



A stronger local voice:

A framework for creating a stronger local voice in the development of health and social care services

A document for information and comment

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Foreword

**By Rosie Winterton,
Minister of State for Health Services**



If we are to create a truly patient-led service, centred around the needs of both individuals and communities, it is essential that we create a stronger voice for patients, service users and citizens at all levels of the health and social care system. With this document, we set out our plans to achieve this.

It is clear from the messages we heard during the consultation leading up to the publication of the White Paper *Our health, our care, our say: a new direction for community services* and from listening to people during the review of patient and public involvement that more people want to have a greater say about their local services. The White Paper aims to create health and social care services that are user-centred, responsive, flexible, open to challenge, accountable to communities and constantly improving.

We are committed to empowering citizens to give them more confidence and more opportunities to influence public services in ways that are relevant and meaningful to them, and in ways that will make a real difference to services. This is part of a wider Government commitment to revitalise community empowerment and engagement across the broad range of public services that will be set out in more detail in the forthcoming White Paper on local government and communities. We want people to become active partners in their healthcare and wish to create a system where people are no longer passive recipients of NHS and social care services.

People are now better informed about making healthy choices and better equipped to make decisions about their healthcare, so it is essential that we use people's knowledge and experience to improve the services they use.

There are excellent examples of how citizens and service users are already influencing their local services. We recognise the huge amount of time, skill and energy that people involved in patient forums, patient participation groups and other networks have put into influencing and improving their local services. Now we want to go further for all patients, and to reach out to those people whose needs are the greatest, to people who do not normally get involved and to those who find it hard to give their views.

There are five elements of the new arrangements: local involvement networks; overview and scrutiny committees; more explicit duties on providers and commissioners of services to involve and consult; a stronger national voice; and a stronger voice in regulation. The new arrangements will build on the work of patient forums and overview and scrutiny committees, and the engagement activities of NHS and social care organisations. The arrangements will enable genuine involvement in a much wider range of ways, bring real accountability at the commissioning level, and enable a broad spectrum of people to influence how their local services are designed and delivered.



I have spent a great deal of time with many people who are involved in these activities and have seen their energy and expertise at close hand. I am full of admiration for their work and as a result of what I have seen am convinced that we must support their input and encourage still more people to get involved in ways that suit them.

I appreciate the time many people have taken to feed their ideas into the review process and I am grateful to Harry Cayton, National Director for Patients and the Public at the Department of Health, Ed Mayo, Chief Executive of the National Consumer Council and the members of the expert panel for their consideration of all the evidence and the recommendations they have made.

Our health services belong to all of us and we all have the right to get involved. By doing so we can make our services better for ourselves and our communities. I therefore hope you will welcome these proposals and I am keen to hear your views.

Introduction



**By Harry Cayton,
National Director for Patients and the Public**

The health and social care system exists for the benefit of people who need care, so it is essential that we put the needs and preferences of patients and service users at the centre of all we do. This document sets out our plans for widening and strengthening patient, user and citizen engagement in health and social care. It takes into account the recommendations of the expert panel that concluded the review of patient and public involvement and describes the new arrangements.

Many people have contributed to the proposals outlined in this document; people who took part in consultation events, patient organisations and community groups, members of patient forums and a range of representative organisations in health and social care. The new arrangements, built on their evidence and advice, are based on some important principles: independence and engagement, accountability and transparency. We wish to create flexible ways to engage people which are appropriate to local communities and locally resourced and managed.

Because we want the transition to the new arrangements to be as smooth as possible, we are seeking your views on some points relating to how the new systems should be developed. The points we would welcome views on are highlighted in the text with a .

I should like to acknowledge the work of the Commission for Patient and Public Involvement in Health, chaired by Sharon Grant and the patient forums. Thousands of individuals have stayed committed as active citizens through a difficult period of change. I hope they will continue to play a part in shaping and improving health and social care.

