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FOREWORD BY DAVID NICHOLSON

The NHS continues to evolve. In order to keep up with developments in technology and medicine, adapt to the needs of all patients and be fit for purpose in the 21st century, NHS leaders must make sure that the bar is raised on how important decisions about changes and improvements to services are made and implemented and how users have shaped change.

To do this, the NHS needs to have a better understanding of when and how it involves users, and how to listen and respond to what it has heard. One of the five pledges to users in Lord Darzi's *NHS Next Stage Review: Leading Local Change* is that 'You will be involved'. This guidance will assist NHS leaders to be more confident in their approach to good involvement practice which will lead to better decisions being made because there have been opportunities for the views and opinions of users to influence each step of the process.

The NHS is expected to make sure that proposals for plans to develop services or change the way in which they operate will benefit the users of those services as well as improve clinical standards and deliver value for money to the taxpayer.

We all recognise that making changes on any scale can be difficult and may provoke powerful reactions from some stakeholders. The NHS needs to be much better at involving all stakeholders. This includes patients and their representatives, carers, members of the public, clinicians, staff and political leaders, and it needs to become more open and transparent about why it is proposing changes, what it is proposing to change and what it believes the benefits will be for the people who use the services.

Whether change is on the scale of a major service reconfiguration or how a particular service operates, the NHS must get better at explaining why change is needed. It must make sure that people who use or may use local health services are actively involved in the planning of services, and the development and consideration of proposals for changes that impact on the provision of services and decision-making.

The legislation makes changes to the duty to involve and consult users of health services. The changes include new duties and arrangements for strategic health authorities and primary care trusts about carrying out involvement and reporting on how the views and opinions of users given during a consultation have influenced commissioning decisions.

This guidance will help NHS organisations undertake real involvement and will lead to commissioning decisions that better reflect the needs, priorities and aspirations of users.

▶▶ INTRODUCTION

Real involvement
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ABOUT THIS GUIDANCE

The guidance is set out in two parts with the intention that each part can be used as a reference and guide. The introduction provides background information to the legislation and other useful contextual information.

Part 1 – guidance on section 242(1B), the duty to involve and good involvement practice

Part 1 includes statutory guidance that NHS organisations must have regard to (in accordance with section 242(1G) of the NHS Act 2006) when undertaking their duty to involve under section 242(1B) of the NHS Act 2006.

It provides advice and guidance on how NHS organisations can carry out involvement activity. Chief executives, executive teams, non-executive directors and all other staff responsible for commissioning and providing services for the NHS should familiarise themselves with this guidance.

Part 1 has four sections

Section 1 – The obligation under section 242(1B) of the NHS Act 2006.

This section explains the meaning of section 242(1B), what it means for strategic health authorities (SHAs), primary care trusts (PCTs), NHS trusts that are not relevant Welsh bodies and NHS foundation trusts.

Section 2 – The framework. This section provides a framework for undertaking involvement activity in accordance with section 242(1B).

Section 3 – How to carry out involvement. This section provides practical help, advice and suggestions which the NHS might find helpful in planning and undertaking involvement activity. It includes a number of recommendations, references to related guidance, links to websites and a set of suggested checklists.

Section 4 – User involvement in commissioning and contracting. This section looks at involvement in the stages of the commissioning cycle, practice-based commissioning and specific commissioning situations when section 242(1B) applies.



Points to note

1. Section 242(1G) of the NHS Act 2006 states that NHS organisations must have regard to any guidance given by the Secretary of State as to the discharge of the organisation's duty set out in section 242(1B). 'Have regard to' means that an NHS organisation must properly consider and take into account the guidance when undertaking the section 242(1B) duty. That does not mean that the NHS organisation must comply with the guidance in all cases, but it must have good reasons for any decision to depart from it.
2. All documents referred to in this section are listed in the references and further reading section of the guidance which can be found at the end of part 2.
3. Where this guidance refers to sections 17A, 24A, 242A, 242B and 242(1B) of the Act, those references are to sections of the National Health Service Act 2006, unless otherwise specified.

Part 2 – sections 17A, 24A and 242B of the NHS Act 2006, includes guidance on reporting on consultations and information about section 242A of the Act

Part 2 is not statutory guidance. It explains the legislation set out in sections 17A, 24A and 242B of the NHS Act 2006. It gives guidance about each section of legislation and about Regulations made under section 242B and directions made in relation to sections 17A and 24A. It also provides information about section 242A of the Act.

References and further reading and the appendices can be found at the end of part 2.

