

Title	Guidance on Involving Adult NHS Service Users and Carers
Date of publication	April 2010
Description	Provide guidance on involving adult NHS service users and carers in the development and planning of health services
Target audience	Adult NHS Service Users and Carers, NHS, Other Partner Organisations
Originator	Helen Husband, Peter Carr and Wayne Jepson
Publisher	National Leadership and Innovation Agency for Healthcare
Copyright	Welsh Assembly Government National Leadership and Innovation Agency for Healthcare
Design	Design Stage www.designstage.co.uk
Further information	National Leadership and Innovation Agency for Healthcare Innovation House Bridgend Road Llanharan CF72 9RP Telephone: 01443 233333 Facsimile: 01443 233334
Alternative formats	If you require this publication in a larger font or in an alternative format, please contact Wayne Jepson at the National Leadership and Innovation Agency for Healthcare on Telephone: 01443 233333



Foreword

People generously give up their valuable time and invest a great deal of effort to ensure that their voice is heard on behalf of all service users and carers in designing better, user friendly, more effective health services in different settings.

Supporting adults to engage confidently and effectively with a range of health professionals, government officials, charitable organisations, other service users and carers is a high priority for the Welsh Assembly Government and their partners.

Welsh Assembly Government (WAG) officials, charitable organisations (British Heart Foundation, Diabetes UK Cymru, Welsh Kidney Patients Association, The Stroke Association), cancer patient groups and the National Leadership and Innovation Agency for Health in Wales (NLIAH) have worked together with a variety of adult service users and carers to develop this guidance document to support their involvement.

I would like to thank all those who have been involved in developing *Guidance on Involving Adult NHS Service Users and Carers* particularly British Heart Foundation (BHF) for enabling the use of their Hearty Voices training resource and supporting training events. The aim of the guidance is to ensure that adults wanting to get involved in the development and planning of health services are supported with adequate training and guidance to undertake the role effectively and competently. The guidance will also be helpful in a wider application to support Local Health Boards (LHBs) and NHS Trusts in their provision of training and guidance for service users and carers involved locally.



Edwina Hart AM

Minister for Health and Social Services



Contents

Background and Introduction	4
Working in partnership	5
• What and Who is this Guide For	5
• Why Involve People	5
• Why is Guidance Needed	7
• Being Clear About the Purpose	7
• Types of Involvement	8
• How are People Who Get Involved Supported	9
Service User and Carer Involvement Principles	16
• The User Representative's Role	16
• Selection and Engaging Patient Participants	17
• Buddying	18
• Working Effectively - The 4 Rs of Working Together	19
• Rights and Responsibilities	20
• Communication	21
• Support, Training and Induction	21
• Payments and Expenses	21
• Confidentiality	22
• Feedback and Evaluation	22
• Challenges of User Engagement and How to Overcome Them	23
• Key Do's and Don'ts	24
Links	25
Annex 1 - Information Points for NHS Service User and Carer Information	26
Annex 2 - Good Practice Checklist and Monitoring Tool	28
Definitions and Other Information	30
• Glossary of Terms	30
• References	30
• Useful Resources	31
• Acknowledgements	32

Background and Introduction

Citizens are at the heart of all public services in Wales, and it is crucial that services are planned, delivered and reviewed with the perspective of the service user or patient at their centre. The importance of citizen centred engagement in the development of all public services is demonstrated in WAG policy as set out in *Making the Connections: Delivering Better Services for Wales*, its response to the Beecham Review *Beyond Boundaries and One Wales*.

Without service user and carer involvement in the development of the National Health Service (NHS), we may find ourselves with a service which users find difficult to access, understand and which may not meet their needs. For the NHS to deliver world class healthcare and function in the modern world, its processes need to be developed to meet the needs of users - patients, relatives, carers and the wider public.

WAG is determined to ensure that people who use services (and in this case those who receive services in relation to their chronic condition) and their carers are genuinely and constructively involved in all aspects of the service. WAG endorses the view that genuine user and carer involvement can best be demonstrated when service users and

carers believe and perceive they are being involved (Stronger in Partnership 2 - Policy Implementation Guidance).

The National Service Framework (NSF) for Diabetes in Wales: Delivery Strategy 2003, National Cancer Standards 2005, the NSF for Older People in Wales 2006, the NSF for renal disease: Designed to Tackle Renal Disease in Wales 2007 and The Cardiac Disease NSF for Wales 2009 all advocate user / carer involvement to influence the planning and delivery of services.