I also thank the members of the expert panel and all who contributed to our discussions and therefore to these proposals.

A handwritten signature in black ink that reads "Harry Cayton." The signature is written in a cursive, flowing style.



Summary

This document sets out a framework for creating a stronger local voice in the development of health and social care services.

The arrangements for involving patients and the public need to be updated to support the significant changes being made to the health and social care systems. The new arrangements aim to build on the excellent work of patient forums and the vast array of involvement activities of individuals, groups and networks and will strengthen and widen the way in which people's views are gathered, listened to and taken account of when health and social care services are planned, developed and commissioned.

They will allow for flexible, locally determined ways of working that meet the needs and preferences of local people and create capacity for an independent voice at a local level in commissioning health and care services, assessing the quality of services provided and in the regulation of the health and social care system.

- The Commission for Patient and Public Involvement in Health (CPPIH) and patient forums will be abolished and local involvement networks (LINKs) will be established for every local authority area with social services responsibilities. These networks will be able to provide flexible ways for communities to engage with health and social care organisations in ways that best suit the communities and the people in them. They will build on the best work of patient forums by creating a strengthened system of user involvement and will promote public accountability in health and social care through open and transparent communication with commissioners and providers.
- LINKs will establish a specific relationship with overview and scrutiny committees (OSCs) and have the power to refer matters to the OSCs.
- OSCs will be encouraged to focus their attention on the work of commissioners of health and social care services and are ideally placed to ask commissioners about the decisions they have made.
- The duties to involve and consult will be simplified and strengthened. There will be a new duty placed on commissioners to respond to what patients and the public have said.
- Work is being undertaken to explore ways of creating a stronger voice for patients, service users and members of the public at a national level.
- There will be a stronger user voice in regulation and in the regulation of involvement.

We will legislate on these new arrangements when parliamentary time allows.

A stronger local voice

This document:

1. describes what we are going to do to strengthen and broaden user and public involvement in the commissioning and provision of services; and
2. asks for your ideas on a number of points to help us get it right. These points are indicated **Q** and questions relating to them appear at the back of the document.

The current arrangements and what will change

- Currently there is a patient forum for every NHS trust (including foundation trusts) and primary care trust (PCT). They have a range of functions including monitoring and reviewing the health service. We plan to build on the role of patient forums and in their place will create LINKs, which will cover an area rather than be tied to a specific organisation.
- The CPPIH was set up to support and manage patient forums. The decision to abolish the CPPIH was made by the Arm's Length Body Review in 2004.
- Local authority OSCs review and scrutinise matters relating to the health service. NHS organisations must consult them on substantial variations and developments to health services. OSCs will be encouraged to focus their attention on the work of commissioners to make sure they are commissioning services that reflect the health needs of local populations and that they are reflecting public priorities in the communities.
- Section 11 of the Health and Social Care Act 2001 places a duty on NHS trusts and PCTs to make arrangements to involve and consult patients and the public in the planning and development of health services and in how the services operate. The requirements of section 11 will be made more explicit and a new duty to respond will be placed on commissioners.
- The Independent Complaints Advocacy Service (ICAS) assists individuals who wish to make a complaint about health services. No changes will be made to ICAS.
- The Patient Advice and Liaison Service (PALS) helps patients and their carers address concerns relating to their care and treatment and tries to sort out problems quickly by liaising with staff, managers and other organisations. No changes will be made to PALS.

Why a stronger local voice is needed

In many parts of the country, local people – young and old – are involved in planning, developing and making decisions about their health and social care services, and their views are changing how services are delivered.



There are some excellent examples to illustrate how powerful the views of local people can be.

In Manchester, the carer of a patient with learning difficulties highlighted to PALS the problems around treating and communicating with patients with learning difficulties.

PALS worked with Manchester People First, a self-help advocacy group for people with learning disabilities, and Manchester Learning Disability Partnership to identify the problems and ways of overcoming them.