Who and what this guidance is for

This guidance is to help people working at a range of levels in SHAs, PCTs, NHS trusts and NHS foundation trusts, from chief executives, directors, commissioners and managers to front-line staff, to:

- understand and follow the legislation that requires them to make arrangements to involve users in planning, developing and delivering health services commissioned and provided by the NHS;
- develop robust involvement practices that will stand up to scrutiny; and
- help make sure that the outcomes from sound involvement practice inform all decisions that are taken about changes to national health services and, where applicable, to report on consultations.

The examples in part 1 of this guidance are used to illustrate how different NHS organisations have approached specific involvement activities. NHS organisations should note that what has worked well for one organisation may or may not be the right approach for another organisation. Each NHS organisation should find the approach that is right for the level of involvement needed and for the users it is planning to involve.

This guidance may be of interest to overview and scrutiny committees (OSCs), Local Involvement Networks (LINKs), voluntary organisations, community groups and the many people who use or may use the NHS.



Points to note

1. The guidance mainly refers to users, taking the definition from the NHS Act 2006 that a user is someone who is using health services or who may use health services. Additionally, the Act refers to a duty to involve users, directly or through representatives. We recognise that carers are a very important group of people who have a valid role as representatives of users and as potential users themselves. Whenever the guidance refers to users or patients and the public, this includes carers as users or patient representatives.
2. The duty set out in section 242(1B) applies to SHAs, PCTs, NHS trusts that are not relevant Welsh bodies and NHS foundation trusts. A relevant Welsh body is an NHS trust, all or most of whose hospitals, establishments and facilities are in Wales.
3. Wherever this guidance refers to NHS organisations, it is referring to those NHS organisations listed above to whom the section 242(1B) duty applies.

BACKGROUND

Over the past few years, the NHS has been getting better and better at involving users in the development, planning and delivery of health services. While nationally there are many examples of innovative practice, there is still little evidence that involvement is a mainstream activity alongside other policy and performance requirements. Rather than being embedded in the day-to-day activity of NHS organisations, involvement continues to be viewed as a marginal activity, largely centred on process and dependent on the commitment of individual managers.

There is scant evidence to show that involvement activity is stitched into all the strands of NHS organisations' work, including their decision-making processes; of 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. However, there is evidence that suggests that some NHS staff, including those working at an executive level, do not properly understand the involvement legislation or what it means for how an NHS organisation needs to work. We also know that the NHS is not always:

- sure about when it needs to involve users;
- clear about whether involving users is the same or different to consulting them;
- ready to involve people at the very beginning of a process;
- clear about what can be influenced;
- open and transparent in the way it consults with users, which can lead to mistrust and the belief that many consultations are a sham; or
- prepared to listen and respond to what users are telling them.

World class commissioning, the operating framework for 2008/09 and the Next Stage Review reflect the shift of involvement to the forefront of the policy agenda and establish it as one of the key developmental challenges for NHS organisations. High-performing organisations are increasingly mainstreaming and embedding involvement activity in all aspects of their work.

As commissioners, PCTs have a particularly important role in gathering and acting on the views of users, including those who are 'easy to overlook'. Some PCTs are already testing out new approaches such as building up a local membership, forming joint governance and planning arrangements with their local council, and finding innovative ways to target and seek the views of their populations. All PCTs should work with their communities to choose an approach that suits their local circumstances.

Leading Local Change, part of the Next Stage Review, includes five pledges that PCTs are expected to have regard to. Pledge 4 is 'You will be involved'.

This guidance should help PCTs and other NHS organisations identify who they need to involve and what they need to do to deliver better involvement practices.

This people-centred, responsive agenda will make sure that the NHS is more locally accountable and shaped by the people who use it. To make this happen, NHS organisations may need to:

- establish new ways of working;
- forge new relationships both internally and externally; and
- make sure that user involvement is moved from the margins into the mainstream of every NHS organisation that is responsible for planning, commissioning and providing health services.

To deliver this responsive agenda, all the NHS bodies to whom section 242(1B) applies need to have regard to this guidance and may find some of the examples and suggestions helpful.

THE CONTEXT FOR THE LEGISLATION

User involvement is integral to many recent national policies. These include the following.

The operating framework for the NHS in England 2008/09

The operating framework for the NHS in England 2008/09 states that:

“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.”

One of the areas in which the NHS needs sustained improvement is public engagement.


“Commissioners have a responsibility 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.”

