

Putting patients at the heart of care

The vision for patient and public engagement in health and social care



Introduction



The needs of the people who use services have always been central to health and social care. However, if we are going to transform services, acting on what really matters to patients and the public is essential.

Patient and public engagement (PPE) is an approach that puts the people who use services at the heart of care. It involves understanding their experience of services, empowering them to make decisions and involving them in the design and delivery of care.

In June 2009, the Department of Health brought together patients, third sector representatives, clinicians and managers to look at the role that PPE is already playing in shaping and improving services.

This document outlines the emerging vision for PPE, what it means and the role it can play in driving up the efficiency, quality and productivity of services.

It is supported by a second document, *Helping the NHS put patients at the heart of care*, which sets out how the Department is working to help services to be better at acting on what really matters to patients and communities.



Vision and objectives

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“Our vision is for patients and the public to drive the design and delivery of high-quality services. To achieve this, every day, everyone working in the NHS needs to engage patients and the public in making decisions.”

The objectives for PPE are:

- to offer world-class, patient-centred health and social care for everyone;
- to use patient experience to improve service quality;
- to positively engage and empower everyone through shared knowledge, activities, outcomes and best practice.

The section ‘Our aspirations for the future’ on pages 12–14 explains what we mean by the words used in the vision.



Why engage patients and the public?

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We will all, at some point, use an NHS service, so we all have a unique perspective that could help make care better.

When the NHS was founded, the needs of the public were at its heart – it was designed to be a service available to everyone, free at the point of need. This principle remains true today, but we need to do more if services are to provide the high-quality care that we all expect.

As modern consumers, we demand services that understand and respond to our individual needs. In the minds of most people, the NHS should be no different.

The public have told the Government that they want an NHS that gets the basics right, fits services around their lives, treats them as individuals and not just as a set of symptoms, and works with them as equal partners.



As well as having to meet these higher expectations, the NHS is also facing other challenges.

The cost of keeping pace with modern technology and medicine is already putting pressure on funding. Demographic change and the pattern of disease will exacerbate this. The NHS has the challenge of making more of existing resources by boosting the efficiency, quality and productivity of services in difficult economic times.

Services are also increasingly being held to account by the strong community of patients' advocates that has grown with the NHS. Managers and commissioners are being challenged to be more patient-centred and PPE is helping people who want to make a difference to have their voices heard and their aspirations acted on.

The necessary changes to overcome these challenges, drive up quality and get the best possible value for taxpayers are taking shape, but many private and public services have found that they cannot move forward without paying the right kind of attention to their customers.

How is this happening?

In the NHS, the move to make services more patient-centred is being supported in a number of ways.

Empowering service users: Since 2000, there has been a gradual move towards giving patients more power over their own health and care. The NHS Constitution, which raises awareness of the rights that people have in determining their own care, and the increasing ability of patients to choose which service they use are just the latest signs of this trend.



Informing service users: If people are to make informed choices, then they need access to good information. The NHS Choices website is leading the way. It offers a host of services, enabling people to:

- get information about living healthily and managing over 750 conditions;
- choose a service, by telling people what is offered and how it rates in terms of safety, quality of care and other factors;
- rate a service and comment on their experience.

Informing staff: The better a service understands its patients, the more responsive it can be to them. NHS managers are increasingly investing in systems to help them gather, interpret and use real-time information about patients to improve both care and prevention.

In a world where the quality of services will be judged by the experience of patients, and where managers need to find new ways to drive up quality and productivity, these systems will be key.

Accountable services: The NHS is moving towards becoming a local health service that reflects local needs. NHS managers are increasingly investing in talking to communities about how local money should be spent and how care can be improved. Managers are also increasingly being held to account. World Class Commissioning, Quality Accounts and the NHS Performance Regime all try to assess the extent to which people's views and experiences influence decision-making.

What is patient and public engagement?

Patient and public engagement (PPE) is an approach to involving and empowering the people using services, and taking their experiences into account. PPE is not something that has emerged overnight; it has evolved with the NHS and has resulted from statutory organisations and the third sector challenging services to be patient-centred.

The importance of PPE is reinforced by the emphasis, following the Next Stage Review, on three strands of quality, with patient experience sitting alongside patient safety and clinical effectiveness as an equal partner. The Chief Executive of the NHS has stated that:

“Quality means becoming truly responsive to what patients, local communities and staff want and putting them at the heart of what we do.”¹



The vision for PPE recognises that patient experience is key to informing the process of engagement as well as being part of the service improvement produced by that engagement.