At an event, people with learning difficulties told staff they felt ignored, scared, bullied and uncared for. They wanted explanations, such as “What an illness means, what needs to be done. You leave the hospital worrying and feeling more ill because you haven’t understood what is wrong with you, what it means or what to do!” and they told the staff what they would like.

With their help and the assistance of the Medical Director, the Head of Training, the Clinical Governance Manager and the Chief Nurse, changes were made. Pictorial guides to accident and emergency departments and theatre were specifically prepared (these were also useful for people who have difficulty reading English), alerts were put on the hospital computer system in accident and emergency and ‘protected admission’ was set up for patients with complex needs.

Patients who previously were so frightened of attending the hospital that they would stop eating now say they like the hospital, and the ‘did not attend’ rates have dropped.

From *‘Now I feel tall’: What a patient-led NHS feels like* (DH, 2005a).

Although many examples of good practice can be found across the NHS, there is inconsistency, and the NHS still has much to learn from the more localised, social care approach to involvement. The trend in social care is to give as much power as possible to service users to design, purchase and manage their own services. This is supported through direct payments and individualised budgets.

In many NHS trusts and PCTs there continues to be a lack of meaningful engagement when services are being planned and commissioned. (Commissioning is the process by which the health and care needs of local people are identified, priorities determined and appropriate services purchased.) People frequently feel that their views are not being acted upon and that they have had little impact on the decisions that are taken. A continuous dialogue with people is needed, on many levels, to strengthen public understanding of the issues.



The Government is committed to:

- developing a health and social care system planned around the needs of individual people and those of the wider community;
- creating health and social care services that are, regardless of who provides them, user-centred, responsive, flexible, open to challenge, accountable to communities and constantly open to improvement; and
- devolving decision making to the local level. Some 80% of the NHS budget is now devolved to PCTs, meaning that priorities are decided locally.

To achieve, this we recognise that the current systems for involving and engaging with patients and citizens will have to be strengthened and improved.

The White Paper *Our health, our care, our say* (DH, 2006a) says that a stronger voice for local people is needed as 'when people get involved and use their voice they can shape improvements in provision and contribute to greater fairness in service use'.

A number of significant changes are being made to health and social care systems, and people are being given a greater choice and control over the services they use. For example, practice-based commissioning will enable groups of GP practices to work together to commission community-based services that are more convenient for patients.

These changes mean that NHS organisations, with their social care colleagues, need to have more effective and systematic ways of finding out what people want and need from their services. They need to reach out to those people whose needs are the greatest, to people who do not normally get involved and to people who find it hard to give their views.

Four principles underpin the new arrangements for involving people in improvements and changes to health and social care services. They are independence and engagement, accountability and transparency.

The new arrangements aim to achieve a balance between independence and engagement. They will enable the people involved to be sufficiently:

- independent of commissioners and providers so that they can act in the interest of the local community; and
- engaged in debates with commissioners and providers to be able to influence decisions being taken about their health and social care services.

NHS organisations need to be more accountable to their local populations for the services they provide and commission. One of the strongest forms of accountability is through transparency, so that everyone can see what is going on and why.



The new arrangements for involving patients and the public will:

- build the capacity of local populations as well as voluntary and community organisations to engage with health and social care; and
- strengthen the way in which people's views are gathered, listened to, responded to and taken into account when healthcare services are being planned, developed and commissioned.

They will make sure that:

- people are encouraged and given opportunities to have their say in how providers improve their services;
- local people are involved in how the quality of services is assessed and continually improved;
- NHS trusts and PCTs are accountable to their local populations, and that the organisations are held to account; and
- commissioners engage with, respond to and are accountable to the communities and groups within their populations.



A new framework for user and public involvement

Between August 2005 and May 2006, the Department of Health undertook a review of patient and public involvement. From this we know that many people want to have a greater say in how their local health services are provided and think it is very important they are consulted, not only about changes to existing services but also about the design of new services and future local priorities for health and social care. Some people want to have an ongoing role while others want to dip in and out. An ongoing involvement and engagement process will support the constant cycle of service improvement.