“PCTs will want to ensure that they and NHS providers:

- adopt a systematic and rigorous approach to seeking, collecting and acting on the views of individuals and partners in the local community, as required by Section 242 – not just during periods of change but on an ongoing basis;
- create greater opportunities for their communities to make their voices heard, raising awareness of those opportunities and empowering patients and the public to use them and LINks;
- take greater responsibility for communicating with their local populations and stakeholders to ensure better understanding of, and confidence in, local NHS services.”

NHS Constitution

The draft NHS Constitution underlines the fact that public and user involvement should be part of the fabric of the NHS by setting out a right for people to be involved. It says:



“You have the right to be involved, directly or through representatives, in the planning of healthcare services, in 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.”

WHAT 'INVOLVEMENT' REALLY MEANS

Section 242(1B) of the NHS Act 2006 (the duty to make arrangements for involvement) is not prescriptive about what constitutes 'involvement'. The term is not defined, but the provision makes it clear that users may be involved by being consulted, or by being given information, or in other ways. Users may be involved directly or by representatives. Engagement, consultation and participation are all words that can be used to describe different types of involvement activity.

Many people working in the NHS believe that involving users means doing something different to consulting with them. This is not necessarily the case, as a number of activities can constitute involvement, including consultation.

When you are planning involvement activity, you need to think about proportionality and appropriateness, understand and use a spectrum of involvement, and know when to use the different activities which range from giving information through to active participation in planning the provision of services.

See part 1 section 3 page 68

Whatever form of involvement you are undertaking with users, you are undertaking the activity for the same reasons, to:

- discuss with them their ideas, your plans, their experiences, why services need to change, what they want from services and how to make the best use of resources; and
- make sure that the services you are responsible for planning, commissioning or providing meet their needs and preferences.

Good involvement practice:

- happens early and continues throughout the process;
- is inclusive;
- is informed;
- is fit for purpose;
- is transparent;
- is influential – it makes a difference;
- is reciprocal – includes feedback; and
- is proportionate to the issue.

WHY EFFECTIVE INVOLVEMENT IS SO IMPORTANT

NHS organisations should develop long-standing and inclusive relationships with users so that they have a clear and up-to-date understanding of the views, needs and preferences of the people for whom they commission and provide services.

These relationships can be built up over time, and to do this organisations may need to find effective ways of having conversations with their communities that can be developed in a systematic way and, as needed, around specific service issues and initiatives. Where this way of working becomes part of the everyday culture or practice of an organisation, there should be benefits for staff and users.

It will give users a better understanding of the issues faced by the NHS and of why their health services may need to change. They should have more:

- information about the health of their community and local health services;
- commitment to, and ownership of, the local NHS;
- trust and confidence in local health services;
- ownership of solutions;
- awareness of the complexities and constraints of healthcare planning;
- influence over how and where health services are provided; and
- health services that meet their needs and preferences.

Where involvement is undertaken as an integral part of the normal, everyday business of an NHS organisation, staff should be able to do their jobs better, and the organisation should:

- have a better understanding of the needs and priorities of the local community;
- make better decisions;
- design services that reflect the needs of users;
- provide services that are efficient, effective and more accessible; and
- experience less conflict and adverse media attention as there is an increase in user satisfaction.



Example

Staff in NHS South West who routinely involve users say, "Involvement is absolutely crucial to developing services. If we are starting from scratch we must have people who have had the experience and involve them from the earliest stage."

▶▶ PART 1 SECTION 1

THE OBLIGATION UNDER
SECTION 242(1B) OF THE
NHS ACT 2006

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THE LEGISLATION – SECTION 242 OF THE NHS ACT 2006 EXPLAINED

The National Health Service Act 2006 consolidated much of the current legislation concerning the health service. Section 11 of the Health and Social Care Act 2001, the duty to involve and consult, became section 242 of the NHS Act 2006. Section 242 was amended by the Local Government and Public Involvement in Health Act 2007. The duty on English bodies to involve users can be found in section 242(1B) of the NHS Act 2006.

Section 242(1B) of the NHS Act 2006 comes into force on 3 November 2008.

Appendix 4 – Section 242(1B) of the NHS Act 2006



Point to note

In the following section, the **blue** text is taken directly from the Act. The explanations are in black.

SECTION 242(1B) OF THE NHS ACT 2006 – PUBLIC INVOLVEMENT AND CONSULTATION

Section 242(1B) applies to “relevant English bodies”.

Relevant English bodies are:

- strategic health authorities (SHAs);
- primary care trusts (PCTs);
- NHS trusts (which are not relevant Welsh bodies); and
- NHS foundation trusts.