The definition

PPE has been defined as:

“... the active participation of patients, carers, community representatives, community groups and the public in how services are planned, delivered and evaluated. It is broader and deeper than traditional consultation. It involves the ongoing process of developing and sustaining constructive relationships, building strong, active partnerships and holding a meaningful dialogue with stakeholders. Effective PPE leads to improvements in health services and is part of everyone’s role in the NHS.”²

A positive patient experience has been defined as:

“Getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way; having information to make choices, to feel confident and feel in control; being talked to and listened to as an equal; and being treated with honesty, respect and dignity.”³

The history

Public services are changing. PPE is at the heart of that change.

Building Britain's Future states: "the key relationship in the next decade will be ... between the empowered individual service-user and the public service professional."⁴

Over the last ten years, health and social care services have been moving in this direction.

2000 *The NHS Plan* set the direction of reform by stating that "The NHS will shape its services around the needs and preferences of individual patients, their families and their carers".⁵

2002 *Shifting the Balance of Power* explained how patients would be more involved and have more information about and influence over health services.⁶

2003 Local authority health **overview and scrutiny committees** were established to look at the work of the local NHS.

2006 *Our health, our care, our say* marked a recognition that "people's voices need to be heard at a local level" and that those voices would be "most effective if they directly affect how resources are used".⁷

2007 The vision of **World Class Commissioning** embodied this approach by building PPE into the process by which NHS services are commissioned.⁸

2008 **Local Involvement Networks** (LINKs) started work, giving local communities a way to influence local health and social care services. **NHS Choices** website goes live with the aim of providing a comprehensive information service that helps to put people in control of their healthcare.

2008 **High Quality Care for All: NHS Next Stage Review** set out a vision of the NHS. It painted a picture of services that are *“fair, personalised, safe and locally accountable”*⁹ and explained that *“effective change needs to be empowered by the needs and preferences of patients”*. It stated that we must *“empower patients with greater choice, better information and more control and influence”*.

High Quality Care for All made patient experience one of the three measures of service quality.

2008 This approach was underlined by **Putting People First**, which stated that *“real change will only be achieved by the participation of users and carers at every stage”*.¹⁰

2008 The legal **NHS duty to involve** was strengthened to support systematic engagement of patients and the public in decisions about the design and delivery of services.

2009 **The NHS Constitution** underlined the new relationship between the NHS and the public by making clear the rights people have to influence their own care and local services.

2009 A new legal duty was introduced, requiring primary care trusts and strategic health authorities to report on how people’s views have shaped commissioning decisions.

Our aspirations for the future

World class: The experience that the health and social care system delivers to patients, carers and the public will be not only of a high standard, but increasingly world class. Their experiences will inform the commissioning process and complement the standards set for delivering better health, better care and better value for all.

Patient-centred: Patients and their needs will be at the heart of the system and central to everything from senior leadership down to the delivery of services on the ground. In achieving this, leaders will become more accountable to patients and their communities.

Health and social care: The experience delivered by the whole health and social care system will be seamless. No matter which organisations are involved, they will all work together to deliver the

best possible experience and outcomes for patients, members of the public and staff. The transition of patients from one organisation to another will be smooth, and a high quality of care will be maintained.



For everyone: The opportunity to benefit from high-quality care and engage with the health and social care system is for everyone. Nobody will be excluded or receive a poorer experience because of their age, gender, ethnicity, disability, sexual orientation, religion or belief or any other individual characteristic. Those who need more help than others in engaging with services or articulating their experiences will receive support in accordance with their needs. Care will be delivered in a sustainable and cost-effective way that enables it to be available to all.

Use of patient experience to improve quality: Patients, carers, members of the public and staff will work together to ensure that patients continuously receive better treatment, better information and better communication. Patients will be offered a choice of options for involvement in activities which can use their experiences to influence services positively. Everyone will be involved as much as they want to be and in a way that they choose.

Engaging and empowering individuals: Everyone involved in experiencing services will have the power and responsibility to instigate change to enhance service quality. This will be delivered in a cost-effective and sustainable way that does not enhance one person's experience while having a negative impact on another's. The patient will have control over their personal journey, understanding their options and the reasoning behind them. This will be delivered through everyone sharing their knowledge throughout the journey.

Shared knowledge: We will encourage patients, carers, community groups, members of the public and staff to share their experiences of health and social care. We will provide the space and time to talk and listen to everyone involved in the experience. Barriers preventing this from happening will be removed. Knowledge will be shared across the system and within the individual patient journey.

Shared activities: Learning from activities undertaken to improve patient experience through positive engagement will be shared across the country. By exploring different ways of engaging patients and the public in service design and planning, decision-making and resource allocation, we will add to collective learning and continuous improvement. This will help to remove organisational and professional barriers and create a culture of sharing and mutual respect.

