Descriptions from user/public perspective	Actions by healthcare organisations
Promoting people's rights to a voice.	When I, or my family, use a health service, we are asked about our experiences. We are encouraged to contribute our views of health services that affect us or that we have used. We are given extra help to share our views and experiences if we need it. Through our LINk, or local user/community group, we can raise issues to health service managers on behalf of our community.	The experiences of patients and carers are routinely gathered; all patients and carers have opportunities to contribute their views or experiences. There are proactive attempts to promote people's rights to a voice – as patients, carers and the public. Advocacy, outreach and support services are promoted and used to enable priority groups to engage. There are mechanisms in place for local groups/LINks/OSCs to contribute views and these are promoted and used.
Keeping people engaged.	I get regular information about the health services in my area and how to get involved. My local user and community groups/LINk have regular opportunities to meet with health service managers to discuss issues that concern me. We can work together with health service staff to plan and improve health services.	Accessible information is routinely provided for patients, carers and the public, particularly priority groups, about local services and how to influence them. There is an active dialogue with patient and users' groups, LINks and overview and scrutiny committees (OSCs), which are able to raise issues on their terms. LINks are actively supported to reach out across the whole community as part of this dialogue. Individuals, groups and LINks are participating in decision-making forums at corporate and service levels. If there are any services or areas of trust business where there is little or no participation, action is being taken to address this.

Aspects of performance	Descriptions from user/public perspective	Actions by healthcare organisations
People's views are used to plan and improve services.	Our views and experiences are used to inform which services are commissioned, the plans for those services, and how they are provided and delivered. Our local user/community groups or LINk are part of decision-making groups on our behalf. We know how our views and experiences have been used and the difference it has made to health services.	It is clear how people's views and experiences have influenced decisions at corporate and service level. In the first instance, there is evidence of this in: • The main corporate decision-making forums. • For services or issues that are a priority in the organisation's business plan. There is also evidence that those groups that have been identified as priorities to engage with have influenced the corporate and service level decisions set out above. People are participating in trusts at corporate and service levels (and this participation includes priority communities and groups). Feedback is routinely given to patients, users and the public about whether and how their contribution influenced the organisation or its services. The influence that people have had on the organisation or its services is recorded and reviewed. The specific changes made to policies and services that are in response to people's views and experiences are set out publicly. When changes are made, people are asked if they have improved their experience or care.

Aspects of performance	Descriptions from user/public perspective	Actions by healthcare organisations
People are engaged in appropriate and accessible ways.	We can give our views and work with healthcare services in different ways to suit our circumstances. We are given the time and help we need.	People's views and experiences are gathered in appropriate ways to enable them to share their views, tell their story or contribute to decision-making. People in priority groups in the community are contributing their views, experiences and expertise. All engagement activities are accessible to people who may want to take part and those groups who need help are offered it.
Services learn how to engage people better.	We are offered opportunities to share our views and experiences in new ways. We are asked what it was like to be engaged.	There are attempts to innovate, by using new approaches to engage with people who have not shared their views in the past. There is an evaluation programme to learn any lessons about how to engage people more effectively. These lessons are then acted upon.

Performance checklist for different types of healthcare organisation

The framework above can be used by all trusts. However, different types of organisation need to consider additional questions on the quality and quantity of their engagement. The questions below set out the aspects of performance that we found to be most important in primary care trusts, provider trusts and foundation trusts, in addition to the basic elements above.

Primary care trusts

- Are trusts engaging both with patients and the public, and responding to them in all aspects of the commissioning process – for at least the major commissions of the year? This includes health needs assessment, service review, developing service specifications and quality standards, procuring services, monitoring services and budgeting.
- Have trusts built in requirements for patient and public engagement into service level agreements with providers, including GPs and practice-based commissioners?
- Are trusts building the capacity of user and community groups to engage with them?
- Have trusts an open and constructive relationship with LINks and OSCs?
- Is the development and influence of GP practice participation groups being supported?
- Is the influence of the local community on the PCT's decision-making being extended through joint engagement planning, as part of local strategic partnerships, local area agreements and healthcare partnership working?
- Are the needs and aspirations that are identified by communities in the joint strategic needs assessment being used to develop services, in conjunction with the local authority?
- Are trusts communicating with the public about the local health services available and how to engage with them?
- Is the impact of using people's views and experiences to improve services across a local area being evaluated?
- Are PCTs working jointly with service providers to coordinate how people are engaged in the local area and how the information they give is best used?

Acute, ambulance, mental health and learning disability trusts

- Is data about patients' and carers' experiences being used in routine decision-making?
- Is data collected from patients in real time, and through the use of patients' own stories, to extend the way their experiences are captured? (For example, through patients' and users' diaries and mapping exercises throughout patients' care).
- Are trusts building an understanding of patients' pathways from the patient's point of view?
- Are patients and the public able to influence decisions about clinical governance and to have a dialogue with clinicians?
- Are trusts maintaining relationships and engaging with the wider community, beyond users of services?
- Are long-term users of services and carers being engaged about how to develop services, as an integral part of their care?
- Are trusts working jointly with PCTs to coordinate how people are engaged in the local area and how the information they give used most effectively?
- Is the influence of the local community on their services being extended through the trust's relationship with LINks and OSCs?

Foundation trusts (in addition to the points for provider organisations)

- Does the membership reflect the communities served by the trust?
- Are governors active in engaging with local communities?
- Are members' views and experiences used at both corporate and service levels?
- Is the trust enabling users and communities to influence its decisions through a combination of LINks, OSCs, governors and members?
- Is the trust actively engaging and responding to the wider public beyond its membership?

Introduction

Between January 2008 and January 2009, we undertook a national study to find out how patients, users of services and members of the wider public are involved and engaged in health services. The study set out to explore current practice, support local improvements and identify ways of improving the regulator's approach to assessment.

We currently assess, through our annual health check, NHS organisations' performance against core standard 17, which is set by the Government. The standard requires that "the views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving healthcare services".[1] It is underpinned by a legal duty on all NHS trusts to consult and involve patients, users of services and the public about how they plan and operate their services and when they develop proposals for change.[2]

We undertook this study because we identified inconsistent standards of patient and public engagement across the country through the annual health check 2006 and 2007 (see below). At the same time, the Government has strengthened the legislation related to patient and public engagement and created new local arrangements for engagement through local involvement networks (LINks).[3,4] It has also set out the role of the new health and social care regulator, the Care Quality Commission, from 2009, which will include regulating how local health and social care organisations engage patients, users and the public. Also, importantly, the National Institute for Health and Clinical Excellence (NICE) published its first guidance on community engagement for health improvement in early 2008, that sets down a marker of quality for all healthcare organisations.[5]

We have taken account of the following information for this study:

- Policy developments in the Department of Health, notably: the NHS Constitution[24], new legislation and statutory guidance on involving patients and the public[2,3]; requirements in the framework for World Class Commissioning[22]; and the evolving programme of work to establish measures of patient experience for assessing performance in the NHS.[25]
- NICE guidance on community engagement for health improvement.[5]
- The development of the Comprehensive Area Assessment, led by the Audit Commission, and the emerging requirements for user involvement by local authorities and local strategic partnerships, recognising the role of healthcare organisations in working collaboratively across geographical areas.[26]
- Censuses conducted by the NHS National Centre for Involvement in 2007 and 2008.[16,17]
- Anticipating the arrival of the Care Quality Commission in April 2009, we have involved the Commission for Social Care Inspection and the Mental Health Act Commission in this study.

Concerns identified in Healthcare Commission assessments and surveys

Taken together, the concerns below prompted the need for our study. In 2007/08, 98% of all NHS trusts declared that they met core standard 17 of the annual health check (up from 96% in 2006/07). However, we identified evidence from national and local sources that suggested a number of trusts may not be taking account of the views and experiences of people as required by the standard. The majority of the trusts in this study, while reporting that they comply with the standard, recognised that they needed to improve how they engage with people.

In 2007/08, patient and public involvement forums commented more often on healthcare organisations' performance against core standard 17 than on any other standard. Forums commented on how well three-quarters of healthcare organisations met the standard, while OSCs commented on almost two-thirds of trusts. Boards of governors commented on engagement in just over a third of foundation trusts.

Engagement is an area that is of particular interest to them, and one that they have direct experience of.

In 2007/08, around 25% of all comments about core standard 17 received from forums and OSCs were negative. More than 80% of these were about trusts failing to seek the views of patients and the public. Around 50% were about how far, if at all, their views were taken into account. The negative comments focused on trusts:

- Providing poor information on how to engage and about proposed changes to services, for example.
- Failing to involve forums and OSCs in important issues.
- Failing to act on comments made by the forums and OSCs.

National voluntary organisations have also raised concerns with us about the level of compliance with core standard 17[6-9]. Some of their local networks have identified that patient and community groups can face considerable challenges in raising issues about health

Reasons for the study

- Mixed evidence about how well NHS organisations are engaging patients and the public gathered through our annual health check.
- Limited evidence about how independent providers are using patients' views to improve their services (in line with National Minimum Standard C6).
- New local arrangements for involving patients and the public (the introduction of LINks).
- Legislation giving people a right to be involved in their health services and giving health services a duty to involve people (section 242 1B of the NHS Act 2006).
- A strengthened role for the new regulator, the Care Quality Commission, in assessing how health and social care services engage patients, users and the public.
- Evidence from other regulators and national studies showing mixed performance across the country.

services and in influencing how services are developed. For example, local community groups, in some of the most vulnerable circumstances, told us of the barriers they had to overcome to participate in some local surveys and discussions about their health or their care. These included not having the support they need to complete survey questions. Some of them have no relationship with their health services at all, despite their efforts to develop one.

There is no national data about people's engagement in planning and improving services to act as a benchmark for performance across the country. There is, however, some limited national survey data about people's involvement in their own care. In 2007, the national survey of inpatients (of almost 70,000 patients) found that 7% said they were asked to give their views on the quality of their care and 93% said they were not asked. This is unchanged from 2006 and up only 1% from 2005 when 6% of patients said they had been asked to give their views. In some trusts this figure was as low as 2%. Patients were also asked whether they were involved as much as they wanted to be in decisions about their care and treatment. Only 51% said "yes, definitely" while 11% said no.[27] (It is important to note that these questions relate only to existing patients and only to their own care.)

Some of our other recent studies have identified the need for certain groups of people in vulnerable circumstances to be more involved in health services, including:

- People with learning difficulties, including young people.
- Older people, older people with dementia, and older people from black and minority ethnic communities.
- Users of substance misuse services.
- Users of chronic obstructive pulmonary disease services.[10-14]

The recent review of urgent and emergency care services in England recommended that PCTs need to do more to ensure that patients and the public are fully engaged in plans for the future of services, particularly those from vulnerable groups and those with complex needs.[15]

Evidence from the registration of independent healthcare organisations

We also assess how well independent healthcare organisations take account of people's views in improving their services, against National Minimum Standards, published in 2002 under the Care Standards Act 2000. Core standard 6 is intended to ensure that "Patients' views are obtained by the establishment and used to inform the provision of treatment and care and prospective patients".[28] It requires that:

- A survey of patients is carried out annually, as a minimum, to seek the views of patients on the quality of the treatment and care provided.
- The content of the survey reflects the content of the NHS survey of patients.
- The results of the surveys are collected in a report every year that is available on request to patients, prospective patients and their families, and is provided to the National Care Standards Commission.
- The outcome of the surveys are made available to staff and used by the regulated body to contribute to its assessment of whether it is meeting its aims, objectives and statement of purpose. Regulation 6 and schedule 1 of the Private and Voluntary Health Care (England) Regulations 2001 set out the statement of purpose and what it must contain.

Providers of independent healthcare submit evidence as to whether they meet this standard, but this only gives us limited information about the state of patient and public engagement in the independent healthcare sector. Our study provided an opportunity to explore practice in the independent sector in more detail.

Evidence from other studies

The Department of Health recognises that "far too many people still feel that the NHS does not identify or properly address their concerns, particularly when tough decisions have to be made".[3] "There is still little evidence that involvement is a mainstream activity alongside other policy and performance requirements....There is scant evidence to show that involvement activity is stitched into....decision-making processes, how organisations have listened and responded to what users have told them; or of how health services have been shaped according to the needs and preferences of users".[3]

The national census of patient and public involvement in England over the last two years has found that some patient and public involvement "is becoming more embedded into everything that trusts do, but that there is still work to be done".[16,17] The challenges included variable and insufficient resources and funding for patient and public engagement; different approaches being needed for different types of trusts; those at corporate level needing to be more aware of their engagement duties; and further guidance being needed to help trusts.[17] The 2008 census identified that World Class Commissioning and the introduction of LINks are beginning to have an impact on how patient and public engagement is developed and delivered.[17]

Other research has shown that, while some primary care trusts (PCTs) are establishing "ambitious programmes" to involve people, many others share a range of problems, including insufficient resources and staff; tight timescales; clinical staff and managers not valuing patient and public involvement; lack of relevant data; difficulties engaging the public on commissioning issues and accessing seldom heard groups. Overall there are not enough incentives at a strategic level to make patient and public involvement a priority.[18]

The National Audit Office has identified a lack of involvement of users of services in service development as a risk to improving clinical quality. This is despite 98% of PCTs having structures and processes in place to involve patients and the public in the design of services.[19] There is a lack of senior management drive to build greater public participation in decision-making[17] and a failure of clinical staff to provide active support for patient engagement.[18]

Family doctors were still not sufficiently accountable to their patients in many areas. Only between a quarter and a third of general practices reported having a patient participation group.[29] While this figure is rising, reasons given by practices for not setting up a group were mainly negative, including a perceived lack of interest among patients, fear that the wrong patients will be interested, the difficulties of working with a diverse patient population and an earlier failed attempt to establish a group.[29]

There is some evidence of healthcare organisations having trouble engaging particular groups. For example, studies show that users of services from black and minority ethnic communities have become less involved in health services over the last 20 years[21] and

there is little evidence to show how children and young people have helped to change or improve social care services.[20]

People's rights to a voice and health services' duties to engage

The Government wants the NHS to put people at the centre of decision-making. The NHS Constitution states that "You have the right to be involved, directly or through representatives, in the planning of healthcare services, the development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting the operation of those services."[24] The Constitution is intended to help patients, users and the public, by setting out their legal rights and "ensuring that decision-making is local where possible and more accountable than it is today, providing clarity and transparency about who takes what decisions on our behalf".[24]

In return, "The NHS also commits to provide you with the information you need to influence and scrutinise the planning and delivery of NHS services and to work in partnership with you, your family, carers and representatives".[24] "The NHS must get much better at listening and responding to the patients who use our services, the staff who provide them and the citizens who fund them".[30] Involvement is now considered to be "one of the key developmental challenges for NHS organisations".[3] "The local NHS will involve patients, carers the public and other key partners. Those affected by proposed changes will have a chance to have their say and offer their contribution. NHS organisations will work openly and collaboratively."[31]

The Darzi Report sets out a vision for the NHS where patients and the public are involved and engaged at every level, recognising that "patients lack 'clout' inside our healthcare system". This vision includes:

- "Gathering and using the views and experiences of patients and communities."
- "Responding to the aspirations of patients and the public."
- "Effective change is animated by the needs and preferences of patients empowered to make their decisions count within the NHS."
- "Consultation on major change to hospital services proceeds only where there is effective and early engagement with the public."[23]

Recent legislation has strengthened the duty on trusts to involve patients, the public and their representatives in the planning, development and operation of health services, including proposals for changes to services. Section 242 (1B) of the NHS Act 2006 (the duty to make arrangements for involvement) sets out the duties that apply to NHS organisations that commission or provide health services. Trusts are now expected to:

- Empower people through engagement and information.
- Listen, understand and respond to communities.
- Give people a stronger voice using LINks.
- Act on the new NHS duties to involve and report on consultations.
- Make more effective use of feedback from patients and local communities to inform service design and commissioning, including complaints and the national patient surveys.
- Make information to people reliable and easy to use.[32]

There are particular responsibilities for commissioning organisations "to ensure that their local communities have the opportunity to be fully engaged in the decisions they take, and to take greater efforts to communicate what they are doing and why to their populations."[30]

The new World Class Commissioning framework for PCTs requires them to "proactively seek and build continuous and meaningful engagement with the public and patients, to shape services and improve health.... Commissioners... will make commissioning decisions that reflect the needs, priorities and aspirations of the local population. This new relationship with the public is long term, inclusive and enduring.... Decisions are made with a strong mandate from the local population and other partners."[22]

There are other continuing requirements for NHS organisations in relation to consulting OSCs and for commissioners when involving patients and the public in practice-based commissioning.[33,34]

Strengthened duty on local authorities to involve local people

Guidance for local authorities sets out the new duty to promote democracy and extends the duty to involve people.