Point to note

A relevant Welsh body is an NHS trust that has all or most of its hospitals, establishments and facilities in Wales.

The duty under section 242(1B) – what NHS organisations must do

Section 242(1B) of the Act states, “Each relevant English body must make arrangements, as respects health services for which it is responsible, which secure that users of those services, whether directly or through representatives, are involved (whether by being consulted or provided with information, or in other ways) in –

- a) the planning of the provision of those services,
- b) the development and consideration of proposals for changes in the way those services are provided, and
- c) decisions to be made by that body affecting the operation of those services.”

Section 242(3) states that an organisation is responsible for health services if:

- “a) the body provides or will provide those services to individuals, or
- b) if another person provides, or will provide, those services to individuals –
 - i) at that body’s direction,
 - ii) on its behalf, or
 - iii) in accordance with an agreement or arrangements made by that body with that other person.”

Part 1 Section 1: Section 242(1B) of the NHS Act 2006 – public involvement and consultation

Under a), users must always be involved when the provision of health services is being planned. For example, this may follow a needs assessment or a strategic or service review. Planning the provision of services can take place at:

- strategic level, for example the reconfiguration of mental health services across an SHA or PCT area;
- service level, when plans are being developed for the configuration of a service or services, for example maternity services; or
- NHS trust or NHS foundation trust level, for example when planning to provide a service from a different site.

Under b) and c), users must only be involved if the implementation of the proposal or the decision, if made, “would have an impact on –
a) the manner in which the services are delivered to users of those services, or
b) the range of health services available to those users”.

Users must be involved not only in the consideration of proposals to change services, but also in the development of any proposal that will change the manner in which a health service is provided or the range of services offered. For example, users must be involved in the development of a range of options for the way community services could be provided within a PCT area, not just asked for their opinion on a model that has been developed behind closed doors by health professionals and managers.

Users must be involved where a decision will change the way a service operates if the change affects the manner in which those services are delivered or the range of services offered; for example, the time a family planning clinic is open or when an NHS trust plans to provide a service from a different hospital/site.



Points to note

1. There is no requirement to involve users where proposals for change or a decision to be made by an NHS organisation, for example a change of provider, does not result in changes to the service that affect the way in which that service is delivered or the range of services available.
2. Provision of services can also include services provided jointly.

SECTION 242(1G)

Section 242(1G) states that: “A relevant English body must have regard to any guidance given by the Secretary of State as to the discharge of the body’s duty under subsection (1B).”



Point to note

‘Have regard to’ means that an NHS organisation must properly consider and take into account the guidance when undertaking the section 242(1B) duty. That does not mean that the NHS organisation must comply with the guidance in all cases, but it must have good reasons for any decision to depart from it.

Statutory guidance as to when or how often involvement under section 242(1B) is to be carried out and the form it should take can be found in this guidance.

▶▶ PART 1 SECTION 2

THE FRAMEWORK

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Appendix 5 – Other things to consider

- makes good use of the intelligence it receives from existing data as well as involvement activity;
- consistently provides an audit trail that sets out who was involved and how, in what decisions, and what action was taken as a result; and
- utilises a range of techniques to involve users.

See part 1 section 3 page 68



Point to note

NHS organisations are not expected to adopt this model in its entirety but may find it helpful to consider the following elements when creating their own model of an 'involving' organisation.

Governance

The NHS organisation thinks about building in user involvement to its governance structures so that there are mechanisms in place for user representatives to be part of the decision-making processes for the organisation's commissioning decisions.



Example

Hull Teaching Primary Care Trust (PCT) is designing a membership system similar to the membership model for foundation trusts. The intention is for there to be three basic constituencies, individual membership drawn from patients and the public, staff members and voluntary and community sector members.

There will be three tiers of membership: core members, 'NHS Hull Champions' and a shadow board of governors. The core members will play a largely reactive role and the 'champions' will work proactively with the PCT as partners supporting locality boards to identify health priorities. Members of the shadow board of governors will be elected from the 'champions'; they will establish a programme of work defined by them, in line with the PCT's corporate objectives.

Leadership

Executive teams, board members, senior managers and clinical leads are upfront with their support for involvement activity and consistently recognise the benefits of doing it well.



Example

Birmingham East and North PCT provides practical 'how to' guides for staff on various aspects of patient and public involvement (PPI). It also has a set of PPI standards so that teams can assess their level and identify gaps and opportunities to do more. PPI is included in the lunchbox sessions to keep staff informed of current requirements and developments.