Shared outcomes: The improved outcomes in service quality gained by using patient experience as the basis of PPE will be shared through the health and social care system and with everyone involved. This will lead not only to a better experience but also to better outcomes.

Shared best practice: Examples of how the experience of individual patients and carers has improved will be shared and made available to all. Best-practice models and case studies will be sought from within the system and outside, so that we can continuously improve and raise standards.

How PPE is making a difference now

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Improvements in healthcare and technology have allowed many people to live longer and healthier lives than would have been possible in previous generations. There is also widespread support for the NHS, which is striving to improve the quality of its services.

However, there is no room for complacency. The public increasingly expects high standards from public services and there are growing demands on both health and social care services. Health inequalities also persist and threats to public health, ranging from pandemics to global warming, require new solutions.

If the NHS is to address current challenges and make use of unfolding opportunities, then there needs to be a focus on driving up quality, innovation, productivity and prevention. PPE is already making a vital contribution in these interconnected areas.

Quality

Quality in the NHS involves three key aspects – patient safety, patient experience and clinical effectiveness. The measurement of quality using patient experience is reflected in the NHS Performance Regime as well as the World Class Commissioning competencies.¹¹



While clinical measures of quality will vary according to the context, patient experience is unique in that it can inform the setting of baselines, targets and measures of improvements across health and social care.

Public concern over healthcare-associated infections

Public concern can enable – and even drive – quality improvements, especially where these might involve a change in organisational culture. The tackling of healthcare-associated infections (HCAs) is just one example of this process. Patient and public involvement forums, which ran from 2003 to 2008, helped to raise the profile of this issue. As well as local campaigns, the forums co-ordinated a series of visits to hospitals across the country to observe whether hygienic practices were followed consistently, the findings of which were widely publicised.

Combined with concern from other quarters, this prompted an NHS-wide drive to improve infection control. According to the National Audit Office, between 2003/04 and 2008/09 the NHS succeeded in reducing the devastating human cost of HCAs and saving at least £143 million on treatment costs as a result,¹² although there is still some way to go. Local involvement networks (LINks), which have replaced forums, are seeking to involve an even wider range of people in improving the quality of care.

Community engagement: improving end-of-life care

Listening to and engaging local communities can lead to better care. Improving end-of-life care, so that people who are terminally ill can die at home while continuing to receive good care, is a national priority.

In Norfolk, the primary care trust has been working with the county council on this issue since 2005, when research for the overview and scrutiny committee revealed that people's experiences of such care ranged from excellent to very poor. Users of services, their carers, NHS and social care staff, hospices and community organisations helped to develop a strategy to improve end-of-life care, which was consulted on and further refined.

Listening to local people led to some unexpected findings. For example, people aged 40–50 who were single or single parents did not want to die at home, where they might lack appropriate support. They also did not think that care homes for older people and acute hospitals were best suited to their needs. Commissioners have recognised the need to cater for the specific needs of this and other groups, and are continuing to work with the community to improve the quality of end-of-life care.

Listening to patients: Mid Staffordshire NHS Foundation Trust

Actively involving patients and ensuring that their perspective is understood and acted on can make a vital contribution to patient safety, as the National Patient Safety Agency has recognised.¹³

Failure to listen and respond had tragic consequences at Mid Staffordshire NHS Foundation Trust. Dr David Colin Thomé wrote that, in his review of lessons learnt:

“Broadening the approach to performance management to ensure that views from patients, relatives and staff take equal place with the existing data on delivery of ... priorities will ensure that performance improves and organisational and system health can be assured ... I feel very strongly that a lack of good patient engagement is the key to why Mid Staffordshire hospital trust continued to provide poor care for a protracted period of time ... Real patient and public power, information and choice are strong drivers for improving the NHS.”¹⁴

Innovation

Innovation enables the NHS to improve the way that services are designed and delivered. Innovation can also help to make care more responsive and address health inequalities. PPE can play a key role in driving innovation and can help ensure that new technologies and approaches are properly evaluated in the light of patient experience.

Technology and real-time feedback

The fact that PPE has helped drive innovation to support service improvement is demonstrated by the increasing use of technology, including hand-held and touchscreen devices to capture real-time patient experience¹⁵ and websites dedicated to disseminating patient experience to benefit both healthcare professionals and other patients.¹⁶

To help improve frontline care, Homerton University Hospital in London uses electronic surveys on wards so that patients can provide instant feedback on issues such as privacy and staff attitude. The results are displayed, along with any agreed actions for improvement.