This document has been developed to guide and support people with vascular conditions and related chronic diseases, and their carers to actively and effectively participate in their engagement with multidisciplinary groups set up to plan and develop health services across a range of settings. In a wider application this will also be helpful to those who provide guidance, training and support for users and carers of health services, such as LHBs, NHS Trusts and voluntary organisations.



Working in Partnership

What and Who is this Guide For

Although this guidance has been developed to support the training needs of users and carers who wish to get involved in the planning and development of services related to vascular conditions it will be helpful in supporting user/carer involvement in a wider context and could act as a useful checklist for service providers.

Enabling the perspective of users and carers to be considered and included not only in planning and development but also in the design, delivery, monitoring and evaluation of services requires support and guidance to help them to develop the skills required for the role.

This guide is designed to help service users and carers, through training and support to have the opportunity:

- to develop the necessary skills to help them to engage at the appropriate level with confidence and;
- to effectively challenge service providers to be more receptive to their needs

Why Involve People

It is essential to adopt a partnership approach to developing and delivering health services for people with chronic conditions in Wales. Service users and carers must be listened to and have a genuine influence over how services are planned, developed, delivered and monitored.

The advantages of involving service users and carers include:

- Service users and carers are recognised as experts in their experience, and often have a good knowledge of services and how the system works.

- Service users and carers bring their own perspective about treatment and care. This can help prompt service providers and practitioners to re-evaluate the provision of services, challenge traditional assumptions and highlight key priorities to be addressed.
- Decisions are more likely to be seen as positive by those who have had an opportunity to contribute to making them. Sharing the agenda promotes constructive working relationships.
- Services will be better designed, be more effective and deliver better value for money with less waste.
- Meeting higher levels of customer care are likely.
- Involvement has a positive impact upon service user and mental health well-being (Mersey Care NHS Trust. 'Involving Service Users and Carers – The Mersey Care Way', 2007).
- Implementing evidence based practice which shows that involving people in planning and developing health services contributes to effective changes in the provision of services across a range of different settings. (Crawford MJ, Rutter D, Manley C et al. 'Systematic review of involving patients in the planning and development of health care.' British Medical Journal 2002; 325:1263 -1265 <http://bmjjournals.com/cgi/reprint/325/7375/1263>).

Partner Example: British Heart Foundation

The Help a Heart Grant (HaHG) Programme is a small grants programme, funded by the British Heart Foundation (BHF), for groups of heart patients, carers and people at high risk of developing heart disease in local communities.

Help a Heart Grants of up to £2,000 are awarded to organisations and groups - in England, Northern Ireland, Scotland or Wales - who will make a real difference to the heart health of their community.

Applications are assessed quarterly by the HaHG committee which is made up of heart patients, BHF staff and community representatives. The involvement of patients in the committee is highly valued by the BHF.

Ray Crocken a patient representative on the committee feels that the BHF encourage patient involvement in many ways and finds it a great privilege to be asked to take part in the HaHG committee.

When asked how it feels to be involved Ray said 'It is an opportunity for me to use my skills to both "put something back" into the healthcare system but more importantly to be able to help those who really need some assistance either in their battle against what can be a very debilitating condition or in helping some to amend their lifestyle and thereby improve their quality of life.'

On a more personal level Ray feels a sense of personal achievement resulting from the real and tangible outcomes the HaHG offers for which he has had involvement.



Why is Guidance Needed?

This guidance is needed to encourage NHS service users and carers who sometimes find they are serving on committees, groups, networks, etc. with little or no organised training to support their engagement. They may be asked to represent their own personal views or those of their peers and can find it difficult to contribute at the appropriate level.

This can result in:

- not being able to get their point of view across
- feeling time and effort has been wasted
- feelings of confusion or frustration
- lack of confidence

This document provides guidance on delivering training and support for LHBs, Local Authorities and any other service providers involving users and carers in the development and planning of services with a view to addressing the above issues.

Being Clear About the Purpose

It is of paramount importance that, at the start of the process, LHBs, Local Authorities and other service providers clarify, agree and understand the purpose of involving service users and carers to:

- Improve the quality of services by making them more sensitive or responsive to the needs of the individuals who use them; and
- Participate in decisions about the way services are designed, managed and monitored.

There is a range of ways in which individuals might be involved (as suggested in 'Researching User Involvement' (1992)), for example:

- In an assessment process or treatment decision;
- As someone contributing their own views and experiences;
- As someone reflecting the voice of a group or community with a particular interest in common, such as use of a particular service, living with a particular condition; and
- As citizens.