"The aspiration for the new duty is to embed a culture of engagement and empowerment. This means that authorities consider, as a matter of course, the possibilities for provision of information to consultation with and involvement of representatives of local persons across all authority functions."[35]

Authorities need to decide whether informing, consulting, involving people in other ways, or not using any of these methods is appropriate to the function being considered.

The new duty covers a large number of measures including:

- Improving access to information.
- Supporting people to be active citizens.
- Using petitions more effectively.
- Involving people in developing policies, planning and commissioning services and allocating budgets.
- Giving older and younger people a stronger voice.
- Improving the accountability of the NHS and health services.[36]

Empowering communities has also been identified as one of the Government's priorities in Public Service Agreement 21 to "build more cohesive, active and empowered communities". This uses "the percentage of people who feel they can influence decisions in their locality" as the main indicator for measuring whether communities are empowered.

This is central to the work of local strategic partnerships (LSPs), which cover healthcare organisations, and the development of local area agreements. The new approach to assessing the performance of public services across local areas (Comprehensive Area Assessment), will require LSPs to demonstrate how community engagement is resulting in better health and care outcomes for people.[26]

Design of the study

Definition of engagement

Health services engage with people to find better ways of meeting their needs and priorities for health and healthcare, and reducing health inequalities.

Engagement with patients and the public is about users, carers and communities sharing their views and experiences with healthcare organisations, and working together to plan and improve services. It includes consultation of patients and the public and their involvement and participation in the work of the trust. They need to be engaged in deciding how services are commissioned, planned, designed and delivered, as well as how health services are organised and funded.

Engaging with people also includes making sure there is communication between trusts, patients and the public – about how they can be engaged, what is done with the views and experiences they contribute and what difference it has made.

This definition reflects core standard 17 of our annual health check, but goes further to reflect best practice guidance, the new legislation and the views of patients and the public. We perceive a strong relationship between how health services communicate with patients and the public, and their attempts to engage them in developing services. When we refer to engaging patients and the public in this report, this should be taken to include users of services and carers.

Purpose and scope

In the light of the evidence set out above, we consulted with a range of national and local organisations, including voluntary organisations, users' groups and community groups to develop our study's purpose and scope. The aims and objectives were to:

- Explore the range of approaches and methods that different types of trusts use to engage patients and the public.
- Explore the impact that engaging patients and the public has had on healthcare organisations, their users of services and the services they provide.
- Comment on how effective and useful patients and the public find these attempts to engage with them.
- Identify what helps and hinders trusts in engaging effectively with patients and the public.
- Pay specific attention to how trusts engage with vulnerable and marginalised groups.
- Explore how healthcare organisations are developing their engagement practice as the new local involvement networks (LINks) replace patient and public involvement forums.
- Identify indicators of good practice and appropriate measures that can be used for future assessment and regulation of engagement.

What is not included in the study?

Patients' involvement in their individual care.

Trusts may use the feedback from individual patients about their care to inform service developments and improvements. However, this study focuses on the wider engagement of individuals and communities in the planning and development of health services beyond any care they may receive as individuals. Less is known about how this can be done well and how it can be assessed effectively.

Complaints procedures

We recognise the importance of using data from patients' complaints to inform service planning and improvement. However, we have recently completed a detailed audit of complaints' handling, and the Department of Health has been undertaking work to explore the use of complaints data. We have not examined the complaints procedure in this study.

Substantial variations in health services

We have not explored how health services are deciding whether or not to consult people about changes, or so-called 'substantial variations' to services. We have, however, considered trusts' relationships with overview and scrutiny committees (OSCs).

Study methods

Scoping phase – January to April 2008

We reviewed the Government's policies and best practice guidance; brought together existing Healthcare Commission data from our annual health check and other studies; and held initial consultations with a wide range of national and local stakeholders to design the study, including a citizens' panel with members of the public.[37] A sample of five interviews were held with local community groups representing communities who are 'seldom heard' in health services. Twelve interviews had been conducted with independent healthcare organisations in late 2007 and this data was used to inform the scoping phase.

Field work – May to October 2008

We conducted telephone interviews with 47 NHS trusts and 19 independent sector organisations (in each case with the lead officer for patient and public engagement). We selected a sample of different types of trusts from across the country. The majority were selected at random, and a small group were selected because they were either winners of National Centre for Involvement awards, or because they had declared some problems to us in complying with the national standard for patient and public involvement over the last two years. The independent healthcare organisations were all selected at random to reflect a mix of different types of organisations from across the country.

We conducted a survey of 42 local users' groups – either electronically, by telephone or written. A range of users' groups were invited from databases held by the Healthcare Commission, the Commission for Social Care Inspection and the Mental Health Act Commission. Some practice participation groups and LINk members were also invited to contribute through their national networks.

We held 20 workshops across the country, involving 500 participants from NHS trusts, representatives from user and community groups, LINk members and OSC members, practice participation groups and some individual patient representatives, including some foundation trust governors. Trusts were invited to ensure a sample

of different types of services, from across the country. Local users' groups and community groups were sampled from across the country to ensure a mix of patients' groups, community interests and groups of people. LINks and OSCs were invited to provide a sample from across the country, including both rural and urban areas.

Review of findings – November to December 2008

We held two meetings to consider our emerging findings from the interviews and local workshops described above. The meetings were attended by national stakeholders, including representatives of patients and the public and interested healthcare organisations, who also helped to shape this report.

We also took account of comments we received throughout the study and sought advice from a reference group, including national organisations and patient and public representatives (see appendix).

Table 1: Main types of organisation or individual that participated in our study

Type of organisation	Numbers participating in our study
Primary care trusts	51
Mental health/learning disability trusts	20
Acute trusts	26
Ambulance trusts	5
Foundation trusts	36
Care trusts	1
Independent sector organisations	33
Total NHS and independent sector organisations	**172**
National voluntary organisations	27
Patient and public involvement forums (prior to April 2008)	8
Local involvement networks (since April 2008)	25
Health overview and scrutiny committees	22
Local patients'/users'/community groups	74
Practice participation groups	9
Individual patient representatives	Approx 30
Total number of community and user organisations	**106**
Total number of patient/public representative organisations	**64**

1. Why do healthcare organisations engage with people?

This section brings together findings both from the interviews held with healthcare organisations and the messages that emerged from the 20 workshops held with trusts, users' and community groups. It describes the perceived benefits of engaging people, for which there is remarkable agreement from all participants. We set out the main factors and influences affecting how well trusts engage people and describe the purposes for which people are engaged in different types of healthcare organisation.

Perceived benefits of engaging people

Trusts have told us that engaging with patients and the public can benefit all aspects of healthcare, including how services are planned, organised and provided, how services are used, the outcomes of care, and wider benefits for those who are engaged, for their staff, as well as for the public.

Patients, carers and the public described how effective engagement can give them a voice in the health service, recognise their right to be heard, and can increase their understanding, trust and confidence in services and their knowledge about their local services. They also strongly believed it leads to improvements in their care and their health.

These mirror the benefits set out by the Government[3] and those described in best practice guidance. They are based on the practical experience of trusts and users' and community groups. In a small number of cases, patient and public engagement has been evaluated locally (see section 7). The following list sets out the benefits of engagement identified by participants in this study, with the most important listed first in each section.

Benefits to people's understanding and experience of health services

- People have a better understanding of how to engage with services and will become more engaged if they want to.
- People feel their voice is heard and health services listen.
- The public has an increased trust and confidence in services and reduced cynicism.
- People become more informed about services, their health, and other people's conditions.
- Patients and users of services have an improved experience of care.
- People feel an increased local ownership of services.
- The public has more realistic expectations about health services.
- People improve their skills, confidence and abilities as a result of being involved, with increased job opportunities.
- People feel more empowered about their healthcare and have an improved experience of being involved.
- The public uses services more effectively.

Benefits to health

- Health inequalities are reduced.
- People experience better health outcomes.
- Fewer healthcare mistakes are made.
- Social as well as clinical outcomes are improved, in line with patients' priorities.

Benefits to communities

- There are better relationships between the NHS and local communities, including a greater sense of partnership and mutual understanding of what can be achieved to improve health.
- More voices are heard – health services can reach out to a wider set of communities.
- The community and voluntary sectors are strengthened.

Benefits to service delivery

- Services understand and meet the needs of communities and users better. They are more responsive and sensitive, especially to minority communities.
- Care is more user-led or patient-centred and services are based on wants and aspirations as well as needs.
- Services are more proactive and responsive, so that they are better able to prevent problems arising, such as risks to the safety of patients. There is improved access to, and choice of, services.
- Services are more integrated across health and social care and primary and secondary care.
- Information for patients is improved and the language used is more accessible.

Benefits to trusts and how they plan services

- Services are commissioned more effectively.
- Primary care trusts (PCTs) are better at assessing people's needs, for example, in GP practices, and at identifying gaps and trends in healthcare needs.
- Services are more cost effective and offer better value for money.
- Resources are better distributed.
- Organisations that commission and provide services have an improved understanding of the patient's perspective and their journey through services. They also have a better understanding of the voluntary sector's perspective as representatives of users of services.
- Services are more open and transparent in their decision-making and are more accountable to patients and the public.
- Staff are more satisfied and more likely to stay in their jobs.
- Service providers communicate better with patients and the public about their respective views and priorities.
- Services are planned more effectively by providers and make better use of the expertise in the community.

What influences engagement?

We used the interviews and workshops with trusts, users' and community groups to explore what influences whether people are engaged in health services, and whether their views are listened to. People's engagement in their local health services is influenced by many factors, but there is a consensus about what is most likely to help or to hinder.

The most important factors influencing engagement were the commitment of senior staff in trusts, and the resources and capacity of both trusts and community groups. These factors combine with the others listed in table 2, to create very different environments for people to engage with health services across the country.

Table 2: Influences on how trusts engage with people	
Area of influence	**Most common issues**
Healthcare staff commitment	The commitment of senior health service managers and clinical staff.
Resources and capacity in all local organisations	The resources available within trusts. The capacity of individual community groups and the support given to them. The public's understanding of the local healthcare system. The financial stability and independence of local groups.
Legislation and performance requirements	The drive for foundation trust status and the obligation of foundation trusts to build a membership from the local community. World Class Commissioning requirements for PCTs – and the extent to which the PCT is leading engagement across the health economy. National quality and performance frameworks that include patient and public involvement and experience as an indicator. Requirements in local contracts and quality standards between PCTs and service providers.
Strength and activity of user and community organisations	The strength of local users' organisations and their networks. The development of the local involvement network. The work of the overview and scrutiny committee. The existence and networks of patient participation groups in general practices.
Partner agencies and degree of joint working	Relationships between PCTs and provider organisations. Relationships between local authorities and health services and joint commitments to engagement. The engagement work of local partner agencies.
Local geography and demographics	Local geography – rural and urban areas create different pressures. The demographic mix, and the changing pattern of communities.
National data	In particular, awareness of the annual NHS Patient Survey and its findings.
Pressure from individual complaints and the press	Media coverage of trusts. Individual complaints.
Culture of openness and power-sharing	The level of openness and accountability that already exists between health services and the public in the area. The history of sharing resources and decision-making between health services and local user and community groups.

The ability of health services and local groups to come together also depends on the strength of users' networks (particularly in mental health services and services for people with learning disabilities), and the degree to which health services have shared their decision-making with user and community groups in the past. Patients' and users' groups in particular, who have the necessary support and resources can play a significant role in helping to improve health services.

Trusts face considerable practical problems in reaching out to communities in both urban and rural areas, for different reasons. In urban areas there may be larger numbers of minority communities with more organised networks of community representatives and leaders to contact. However, trusts can find it difficult to prioritise which groups to engage with and how to maintain these contacts once they are established. In rural areas, there may be smaller numbers of people who have particular health needs, and fewer community leaders or centres to engage with as a point of entry to the community. Some of these practical problems can be overcome if trusts are working closely with each other or with local authorities to share resources and information. We found some examples of this during the study, but it is not widespread.

We heard examples from users' and community groups of problems where a perceived lack of openness by healthcare organisations and a mistrust of managers by local groups contribute to poor relationships in a local area. Trusts then find it more difficult to engage with people about service changes or new developments.

The media can help or hinder the development of relationships. In many areas trusts have been prompted to engage with local communities in response to poor media coverage. There are a few examples of relationships developing between trusts and the media in some areas, allowing a dialogue with local communities through local papers and radio. However, these examples are rare, and usually, the relationship with the media is one-way, with trusts trying to promote their services rather than inviting responses and encouraging participation. We heard a number of concerns from trusts and users' and community groups about negative healthcare stories in local papers creating tensions between them.

The public's understanding of local health services is also important. We have heard from trusts, as well as community groups, that unless local people understand the current services available and the ways in which they might change, it is very difficult for them to engage in a discussion or give their views. A particular problem is when trusts propose to reconfigure popular local hospitals to improve clinical quality, but public perception is that a local service will be lost.

In the independent sector, the support of senior management, the available resources and the capacity of the staff to engage are also the most important influences. In some services for the terminally ill and their carers, for example, there is considerable senior-level commitment to engaging with people to improve their care and to help the public better understand death and dying. Clearly, for all independent organisations, there is also an underlying drive to promote the business and increase the use of services from a commercial point of view.

We found some specific evidence about what hinders independent providers from engaging with patients and the public – mainly from

hospices. Problems included a lack of confidence among staff to engage, and not enough resources, time, personnel, space, money and funding given for facilitation and involvement, due to managers not seeing engagment as a priority. Hospices, for example, have some specific problems in developing ongoing relationships with patients, such as:

- Recruiting users.
- The health of users – they can be too ill to participate or be experiencing a period of better health and not wanting to take part.
- The death of users and the need to find new people.
- Groups not being popular.
- Difficulties in finding an adequate range of people to get involved.

Neither NHS or independent healthcare providers are significantly influenced by the requirements to engage people that are set out by their commissioning PCT – mainly because the majority of providers do not yet have such requirements in their contracts.

In the independent sector, insurers do not include evidence of engaging with patients and the public in their contracting arrangements. There were no examples of NHS commissioners encouraging the engagement of patients and the public as part of commissioning with independent providers.

The reasons for engaging with people

The findings from our study demonstrate that there was a general commitment by healthcare organisations to engage with users of services and their local population.

Many trusts viewed it as a core part of their role and integral to many of their strategic objectives. For example, "Previously the emphasis has been talking to people to find out what they think. The future emphasis is more about getting people involved in what we're doing" (acute hospital trust).

Most staff with a responsibility for leading work on engaging with patients and the public had a shared understanding of why trusts engage people and the benefits of doing so (see section above). In line with other national studies, we found that most trusts are establishing systems and processes to engage with their users and communities.

However, these are at very different stages of development. We also found considerable differences within organisations. Some services and departments had well-established mechanisms for engaging with their patients and carers, while others did not.

A small number of healthcare organisations, particularly mental health and learning disability trusts, started from a human rights perspective. For example, "In essence, the trust's view is that users of services and carers have the right to be involved" (patient and public involvement manager, mental health trust). The more proactive of these worked to engage people as an integral part of their care, giving them opportunities to take part in service planning and improvement alongside their treatment and care programme. "There is a strong message from the top team that we are open to involvement....this creates an air of optimism in staff and local communities" (mental health foundation trust).

For PCTs, engagement was typically seen as the way to identify the needs and aspirations of the local community to inform commissioning and

ultimately service delivery, and the route to creating services together. For example, "We work on the premise that information and consultation is important and needs to be done well. We co-create solutions with individual patients and communicate as much as possible" (patient and public involvement manager, PCT).

Organisations providing health services primarily engaged with people in order to help improve their experience of care. They focused on gathering feedback from patients and carers about their experience of services, the information they receive and the care environment. For example, "making sure that patients and the public are involved in key committees, strategic decisions and projects, and supporting staff across the service to engage in patient and public involvement activity in their areas" (patient and public involvement manager, ambulance trust). For many of the trusts in this study, these are goals or aspirations that have not yet been realised across their organisations.

Independent sector organisations engaged with people for the same reasons as NHS provider organisations, but were also focused on measuring and improving patients' satisfaction with their care, in order to promote the use of their services to new patients and users of services. There were differences across the sector. Hospices and mental health service providers were also concerned with promoting community relations and encouraging fundraising activities in the local area. Private doctors were concerned with maintaining the trust of their individual patients and being seen to respond to their immediate health concerns. For example, "As a company our reputation is paramount to us. We have always listened to patient feedback – it's what tells us how we can improve and offer the best services" (private doctors' clinic).