The new arrangements have:

- a strong focus on involving patients and the public in commissioning services;
- a robust framework of duties for people working in healthcare to achieve effective involvement;
- opportunities to develop and build public involvement in more flexible and creative ways;
- a commitment to building capacity in voluntary and community organisations and supporting people, so they can contribute effectively to the development of healthcare services; and
- the flexibility to build on the many involvement activities and expertise already in the health and social care system.

The new framework has five elements:

- local involvement networks (LINKs);
- overview and scrutiny committees and commissioning;
- explicit duties to involve and consult;
- a stronger national voice; and
- a stronger voice in regulation.



Local involvement networks (LINKs)

LINKs will be at the heart of the new arrangements to strengthen the voice of local people. Each local authority with social service responsibilities will be appropriately funded to carry out a new statutory duty to make arrangements providing for the establishment of a LINK in its area.

Purpose

We believe that people can have a real impact on the nature and quality of services, and for that to happen we need to:

- provide a flexible way for local people and communities to engage with health and social care organisations;
- support and strengthen open and transparent communication between people, commissioners and providers; and
- make sure organisations that commission and provide health and social care services are more accountable to the public and build positive relationships with them.

We believe LINKs will be able to deliver these aims in ways that are flexible, inclusive and appropriate to local people and communities, and for this reason, we think it is important that LINKs are set up and managed locally.

What will LINKs do?

LINKs will have the flexibility to work with the changing landscape of the NHS and social care systems and to fit in with their local circumstances. They can:

- gather information from a wide range of people and a wide range of sources – information about what local people need in terms of both their health and social care services and about their experiences of using these services in their area. Information could be gathered from existing sources such as PALS, complaints, the national survey and through other means of engaging people such as dedicated websites, user groups and focus groups;
- analyse the information and decide what to pass on. They will identify and pass on trends and make recommendations to the organisations (commissioners, providers, managers, OSCs and regulators) responsible for delivering and scrutinising health and social care services;
- be a means by which commissioners, OSCs and regulators access the views of the local population;

- 
- encourage and support users and the public to participate in commissioning, scrutinising and reviewing health and social care services; and
 - be involved in the development of the 'prospectus-style' document, proposed in *Health reform in England: commissioning framework* (DH, 2006c).

The information they gather will help:

- commissioners make informed decisions about what people in the area need, and assist them in their role as contract managers;
- providers who need ongoing feedback to know what it is like to be a recipient of the services they have delivered;
- managers to know whether commissioners are purchasing services that meet the needs of local people and whether providers are meeting those needs;
- OSCs base their reviews on actual feedback (the LINK can inform the OSC, and members of the LINK may be able to participate in OSC activity);
- the regulators have access to local information on the public's and users' needs and experiences; and
- local strategic partnerships, which work to draw together priorities and initiatives within local area agreements.

The LINK:

- will have the ability to set its own agenda within the scope of its statutory functions, enabling local people to champion local issues;
- is not there to replace wider involvement, it is there to promote it – it is one of the ways in which commissioners and other decision makers can access local opinion;
- will establish a specific relationship with OSCs, and the information it gathers will help OSCs carry out their functions; and
- will want to build an effective relationship with the local strategic partnerships.

Opportunities

LINks should operate in an inclusive way with a membership that includes user groups, local voluntary and community sector organisations and interested individuals. It is important that these arrangements offer scope to groups such as children and young people, especially those who are not always included. There will be opportunities for existing patient forum members to get involved in the new arrangements and to work



alongside a more diverse range of people and organisations. However, how members are appointed will be decided at a local level.

We think that members of the community who are involved in LINKs may be ideally placed to take an active role in the OSCs' review activities. This may include, for example, acting as an adviser during a particular review.