Contributing to:

- The overall direction of services within National Guidelines;
- Identifying and prioritising needs and allocating resources;
- Planning and purchasing services;
- Developing assessments and providing services and packages of care and support;
- Monitoring, reviewing and evaluating services and taking part in inspections and reviews; and
- Staff recruitment and selection, training and development; and improving the patient experience.

Types of Involvement

The following section provides a range of some of the techniques that are most often used in the area of service user involvement.

Discovery Interviews/Patient Story Collecting:

Discovery Interviews/Patient Story Collecting are ways in which individuals can recount in detail their experiences of the NHS - in their own words and in their own way but with carefully structured support. Hearing what patients and carers have to say in audio or audio visual form is powerful and accounts for the increasing popularity of this approach to user involvement. Discovery interviews / patient stories can be used in their own right, to complement other methods, or as ways of digging deeper following on from focus groups, patient and public feedback, or a chance remark.

Focus Groups:

Focus groups are informal groups of around 8 to 15 people who are brought together to discuss and give detailed responses to a particular issue. An independent facilitator or moderator guides the groups through a series of themes or topics. The focus group then develops its own ideas and shares experiences and understanding.

Opinion Surveys:

Surveys can be conducted as self completion postal surveys, face-to-face surveys and telephone surveys. Surveys can be used to cover a wide range of perspectives on varying issues. Surveys are appropriate for finding out public opinion on broad policy issues and/or for measuring satisfaction. Surveys of service users can be useful in assessing reaction to changes in services, concentrating on user experience.

Forums:

Interest and user group forums may be used. They are comprised of groups of service users or their representatives who meet regularly to consult on issues, and they may be in the form of face to face meetings or participation may be virtual by email, text or telephone.

Health Panels:

Health panels can be used to look at health care policy issues. They consist of a number of separate panels, each consisting of approximately 12 service users who meet on several occasions to discuss issues put to them by the planning and provider organisation.

Citizens' Juries:

A citizens' jury provides a structured approach to obtaining citizens' views on controversial issues or an issue of local importance where choices have to be made concerning planning or policy. A jury consists of 12 to 16 people, selected as a cross-section of the community and meeting over several days to hear 'witnesses' providing different perspectives on the issue. The jury brings explicit criteria to bear on the issue and examines it in depth before making recommendations to the relevant authority. An independent moderator assists in the smooth running of the process.

Large Scale Events:

These techniques allow people to be involved in planning and policy processes. To map out services and gain information about people's views and experiences of services, and to inform needs assessment. They aim to involve the public, service users, carers, the voluntary and independent sectors as well as the statutory service providers.

How are People Who Get Involved Supported

There are various and different levels of support for people who choose to be involved and each level will have different purposes and outcomes.

Building of confidence:

Service users and carers have unique skills and abilities, and are 'experts' in their own illness and experts by experience. These skills and experience should be recognised and appreciated by the service providers, who actively seek the opinions, views and feelings of the service users and carers. Service providers need to provide support and training to enable service users and carers to understand and analyse the information and views provided. This will help build the confidence of service users and carers in being able to communicate views. Effective, appropriate communication support may be required to enable all members to participate. Accessible communication support may include providing information in the following formats:

- Large print
- Easy read
- Plain English
- British Sign Language Video
- Audio cassette
- Braille
- Welsh Language
- Minority languages

The following may also be required to enable people to communicate effectively:

- Hearing loop induction systems
- Lip speakers
- British Sign Language Interpreters
- Palyntypists
- Language translation services



Partner Example: Taf Ely and Rhondda Diabetes Patient Reference Group

Cwm Taf LHB has a long-standing, well-established Local Diabetes Service Advisory Group (LDSAG). The LDSAG recognises that personal contributions from people with diabetes enhance health care professional insight into diabetes services.

There are three diabetes patient reference groups across Cwm Taf health community (Taf Ely and Rhondda; Merthyr Tydfil; and Cynon) these reference groups work to support the LDSAG.

Each diabetes reference group is a group of people who live with diabetes, meet to discuss local diabetes service, consider proposals for developments and are open to all people with diabetes and their carers. After every meeting each reference group elects one or two people to attend the LDSAG and to present issues raised during the reference group meeting. These elected representatives also feed back from the LDSAG to the reference group.

The role of the reference group is to:

- Discuss local diabetes services and consider areas for development.
- Act as a local source of user representatives ensuring effective capture of user skills/interests/tasks.
- Feed into the LDSAG issues of interest or concern.
- Identify representatives for bodies requiring the skills and experience of people living with diabetes.
- Support their representatives on the LDSAG.
- Support and encourage the work of the LDSAG.
- Act as a 'critical friend' to the service, offering an alternative perspective, and sometimes challenging the assumptions of healthcare professionals and managers.