2. People's experience of engaging with health services

This section describes what patients, users of services and the public have told us about their experiences of being engaged with health services. Evidence is drawn from the survey of users' groups, all the commentaries on NHS performance from patient forums and overview and scrutiny committees in the last two years, and feedback from over 100 local groups at our workshops, including national and local users' and community groups, LINks and practice participation groups.

Overall, the message is that patients, users and the public did not feel that trusts engaged effectively with them. There were problems of poor communication, lack of openness and examples of poorly designed local surveys and questionnaires that can be difficult for people to complete. There were not felt to be enough opportunities for people to tell their stories about their experiences of care or to discuss their views in environments where they feel comfortable. Crucially, for patients' and users' groups, there was often no sense of trusts building a relationship with them over time, or creating the kinds of partnerships that groups would like to share their experiences and expertise. We have heard some positive stories from people about strong relationships with health services and constructive consultations where people feel they have been listened to. We have used examples that reflect this better practice.

Individuals' experiences

Examples of the public's views

"We could sit here and tell you all what's wrong with the NHS but who is putting it right?"

"I sometimes feel overwhelmed by the NHS. I don't know who to go to or where to go and information is really hard to get."

"They should listen to those who have qualms with the health service from experience."

"What has happened to hospital standards? I complain and nothing happens."

"I am a GP but I have also been treated for cancer this year. My observation is that the feedback loop doesn't work very well in the NHS."

There was a strong view from patients and the public that the people who want to, do not get enough of a say in the health services that are planned or provided in their area. Some patients and members of the public wanted to be consulted and involved more often and more effectively than at present.

We have heard about the 'silent majority' and the 'usual suspects'. A majority of the public are not contributing their views or experiences, and are not participating in health services. Some of these people do not want to be engaged; others have never been given the opportunity; some do not know how to engage and others have no time. There is a small minority of individuals who have particular concerns or issues with health services or who are committed to representing fellow patients or community members in health service

discussions. They are more likely to take part in consultations and be active in patients' forums.

The members of the public we spoke to said that it was difficult for most people to get their voices heard in the NHS, for example, in raising an issue about their GP practice or, more widely, wanting to talk about the provision of health services in their community. People were prevented from engaging because they did not know what routes were open to them to raise their voice, the attitudes and behaviour of staff discouraged them, and NHS organisations and staff presented cultural barriers.[37]

People with longer-term conditions can face different challenges. They told us that opportunities to contribute to planning and improving services as part of their own care programme were often limited. They were also more likely to have concerns that their care would be compromised if they identified problems with services or challenged the staff providing their care.

We heard from a small number of individuals that have experienced problems or mistakes with their care, who have faced particular difficulties in trying to share their experiences. While there may be opportunities to do this through an individual complaints process, it can be very difficult for these patients or carers to contribute to improving services or to help trusts learn from their mistakes.

People told us that they may want to get involved in very different ways. This could depend on many factors, including their health, the time available to them, their other caring and work responsibilities, their education, skills, language, ability to communicate in group discussions, cultural background and their understanding and knowledge of the health service.

The points below provide a strong message to trusts about what people want to enable them to engage with health services on their own terms.

What people wanted to enable them to engage with health services on their own terms:

- An understanding of the health services in their local area and how they work.
- Knowing how to use the services if they need them.
- Having contacts with health services that they trust and feel comfortable with – or being able to talk to people like themselves who can pass information to health services on their behalf.
- Being able to talk about the issues that most concern them first.
- Being told the realities of a situation, such as costs, and the true options for change.
- If they need it, being helped to share their views or experiences.
- Feeling confident that their care will not be affected.
- Having opportunities to engage in the ways that suit them best; and sometimes not to engage at all.
- Being happy about the level of contribution they are making and the commitment it requires.
- Having their time and effort recognised and any costs covered.
- Hearing what happens with the views and contributions they have made.

- People who are representing local communities or engaging on a number of issues want to have an enduring relationship and status with trusts.

Experiences of users and community groups

Users' and community groups have very mixed experiences of engaging with health services. Table 3 describes what it feels like to be involved – from their point of view. The majority of views we heard were negative.

Those patients' groups representing people with specific conditions, such as cancer and diabetes, described the most positive relationships with trusts. They were more likely to have regular contact with specific members of staff, sometimes clinical staff who work with their users. They may have sat on partnership boards, forums and planning committees that were developing the services they use. They were more likely to describe being asked to complete local surveys and undertake interviews. They were also more likely to participate directly in planning pathways of care. For example, "We have invited healthcare providers to our meetings and we have listened to each other. We have undertaken surveys with the public and our results have been presented to the providers – for example, diabetes care, pain clinic, dental care" (local diabetes users' group).

However, members of these groups also highlighted the realities of engaging with trusts when dealing with a new diagnosis or a long-term condition. For example "When you have cancer you are so distressed it's hard to think about the care you are getting" (patient with cancer), and "Patients should be able to dip in and out of involvement as their health allows" (users' group).

Table 3: Views of being involved in users' and community groups

Negative views of being involved	Positive views of being involved
• Disempowering – our views are ignored	• Empowering – I can give something back
• Patronised	• Valued and able to make a difference
• Frustrated and powerless – decisions already made	• Scary but satisfying
• Restricted by rules and paperwork	• A way to use my experience
• Feeling let down	• Feel part of a team to improve conditions for patients
• Fobbed off – not taken seriously	• Worthwhile
• Our views are an afterthought	• Listened to
	• Treated as an equal

(Taken from responses of user and community groups survey for Healthcare Commission November 2008)

A few groups representing patients in general practice contributed their views to this study. A few described having considerable support from their PCT and general practice, but others were struggling to establish themselves. The two examples below illustrate this:

"Our GP clinic has asked our view on many subjects from phone consultations to extra hours. They listen and then act for the benefit of patients" (practice participation group).

"Currently we feel our practice is not really communicating with us and only puts up with us because it looks good to have a practice participation group. They do not take on board what we say nor do they take time out to meet with us" (practice participation group).

Mental health and learning disability groups also had very varied experiences of working with health services. For smaller groups, it can be particularly difficult to raise issues or get involved. Those groups that are recognised by their local services could feel that their views were not being acted upon. One group involved in many policy and planning groups in their local mental healthcare trust described a common problem, "I get a sense that things are tweaked to accommodate our views and that small changes are made. I don't get the feeling that we radically change the delivery of service".

In the more positive examples, some groups worked with advocates and specific community development workers from trusts to feed in their views. They were also more likely to sit on staff recruitment panels and support staff training. In a few cases, members of users' groups were trained and employed by health services to gather the views of other users. This was seen as particularly successful. However, it was not widespread practice.

Groups that represent local communities described the most problematic experiences of trying to represent their communities to trusts. They were less likely to feel that they could raise issues on their terms or to know the best routes to feed their views across the organisation. This was particularly true, for example, among some black and minority ethnic community groups and disability rights groups. The following example illustrates this:

"As an umbrella group of 78 organisations specialising in black and minority ethnic issues, having been in existence for 24 years, we are constantly saddened how the NHS, on not liking the views we share – in good faith – discards them and then creates another group of 'friends'" (community group).

In some areas groups representing older people and carers were well served through planning forums and direct consultations. We spoke to a number of groups representing people from smaller faith communities and some other minority communities. They had the most negative experiences, often having no contact at all with their local health services, or rarely offered an opportunity to give their views or contribute their experience.

The experiences of forums and overview and scrutiny committees

Patient and public involvement forums and overview and scrutiny committees (OSCs) have particular rights to be engaged with health services, and they provide commentaries to the Healthcare Commission on their experiences. The majority of comments received from the 2006/07 and 2007/08 annual health checks about engaging with health services were positive, but a significant minority (up to a third) were negative.

Their relationships with healthcare organisations have been the most positive when there is an openness between senior managers and the forum or OSC, especially where an open door policy operates to allow comments and issues to be raised on a continuing basis. The forums or OSCs were more likely to be able to link with specific staff who can help take issues forward.

Forums, in particular, felt they had the most influence when they had representatives on internal health service groups and boards and they were involved in quality assurance, planning and strategy development, performance management, service commissioning, staff recruitment, tendering processes, service design and individual service improvements. It helped when healthcare organisations provided useful information for people to engage with issues, communication about current developments and feedback on how their comments were used.

It was felt that community groups linked to the forum or OSC could contribute more effectively where strong and supported relationships with them have been built up by healthcare organisations. There were other important conditions that forums and OSCs believed were necessary to have an influence. These include a joined-up approach with healthcare organisations working together and with the local authority or social services; a clear process for consultations on service reconfigurations and engagement activities that are well resourced and organised. Finally and most importantly, there needs to be a willingness among healthcare organisations to act.

When forums and OSCs have experienced problems, they have usually been related to healthcare organisations failing to provide them with adequate information, not consulting them at all, or 'paying lipservice' to consultation – for example, not involving them early enough to make a difference. Sometimes forums have heard information third-hand via the media, or have not received responses from major reports they have undertaken.

There were criticisms that healthcare organisations have not promoted the forums enough or have not reached out to get to know the voluntary sector or the communities they represent. Poor handling of major consultations was a common cause of concern and could lead to significant ill feeling about healthcare organisations if the problem was not resolved. The same is true of poor feedback on what has been done with the views and experiences they have provided. A frequent observation was that healthcare organisations do not put enough resources into the engagement activities they do run. For example, they did not ensure timely or accessible publicity about events, and provided inaccessible venues and inconvenient times of meetings.

Local groups taking the lead

Many user and community groups do not wait for health services to engage with them; they take the first step. This experience is often time-consuming and frustrating. However, we have also identified positive examples that can be used to support improvement.

Examples of user and community groups taking the lead:

- A forum and a health scrutiny committee worked together to address concerns about an independent service provider who changed the provision of service without consultation – the service was eventually discontinued.
- A black and minority ethnic community group undertook a focus group with their communities and identified issues about health services that were not being addressed. They used the information to bid successfully for a community worker from the local authority and PCT.
- A health forum of an older people's voluntary group invited the PCT and various providers to attend a special event. Older people were invited to table questions to providers and the PCT, which provided responses during the event.
- A local involvement network held an event in a city centre where a wide range of health and social care professionals attended and the public were able to ask questions about any aspect of health and social care they wanted. The participants included users of mental health services, some of whom were interested in how they could be involved in recruiting the mental health trust's chief executive.

3. How healthcare organisations are engaging people

This section describes the strategies that healthcare organisations have put in place to engage with people, and the roles of staff groups to deliver these strategies. It then sets out the main approaches used by all types of trusts to engage with individual patients or members of the public and with groups of people.

Overall, the majority of trusts had strategies for engaging people and staff responsible for them.[17] A range of different approaches were being used to engage people across the country, with some innovative approaches being jointly developed across local areas with local authorities and NHS organisations working together. However, there were also capacity issues for trusts in delivering these strategies and concerns about management and clinical leadership in some organisations. In terms of the approaches used, the main focus continued to be on the use of research surveys and one-off consultations. This was sometimes at the expense of more developmental approaches to building relationships and partnerships with communities to enable them to provide more continuous feedback on services and to actively support their improvement.

Strategies for engaging patients and the public

The majority of trusts said they had a strategy for engagement or were working towards one. This also reflects the findings of the NCI census 2008.[17] However, it is clear that these were at very different stages of implementation. There is some evidence that the strategies have been developed in partnership with patients and the public, but it is often not clear to what extent this has happened.

There is a common set of challenges to implementing the strategies. These include gaining commitment from other senior managers and clinicians, building responsibilities for engagement into front line staff roles, having the skills and resources in the organisation to engage people appropriately and a system for gathering and using the views and experiences that people provide. These mirror the issues identified in the National Centre for Involvement Census 2008.[17]

The more developed strategies were linked to action plans with responsibilities and timescales across the organisation. Occasionally, priorities for engaging patients and the public were part of organisations' frameworks for performance management. For example, a foundation trust described how it has "a performance management framework for involvement". For some trusts, the focus was to integrate engagement priorities within the corporate strategy and business plans of individual services and departments.

Key aspects of trusts' engagement strategies were typically to:

- Establish engagement systems and processes across the organisation.
- Build the capacity of staff and the voluntary sector for engagement.
- Make better use of data on the experiences of patients – a greater focus in provider organisations.
- Build partnership working – particularly for PCTs.

Some PCT strategies set out the respective roles of the PCT and the local authority in local engagement activities. For example: "We have an engagement strategy which was drawn up in partnership with the local authority three years ago.

We are also jointly integrated with the local authority's work plan on community engagement" (PCT). The local area agreement (LAA) provided the basis for joint engagement work in some areas, with PCTs and local authorities agreeing engagement priorities in line with the LAA priorities. For example, one PCT and local authority had community involvement commitments signed up to by all local statutory partners and a community involvement partnership that reported to the strengthening communities partnership. Very few trusts in the study set out their joint arrangements as clearly as this.

Foundation trusts were particularly focused on their engagement strategies, as they work to recruit and develop their membership and the role of their board of governors. For example, "We have a ten-year strategy in place. We focus on engaging with the local population to get their trust and confidence and set out the structures to achieve the objectives of patient and public engagement" (foundation trust).

The majority of the independent healthcare providers included in our study also had a strategy, and these focused primarily on improving ways of gathering and using information about patients' satisfaction with services. However, there were examples, particularly in hospices and some mental health organisations, which were aiming to take account of patients' views at all levels of decision-making. In a few cases there was also an interest on engaging with the public, although this was less common. The two examples below illustrate these points,

"We are very proud of our overall philosophy of involving people in everything we do" (hospice).

"As a company our reputation is paramount to us. We have always listened to patient feedback – it's what tells us how we can improve and offer the best services. The Directors ask for regular updates. They want to see exactly how well each individual clinic is doing in terms of patient satisfaction. I'd say right from the top down there is a definite interest. We expect high patient satisfaction" (private doctors' clinic).

Staff responsible for engaging patients and the public

Staff responsible for engaging patients and the public play a strategic role in developing strategies and action plans and also often support the roll out of the strategy across the organisation. However, some are responsible for a number of services, including the management of patient advice and liaison services, complaints, foundation trust membership, and equalities and diversity work. Some staff leading patient and public engagement try to integrate activity on engagement with communications activities and health needs assessment, and others work very closely with local authority colleagues.

In most healthcare organisations in this study, there were issues about the capacity of the staff responsible for engaging patients and the public. They often had a small team of staff and were unable to support engagement activity across the whole organisation. Many were trying to train 'champions' in each department or service to support patient and public engagement, and work with them.

There is a strong message from these staff members that it is essential for chief executives, non-executive directors and other senior staff, including clinicians, to have their own responsibilities for how people are engaged across the organisation. If chief executives and board members make a public commitment to engaging patients and the

public, this is felt to have an impact on how far people's views are used in decision-making. Where this was happening, it was seen to influence the organisation as a whole. These examples reflect the more developed practice;

"The board and the chief executive are particularly committed to public engagement and set the culture of the organisation. We work by expecting public engagement to be a mainstream activity for all managers. We see public engagement as being embedded in all business rather than a specific responsibility for one or two individuals. Taking this approach makes public engagement sustainable and part of everyday activity, rather than a specialism" (patient and public involvement manager, foundation trust).

"We have tried to get all members of staff signed up to patient and public involvement as a key feature of changing their services. This is gradually filtering through the organisation, with the Director as a strong lead" (patient and public involvement manager, PCT).

The role of clinical staff in engaging patients and the public

Clinical staff were also seen as having a key role to play in making sure patients' views were taken into account in planning and delivering care. We have found a few examples of clinical staff leading work to involve patients and the public in improving clinical care, but this is not commonplace. Some of the examples include:

- Hospital doctors attending question and answer sessions with users of services to help improve services.
- Senior medical staff attending consultation events on service reviews.
- Healthcare professionals working with users and carers on committees or groups to develop care pathways – for example, regular meetings between medical and nursing staff and people with Parkinsons' disease to improve their care.
- Medical teams working with inpatients to improve the organisation of care – for example, a consultant initiating engagement with patients about ward rounds.
- Clinical specialists working to improve hospital policies – for example, a haeomatologist leading engagement with religious communities about their transfusion policy.
- Patients being involved in clinical meetings.

Clinical nurse specialists were more likely than other clinical staff to be leading work to capture patients' views; for example:

"Clinical specialist nurses drive a lot of patient and public engagement. Ironically, if you talked to them they may not recognise it as that... there was some work done about services for irritable bowel syndrome through consulting and working with the clinical nurse specialist and the gastroenterologists were keen to improve care and treatment – as an approach it was very successful, with the whole team involved" (patient and public involvement manager, acute trust).