The period leading up to LINKs being established will be an opportunity for forum members to forge and strengthen links with relevant community groups and voluntary organisations. 

In the future there will be a greater emphasis on joint commissioning for health and well-being; LINKs will well placed to work with commissioners across health and social care boundaries.

Funding

We wish to make funds available to local communities to help them develop LINKs in ways that are right for them. Money will be given to the local authorities, which will, perhaps jointly where that seems appropriate, consult with local organisations such as voluntary and community groups or social enterprises to identify the most appropriate arrangements for hosting the LINKs. A guide and model contract outlining the basic principles will be provided to assist local authorities in tendering for a host organisation to run the LINK. 

Governance

The host organisation will:

- develop the LINK;
- recruit members; 
- establish good communication arrangements; and
- support the development and management of a governance structure. 



Overview and scrutiny committees (OSCs) and commissioning

The OSC has a vital role in scrutinising the activities of organisations that provide local health and social care services and asking:

- whether the services are appropriate to the needs of local people;
- if decisions are based on evidence; and
- if the experiences of patients and users of services are leading to improvements in the way services are delivered.

They will be encouraged to focus their attention on the work of commissioners but there is no intention to limit their role. Commissioners are very important in the new system and will be responsible for the decisions they make about which services to purchase and for making sure providers deliver services against the requirements set out in the contracts.

OSCs are ideally placed to ask commissioners about:

- how they have involved local people in the decisions they have made and how they have decided local priorities;
- what evidence they have to support the decisions; and
- the actions they are proposing to take to address failings, concerns and gaps in services.

OSC reviews will have the most impact if they centre on the decision-making activities of PCTs and local authorities, in particular to scrutinise how well they have met the requirements of the revised duties to involve, consult and respond.

Opportunities

It is recognised that there are limits to the capacity of OSCs, not only on their time but also to the degree to which they can be fully informed about the needs and experiences of users and the public. There is a need to make sure that OSCs can access a wider range of views and to equip them to pursue critical issues based on the evidence of users' experience. The best way to do this will be through the OSCs having a strong relationship with the LINK.

LINKs will have the power to refer matters to OSCs and receive an appropriate response.



Simplifying and strengthening the duties to involve and consult

Purpose

We will simplify, clarify and strengthen the current legislation on health service consultation. Section 11 of the Health and Social Care Act 2001 places a duty on all NHS organisations to make arrangements to involve and consult patients and the public in the development, planning and operation of services. These requirements will be strengthened, and new legislation will set out clearly what is required of both NHS commissioners and providers.

In addition to the existing duties, commissioners of NHS services will also be required to respond to the community, as well as involve and consult them. As part of their existing planning arrangements commissioners will be required to have arrangements in place for engaging service users and the public. There will be a structured process whereby commissioners will publish regular reports of what they have done differently as a result of what they have heard and say why they might not have taken forward some suggestions. The process will be open and there will be transparent communication to develop trust and confidence and increase accountability to local people. 

The LINK will be one way in which commissioners can reach a range of views from local people. However, all organisations should develop their own ways of involving and consulting patients and the public so they can be sure that they have as wide a range of views and experiences as possible available to inform their planning and decisions.

Underpinning all these requirements will be one constant theme – to make sure people affected by change, of whatever nature, are appropriately involved in planning, and consulted on proposals for change. This includes consulting with all staff who may be affected by the changes.

The new PPI Resource Centre and the Social Care Institute for Excellence (SCIE) will provide advice and support to NHS and social care organisations to promote and support the benefits of engagement to commissioners, providers and regulators.



A stronger national voice

Currently there are a number of different arrangements for the Government to work with national patient and user organisations, and we recognise that a more systematic approach is needed for involving patients, service users and members of the public in the development of national policy.

A group of patient organisations is exploring setting up a networked body at a national level. The national network would:

- be a channel for communication and engagement with patients, service users and carers;
- be committed to promoting equal access for less resourced groups, particularly those that are user-led; and
- engage at a national level, providing input and advice on policy development.