Use of existing information

NHS organisations have large amounts of valuable data within their knowledge management systems, which are accessible by all staff and users (via the website) which provide:

- a central point for recording, collating and updating routine data the organisation collects about patient experiences, for example waiting times and infection rates, and self-reported data;
- a record of current involvement activities and links to reports on feedback, organisational responses and relevant resources;
- Patient Advice and Liaison Services (PALS) and complaints data; and
- ways to systematically use the data to identify areas for service improvement.

Managers routinely access the data, commission further data-gathering exercises where there are gaps and seek advice from the involvement 'experts' and Local Involvement Networks (LINKs). Data is routinely fed into decision-making processes.

Finance

The organisation has a dedicated and realistic budget allocated for user involvement activity. The finance director, strategic lead and operational lead for involvement have early business planning discussions to make sure that the resource requirements are understood and that a model for resource allocation is agreed. Departments such as organisational development and public health are prepared to allocate additional funding for involvement activities where this is appropriate.

Part 1 Section 2: Involving people who work in the NHS

On occasion some staff, including clinicians, see themselves as representing users' views. Without involving users, they believe that they know what they need and want. It is important that clinicians, GPs and other staff understand:

- what it means to represent users' views as they cannot assume that their own views are the same as patients' views – to do this, it is important that they hear patients' own experiences and about their ideas and concerns;
- why their views (as staff and users) are being sought; and
- that they may be able to represent users' views, as long as they are speaking with their agreement, or as users themselves.

It is important for staff to recognise and understand the different ways in which they might be involved. Under section 242(1B), they might be involved as:

- users of services; and
- representatives of users of services.

They might also be involved as practising clinicians in their professional capacity although there is no obligation on NHS organisations under section 242(1B) to involve them in that capacity.

See part 1 section 3 page 60

A member of staff may be engaged in the involvement process because they are able to:

- explain the rationale for a particular change and make recommendations;
- balance professional interests with those of users;
- make the best use of resources;
- update colleagues on advances in a medical field; or
- use patients' experiences to help reflect on their practice.

As a user, they might be involved because they:

- have personal experience of living with an illness or using a particular service;
- are a friend, relative or carer of someone who lives with a condition;
- know other people and families in similar situations;
- have knowledge of research and practice relating to their condition;
- know many people in the community and are widely trusted;
- have experience as an activist; or
- are a formal representative of a consumer group or organisation.

The responsibilities that go with the role of the user representative might include:

- feeding back the experience of other people as well as their own;
- checking back with people in their network or who they are representing;
- informing their networks; or
- sharing the views and preferences of users.

Part 1 Section 2: Working with Local Involvement Networks (LINKs)

This feedback should enable commissioners, including practice-based commissioners, specialist commissioners, commissioners in local authorities and joint commissioning groups, to have a better understanding of the services people wish to receive and to negotiate contracts for services that meet the needs and expectations of local people.

LINKs are a source of information that is valuable to organisations in helping them commission and provide services that are responsive and accountable to local people.



Point to note

Commissioners are expected to create a range of opportunities to involve users throughout the commissioning cycle. Working with the LINK is one way of obtaining their views but should not be seen as the only way to involve users.

See part 1 section 3 page 68

See www.nhscentreforinvolvement.nhs.uk for more information about LINKs.

A partnership approach

Working with partners requires good communication and the sharing of appropriate and non-confidential information about the needs and wants of people, in a climate of openness and trust, subject to the organisations involved complying with any rules about data protection and confidential information which might restrict what they share. Joint appointments of staff with recognised expertise in user involvement may also provide a useful way to promote a partnership approach.



Example

Neighbourhood development officers working at ward level in Birmingham East and North PCT identify who the key people are in the local communities and how to reach them. Engaging certain faith groups after Friday prayers has proved to be a good vehicle for sharing information. Health plans and priorities informed by local communities have been incorporated into constituency plans.

The benefits of joint working

Health bodies, local government organisations, other public bodies and organisations – including the police and organisations working in the criminal justice field – and the voluntary sector should be aware of what each other are doing in the area of user involvement and how their individual activities connect and interrelate.

Users are not usually aware of the boundaries and distinctions between the different providers. They are more interested in the delivery of seamless quality care.

You may find it helpful to establish a joint approach to involving users in planning, commissioning and delivering patient-centred services. User involvement can be the glue that binds organisations and agencies together. Having a common task can promote:

- a mutual understanding between agencies;
- legitimacy for the work;
- dialogue between different agencies; and
- shared agendas, goals and objectives, and information and resources.