Users' and community groups have described considerable problems trying to communicate and build relationships with clinical and medical staff. Some users' groups have established dedicated advocacy workers to liaise directly with clinical staff to support people with disabilities or communication needs. However, when medical staff and users of services come together it can be enlightening for both sides, "Doctors often attend (question and answer sessions) with some trepidation....however, they are usually surprised at the level of support they get from the users of services" (acute trust).

Involving people in recruiting and training NHS staff

Some of the most powerful ways that people are engaged in health services are in recruiting and training healthcare staff and in taking on specific roles within healthcare organisations to support communities to engage with them. This is illustrated by the words of a LINk member who is a wheelchair user, "I have been involved with social care training for some years now but breaking into the actual health service is really quite exciting. I can see lots of potential for my knowledge to enhance the training of healthcare professionals".

There are different ways that this currently happens, but again we found relatively few examples during the study. They were more likely to occur in an individual service within an organisation, rather than as a corporate approach, or they may be one-off projects or pilot studies with particular communities; for example:

- Recruiting staff from local communities to reflect those communities.
- Users of services and carers participating in staff appointments and recruitment.
- Developing the role of carers, volunteers and long-term users of services to work within healthcare organisations, for example in staff induction and training. For example a local diabetes group described how they "helped the newly appointed black and minority ethnic diabetic liaison nurse to orientate herself and also showed her how to get hold of patients from black and minority ethnic communities. She had little idea what to do (being newly qualified) and nor did her line managers".
- Local community trainers working with healthcare staff to improve their understanding of the cultures of particular groups or their experiences of care – examples included representatives from gypsy and traveller communities, and people from lesbian, gay, bisexual and transgender communities.
- Children, people with learning disabilities or physical disabilities developing DVDs describing their experiences for staff training purposes.

In one example, a specialist children's hospital held an event for 10–16 year olds where 50 children were invited to make a DVD about how they would like to be treated. Twenty children took part in the event which was filmed at the same time. The children taking part were from diverse groups with different disabilities and conditions. When they were asked why they came to the event they said they wanted to give something back. They wanted to be treated as an individual, not seen as a "condition" or "disease". The DVD is shown to staff on induction and junior doctors training. The children came up with 10 top tips to let staff know how they wanted to be treated by them. These included:

- I want the doctors to talk to me.
- I want the doctors to look at me.
- I don't want lots of people in the room looking down at me.
- I want nurses to come back and play with me when they said they were going to.
- I want to see the doctor on my own.
- I want to be treated as independent and as a real human being.

The approaches used to engage people

The majority of healthcare organisations in this study described how they want to improve the approaches they use to engage people. User and community groups highlighted the problems they face trying to respond to poor quality local questionnaires and surveys or taking part in events that are not accessible – for example, inappropriate venues, timings or language being used. The most commonly identified priorities for healthcare organisations are to:

- Use a wider range of approaches to engaging people – beyond formal research.
- 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 questionnaires and surveys of local patients.
- Work with other agencies to gather and use information together.

Main types of approaches

The different approaches are described below, looking firstly at how trusts are engaging with individuals, and then with groups of people in the area. People are engaged in health services in many different ways, but these fall broadly into four categories:

- **Giving information** to patients and the public about health services and how to engage with them.
- **Getting information** about people and their views and experiences of health services.
- **Building relationships** with people to enable them to share experiences, discuss their views and help identify solutions to problems.
- **Creating partnerships** with people to work together to agree shared priorities and make the improvements needed.

The main differences in the approaches are:

- Whether they are one-off consultation activities or longer-term engagement processes.
- Whether they focus on gathering quantitative information from people or more qualitative accounts of their views and experiences.
- How far they give people a chance to discuss and develop their views – to deliberate.
- How far people are leading the approach, for example, taking a lead in developing the questions to be asked, talking to patients themselves, chairing the committee or managing the change.

The majority of approaches found in this study involved giving and getting information about people's views and experiences of health services. These were often one-off events or consultations. Building relationships with people to share their experiences and help identify solutions was less common, but PCTs in particular were increasing their efforts to build these relationships into the commissioning of services. Creating partnerships with people to agree shared

priorities and make improvements to services together was the least common approach, but again, we found evidence that most healthcare organisations were working to develop this type of partnership.

There were more examples of partnerships with users of services operating in services for people needing long-term care, including people with mental health problems or with learning disabilities. A number of trusts recognised that working with local communities that experience disadvantage or discrimination requires relationships to be built as a first step, rather than a focus on more traditional research into their needs.

Gathering the views and experiences of individual people

National and local surveys, and gathering real-time data

Patients were most likely to contribute their individual views through national or local surveys, completed either during or after they have used health services. These were used in some services, but not routinely across all services in an organisation. Some were being developed electronically, including the use of patient experience tracker surveys, which gather patients' views through handheld devices while they are in hospital.

The findings from the national patient survey programme can be influential. For example:

"We had quite a shock with the findings from our last national patient survey data. We thought some of the services were alright but patients told us something different. It led to us taking a very different approach to how we get feedback from users of services more regularly and we held a particular consultation on the issues raised in the national survey so we could take action" (acute trust).

There are some examples of local surveys of children and young people being conducted. This included adult inpatient surveys being revised to make them appropriate. However, there ws a perceived lack of national data about children and young people's views of hospital services. There are also examples of surveys being adapted for people with learning disabilities, working with users of services to make them more accessible. There were a few examples of surveys for carers. Much less commonly, members of the public were asked their views about healthcare through public opinion surveys, again, with increasing use of web-based surveys and household surveys.

Comments and complaints from Patient Advice and Liaison Services (PALS)

Beyond surveys, the most common sources of patients' views for trusts were complaints, compliments and feedback from Patient Advice and Liaison Services. There were usually formal mechanisms for reporting these to senior management and clinical teams, bringing together themes and areas for service improvement. In some cases they were used to produce performance information for GP practices. Individuals who have made complaints or people who have had a poor experience of health services as a result of accidents or mistakes were rarely involved directly in sharing their experiences or working to improve services.

Written comments and stories from individual patients

Patients were most likely to instigate their own feedback through feedback forms, comment or suggestion cards and boxes, and 'listening boards' in GP surgeries, dental surgeries, clinics, wards, outpatients departments, and so on. Some trusts have introduced 'You said, We did' listening boards to show people the feedback they have received and what they have

done with it to improve services. Interviews with individual patients and listening to patients' stories remained much less common – but there were plans to develop these in many trusts.

We found some individual examples of more innovative approaches to capturing the views of individuals. These include people being asked for their stories by sending an invitation to all households across a city; a project to interview all patients following discharge and a diary room drop-in video opportunity for patients to record their views.

Regular feedback from 'members' of healthcare organisations

Increasing numbers of people are becoming members of healthcare organisations, as part of the development of foundation trust memberships. Over 1.2 million people are expected to be members in 2009.[38] This approach is being copied in some PCTs that have been recruiting members to join involvement registers and by some acute trusts and ambulance trusts setting up hospital 'user banks' and networks of 'critical friends'. Members were usually individuals who have used the services over recent years and have expressed an interest in getting involved.

Trusts were focused on establishing these memberships and it is not clear whether they were increasing the influence of local people in planning or improving services at this stage. It is also difficult to gauge how far the membership of trusts adequately reflected those people who need the services, and those people who need additional support to provide their views.

For example, a PCT sends a panel of 500 people a questionnaire every month about different issues, for example, GP opening hours. The panel members are identified from previous consultations as they expressed an interest in getting involved. People are also recruited through neighbourhood forums. The information from the panel is fed back to the relevant commissioning team and the Director of Commissioning.

Engaging with people in groups

Feedback from patients' groups and representatives

Groups of patients and carers were most likely to engage through patients' councils, forums and other groups set up to support trusts. These varied according to whether they report to senior management groups or the main trust board, whether they were attended by senior managers, and the extent to which they could contribute to decision-making or simply raise issues for consideration. In the majority of examples gathered in this study, these groups were raising issues rather than helping to make decisions.

We found some examples of networks of patients' groups at different levels of the organisation, focused on specific services and issues, sometimes reporting back to a more strategic patient experience group. There are also some examples of groups of individual patient advisers used across organisations as representatives, and being trained and supported to participate in decision-making. This includes the expert patient programme. The models for these groups and their roles varied widely in different organisations and across the country, and in many cases, healthcare providers wanted to improve the way they use patients' groups, including using the LINks to help them.

In PCTs, as described below, groups of patients and carers are more likely to be brought together to feed into commissioning or partnership boards, or to sit as representatives on these groups.

Regular feedback from groups representing patients, users and the community

The majority of trusts wanted to improve the relationships they have with users' and community groups and the evidence from local groups is that this is much needed. Patients', users' and community groups were a critical source of information about the experiences of people with similar conditions, interests or concerns. Feedback may come from reports from patients' or users' groups, from direct contact through meetings or from users' groups being represented on working groups.

Some PCTs have established more formal partnership arrangements with local groups to support the commissioning of services, but this was not widespread.

For example, a PCT has established commissioning support services with the Motor Neurone Association, Multiple Sclerosis Society and Parkinson's Society. Researchers arrange focus groups of carers and users to discuss issues, with feedback influencing the way services are commissioned. Patient groups also provided 'expert' patients to healthcare organisations who have experience of a particular condition or service and may have been trained to work with health services to help improve care.

All trusts have been working to build better relationships both with users' groups representing people with particular conditions or health issues, and local community groups (typically representing older people, people with mental health problems, people with learning disabilities, carers, black and minority ethnic communities and people with physical disabilities). However, the extent to which this has been happening varies very greatly across the country. Local involvement networks (LINks) have been putting arrangements in place to enable networks of local groups to feed information through to trusts and to raise issues with them collectively. This was at an early stage during the time of this study, but there is some promising practice emerging (see section 5).

There are some examples of PCTs working with local communities in particular areas, usually through neighbourhood forums and local area committees, in conjunction with the local authority.

Working with overview and scrutiny committees

Trusts are already required to respond to health overview and scrutiny committees. Some have regular and informal discussions about work plans and current issues, as well as formal dialogue in relation to service reconfigurations and agreeing the process of consultation for these. In other areas, dialogue does not take place beyond occasional formal correspondence. In the most positive examples, trusts worked together with committees to access their networks of councillors and community groups to explore issues of mutual concern. The influence of health overview and scrutiny committees varied widely, with some trusts giving much greater priority to the issues raised by the committee than others.

Public events

There are various ways that members of the public may be brought together to share their views with trusts. Public meetings are the traditional approach, although some organisations were trying to organise events and activities around such meetings to increase

attendance – such as health fairs. Open days were increasingly being used by foundation trusts trying to build their membership and gather people's views at the same time. Some PCTs attended local area committees or public meetings in local neighbourhoods organised by local authorities as part of regeneration and community development activities.

Focus groups and panels

Focus groups were being used by some PCTs to gather the views of representative samples of the public to help determine commissioning priorities and in redesigning services. Some service providers were also using focus groups with patients or users of particular services, typically to explore care pathways and how they can be improved.

A small number of trusts were either using their local authorities' citizens' panels or jointly establishing panels with partner agencies. This was an area of growing interest for PCTs, some of whom were commissioning their own panels.

For example, one PCT used citizens' panels involving 7,500 people in continuing engagement, for which individuals have been drawn from cardiac and cancer networks, LINks, overview and scrutiny committees and the voluntary sector. These panels are regularly consulted on relevant issues.

Patients and the public influencing staff and organisational development

There are some examples of people playing more active roles, such as in the recruitment and training of healthcare staff; participating in audit and service monitoring and in leading engagement activities to work with users of services or communities directly, to encourage them to share their views. There are some examples of these approaches in the next sections.

Training and payment policies

Patients and the public need a range of support to engage with health services. Healthcare organisations have been increasingly developing training programmes for groups and individual representatives to support them in participating in decision-making. It was also common practice to recognise the contributions of patients and the public by reimbursing their time and expenses. This is not without controversy, as there was a minority view that payments can compromise the relationship and distort the feedback that people give.

4. Engaging with priority groups or people who have been 'seldom heard'

The majority of the healthcare organisations involved in the study recognised that they are not doing enough to ensure that the views of the whole community drive their decision-making. Many described how their engagement strategies set out their commitment to focus on those in poorest health or in vulnerable circumstances, or who have not traditionally had their voices heard. In some organisations this resulted in specific projects to build new relationships. In others, the work was still being done. In a few examples, healthcare organisations described very positive relationships with some priority groups whose views are regularly taken into account.

Who are the priority groups?

The following groups were most commonly identified by healthcare organisations in this study as a priority to engage. Some people are in several priority groups, such as young carers:

- Black and minority ethnic communities.
- Older people, including black and minority ethnic community 'elders', housebound older people, widowed men, older people with sensory disabilities, isolated or confused older people.
- Carers, including young carers, black carers, carers of children with complex needs, carers of people with mental health problems, alzheimers, autism, people with learning difficulties, carers of people with cardiac conditions, cancer and stroke.
- Gypsy and traveller communities.
- People with learning disabilities.
- Refugees and asylum seekers.
- Disabled people.
- Children and young people, including young carers (particularly those caring for people with mental health problems), children with complex health needs or long-term conditions and their parents or carers, children with disabilities, 16 to 18 year-olds,

Examples of healthcare organisations' priorities for engaging local communities

"We are giving priority to work with older people, younger people, black and minority ethnic groups, those who have English as a second language, the Roma population, lesbian, gay, bisexual and transgender people, people who think they are not heard – whoever has a perception of not being heard" (PCT).

"We can't work to the same level with everyone, so this year, as well as other groups we work with, we are focusing special effort on engaging prisoners and also doing more with the working population to understand their priorities" (PCT).

"We have large black and minority ethnic communities and we are moving to establish a very clear working relationship with them and their representative organisation, as well as with the local faith groups, as they do not always represent the same communities" (PCT).

"We are working to make lesbian, gay, bisexual and transgender people feel visible, heard and welcome...we want to break the circle of what we know happens – ie, groups are not understood; evidence is not collected and the right services are not commissioned" (PCT).

users of child and adolescent mental health services, young people involved in criminal behaviour or substance misuse, young people with learning disabilities, young mothers and looked after children.

- Migrants who were newly arrived from Eastern Europe.
- Lesbian, gay, bisexual and transgender communities – particularly in larger cities.
- The working population.

Others mentioned were teenage parents, drug and substance misusers, homeless people and migrants from southern Europe.

Approaches to working with priority groups in the community

A common set of 'community development' approaches were sometimes employed with these priority groups, tailored to their specific needs and requirements. Healthcare organisations stressed that these approaches were most effective when health services work together, for example the PCT with local acute and ambulance trusts and with the local authority.

These approaches are also believed to work to best effect as a package, with a commitment to working with groups and communities over time to build their confidence and trust, and mutual understanding.

For example, a foundation trust describes how "We use methods that are applicable to different groups. We also attempt to remove the formality of the way we engage with groups. We are less traditional and defensive and more open to casual but effective methods of engagement. Giving these groups the opportunity to raise their own issues...part of our investment in the voluntary sector is resourcing and coordinating advocates to liaise between participants and managers".

Examples of positive practice

Engaging with children and young people

There was a strong view from participants in this study that children and young people have not been sufficiently engaged in planning or improving services. Notable exceptions included some specialist children's services and national centres. There are also more examples of involvement in children's mental health services and in developing foundation trust membership. There are few examples of involving children and young people in commissioning.

We found a small number of examples of children being involved in the design of services, such as in accident and emergency departments and CAMHS units, family rooms on acute wards being designed by young carers, and school children designing childrens' wards and the ward environment. Looked after children were involved in one trust, along with other voluntary groups, to gain their views on service plans for a new children's unit. They also helped check the transport routes for the new units. There are good examples of children and young people providing feedback from using services in specialist centres, and influencing service delivery.

Children are being involved in developing information about services and conditions, such as asthma and pain booklets. Some of these projects involved school children as well as users of services. There are very few examples of children and young people being given a chance to influence and shape decisions as part of a team with healthcare staff.

Approaches being used to develop relationships with priority communities and individuals

- Mapping local communities.
- Identifying and acting on communities' immediate health needs.
- Outreach services to work with local communities in particular areas.
- Using the existing centres and networks where people meet.
- Working in partnership with voluntary organisations.
- Improving communication with groups.
- Recruiting community members to provide advice about their traditions.
- Workshops and focus groups for particular groups, 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, and to promote consultation events and services.
- Developing tailored information with communities themselves, about health services and how to engage with healthcare organisations.
- Using creative approaches and trying new techniques.

Evidence from healthcare organisations and from user and community groups themselves has been brought together to produce the examples below. Few healthcare organisations involved in this study described using such a package of approaches. However, those that did were very positive about the improvements in community relationships and influence over their services they felt had resulted from their investment.