We believe that a national network will complement the LINKs and that once the LINKs have developed, they will be well placed to feed into the national voice network.



A stronger voice in regulation

As well as more flexible, localised arrangements for involving users and the public, we would like to see stronger:

- user involvement in regulation; and
- regulation of involvement to ensure NHS organisations comply with and fulfil their duties to involve and consult.

Whilst we are not seeking any legislative change in this area, the proposed merger of current health and social care regulation and inspection bodies does provide an opportunity to integrate and build on the current strengths.

User involvement in regulation

The regulators have a role in assessing the overall quality of delivery for the health and social care system. Their assessments will increasingly incorporate the views of users. Service users' own experience and their interaction with other service users will bring the critical 'user' perspective to the quality review process.

User and public involvement should be part of the infrastructure and governance of all health and social care organisations. It is expected that the regulators will set a good example by including a user perspective in their work.

Opportunities

The plan to merge health and social care regulators provides the ideal opportunity to bring together the organisations' wealth of experience in the area of user and public involvement. The single organisation will seek to involve users of services and the public, putting their interests at the heart of its work.

The regulation of involvement

To make sure providers are delivering their responsibilities appropriately, the regulators will seek to develop assessment criteria to measure performance against national standards. We welcome the fact that current core standards for the NHS include the need to seek out and take account of the views of patients, carers and others in designing, planning, delivering and improving healthcare services. LINKs and OSCs will help commissioners be more accountable to local people. There is a formal line of accountability from PCTs to strategic health authorities (SHAs), and LINKs and OSCs will be able to make formal representation to an SHA if they have concerns.



Opportunities

We believe that the criteria used to assess performance against such standards should include an assessment of how local arrangements for involving service users, the public and the LINKs are supported and utilised, and how well commissioners and providers of health and social care services have sought and responded to the views and needs of the communities and groups within their populations. We believe that this should form part of an organisation's annual performance rating.

Regulators should be able to look at arrangements for engaging service users and the public, and should involve people from local communities, including the LINK, to find out how well their plan was carried out.



Timescale and transitional arrangements

There will be a managed transition to the new arrangements to help the current patient and public involvement structures continue to function until the new arrangements are set up and to keep the valuable skills and experience of people who are currently involved.

People's opinions, preferences and views need to be heard at a local level, as this is where most of the decisions are made and where priorities are set. People need to have more than one way to give their views and they have to have confidence that their views will make a difference.

The new arrangements will:

- build on the best of the work of the patient forums, creating a strengthened system of user involvement;
- support involvement activity across the increased number of providers, including foundation trusts and the new map of PCTs (LINKs will be established for local authority areas with social services responsibilities, which will be largely coterminous with the new map of PCTs); and
- focus on joined-up commissioning across health and social care and the new direction of devolution in local government.



Q The questions

The questions relate to sections on the following pages:

Page 16

Q What arrangements can we put in place to make sure there is a smooth transition to the new system?

How can we build on existing activity in the voluntary and community sector?

Page 16

Q What do you think should be included in a basic model contract to assist local authorities tendering for a host organisation to run a LINK?

Page 16

Q How can we best attract members and make people aware of the opportunities to be members of LINKs?

Page 16

Q What governance arrangements do you think a LINK should have to make sure it is managed effectively?

Page 18

Q What is the best way for commissioners to respond to the community on what they have done differently as a result of the views they have heard? For example, should it be part of the proposed PCT prospectus? (As referred to in *Health reform in England: commissioning framework* (DH, 2006c))

Having read this document you may have further questions. We would welcome hearing from you so we can address any queries you have. Please send your ideas and comments to ppimailbox@dh.gsi.gov.uk or write to the PPI Team, 692D Skipton House, 80 London Road, London SE1 6LH no later than 7 September 2006.



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