Working in partnership may help organisations to:

- get a better picture of what is happening in an area;
- identify and work to fill the gaps; and
- make more imaginative use of resources.



Example

In Derby the drug strategy sits within the Community Safety Partnership. The drug strategy team employed by Derby City PCT delivers the strategy and is responsible for all the drug service provision in the city.

A users' forum has proved to be very proactive in engaging with the drug strategy team, commissioners and providers on service delivery. The group, known as Derby First Forum, is fully independent and autonomous of any treatment provider, strategic body or sponsor, and is funded through a small change grant. The forum:

- assisted in a consultation exercise on a new drug treatment model;
- was actively involved in the assessment of tender bids;
- engaged in the consultation on the Government's new drug strategy;
- is developing a peer-led harm reduction and overdose prevention DVD;
- developed and delivered a training programme;
- feeds into the harm reduction strategy for the city; and
- is actively involved at a number of levels in designing and developing drug treatment and harm-related literature for users and professionals.

Public sector organisations, including health bodies, are increasingly required to work in partnership to tackle the challenges facing their communities.

Appendix 7 – Joint planning processes that present opportunities for joint involvement activity

▶▶ PART 1 SECTION 3

HOW TO CARRY OUT
INVOLVEMENT

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HOW TO APPROACH INVOLVEMENT PRACTICE

Commissioners and providers will become 'world class' when they have the capability and capacity to buy and deliver the health services people want. To achieve this goal they will have to have a thorough understanding of patients' experiences and the needs and preferences of users.

The major challenges for NHS organisations are to:

1. Identify and involve the users who are 'easy to overlook'. Until this is done well the most marginalised, isolated and deprived people in the community may be excluded from involvement processes.



Recommendation

NHS organisations should consider working with local partners, Local Involvement Networks (LINks) and other organisations in the community such as national or voluntary organisations, local charities and community and faith groups, to identify appropriate ways of involving people who are 'easy to overlook'. In this way, inclusive processes can be developed and NHS organisations should gain a better understanding of the needs and preferences of the whole population.

See part 1 section 3 page 63

2. Understand users' lack of knowledge of the planning and commissioning processes in the NHS.




Recommendation

NHS organisations may achieve this by:

- having a better understanding of how to identify who they need to involve; and
- developing role and person specifications to recruit the right people into specific roles, for example to attend meetings, and provide training and support programmes where needed.

See part 1 section 3 page 60 and appendix 6 for an example of a role and person specification for user representatives


3. Refrain from using jargon and complex language that is difficult for people to understand.



Recommendation

NHS organisations may find it helpful to review the language they use to communicate with people and make sure that they use high standards of plain English in all written and oral communication.

4. Make use of existing non-confidential data on patients' experiences.




Recommendation

NHS organisations may achieve this by establishing early warning systems to collate and review existing data on patients' experiences.

Commissioners and planners will find it helpful to be aware of, understand and make use of this data and use it to inform the development of commissioning plans and decision-making processes in a systematic way. The data could include the regular national surveys conducted by the Healthcare Commission, local data gathered by LINKs, and data from Patient Advice and Liaison Services (PALS), complaints and from previous, relevant involvement activity.

5. Make sure that there is strategic level prioritisation of patient and public involvement.



Recommendation

NHS organisations should give careful consideration as to the best place for user involvement within their structures. Wherever it sits, user involvement will need to be integral to all other directorates or departments, including commissioning.

Part 1 Section 3: How to plan involvement activity

- make sure that the consultation is as effective as possible and that particular groups and individuals do not get 'consultation fatigue'; and
- make sure that there is a co-ordinated approach on issues that cut across more than one organisation.

Again, although not a specific obligation under section 242(1B), it may be helpful to work closely with different agencies, for instance joint working with the local authority, for many of the same reasons.

See part 1 section 2 page 37

Monitoring and evaluating involvement processes

Monitoring is used to assess progress against a plan. Its purpose is to support project management and accountability.

Evaluation is an assessment of the impact of an involvement process. It is usually undertaken upon the completion of a piece of work or at a point built into the process at the start. The purpose is to determine what has worked and what hasn't, and to develop an iterative process that builds on experience.

You need to be clear about what you are evaluating. The involvement strategy and the processes undertaken should be included in an evaluation. The focus should be on whether the aims and objectives defined for the work before and during the planning stages of the process have been achieved.