Mapping local communities

Some healthcare organisations, mainly PCTs, described how they were undertaking detailed mapping exercises, some with local authority partners, to better understand the size and nature of the communities in the area, and their possible health needs. They were most likely to use information on local populations held by local authorities, equalities and diversity teams, general practices and local umbrella organisations in the voluntary sector. Some PCTs worked in partnership with these agencies to 'network their intelligence' about smaller sized communities and how best to reach them. Others had more informal mechanisms for gathering information about their communities – such as through intelligence from their relationships with local voluntary and community organisations. These groups also provided a channel for PCTs to disseminate information to minority communities. LINks are expected to fulfil this role as they develop.

One-off mapping exercises were seen as important to establish a baseline profile of the community. There were strong views, especially from the voluntary sector, that continuous tracking of communities is essential to help identify changes in the community profile or to identify groups that may need more support to engage with health services at particular times, such as newly arrived communities, or groups whose support networks are less active.

"We know that for our local population our hard-to-reach or seldom heard groups are less about asylum seekers and newly arrived communities, and more about disabled groups and lone parents." (PCT)

"The Polish and Somali communities are the biggest growing and emerging groups in our area and we have been to their community centres" (PCT)

Identifying and acting on communities' immediate health needs

We have heard how important it is to give local groups the opportunity to describe their immediate health needs, before exploring their views on issues that health services want to talk about – see the examples with gypsy and traveller communities opposite. Some healthcare organisations have described how they have had to take action to address some of these needs as a demonstration of their commitment to the community, and as the basis for future dialogue.

Outreach services to work in local areas with particular communities

We found examples of facilitators and development workers in the community, such as people supporting black and minority ethnic communities or gypsy and traveller populations. In some areas, these workers came together from different services to share progress on how well they are reaching these communities. In some acute services, individual members of staff working within a hospital were being appointed to be the link with specific communities, to build up trust and rapport – for example, with the Somali population.

Example of positive practice

A PCT identified the need to engage with people living on a travellers' site following reports of people being unable to use forms or access GPs, and because emergency services were reluctant to go to the site. As part of a health needs assessment, the trust asked people living there about their health and their experiences of healthcare and found that there was a need for a range of services, including help with literacy. The trust worked to develop the skills and confidence of the community, to enable them to engage. They also helped the community deal with some of the housing issues that were affecting their health. A toolkit, including leaflets in simple language, was developed in conjunction with a worker already on the site. A travellers' forum was set up which included staff from the housing department and the PCT and hospital executives. Senior staff were to be held accountable for the decisions taken. Relationships were built and the confidence of the participants and the community increased. The forum was held in an environment where the travellers felt comfortable and childcare was provided.

Using the existing community networks, centres and hubs where people meet

This allows healthcare organisations to disseminate information and better understand people's health needs. Examples include visiting youth centres to contact young people; community centres; working with faith groups in local places of worship, such as talking to the Polish community using their local Roman Catholic Church to target Polish communities; reaching young Muslims at their mosque; lunch clubs for certain groups of older people; schools and youth centres to contact children and young people. Some trusts were also using outreach working with football clubs, schools, colleges and universities.

Working in partnership with voluntary organisations

Healthcare organisations may need to build a relationship with communities. Working in partnership with voluntary organisations allows them to contact groups, provide information and begin a dialogue. Some groups worked as intermediaries and advocates, especially those who already have a community's trust and confidence, such as with lesbian, gay, bisexual and transgender communities, young people involved in crime, gypsy and traveller communities.

Examples of positive practice

Some trusts were working jointly with local authorities to make use of the children and young people's networks that operate through council services. Examples include working with youth services, children's centres, young people's networks, youth parliaments and independently funded youth advisors. For example:

"We tapped into youth clubs and tried to use the hubs in the community where possible. This allows you to reach a lot of people in contrast to attempting one-to-one work and you get much better feedback" (PCT).

Local authorities were also working to measure young people's participation in their services in many areas. A few PCTs were working jointly with local authorities to make use of these tools and the emerging data.

Example of positive practice

A project was organised by a community group and funded by the PCT aimed at addressing the problem of Asian women not accessing services due to a lack of understanding of the systems. The project was a partnership between agencies, including health and social care services, the voluntary and community sector and the PCT. It involved a series of sessions with groups designing and producing quilts with health and health service messages. It enabled health workers to have a better understanding of the community and the different cultures within it.

Improving communication with communities

This includes interpreting and advocacy teams training other advocates, interpreters and social researchers to work with communities. It may involve training local people to be community influencers, such as Pakistani women, some older people and teenagers.

Example of positive practice

Older people living in a remote rural setting were given hand-held computers to provide views and share information with health services. This became an effective way of people keeping in contact with the hospital and they were reluctant to give them back!

Recruiting community members to provide advice about their traditions

Most often, this was to train NHS staff about their communities and cultures, for example, gypsy and traveller communities, asylum seekers and refugees. It also included developing guidance for staff about working with certain communities, in conjunction with local groups themselves.

Example of positive practice

An acute trust and an ambulance service worked together to connect with gypsy and traveller communities through gypsy liaison groups. Meetings were set up with the 'elders' to break down barriers, increase understanding on both sides and reduce the risk of confrontation between the trust's staff and the gypsy and traveller communities. Training and information were given to staff on how to work with these groups, and verbal information was given to gypsies and travellers via the gypsy liaison officer, recognising the limited literacy of some members of this community.

Workshops and focus groups for particular groups

There are examples of this approach as stand-alone research, or as part of wider consultation exercises. Sometimes people were recruited from priority groups to temporary panels and groups to help with commissioning services.

Example of positive practice

One PCT held workshops with asylum seekers, developed in partnership with other health and social services. In another PCT, focus groups were held for Portuguese-speaking parents, traveller women, homeless women, lesbian, gay, bisexual and transgender communities as part of a wider consultation on service redevelopments.

Providing resources to communities to help them identify needs and develop services

This includes helping communities and local groups to develop their own capacity to engage by providing resources and training, including funding for communities to undertake an assessment of their own health needs.

Example of positive practice

An older people's network was jointly funded by the PCT and local authority to undertake a needs assessment with its members. The resulting findings were used to establish a service run by older people for older people in the community to answer their questions about health services and to direct them to further help and advice. Training and support for the network was provided.

Working with local councillors, community leaders and 'elders' and the community press to help build relationships, and to promote consultation events and services

Example of positive practice

A Jehovah's Witness group was involved in drafting the trust's policy on transfusions of blood products. The trust reached the Jehovah's Witness community through community leaders, gave them an opportunity to put questions to staff, and built a relationship with the community through both clinicians and managers. Clinicians gave a commitment to abide by the finished policy. The involvement of the group helped to open up a wider debate about the policy on transfusions.

An ambulance trust engaged with a local, well respected Rabbi, who carried out a number of awareness sessions with staff on why Jewish patients did not carry their bags on the Sabbath. This led to a reduction in complaints from the patients and increased understanding from staff.

There are examples of the community press being used to provide information about relevant health services and to explain how particular groups can get involved or contribute to particular consultations. For example, accessing carers through carers' magazines, publicity about services in the gay press, and information broadcast through Muslim radio channels.

Working with individuals with poor healthcare experiences, including complainants, to act as critical friends

Some patient and community groups, particularly those who have had a poor experience of healthcare, raised concerns about the lack of openness by trusts when mistakes are made. There are very few examples of trusts actively engaging with people who have complaints, but those we identified are shown below.

Examples of positive practice

A mental health trust involved users of services on its critical incident panels "to ensure openness and transparency in decisions".

An acute trust established a research programme, which engaged people in considering 'live' safety issues in the hospital itself.

Parents of children using a hospice service were involved in considering complaints and incidents.

Developing tailored information with communities themselves, about health services and how to engage with healthcare organisations

Example of positive practice

A PCT took ideas for their operating plan for travellers' families to the travellers' sites to get their views on the priorities for the plan. The material was in pictures with key words and staff spoke to the travellers directly to gather their views:

"We are as creative as possible but realistic and adaptable – if one thing doesn't work we try another".

Adopting creative approaches, and trying different techniques

Examples of positive practice

A children's hospital ran an arts programme working with community artists to help families tell their stories of their experiences of hospital. In another hospital play workers were used to hold workshops with children with complex disabilities as a way of reviewing their experiences of the service.

Some services were making more use of technology to reach young people and their parents, such as dedicated websites, pages on Facebook and phone texting to communicate and gather views. One trust had a network of 550 parents of disabled children and regularly gathered data from them by text message.

5. Healthcare organisations and LINks

Local involvement networks (LINks) were being established during the period of this study. Healthcare organisations were largely positive about working with LINks, although there was some uncertainty about the influence they will have, compared to their predecessor bodies, patient and public involvement forums. In areas where forums were not considered to work very effectively, people were more enthusiastic that LINks would help them to engage with a wider number of local groups and communities across a local area and across health and social care. The quotes below illustrate the typical view we heard from healthcare organisations and a recognition of the demands that may be placed on LINks in the short term,

"We expect them to have a positive impact. We get the sense that so far people on the LINks represent groups that are not individuals, so there is more representation. We think that this is the key to success, a more legitimate voice, with different groups" (patient and public involvement manager).

"It will be a long time before the LINk will be in a position to do all the consultation of a trust.... LINks will have to choose their territory and priorities" (LINk member).

Healthcare organisations' priorities with LINks

In many areas, the LINk was focused on establishing its governance arrangements and building its membership. Some healthcare organisations have taken a proactive

approach and embarked on early discussions with partners to think through how transitional arrangements with the host will work and setting out structures and processes to develop a working relationship with the LINk.

Those trusts covering larger geographical areas, such as ambulance trusts and specialist centres, highlighted the particular challenges they face in relating to many different LINks. Some were beginning to make contact with the various host organisations and trying to help LINks understand the services they provide and the way they work. Equally, LINks in these areas were developing ways of working together with other LINks to jointly influence healthcare organisations that cover their areas.

"The LINk invites chief executives to meet members of the LINk, which provides residents with the opportunity to put their personal experiences to those making the decisions" (LINk member).

Other trusts were concentrating their efforts on developing their own membership and involvement structures. This was more common among PCTs, and some aspiring foundation trusts, as well as foundation trusts themselves.

These organisations saw the LINk as one way to access community views, but by no means the only route. They wanted to build relationships with individual voluntary sector organisations on their own terms. For example, "The patient and public involvement manager will develop other engagement processes, and will use the LINk to supplement these" (foundation trust).

Examples of positive practice

Joint working between LINks and healthcare organisations

Some healthcare organisations and LINks described how they were already working together. This included:

- Trusts being active in the tendering process for the host organisation, and supporting the transfer and change to the new organisation.
- Using information gathered from LINk launch events.
- Healthcare staff attending LINk meetings, including patient experience officers, directors of public health.
- Inviting LINk representatives onto trust committees, boards and tender panels.
- LINk members contributing to a PCT's joint strategic needs assessment.

"The LINk has ensured user representation on a wide range of committees on the acute and foundation trusts and on all health and social care committees" (LINk member).

Healthcare organisations were mainly concerned with the time it took to establish the new LINk arrangements, how representative LINks would be, how they would be held to account if they were performing poorly and the limitations of relying on LINks as their only route to accessing the community. There was also some discussion about how the relationship between the LINk, and boards of governors and trust members of foundation trusts would operate in practice.

LINks' priorities

LINks' priorities fell into four main areas: setting up their organisations and systems, launching activity and recruitment to the LINk, building relationships, and holding events.

"In addition to locality groups building on the structures of the patient forums, the LINk is setting up specialised themed groups to enable a better focus on particular issues in health and social care" (LINk member).

Examples of work from these priority areas includes actively recruiting people to the LINk, particularly focusing on recruiting more people in vulnerable circumstances and establishing a pool of visitors that can enter and view health service premises. There was also considerable activity to raise the profile of the LINk in the community and among NHS staff. Relationships were being built with overview and scrutiny committees (OSCs), staff in trusts responsible for patient and public engagement, and with other voluntary organisations. A small number of more established LINks have held events to bring healthcare managers and staff together with patients and the public to raise issues and share information.

A number of LINks and OSCs were developing a protocol to set out the respective roles and responsibilities of the two bodies. There were moves to include OSC members on the LINk and vice versa. Some OSCs described how they would involve the LINk in their forthcoming reviews of health services. Sharing and supporting each others' networks was considered critical to their success in building local involvement:

"The OSC should have a strategic view of patient and public engagement across the patch...it should get information by establishing a good relationship with the LINk, so intelligence is coming up to the OSC from the LINk" (OSC member).

LINks were concerned that healthcare organisations should understand the limits of their capacity, respect their autonomy and enable them to genuinely influence health services. They were also dealing with complex issues of representation, setting out the roles of paid and unpaid members of the LINk and the role of councillors, and how forum members could provide continuity in the new structures, while still enabling new members to participate fully in setting up the new organisation.

"The LINk has limited resources in terms of volunteers, so has a major task in ensuring they are used to best effect and that their input isn't tokenistic. How do you go beyond being part of a trust or board type meeting? How do you get into the fabric of the organisation?" (LINk host).

6. Engaging people in different types of health services

This section describes how and why people are engaged in the different types of NHS organisations. This includes primary care trusts (PCTs), mental health and learning disability trusts, acute and ambulance trusts. We have included a few of the more successful examples of engagement for each type of healthcare organisation. We have had very few examples of how people are being engaged in GP services.

Engaging people in the work of primary care trusts

Joint strategic needs assessment

When PCTs are identifying the health needs of local communities or groups, they sometimes start a dialogue with those communities. This process is now undertaken jointly with local authorities through the joint strategic needs assessment. While PCTs generally recognised the opportunities that this process gives them to engage with communities, we did not identify many examples of how it has increased the engagement with particular communities or led to changes to services and plans.

Examples of positive practice

Engaging people in health needs assessment

- A PCT established a database of people with disabilities and their carers as part of a health needs assessment. This acted as a channel for communication with the PCT. The database register doubled from 1,000 to 2,000, and people on the register were invited to contribute to consultations.
- A PCT worked with the lesbian, gay, bisexual and transgender community to identify their health needs. It showed that the PCT needed to build trust, increase access to mainstream services, train staff with the help of users' groups about sexual orientation. The trust had started to address these needs.
- Patient profiling in a health centre, funded and supported by the PCT. The local authority and a wide range of local third sector organisations were also involved in this exercise aimed at improving health provision at the practice by gathering information about its patient population. The aim was to discover what the patients' health records did not say about the community, and to use this to ensure the practice was offering relevant services. A database was created from the information collected from the questionnaires, discussions with patients and open days. A mapping exercise was also performed. The impacts included:
- People in the community with healthcare qualifications in their country of origin volunteered at the practice.
- A team of paid healthcare development workers was recruited from the community.
- The practice expanded its interpreting service, with input from the healthcare development workers.
- The practice started outreach health promotion in the community.
- Children with learning difficulties and their carers were given increased support.

In some areas, there were well-established networks of community groups feeding information into joint partnership and commissioning boards. Where this was in place, needs assessments were being developed and run with a greater involvement of the communities themselves. In some cases, PCTs created databases of people with certain conditions, or in similar circumstances, that they can contact regularly for information and views. Others took a community development approach, especially when assessing the health needs of groups in vulnerable circumstances or experiencing discrimination, such as gypsy and traveller communities. For example, training community representatives helping to identify health needs (see section 4). However, this did not appear to be widespread, and was usually limited to specific projects, rather than as an approach across the organisation.

Commissioning health services

Only a small number of PCTs engaged people in all stages of commissioning a service, or did so routinely for commissioning services generally. There are some examples of people being engaged in the different stages of the commissioning of health services, including:

- The strategic direction of the PCT.
- Identifying communities' health needs.
- Allocating budgets and resources.
- Major service reconfigurations.
- Reviewing individual services.
- Developing service specifications and contracts.
- Tendering and procuring new services.
- Monitoring services.
- Evaluating commissioning processes.

People were most likely to be engaged in large-scale consultations on service reconfigurations and in reviewing individual services. They were engaged, to some extent, in identifying their health needs, developing service specifications and taking part in the tendering and procuring of services. Some PCTs established mechanisms to engage people in their procurement processes. People were much less likely to be involved in decisions about the way resources are allocated and in developing standards for clinical quality.

PCTs recognised the need to support people by providing adequate information for them to contribute effectively and to engage people early in the process of change. These were two of the most common criticisms from users' and community groups about poor engagement practices. Positive examples include a PCT that held conversations with the community, that included 16 focus groups representing different age groups to ask about their spending priorities for health services in the area. They learned that their opinions changed depending on how much information people had to help them make their decisions. Another PCT explained how they were "starting to involve patients at the early stages of planning and redesign, through storytelling, diary keeping, shadowing...".