NHS Bradford and Airedale has developed a database to capture what people say about its services. Patients are encouraged to share their experiences. The system then analyses each story; tags it as positive, negative or neutral; and files it under one of five quality indicators. The results are used with other data to track patient perceptions and identify where improvements can be made.

Patients and staff: the joint design of services

The joint design of services by patients and staff has led to a range of improvements at Luton and Dunstable Hospital. The trust piloted this approach in the head and neck cancer service before rolling it out to other services. The process began with in-depth interviews with patients, carers and staff. A joint staff and patient group came up with 43 suggestions for improvements to the efficiency, safety and overall patient experience of the service, ranging from relatively simple ideas such as spacing appointment times to reduce overcrowding, to training more ward staff to reinsert dislodged feeding tubes.

This approach is being used across the NHS to help bring about improvements.

Productivity

Productivity is important because it ensures that the NHS makes best use of resources in ways that improve outcomes and avoid waste. PPE can help to ensure that benefits for patients are maximised and that unintended negative consequences are minimised.

Research on productivity in NHS community services indicates that characteristics of the most successful interventions include both practical changes to how services are organised and managed as well as the broadening of the skill base of staff and service users.¹⁷ PPE can help identify these and can result in better resource allocation driven by patients' experience of 'what works'.

Understanding what works: diabetes

Type 2 diabetes, if not diagnosed early and treated effectively, has a huge impact on people's lives and health, and can also be financially costly to the NHS and society as a whole.

It increases the risk of heart disease, blindness, renal failure and disabling neuropathy and dramatically affects people's quality of life. Some minority ethnic communities are particularly affected. Early identification and treatment, including lifestyle changes and regularly taking medication, increase the chances of staying healthy.

Patient and community engagement are at the heart of many diabetes-related programmes. The X-PERT programme, designed by Burnley, Pendle and Rossendale Primary Care Trust in collaboration with patients and the local branch of Diabetes UK, has good biomedical, lifestyle and psychosocial outcomes.

ThinkGlucose, a programme designed to improve the management of people with diabetes when they are admitted to hospital for other conditions, empowers patients to continue self-managing their diabetes and encourages staff to learn from patient stories. The NHS Institute for Innovation and Improvement estimates that this approach offers the average trust savings of £1 million a year in reduced length of hospital stays alone.

Prevention

Effective PPE directly supports increased public awareness of preventive health measures, which in turn promotes cost-effectiveness within the NHS by reducing the prevalence of illness within the population.

Involving communities: sickle cell anaemia screening

The successful current national programme of screening for sickle cell anaemia and thalassaemia was preceded by years of PPE involving black and minority ethnic communities and the NHS, all of whom supported the clinical, social and economic case for introducing screening. PPE is also vital in tackling the social and economic conditions which can lead to greater risk of ill health.

Helping the NHS

Across the NHS, there are examples of NHS organisations demonstrating that effective engagement works. But we need to go further. PPE needs to become part of the NHS's DNA.

The main task for government is to help the NHS – on the front line and in the boardroom – to learn from those who are already leading the change.

We also need to help more people understand that they can exercise their rights and to encourage them to share their ideas for changes and improvements.

The PPE division at the Department of Health exists to facilitate this process. We are focusing our efforts in three ways to help the system respond to the needs and aspirations of people and communities:

Empowering people: Patients and the public want to be able to influence both their own healthcare and the services that provide this care. If this is to happen, then services need to become effective at



engaging people and truly responsive to what they say. Through policies such as the NHS Constitution, local involvement networks (LINKs), information prescriptions and the Information Standard, we aim to give people and communities greater power.

Putting patient experience centre stage:

Organisations should not only routinely and systematically collect and analyse feedback from people who use services, but also use this information to inform decisions about the way services are commissioned and delivered. Through policies such as the new complaints process and the use of real-time patient feedback, we hope to begin to realise these goals. By working with the Parliamentary and Health Service Ombudsman and the NHS Litigation Authority, we help to ensure that when things do go wrong they are handled fairly.

Helping services to become more accountable:

NHS and social care organisations are accountable to their communities and the individuals they care for. By helping the NHS meet its statutory obligations (such as the NHS duty to involve and the NHS duty to report on consultation) and strengthening scrutiny by local communities, we aim to make the system more accountable.

For more information about the work programme, read the accompanying document, *Helping the NHS put patients at the heart of care*.

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Further information

The work of the PPE division will continue to evolve. If you have any comments, ideas or examples of good practice you would like to share, please email: ppe@dh.gsi.gov.uk

For further information about PPE, please visit: www.dh.gov.uk/ppe



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298485 2p 400 Sep 09 (CWP)
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