Monitoring and evaluation arrangements should be part of the initial plan for a consultation, and not added later once the work is under way.

Section 242(1B) always applies when NHS organisations are planning the provision of health services. Where an NHS organisation is developing and considering proposals for change or making decisions affecting the operation of services, section 242(1B) only applies if implementation would have an impact on the way in which services are provided or the range of services provided is affected. If a change does not concern planning the provision of health services or will not impact either on the way a service is delivered or the range of services provided, the duty does not apply. The two scenarios below illustrate when there is no requirement to involve users, whether by consulting them, providing information or in any other ways.



Q: A call centre for a national service is based in the region. It is being closed. Do we have to consult all of the region or just the area it is based in or the entire country? It will not affect the delivery of the service but will affect premises, jobs and staff.

A: Is the closure of the call centre part of an NHS organisation's plans for the provision of services? Is the NHS body responsible for commissioning or providing those services to its local population, or will the closure have an impact on other services for which the body is responsible?

If it is simply a change of contractual arrangements or of personnel then it may not be part of the NHS organisation's plans for providing services. If not part of planning the services, this does not trigger the duty to involve users under section 242(1B).

If the closure of the call centre would not have an impact on the manner of service delivery or the range of services available, the NHS organisation responsible for the call centre would not need to consult with users under section 242(1B) (a).

Involvement under section 242(1B) is not about involving users on a regional or national basis, it is about involving people who use or may use those services, so who should be involved would depend on who is or might be affected. If the body is not responsible for the services, but the closure may affect other services for which it is responsible, then the duty may apply.

Even if the NHS organisation is not required to involve users under section 242(1B), there are other rules and procedures relating to the impact of proposed changes on jobs and staff.



Q: An out-of-hours co-operative has notified the primary care trust (PCT) that it will not continue to provide services. The PCT is preparing to go out to tender for a new out-of-hours provider. Should a consultation take place?

A: Is the change in provider part of the PCT's plans for the provision of services?

If the change of provider is not a result of the PCT's planning arrangements then the duty under section 242(1B) (a) would not be triggered.

If the change in provider does not have an impact on the manner in which the services are delivered or the range of services available to users, the duty to involve under section 242(1B) will not arise.

If the change in provider results in, for example, a change in the current configuration of services, there would need to be appropriate involvement activity.

The PCT should be aware that if the proposal constitutes a substantial development of the health services or a substantial variation in the provision of services the OSC will need to be consulted.

The following scenarios are examples of areas where there has been a lack of clarity about the right involvement process.

Each scenario has an outline process that provides a steer to help work through who needs to do what, when and how. There is no 'one size fits all' model and you need to be clear from the start why you are involving users. Once you are sure about the purpose and who you need to involve, it should be easier to understand what you need to do.



Q: A PCT has consulted on a mental health strategy that will improve services, placing them closer to home. This has been approved, although it was contentious as the plans will see a reduction in the financial value of the provider's contract. The PCT is now moving to implement the individual schemes that make up the strategy; should it consult on the individual schemes?

A: Under section 242(1B), the PCT has a duty to make arrangements to involve users in developing and considering proposals to change services, if the implementation of the proposal will impact on the manner in which the services are delivered or the range of health services available.

If the consultation included proposals for and detail about the individual schemes, the PCT only needs to undertake more involvement if the implementation of the plan would involve further development or consideration of proposals or any further decisions would have an impact on the manner in which the services are delivered or the range of services available.

The PCT should be aware that, if the proposal constitutes a substantial development of the health services or a substantial variation to the provision of services, the OSC will need to be consulted.



Q: A city-based PCT wishes to put dermatology services out to tender. A local district general hospital has been providing these services for some time. A large specialist teaching hospital has expressed an interest in providing these services, as have a number of other local acute providers. What part of the commissioning process can local people be involved in and how can they influence the final decision?

A: Section 242(1B) requires users to be involved in planning the provision of services which may involve a change of provider if that is part of the PCT's plans. Users should be involved in all the stages of the commissioning cycle.

See part 1 section 4 page 95 and references, resources and further reading

It is also good practice but not a requirement under section 242(1B) to involve users throughout the procurement process.

HOW TO FIND THE RIGHT PEOPLE TO INVOLVE

Section 242 of the NHS Act 2006 defines a 'user' as a person who is using services or who may use services. Within the broad definition of 'user', those involved might be members of the public, patients, carers, members of self-help and support groups, or members of user groups or a LINK. Any of these people may also act as representatives.