Large-scale household consultations on service reconfigurations tended to involve a mix of approaches including roadshows, launch events, surveys, focus groups, direct mailing and getting feedback from existing committees and patient or community representatives. The more coordinated examples of consultations were joint exercises between PCTs, sometimes with local authorities and the provider services involved. There was more limited use of approaches to discuss priorities and budget allocation, such as deliberative events, discovery surveys and decision-making workshops.

We found a small number of examples of people being engaged in the tendering and procurement of services, particularly for primary care centres and GP practices, and services for people with long-term conditions, such as HIV services, cancer services and the provision of wheelchairs. In one example, a PCT developed a system for involving those community groups who have the poorest health, in the whole procurement process (see opposite).

Most PCTs were not yet building requirements for patient and public engagement in their provider contracts, but many PCTs in the study identified this as a priority. A few PCTs described how they were beginning to roll out such requirements in their contracts, and some were incorporating quality standards for patient and public engagement in the quality schedules they agree with providers.

There were also only limited examples of PCTs working with practice-based commissioners, but again, this is a priority for future work in many PCTs in the study. Where this was happening, it included work to raise awareness of the role of practice based commissioners to involve patients in shaping commissioning decisions and to develop patient participation groups. For example, one PCT required practice based commissioners to show how they were engaging patients and the public in their plans for new services from the earliest stages. Proposals that did not do so were not accepted.

Example of positive practice

Engaging people throughout the commissioning process

A PCT had a written protocol for engaging patients and the public in each stage of the commissioning cycle. This included a system for how to engage people in redesigning a service or care pathway or in developing a service strategy. Users and carers were involved to enable the PCT to learn from their experiences and to find out their expectations and aspirations. The service, pathway or strategy was then developed with clinicians and LINk representatives and tested out with users, carers, users' groups and others to make changes necessary. The pathway must demonstrate value for money, clinical need and patient wants. Programme boards were in place for different service areas or patients' groups with representation from users. The programme boards helped to identify the initial specification for the care pathway or service and provide continuity through the process. External consultants or voluntary organisations were regularly commissioned to recruit people for focus groups, deliberative events and surveys at key stages of commissioning a service. Everyone engaged in the process was given feedback on what has happened as a result.

Examples of positive practice

Consultations on priorities

- A deliberative event was held by a PCT on priorities for commissioning local services. This was advertised in the local press and participants received a voucher as an incentive for attending. A range of interactive media were used to engage participants, including video and voting systems. Four hundred people attended, representing local communities, patients, GPs and other staff. Two facilitators on each table enabled good discussion. Participants, including people who use Mencap services, felt listened to and valued. The event was followed up with a survey that reached all groups in the community.
- A PCT sent a discovery survey to all households in the city – 5,000 were returned and the results influenced the commissioning and strategic plan.
- A PCT ran decision-making workshops to enable people to understand the criteria and priorities they use to make commissioning decisions, and to enable the PCT to take account of the priorities of the public. Feedback was given to participants on the findings of the workshop and the impact it had.

Examples of positive practice

Engaging people in procuring services

- A PCT has taken an iterative approach to involving users' groups in the procurement process for some services. Users' groups have helped to shape the specification and contracts, and providers were required to go back to these users' groups as part of the ongoing monitoring of services. For example, during the procurement of the first stand-alone urgent care centre, potential bidders were required to speak to a range of hard-to-reach groups, such as people with mental health problems, people with learning disabilities, young people, older people, and those from minority ethnic communities, and use the information gathered from these groups to inform their bid. The same groups were then involved in the implementation and monitoring of the service.
- One PCT has used information from focus groups to influence the development of their contracts with providers, with the aim of improving service quality. The implementation of quality standards was monitored through ongoing surveys of the views of users of services.

Examples of positive practice

Engaging people in service reconfigurations and reviews

- A PCT held a deliberative event to develop a specification for a health centre. Thirty-five people were recruited randomly, reflecting the local population, taking account of age, gender, long-term conditions, disability and ethnicity. Information from the event helped to develop the specification and this was then consulted on across 5,000 households. Feedback was given to people who took part about the outcomes of the service.
- A PCT undertook a review of an HIV service, since it had received comments from patients who had identified problems with it. The review was led by the sexual health steering group, made up of clinicians, commissioners and patient representatives. They undertook consultation, using focus groups and questionnaires and used the feedback to agree the commissioning priorities. A commissioning panel was set up, which included representatives from a forum of HIV patients that was set up as part of the process. They organised the tender for the new service and were told the budget to help them focus priorities for the tender.
- A PCT has held a public debate looking at access to GP centres and community services. It engaged 10,000 patients and members of the local public through a questionnaire, website, local media and GP newsletters. The PCT worked with partner organisations, health forums, community groups, excluded groups and other healthcare trusts. The new strategy has been developed and is now being implemented, with ongoing engagement in reviewing and feeding back on the changes and further improvements. The impacts have been identified through an independent evaluation, and included:
  - A board-level decision to implement the plan that took account of people's views.
  - A new treatment centre.
  - Services that are shaped by a range of patients' needs.

Engaging with people using mental health and learning disabilities services and their carers

We found some of the more developed systems for engaging users of services and carers in mental health and learning disability trusts. Their main focus for engaging with people was generally to improve their experience of care, and improve community as well as inpatient service provision. In particular, mental health services were carrying out more activity to improve the local community's understanding of their services and to reduce the stigma associated with using them. The use of advocates and the recruitment of users of services to gather information from other users is also more widespread in these services compared to other types of healthcare providers. We found more examples of users of services leading local mental health forums, service users' groups and engagement events, compared to other service areas.

The list opposite illustrates the range of approaches used by mental health and learning disability trusts to engage their users, carers and the public. The examples highlight the importance of mixing different methods to ensure that people are engaged as an integral

Examples of positive practice

The range of approaches to engaging people using mental health and learning disability services

- Using a user or carer involvement committee and voluntary group networks to develop the patient and public engagement strategy.
- Holding consultation events on mental health care pathways, including public events.
- Users of services being represented on commissioning panels and partnership boards.
- Using locality planning and monitoring groups to develop services for particular areas, and patients and users on steering groups.
- Users and carers advising on the care environment, particularly for new buildings.
- Users and carers being represented on appointment panels.
- Holding public awareness sessions in shopping centres.
- Putting user and carer partnership councils in place for inpatient services; user and carer councils reporting to the trust's board, and users being represented on care programme approach groups and local teams.
- Local users' groups being employed to visit inpatient wards to listen to patients' concerns and feed back to ward managers and ultimately to the strategic level committee.
- Putting independent advocacy services in place.
- Involving users in developing DVDs about their care experiences for staff training purposes.
- Users being represented on research ethics committees.
- Patients attending clinical meetings and clinical governance groups.
- Users of services and carers having speaking rights at board meetings and direct access to the chair, chief executive and executive directors.

part of their care programmes, but are also supported, through advocates or other users, so that they can talk about more than their immediate care.

Few mental health and learning disability trusts were using such a wide range of approaches. The example below provides one of the better accounts of how a mental health trust is bringing together different approaches.

Examples of positive practice

Engaging users in one mental health trust

A mental health trust had a trust-wide involvement plan that was being reviewed with service users' groups and strategic community and voluntary groups. The new strategy was being developed with a trust-wide involvement group that was working with LINks, children and young people's groups, and patients and users. It had an 'involvement register', which registered users who were interested in being involved. They were paid for their time, as well as to attend a training course. Their work included interviewing other users of services on a fortnightly basis and link working. Members of a local mental health group were also employed by the trust to visit inpatient wards to listen to patients' concerns and this was fed back to ward managers and staff. Improvements were promised within a defined timeframe. The information fed into the trust at a more strategic level – providing data to analyse trends. The director of service development regularly carried out surgeries with users of services at MIND and used the information to look at individual services. It had a code of conduct for ward rounds that has been developed by a service users' group.

Engaging people using acute hospitals

People using hospital services were most likely to be asked their views through surveys, about their individual care, communication with staff, the quality of information they receive, conditions on the ward and the hospital environment, including food and cleanliness. The example opposite, from one acute hospital, illustrates the approaches being used across the sector as a whole. This is one of the better individual examples from the acute sector identified during the study.

Patient representatives and some local patients' groups were widely used on a range of committees. Most commonly, patients using particular services were part of working groups that aimed to improve how care was being delivered. There are some examples of people being more actively engaged in talking to patients and staff and checking how care is provided. The most common examples are in infection control programmes, and improving the designs of wards and hospital environments – particularly projects on future ward designs.

There are some examples of acute hospitals engaging with patients to decide their priorities and service plans – through 'patient involvement or experience' committees at a more strategic level, reporting to the board or senior executives. We identified fewer examples of this level of engagement.

There was generally less engagement with the public, apart from when it was part of a wider consultation exercise with a PCT. Some acute trusts recognised the need to improve their links with local communities and community representatives. For example, one acute trust described how it wanted to join the local strategic partnership in their area to reconnect

with local community groups who it no longer worked with. There are a few examples of acute trusts establishing outreach and specialist workers to engage with local community groups, and this role was also given to some clinical specialists in some areas.

There are various examples of people being engaged during their hospital stay. These include ward-based consultations and discussions, sometimes led by clinical staff, to improve the way the ward was run or the care provided. For example, a 'Matron's Question Time' was held on an older people's wards, where patients and their carers could give feedback in an informal setting. This had led to many small service changes to improve the day-to-day life of older people on these wards.

The move to gathering real-time data from patients on wards and in outpatient departments was providing a focus for some acute trusts' engagement activity, sometimes working with local voluntary organisations or patient champions to administer the surveys during people's stay or visit to the hospital.

There are some examples of work with specific patients' groups to explore care pathways, which use focus groups and patient interviews about their journey through health services. These were not common, but were viewed very positively by the patients' groups and healthcare organisations involved.

Examples of positive practice

Engaging patients in one acute hospital

One acute hospital used a range of techniques to gather patients' views, including post-discharge interviews, face-to-face interviews on the wards, focus groups, surveys and patient diaries. The trust ran focus groups with users of cardiac services and their carers, to map a patient's journey after discharge and identify improvements needed. This led to patients receiving better information about their referral to the hospital. The trust also polled inpatients and outpatients, including children, who receive a revised questionnaire, every quarter to identify views on service quality. This was led corporately and included some service questions as well as trust-wide questions. Each area or department had to analyse its response, act on them and report back. The process was used as part of performance monitoring within directorates.

For some years, the trust has also appointed a number of patient advisors, who were considered very effective in influencing decisions. They have sat on the trust's steering group, clinical governance group, infection control group and patient safety group, each one linked to a clinical directorate. Patient advisors interviewed users of services on a fortnightly basis and fed this information back to the directorates for action. In addition, patient representatives have been appointed to various committees, such as the length of stay committee, to offer their perspective.

The trust provided visual information to patients and visitors that outlined the feedback the hospital has received and the actions it has taken in response – *You Said, We Did*. This included ward-level information on patients' views and changes made.

Engaging people using ambulance services

Ambulance services face different challenges. They have been working to engage the public across large mixed geographical areas, and to engage users of services who are often in very poor health or suffering from an acute condition when using their services. Their work with the public has focused on awareness raising programmes and working in communities to improve the use of their service, or in health promotion. Overview and scrutiny committees (OSCs) and some of the more established LINks have been working with ambulance services to support this work.

Engaging with patients and carers has required different approaches. There has been less frequent information available from national surveys on people's experiences of using ambulance services. Some local services have been developing their own surveys. Some work had also been directed through local community or patients' groups to gather feedback from patients when they are feeling better and are back in the community. Again, there are examples of larger consultation exercises that draw in local people to give their views on ambulance services, usually in conjunction with PCTs.

Examples of positive practice

Engaging people in ambulance services

- An ambulance trust held an event to introduce LINks and OSC representatives to its services. It aimed to start building a relationship and establishing a network between the trust, LINks and OSCs, and other trusts that would filter down through the organisations involved. As a result, the ambulance trust has been a regular item on LINk agendas and has a higher profile.
- After a public consultation on the reconfiguration of control centres, an ambulance trust wanted to respond to public concerns that the new centres would lead to loss of local geographical knowledge. A public campaign was developed that used direct marketing in post offices, PCTs, GPs, the media and the trust's website. It asked people to get in touch if they were concerned that the ambulance service would not be able to find them in an emergency. This led to the creation of a database where people can give information about how to reach their homes.
- A PCT and ambulance trust consulted users' groups about patients having to travel long distances to a tertiary centre. Ambulances are not always appropriate for older cancer patients as they may not be well enough to travel. Discovery interviews were carried out with patients and used to produce a specification for a provider.
- An ambulance trust worked with young people at risk of being involved in knife crime to explore their views and experiences in relation to ambulance services. The trust used people who can speak in a language that the young people can relate to – rather than trying to engage the young people directly.

Engaging people in foundation trusts

Foundation trusts have been concentrating their efforts on recruiting and developing their membership. Members were usually users of services or people with an interest in the trust, who are contacted regularly with information about the trust's work, asked for their views or encouraged to get involved in the trust's business. Membership magazines were used as the main communication tool with members, and often included details of how to give feedback on services. Governors in some trusts took a lead on developing the membership, establishing groups to do this with other staff and users. Some trusts have further developed the role of the governors, who have taken part in running focus groups, joined inspection teams and developed approaches to gathering patient experience.

There are examples of foundation trusts focusing their efforts on recruiting priority groups of all kinds, to improve the representation of their members and to reach out to under-served communities, including consulting children and young people, older people and black and minority ethnic communities. However, we did not identify many examples of how these groups were making an impact on trusts' plans or service improvements.

The main measure of success in foundation trusts' engagement during our study was seen as the size and composition of their membership. Many foundation trusts had plans

Examples of positive practice

Approaches used to recruit and develop foundation trust membership

- One trust described using campaigns and newsletters, advertising, invitations to the annual public meeting, and 'get well soon' cards which were sent to patients to inform them about foundation trust membership. It has also used the membership to consult patients and the public consultation about infection control, smoking policy, and developing the vision for the trust.
- A foundation trust employed an education liaison worker to build relationships with schools, and to increase memberships of the trust. The young people's membership has doubled in less than a year as a result.
- A foundation trust recruited 35 young people aged between nine and 19 to form a children and young people's group to mirror the membership of the board of governors. The group can set their own agenda and meetings are attended by the chief executive, clinical director, and children's services manager among others. Parents do not attend the meetings. A number of improvements to services have been put in place as a result of the group.
- A foundation trust held a series of open meetings involving its members, governors, chief executive and chair. The process was led by the chair, but a partnership approach was taken from the outset. The involvement process was triggered by patients voicing their concerns about the length of time it was taking to receive the results of their clinical investigations. Following the consultation, a work stream was put in place to improve the service. Feedback was given in writing to all participants and to all members in the quarterly newsletter.

to involve their members more actively. Some had identified areas of their service in which individual members were interested, to provide a pool of members who could be contacted directly about specific services or issues.

It was not clear from the examples gathered in this study whether foundation trusts' memberships were having a greater influence on the priorities or plans of the trust.

Engaging people using independent healthcare organisations

The independent sector saw itself as being strong on patient focus. This focus varied between the different service areas – for example, acute providers tended to talk about "patient satisfaction"; mental health providers about "empowerment" and those providing terminations about being a "client-led service". Patient focus was seen as important in order to:

- Provide high-quality patient information.
- Maximise patient satisfaction.
- Use patients' positive feedback for wider marketing.

Across the sector, there was also a strong commitment to assessing patient satisfaction with services or their experiences of using services. The common view from providers that we interviewed was that interactions with patients, providing patient information, and ensuring that patients' views and expectations are met were the basis of good quality patient services.

Surveys of patients were the most commonly used tool for gathering patients' views and experiences. These mainly provided quantitative data and were used primarily to provide information to patients about services, for service improvements and marketing of services. We did not explore in detail how far these surveys assessed patients' experience or simply asked about their satisfaction with the services provided. However, there appeared to be a range of practice in the use of survey tools, some much more limited in their coverage than others. The main areas covered by the surveys include food, facilities, staff, treatment and specific services such as occupational therapy. The surveys were often based on national questionnaires; some providers adapted these for their own purposes and others had developed their own questionnaires. In a few cases, patients and carers had been involved in designing surveys.

There is little evidence that qualitative data is used to any great extent in the larger acute providers. Some specialist centres carried out interviews with ex-patients. There are some examples of focus groups and interviews, mainly in mental health and hospice providers, with front line staff using qualitative information to improve specific aspects of service provision.

Hospices and mental health providers appeared to take a wider view of engagement, involving users and their carers in meetings and forums, and talking to the public as part of their service developments in some cases. In some hospices, patients and families were involved in service planning as well as advising on improvements, and were also involved in helping to learn from mistakes. This is a rare example in both the NHS and independent sector. For example:

"We have set up parent committees who are actively involved in service development and contributing to the reconfiguration strategy. The culture change has been massive and families are the experts on the way their lives need to be run. If things go wrong we involve the

families so they have a better understanding of what went wrong for them and what went wrong for the hospice" (hospice).

There are a few examples of independent sector patients being engaged in reviewing existing services or in designing new services, but this generally appears less common than in the NHS.

7. How are people's views and experiences considered by health services?

Most of the trusts in this study did not have a systematic approach to bringing together the information they have gathered from patients and the public. However, many were working to develop systems to ensure the data they gather feeds into decision-making processes. Others are also trying to improve the quality of the data they use from patients and the public, and to make more use of data that is qualitative and based on people's experiences.

Most of the trusts in the study used Patient Advice and Liaison Services (PALS) data to help decide what engagement activities are needed, and in identifying emerging areas of concern or patterns of complaints. PALS data was usually compiled and collated formally for the board or a sub-committee, such as the clinical governance committee. Most trusts said that they also used data from complaints and compliments in a formal way.

A number of PCTs were developing systems to log the influence that people's views have. Similarly, a number of acute and other provider organisations were starting to compile regular reports about the ways different services and departments were using people's views. Most organisations recognised the growing importance of being able to show people how their views have been used.

Most systems for gathering together views and experiences focused on collating the quantitative surveys and reports of focus groups and interviews. We have heard very little about how trusts record and use the intelligence, experiences and views from discussions with community groups or development work in the community.

Trusts typically produced action plans as a result of gathering people's views for a specific purpose. These set out the actions to be taken in response to the issues raised and provide a way of tracking outcomes. They were usually presented to the board or the relevant committees for action. In some cases, these action plans were brought together to provide an annual report of engagement with patients and the public and its impact. Some trusts had a system in place to deal with issues of serious or significant concern raised by patients or the public as part of routine engagement activity.

In terms of reporting arrangements, we found examples of reports to clinical or integrated governance committees, reports to directors within divisions, reports logged for public consumption, quarterly reports of activities and an annual report to trust's board.

In independent healthcare organisations, there was more systematic use of information from patients' and users' satisfaction surveys and interviews. Most of the organisations we interviewed had systems for acting on patients' views. These were often linked to the performance management systems for individual service areas, or the organisation as a whole, to benchmark with other similar organisations. Both at corporate and local level, senior managers generally placed a high importance on feedback from patients. There are examples of corporate boards assessing the implications of survey findings, and of unit managers checking individual questionnaires. For example, patient views being reported to central care teams, nursing services manager, matrons, cascaded to front line staff, clinical and quality governance meetings and trends being monitored by clinical effectiveness coordinators. Evidence from patient surveys was used in business planning, but mainly in service improvements and staff training.

Evaluating engagement activities

We have found only a small number of examples of trusts evaluating their patient and public engagement. For example, evaluations of:

- The process of a consultation.
- The strengths and weaknesses of certain approaches, such as the effectiveness of patient panels.
- People's experience of involvement at events – "Do you feel you benefited from this exercise and do you think the trust benefited? Did you feel listened to?"
- How people got involved and what it meant to them.

We found a service user research and evaluation group in a mental health and learning disabilities trust that investigated how well users of services and carers felt the trust was engaging with them. The trust was acting on the findings to improve the way it engages with people, and a further review was going to take place. This was an ongoing project. The group includes users of services.

Examples of positive practice

How people's views and experiences are reported to health service planners and decision makers

"There is an established system for collecting data from the feedback process. The hospital has an action plan pro forma which is completed and fed into an individual directorate report, monitored within each directorate.... I also monitor individual responses and compile a quarterly corporate report, which goes to the Trust Board and integrated governance body" (acute trust).

A children's hospital had an involvement champion on each ward and department.

They were trained to work with children and young people to obtain their views on the service they receive. They also used a feedback card system for reporting to the heads of nursing with involvement responsibilities and ward development managers. Responding to the needs and issues identified by children on the cards was linked to the performance management system of the trust.

"We prepare an annual report outlining what has changed for patients, based on monitoring the quarterly reports. This encourages directorates to improve the reporting on their quarterly action plans and to follow up on their actions" (acute trust).

"For all the surveys that we do we produce an action plan and a monitoring body attached to them with a number of actions. Things go to the board and the governors get involved and become advocates of the issue. PALs and complaints have a formal way of recording changes to services as a result of the process they go through" (foundation trust).

A PCT has brought together all the data from patients' views already available and reviewed what had been done about the issues raised. They used this information in discussions with all departments to ensure they took action on recurring problems and avoided further consultation on issues where they already had data. They also set up a system for responding to people about those issues.

Reporting back to patients and the public

We have heard very mixed evidence about the extent to which trusts report back to patients, users and the public about what they have done with their views. Typically a trust would produce an annual report for public consumption making reference to the ways people have influenced its work.

It was becoming more common for people who were engaged in specific activities to be given direct feedback on what has happened with the views and experiences they provided. However, we heard from a number of trusts that accepted that this feedback was not routinely provided, sometimes because they were not able to be explicit about the ways people's views were actually used.

In the better examples, people received feedback through their community groups, through newsletters or direct mailings. Patients who have become members of foundation trusts, or who were on PCT or acute trust's 'involvement registers' usually got direct personal feedback or were sent information in a members' magazine. In some community development programmes, information was fed back to communities through the community press.

"At the end of consultations we get feedback on what worked and what didn't. When we did a set of focus groups we wrote to everyone involved to say thankyou and had a lot of feedback from that. People said they enjoyed it and wanted to be on the database for future work." (PCT)

"We consulted with all patients about what they wanted from a new GP practice and what services should look like. They asked for extended hours, and access to services like podiatry. That led us to a patient-centred service specification. Then the patients formed a panel of 35 people and voted two members to join the PCT team to appoint a provider of medical services. They were involved in developing the person specification, writing the interview questions and deciding which provider should be appointed. A few months later the patient panel were asked what they thought and they were absolutely delighted. The GP was at the same panel meeting and it's a wonder he could get out of the door – the compliments they were giving him." (PCT)

"We use feedback cards with patients called 'your views and experiences matter'. Patients, parents and carers feedback what's good and what could be improved. All wards and departments review these quarterly and produce displays in the hospital of what they are doing to respond to the issues raised." (acute trust)

"We have a 'Your Choice' member magazine, which has a section called 'You said – We did'. We also have a community involvement quarterly report. We respond to each comment posted on the patient opinion and NHS choices, 'your thoughts site'". (foundation trust)

8. What difference do people's views make?

There were many individual examples of how people's views have influenced specific strategies or commissions, or the delivery of individual services. However, most trusts found it difficult to provide evidence of the ways people's views have improved the services or systems across the organisation as a whole.

We also did not find sufficient evidence that people's needs and views were the significant drivers behind many of the changes being made to health services. Only a minority of trusts in this survey had a formal system in place to monitor the impact that people's views had on decision-making. Some organisations relied on single measures of impact, such as their response to complaints or to the national patients' survey.

The views of patients, users and the wider public were most likely to influence the ways individual services were delivered, particularly improving information for patients, the ward environment, patient appointment systems, information and support to visitors and relatives, facilities such as parking and food provision. These were the areas where it seemed to be easiest to make direct links between people's views and experiences and action taken to address them.

For example, patients have influenced:

- Information about endoscopy treatments.
- Information about asthma management for young people.
- Information sent to people about appointments.
- Guidance for people coming into hospital or on discharge from hospital.
- The communication between general practices and patients with cardio-vascular disease.

There are individual examples of improvements to appointment systems leading to reductions in waiting times for phlebotomy services and substance misuse services. In a few cases, clinics have been changed to provide easier appointment systems, longer or more flexible opening hours, such as at evenings and weekends.

There are also a few examples of improvements to healthcare environments, some of which are substantial – including young carers designing family rooms in inpatient mental health units; redesigned hospital areas to improve access for people with physical or sensory disabilities; patients influencing the design of future wards and existing ward developments, the admissions lounge and car parking arrangements.

There are a range of examples of patients and carers helping to trigger service reviews, helping to plan services and influencing the development of new service specifications and care pathways, although the details are often not explicit. It has been difficult to understand how people's views have been taken into account in practice, in these areas.

The most common examples of service reviews being influenced by patients and the public relate to reviews of services for older people. There are also individual examples of patients influencing a service for people living with Parkinsons disease, the development of community health services and community hospitals in an area, and the provision of a crisis house for people experiencing severe psychological distress. There are examples of both patients and the public having influenced specifications for a dermatology service, a cardiac angiograph unit, one hospital's neurological services, an NHS walk-in centre, and several examples relating to sexual health

services, mental health services, child and adolescent mental health services and GP practices.

In terms of care pathways, we heard examples of improvements to pathways for people with multiple sclerosis and with cancer. For example, the introduction in one hospital of an oncology emergency services ward to avoid people with cancer being admitted into general emergency wards. There were also a few examples of improvements to admission and discharge procedures, including improvements for children with complex health needs and their parents.

There are fewer examples of people's influence over the strategies, funding and clinical quality of health services. However, we have heard that this is now more likely to happen as PCTs extend the ways they engage with people, and through the requirements they place on the services they commission. There are a few examples of influence over PCTs' commissioning strategies, trusts' business plans, trusts' single equalities schemes and in some trusts' patient and public engagement strategies. The most common examples of people influencing service strategies are in relation to strategies for older people, mental health services and the patient transport service.

People rarely influenced spending priorities, and in the few examples we heard, these were for PCT priorities and GP services. Examples of patients or the public influencing clinical quality issues are particularly uncommon.

People have had the greatest influences where they have been involved throughout the process of reviewing and developing a service, and when they continued to be engaged to monitor the quality of the new service. However, we have not heard of many examples of users' or community groups leading the process of change in trusts. Where this has happened, it has been due to supportive managers and clinicians being prepared to share power and influence, and local representatives of patients or users – such as patient forums – working with local groups and often with overview and scrutiny committees to make a compelling case for change.

Despite some evidence of joint working with local authorities, there is little evidence from this study of organisations working together to improve services in response to people's views. One example is included in the selection opposite.

In the independent sector, there is evidence of how patients' views were being used to influence the care environment through improvements to layout, rooms, buildings, furniture, lighting, parking, access to entertainment, catering, design; content of information provided before and during admission, and after discharge; staff recruitment and uniforms; and activities for users.

Patients within the independent sector were less likely to be involved in service planning and development, strategic corporate issues, forming community relations, or being engaged in clinical governance or equalities issues. There are some examples in hospices of patients and carers being involved in planning and designing new buildings and new services.

Examples of positive practice

How people's views have improved services

Transport to hospital

"Where the public have flagged up an issue we have looked at it, feedback has gone back to working groups and they have revisited the work they were doing. For example, public transport to the hospital has been raised so we were able to take this to the local council and have helped with partnership working to provide transport to and from the hospital". (acute trust)

Patients raised the issue of transport for patients to renal services with the trust's partnership group. This led to a consultation with renal users of services and ultimately to changes in the delivery of transport services to better meet patients' needs. (acute trust)

Assessment and discharge procedures

Parents of children with specialist psychiatric needs were unhappy with the assessment and discharge processes in one trust. A group was formed to improve these, and the pathways and processes of care were reviewed and changed to ensure that parents felt more supported. Feedback after the changes have been introduced has been very positive. (mental health trust)

The organisation of care

Feedback from patients about waiting long periods for blood test results led to an acute trust issuing them with bleepers so they could go away and come back when the test was completed. Feedback from patients having angiograms highlighted the need for them to know how long to wait on the beds. They were issued with clocks. These have had a positive impact on patient experience. (acute trust)

On an oncology ward, staff worked with inpatients for three months to hear their views about the ward round. Patients indicated that they wanted choice about how many people came on the ward round and how it was managed. Clinicians supported the work and acted on the views. The ward rounds were changed so that people could have one-to-one sessions with a consultant if they preferred. (acute trust)

Education and information

"Children and education staff were unclear about asthma management and young people expressed concern about their asthma and wanted their friends to understand more about the condition. There was involvement from parents and children in developing educational material on asthma management for young people in schools, more individual asthma plans were developed for children and teaching sessions were arranged in schools. Parents and children were happy and supportive of the new arrangements." (PCT)

Appointment systems

"Within the GP practices, as a result of patient group feedback, systems have changed which have improved access. Lots of small but crucial things such as altering the call system – so people can arrange appointments more easily. This has given them a better experience." (PCT)

Trust priorities

"We involved over 1,000 people in developing our local delivery plan. We asked them what they thought the priorities should be and we took account of this." (PCT)

Examples of positive practice

Models of care

"The PCT has involved people directly with managers on the practical issues of service changes, and involved them in assessing and improving the final service model. This has been done for a range of community services in relation to neurological conditions, dermatology, sexual health, reconfiguring mental health services and improving diagnostic awareness of dementia." (PCT)

Improving the care environment

"The hospice has been refurbished, which has tried to make the wards as homely as possible, with themes and curtains and bedding chosen as if in one's own house – taking patients' views into account" (hospice).

A mental health and learning disabilities trust commissioned a voluntary organisation to run a service for young carers. It consulted young people on what they wanted from services and acted as an advocate with the trust. Young people found it stressful to visit parents in the psychiatric ward, and wanted a dedicated space outside the ward to spend time as a family. Young people were involved in the concept of the family room, its design and how the booking system for the room would work. The impacts have included positive feedback, improved recovery times for parents and positive feedback from staff. It also built the skills of the young people involved. The family room was rolled out onto 10 sites at the trust and was standard for new builds.

Service expansion and development

"Our expansion is the biggest demonstration of how we have engaged patients – we've gone from having eight doctors in one clinic to having 22 in several sites. We have now changed our services because of patient feedback. This has included introducing several other services, such as screening tests – including mammography services, and testosterone in screening for men above 55" (private doctors clinic).

"We have increased the services we are providing so now we have a larger patients lounge and more counselling areas. This was a direct result of collaboration with patients" (hospice).

9. What effective engagement looks like

We asked workshop participants and users' groups involved in the survey to set out what they have learned about effective engagement from their local experiences. The comments below illustrate some of the most important aspects of effective engagement.

Comments highlighting key aspects of effective engagement

"Engagement should be meaningful, not tokenistic, and involve people in important decisions like appointing staff and spending decisions" (users' group).

"We need to talk to people in their language, in places they feel comfortable, about issues they want to talk about, in a way that anyone can contribute" (patient and public involvement manager).

"It should start from the point of view that it's peoples right to be involved" (patient and public involvement manager).

"Better communication about what the trust can and can't do" (users' group).

"It's everyone's responsibility to make sure patients are heard" (users' group).

"We have to start asking people what they need; not giving them a service and then asking them if they like it" (patient and public engagement manager).

"Local people feel part of the solution" (LINk).

We have heard a consistent message from patients, the public, and user and community groups about how they want health services to engage with them. While many people may not want to participate directly in how health services are run, many others do want a chance to share their experiences and to give their views about health services. Members of the public also wanted health services to tell them what they were doing and give them a chance to comment or contribute.

Patients and the public argued that trusts – managers in particular – could communicate better with their local populations; build stronger relationships with them; make it easier for all sections of the community to get their voices heard and critically, ensure that actions taken focus on what is important to them. They should also avoid overburdening groups or individuals with unnecessary or inappropriate attempts to involve them.

Community groups and patient representatives believed that good engagement covered a spectrum of activity, from how managers build relationships with the community, through to how consultations are conducted by clinicians in face to face contacts with patients. It involves clear, well targeted and widely available information and everyday consultation and dialogue using a variety of approaches to suit different groups. It must be convenient for people to have their say if and when they want to, and trusts should demonstrate what they have done with their views.

Patients' and the public's checklist of what good engagement looks like	
What people said they wanted for themselves	**What people said the NHS ought to do**
To be asked for our views and experiences. To help gather views and experiences from our communities.	Build relationships with individuals and groups and reach out to all communities. Share issues at an early stage – both problems and possible solutions. Give support and resources to local groups.
Regular and open conversations with NHS managers and staff.	Be open and honest, especially about costs. Share progress and respond to negative press – especially on issues that upset people, like hospital acquired infection rates.
To be asked our views in ways we can understand and to give our views when it is convenient.	Understand people's circumstances and give them help, if they need it, to contribute their views. Provide lots of ways for people to influence services.
Information about services and how they work.	Provide information about services and about how to get involved to as many people in the area as possible.
Everyone to have their say.	Target schools, parents, families, the homeless – and other groups who do not usually get a chance to give their views
Our views to be listened to and to influence services.	Take account of people's stories and concerns, and act on them.
To know what has been done with our views.	Publish results and give feedback.