The following explanations are offered as a guide to help think through which types of users are likely to be called on in any given involvement context.

Members of the public

A member of the public may have been a patient or they may have gained their knowledge through the experiences of a member of their family or a close friend. They are likely to have views and opinions based on these experiences as well as what they read and hear about in the media. Most members of the public are likely to have views on what they think they may need if they are ill or need emergency treatment.

Members of the public may be consulted on strategic issues and major reconfigurations and may have views on smaller changes. Their views may be influenced by campaigners and the local media so it is important to provide a range of opportunities to talk with people in order to identify what the main issues and concerns really are.

Patients

Patients are all people who have a relationship with healthcare professionals who may provide care at different times in their life. They know about, and can describe and judge their own experiences of healthcare. They can also raise points of satisfaction or concern, but they cannot necessarily speak for other patients. Through their experiences, they might gain knowledge of a range of services and are often in a good position to give their ideas on how services could be improved.

Carers

Carers are people who often have a wide experience of healthcare both from their perspective as a carer and as a user. Through these experiences they gain knowledge, insight, views and opinions of the health services they encounter and may represent the views of the people they care for, which may be different to their own.



Example

Steering and joining – one person's reflection

When people are invited to join a group that has already met to do some preparatory work, or when people who have begun to work together are joined by others, there are issues of 'expectation'.

For example, a core group may meet:

- Are there terms of reference, or are they expected to make their own plan for the critical path of the task?
- Do members of the core group know who will be joining them or do they only know that more people will join them?
- Do members of the core group make task and process plans for the people who will be joining them? The 'task' being what has to be done, the 'process' being 'how do we work together?'.

This brings up not only issues of 'expectation' but also of 'feelings'. If the core group does too much of the task, what will be the expectation and feelings of the people who join them – the 'joiners'?

As a joiner, I wish to feel welcome and welcomed, to:

- have the task confirmed and the purpose for doing it explained – commitment comes through mutual agreement to a common purpose;
- know what has to be achieved and by when;
- have my relevance to the group explored by the people managing the event – the 'steerers', so they know what I can offer;
- take part in a review of what has been done so far to see if it touches my expertise and exchange views to gain agreement and my commitment to the future work of the group; and
- mutually agree the future work plan for what the entire group will now be doing.

So how do the steerers, by doing too much, irritate or fail to gain the commitment of the joiners? The answer is in many ways; these are a few. By:

- 'telling' the joiners what to do without telling them why, this leads to purposeless work;
- being patronising in that they have been working on the task and have decided how it should be done without at least checking the skills being brought to the process by the joiners, and looking for synergy;
- seeing themselves as managing the joiners;
- seeing the joiners as a threat to the work they have already done; and
- seeing other people's ideas as a challenge to their own.

Building on ideas should be activated by 'Yes AND', rather than 'Yes BUT'.

HOW TO FIND PEOPLE WHO ARE 'EASY TO OVERLOOK'

'Hard to reach' and 'seldom heard' are terms used in the public sector, particularly in the NHS and social services to refer to:

- people who do not frequently engage in public consultations;
- minority groups, such as non-English speaking people, people from black and minority ethnic communities, gay men and lesbians and homeless people;
- young people, older people and people living in rural communities;
- hidden communities such as drug users, sexually active teenagers and sex workers;
- vulnerable groups that may require different ways of communicating such as people with learning disabilities, those with a visual impairment and people with a mental illness;
- faith groups;
- people who are difficult to contact;
- people who fail to access the services that are available;
- people who tend to have poorer health; and
- people who are just uninterested and/or disillusioned.

It is easy to overlook these people, and it will help to make sure that you involve the right people if you are clear from the outset exactly who you need to involve in the work you are planning. In carrying out the duty under section 242(1B), you should also consider the statutory duties to have regard to the need to eliminate discrimination on the grounds of race, gender and disability and to promote equality of opportunity.



Points to note

1. The term 'hard to reach groups' implies that these people live in homogeneous communities or distinct groups, although the reality is that these groups rarely exist.
2. No one is really 'hard to reach' but some people are harder to reach, and may require more time, money, effort and creativity on the part of the organisation to seek them out and involve them appropriately.
3. There are people within these 'groups' who may like to get involved but for a range of reasons are unable to do so. These include people who are housebound or lack confidence, and those people who it is not convenient to communicate with, for example, people who do not have access to the internet/email in their homes.

You will probably find that local authorities, county councils and public health departments all have different ways of categorising the people for whom they are providing services.