We have built on this checklist from patients and the public and combined it with the ideas about effective practice from trusts themselves, and from best practice guidance, listed at the back of this report. The result is a list of characteristics of what a trust does when it engages people effectively and uses what they say. We found remarkable consistency about which characteristics were most important, from all types of participants in the study and from all parts of the country.

Characteristics of trusts who engage effectively with patients, users and the public

Trusts and partners have the capacity to engage

- A strategic approach to engagement, linked to the business plan and developed with patients and the public.
- Joint investment with local authority and other trusts to map communities, gather and share data.
- Leadership actively promotes a culture of engagement and there is accountability at board and executive level, and through clinicians as well as managers.
- Resources to engage people have been identified to meet needs, including resources to support local groups and recognise the contribution of those who engage.
- There are staff with responsibilities to support engagement at various levels of the organisation, who are held to account for them.

Community relationships are established and sustained

- There is ongoing communication and established relationships with groups and communities.
- A critical friendship is created with the LINk, which is recognised as a resource for all local groups to feed in their views.
- There is open communication and a positive relationship with the overview and scrutiny committee.

Breadth and depth of engagement across the area, organisation and services

- Engagement takes place at all levels of service commissioning and delivery, and at all stages of development of services – with patients, users of services, carers and the public as appropriate, and using the LINk.
- Key decision-making bodies involve people directly wherever possible and are transparent in their use of people's views and experiences; they are networked into the community to improve ongoing dialogue.
- Requirements for engagement are built into providers' contracts and quality standards.
- There is a record of the people who have been engaged, which reflects local populations.

Effective and accessible methods produce evidence that can be used

- A mix of methods are used to engage people, to match their circumstances and preferences to engage, and to provide quantitative and qualitative information.
- People help to shape the methods used to engage them and where appropriate are able to take the lead in using them.
- Outreach services are used to work with communities in the poorest health or vulnerable circumstances or who have not been listened to in the past.
- The communication needs and access requirements of patients and the public are taken into account whenever they are asked to contribute their views or experiences.

People's views and experiences influence services

- A system is in place for using all data from patients and the public.
- Data is collected and used to shape decisions about services that operate across organisations' boundaries, about corporate priorities and policies of individual organisations, about individual service plans and to improve the way services are delivered.
- Routine feedback is given in different forms to patients and the public, to suit their needs and circumstances.

Organisations learn how to engage people better

- Engagement activities are regularly evaluated to find out how they affected people and what was done with the findings to improve care.
- Learning from experience – health services are improving the ways they engage people or use the information they provide, based on the experience of previous engagement activity.
- There is innovation; new approaches to engagement are used to reach groups who may not otherwise have an opportunity to give their views.

10. Conclusions

Our conclusions draw together the main findings from the study. They describe people's experience of being engaged; whether people's views are making a difference to health services; what is helping and hindering engagement, and an overview of the different approaches being used. Progress being made in different types of trusts is also summarised. We have also set out the priorities for improvement, as described by trusts, patients, and users' and community groups.

We have brought together evidence from all the different stakeholders involved in the study. The messages that have emerged have been clear and consistent, with a surprising level of agreement between trusts, patients and the public about the challenges and the priorities for improvement.

People generally felt they did not have enough say in their health services

People involved in this study generally did not feel they had enough say in the health services that are provided in their area or the way they are delivered. Those in the poorest health, in vulnerable circumstances or experiencing discrimination often found it more difficult than others to engage with health services. Many patients', users' and community groups remained to be convinced that health services wanted their views, or would act on them. We heard this consistently from all groups of patients and the public in the study, from those already well engaged to those who had no experience of contributing their views to health services.

People generally wanted more information about their local health services, how to give their views, and about what changes are 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. When people felt they had no influence, it could lead to a loss of trust and confidence in health services, and make future engagement more difficult.

There was particular interest 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 health service staffing and how money was spent, the facilities and the environment in hospitals, and in making healthcare safer. Again, these messages emerged consistently from all those patients' and public groups and their representatives who took part in the study.

People's views were not used routinely in planning and improving health services

Most trusts in the study could provide some examples of using people's views, but few demonstrated that they routinely took account of the views of patients and the public in the planning and improvement of health services. Few organisations had systems in place to engage people at all levels and across all services in their organisation. Patients, users of services and their carers were not routinely asked about their experiences of care in all the services they use. Members of the public had limited opportunities to inform what kinds of services were planned or provided in their area. When people's views were used in decision-making, it was often only in certain departments or services, or as part of a high-profile consultation. Also, trusts in this study were not able to describe how much importance they placed on people's views as compared to clinical measures and cost implications, when making their decisions.

Some communities and groups were still 'not heard'

Most trusts also recognised that they did not do enough to use the views of people in the poorest health, or those most in need of their services. This was reinforced by the negative experiences of engagement we heard from some of these groups. Black and minority ethnic communities, older people, travellers, people with learning disabilities, refugees and asylum seekers, disabled people, children and young people were identified by healthcare organisations as the groups who were least likely to be heard. Improving their confidence and trust in health services was seen as the first goal of engaging with them.

There was limited evidence of how people's views were used to improve services; but people were most likely to influence the information they receive and their care environment

Even when people's views and experiences were taken into account, trusts in this study often found it difficult to demonstrate how they used them and whether any changes led to an improved experience for patients. People were most likely to have influenced the delivery of local services, such as the appointment systems, the ward environment, information for patients and facilities, such as parking and food choices. They were least likely to influence the quality of clinical care or the choice of which types of services are provided in their area. People had some influence on individual service plans and specifications for services. There was limited evaluation or follow-up of engagement to establish the difference it made to the people engaged, the use of the services concerned, the way the organisation worked or whether services delivered better care.

There was some poor practice in the methods used to engage people

Evidence from this and other studies clearly set out the problems of poor engagement practices from patients' and the public's perspective. These included being unable to access information about getting involved or about service performance; being unable to attend key meetings; inconsistent and inadequate provision of information by health services; a lack of responses from health services to local reports by patients' groups; poor involvement of the voluntary sector; failure to involve people early enough in planning service reconfigurations; poor organisation of engagement activities, such as poor publicity and problems with access to venues; lack of support for people with communication needs or sensory disabilities; staff unfamiliar with the procedures for involving health scrutiny committees; and finally a lack of evidence that action has been taken to respond to the issues people have raised and a lack of feedback to patients and the public.

Trusts were increasing their efforts to improve the ways they engage people

Trusts across the country were increasing their efforts to seek, gather and use people's views. There was a general commitment by NHS trusts to engage with users of services and people in their area, with many viewing it as integral to their strategic objectives. The majority had plans to get more people involved, make better use of their views and experiences, and increase the confidence and trust people have in their services. Trusts also recognised the need to reach out beyond the 'usual suspects'; those committed individuals who do regularly contribute their views on particular healthcare issues, but who may not represent the views of the wider community.

There was agreement about the benefits of engaging with people; it makes people feel valued and improves healthcare services

There was a consensus among trusts, patients', users' and community groups in this study about the benefits of engaging people. It was widely believed to improve the way services are delivered, and how they are planned and organised; improve people's attitudes to, knowledge and use of services; their experience of care, and ultimately the outcomes of their care and their health. It was also seen to improve people's aspirations for their health and health services.

There are pressures from new Government policies encouraging trusts to improve

There are significant new rights for people to be engaged in decisions about health services and about their care; and duties on trusts to demonstrate how they are taking account of people's views and experiences in decision-making. People's experience of care will be reported as part of new Quality Accounts that trusts will be required to publish, setting out the quality of their care. The Government's requirements for PCTs to improve the way they commission services, known as World Class Commissioning, is driving PCTs' approaches to engaging people. Finally, the move to foundation trust status is requiring service providers to communicate with and try to involve more local people in the services they provide and the way they are run.

People's understanding of local health services was an important factor – particularly when they believed they might be losing local services

The public's understanding of local health services was also an important factor in how well trusts engage with local people. We have heard from trusts, as well as community groups, that unless local people understand the current services available and the ways in which they might change, it was very difficult for them to engage in a discussion or give their views. This was a particular problem when trusts were proposing to reconfigure popular local hospitals or services on the grounds that clinical quality would improve, but the public perception was that a local service would be lost.

Senior managers and clinicians have a key role to play in creating 'responsive' organisations

Trusts were most likely to be influenced to engage with patients and the public by the commitment of senior managers and clinicians. The second biggest influence was the resources and skills that were available in their own organisations and also in local community groups. LINks were not yet having much influence over the ways trusts engage people, but this influence was expected to increase rapidly. In comparison, the pressure of patient and public groups was much less influential.

There were some examples of excellent practice, but much progress remained to be made in PCTs

Many PCTs in this study believed they were in a unique position to build new relationships with patients and the public and to put them at the centre of their work to commission health services across a local area. Some were embracing this opportunity and working hard to involve people in all aspects of service commissioning. However, this remained piecemeal across the country. People were being engaged in some aspects of commissioning and in the commissioning of certain services, but this was not routine practice for the majority of PCTs involved in this study. There was only limited evidence that service providers are required to engage people through their contracts or any quality agreements with PCTs. Most PCTs were not yet driving engagement in practice based commissioning. The small sample of practice participation groups in this study had varied influences on their GP practices, but the majority of general practices still had not convened a group of this kind with which to engage.

There was limited evidence of joint working to engage people across service boundaries

Some PCTs were working more closely with local authorities to engage local communities together and make better use of the information gathered from users and the public. However, there was only limited evidence of area-wide engagement planning across local strategic partnerships. Within the NHS, there was some evidence of PCTs and healthcare providers working together on consultations about major service changes. Trusts recognised they could do much more to join up their approaches to engaging people. Indeed, communities could only engage effectively with local agencies if those agencies acted together on the issues and views that people raised, and where necessary jointly plan or commission better services. The opportunities to engage with communities jointly through the strategic needs assessment were not widely used.

Acute and ambulance services were committed to improving their understanding of patients' experiences

Healthcare providers were committed to improving the ways they capture patients' and carers' experiences and to make better use of this information to improve services. Patients were more likely to be asked about their views and experience of using health services, but for many this still did not happen as a matter of course. Some organisations were still engaging reactively – as a result of individual complaints and negative press.

There were examples of more active participation of users in mental health and learning disability trusts

Mental health and learning disability trusts tended to have more experience of building partnerships with their users of services, carers and representatives in the community. The experience of reconfiguring many services, so that care is moved from hospital to community settings, had created strong user movements for these groups. It also led to a greater focus on direct participation of users of services in gathering the views of other users and contributing to planning groups.

A health service 'membership' culture is developing – led by foundation trusts, but the influence on services was not clear

Foundation trusts were exploring ways of increasing the engagement of local people and their representatives – through their memberships and boards of governors. There was a growing population of members of trusts who received information about their local services and were likely to be offered more opportunities to engage with them. Some PCTs and other provider trusts were also encouraging people to join registers, databases and membership of their organisations in a similar way. Foundation trusts' governors were being encouraged to take a lead in developing a membership and to find new approaches to engaging people in service developments. Whether these approaches increased people's actual involvement in decision-making was not clear. There were some concerns among LINks and OSCs about how foundation trusts could maintain a balance between working with their members and continuing to engage with the wider public.

Trusts recognised the need to get better at understanding people's stories about their health and their care

When using data about patients' experiences in their decision-making, most trusts relied predominantly on the national patient survey data, local patient survey data, and data gathered from PALS and complaints. From the patients' point of view, these are the least popular approaches to gathering information about their experiences. There was a trend to develop more patient-led surveys of individual services, and to gather and use evidence from the stories told by patients and local groups, as part of routine monitoring. Both commissioners and provider organisations recognised the value of tracking patients' and carers' journeys through health and social care services to better inform service planning and improvements. Much more progress needs to be made in gathering people's stories and ideas about the health services they need, and allowing them to raise issues on their own terms.

Community development was seen as the basis for effective engagement – supporting and building relationships with local groups

There were increasing efforts to develop relationships with community and users' groups – but trusts recognised that much more needs to be done to build their trust. We have heard many stories about trusts' lack of understanding and knowledge about their local community and voluntary sector. There were also positive examples that show how a supported system of networked user and community groups could be very effective in strengthening healthcare planning and service improvement. This takes time to develop.

Those in the poorest health needed their basic health needs met, to enable them to engage on other issues

Those groups with pressing health and social problems often had fewer resources to engage with health services. Health services needed to support these groups as part of the process of assessing their health needs, working with local authorities. Immediate action to address some of their concerns (such as access to a GP) can then encourage them to engage further.

There was no national data gathered about the quality or extent of patient and public engagement

There was a lack of national or local benchmarked data about how trusts engage patients and the public to enable a regulator or a local organisation to assess performance over time. Few trusts could provide evidence from local surveys, reviews or evaluations to show how well people were being engaged in their services now or in the past.

The findings of this study raise questions about the level of compliance with the national standard

Ninety-eight per cent of trusts told us that they complied with the Government's standard requiring them to "seek and take account of the views of patients, their carers and others in designing, planning, delivering and improving healthcare services" (core standard 17). Despite this apparently high compliance rate, many trusts also thought they should be doing much more to engage people and take account of what they say. Patients and the public did not believe that such a high proportion of trusts achieved this standard. There were clearly different interpretations of how the Government's standard was being met.

The requirements for independent healthcare organisations did not reflect the range of activity in the sector

The current registration requirements for independent sector organisations are focused on the use of patient satisfaction surveys. We have found evidence that many organisations are engaging patients using a much wider range of approaches. The current requirements do not take account of the quantity or quality of the engagement in the independent sector, or make any reference to the engagement of the public in independent healthcare.

Appendix

Acknowledgements and contributors to the study

We would like to thank all those organisations and individuals who contributed to our study. This includes all those who provided information, told us their experiences, or gave us advice. We would also like to thank the Office of Public Management that ran parts of the study and undertook some data analysis, and to Resolex Ltd for their additional data analysis.

List of the main types of organisations contributing to the study

Type of organisation	Breakdown of organisations	Numbers participating
National organisations	Including some regulators, representative bodies, development agencies	29
National voluntary organisations	Including organisations representing older people, children, patients' groups, etc	27
Research organisations		14
NHS organisations	Primary care trusts	51
	Mental health/learning disability trusts	20
	Mental health/social care trusts	2
	Acute trusts	26
	Ambulance trusts	5
	Foundation trusts	36
	Care trusts	1
Independent healthcare organisations	Mental health/learning disabilities organisations	8
	Hospices	11
	Acute hospitals	7
	Clinics/walk-in centres	3
	Private doctors	4
Local authorities		11
Patient and public representative groups	Health overview and scrutiny committees	22
	Patient and public involvement forums (prior to April 2008)	8
	Practice participation groups	9
	Individual patient representatives	30
	Local involvement networks (since April 2008)	25

List of the main types of organisations contributing to the study (continued)		
Type of organisation	**Breakdown of organisations**	**Numbers participating**
Local patient/user groups/networks	Mental health/learning disabilities groups	14
	Disease specific groups	8
	Carers groups	7
	Cancer networks	3
Local community groups	Umbrella groups	10
	Black, minority ethnic and faith groups	11
	Older people's groups	7
	People with disabilities groups	6
	Housing and employment groups for people with mental health/learning disabilities	5
	Men's/women's groups	2
	Lesbian/gay/bisexual/transgender groups	1

List of organisations that attended advisory meetings during the study

Age Concern

Audit Commission

Cambridgeshire NHS PCT

Centre for Public Scrutiny

Commission for Social Care Inspection

Connect – the communication disability network

Croydon PCT

Department of Health

Hammersmith and Fulham PCT

Improvement and Development Agency

Involve

Long Term Conditions Alliance (now National Voices)

Mental Health Act Commission

National Association of LINk Members (NALM)

National Association of Patient Participation

National Children's Bureau

National Consumer Council (now Consumer Focus)

National Institute for Health and Clinical Excellence (NICE)

NHS Alliance

NHS Centre for Involvement (NCI)

NHS Confederation (Foundation Trust Network)

NHS National Institute for Innovation and Improvement (NII)

NHS Yorkshire and Humber

Norfolk NHS PCT

Picker Institute Europe

Royal Brompton and Harefield Hospital NHS Trust

Royal College of Nursing

Skills for Health

South Staffordshire NHS PCT

Stockport NHS Foundation Trust

Torbay Care Trust

United Response

University Hospitals of Leicester NHS Trust

Volunteering England

Which?

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Albanian

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Arabic

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French

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Gujarati

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Kurdish

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تکایە تەلەفۆن بکە بۆ ژمارە تەلەفۆنی 0845 601 3012.

Pashto

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