Each group reserves the right to invite health care professionals to the meeting to advise and/or act in an expert capacity. Reference group members have the opportunity to influence how local services are delivered and to ensure that they are organised in a way that suits and benefits all people with diabetes. The group actively networks with other people with diabetes and acts as an advocate for people with diabetes. The group meet at a locally agreed, convenient venue between four and six times a year shortly before each LDSAG meeting.





Minutes and Agenda

The group agreed that the minutes and agenda of the reference group could be shared with the LDSAG and the Welsh Assembly Government.

Positive outcomes

- The reference group challenged the use of abbreviations in meetings and asked for a list of common abbreviations used within the NHS.
- Members of the reference group gave valuable input from the service user point of view into the All Wales Guidelines for Adults with Diabetes
- The reference group attended a training day in 2005, positive responses included;
 - The session on communication skills (were) valuable (giving) practical tips for confidence building to face an audience.
 - The information given has helped me to clarify my role as a member of a reference group.
 - The session on the structure of the NHS put our position in the system clearly.
 - Very good for people who aren't keen on speaking in public.
 - I will undertake to go armed to the meetings with prepared questions.
- A second training day is planned for early 2010.

Providing relevant and timely information:

Relevant and timely information from the service providers should include what services are available nationally as well as locally and what alternative types of service exist to enable input into strategic vision and not just operational matters.



Partner Example: Welsh Kidney Patient Association

Rose is a lady of 70 years of age who had a kidney transplant 10 years ago and subsequently developed type 2 diabetes. She is known to be keen to know about trends in the care and treatment of persons, especially those with similar conditions as herself.

Rose is a member of her local Diabetic Support Group and attended a meeting where the invited speaker for the evening was a Specialist in Diabetic Medicine. He presented a talk about some recent developments and progress in the treatment of diabetic patients.

At question time following the talk, Rose was able to ask about possible progress in the treatment of neuropathy, a condition that Rose had developed like many other diabetic patients. She was surprised to learn that there were new drugs available that would help to control the pain that she had been experiencing.

Following an appointment with her GP, Rose was referred to see a 'pain specialist' at her local hospital. As a result Rose was prescribed the new drug and within a month the pain had eased and she was able to walk without pain for the first time in many years.

Sharing relevant information with others, through her local patient group, made it possible for Rose to have the benefit of advice on recent advances in medicine. Although she regularly attended a diabetic clinic she was not aware of the recent developments for her condition and felt unable to ask questions in the clinic situation but found it easier in the more relaxed setting of her local patient group.

By empowering service users and carers with relevant information, many people may be able to review their situation and seek advice leading to improved care as appropriate.

Providing suitable space and time:

Organisations should not solely rely on service users and carers attending official meetings, but should be proactive in attending local venues, service user group meetings or other places where service users are likely to be.

This may include arranging evening and weekend meetings so all have the opportunity to attend. Venues which are used for meetings should be checked for accessibility. This includes ensuring the venue is easy to get to, on a public transport route as not all service users

and carers have access to a car, and that the building can be accessed by disabled people or those whom may have mobility difficulties. Organisers should check whether a loop induction system is required and available for people with hearing loss and whether any other communication support is required.

Further good practice on accessible venues can be obtained from the Welsh Assembly Government's 'Accessible Venue Guidance' document.

Partner Example: Patient Involvement in the South East Wales Cancer Network

The Macmillan User/Carer Involvement Project was set up in partnership with Macmillan Cancer Support and the three Cancer Networks in Wales in 2004. The Network's User Involvement (or partnership) Group, CaSE Wales, was set up September 2005.

CaSE Wales stands for Cancer in South East Wales and is made up of Cancer patients, carers and a small number of health professionals from all over South East Wales. The members of the group come from across South East Wales responding to posters in GP surgeries; direct invitations to self help and support groups, and word of mouth.

- As the facilitator there are other duties around patient involvement within the Network as well as supporting the work of CaSE Wales and these include:
- Facilitating CaSE Wales and providing administrative support for the CaSE Wales meetings which are held every 2 months. Organising guest speakers to attend the meetings.
- Supporting and assisting the roles of the Chair and Vice Chair of CaSE Wales.
- Organising CancerVoices training from Macmillan Cancer Support for the members of CaSE Wales.
- Developing, promoting and maintaining patient involvement within the South East Wales Cancer Network.

- Acting as a link to other organisations and health professions in relation to patient involvement both within the Network area and on an All Wales basis, and working with health professionals to assist them in including patient involvement within their work, wherever they work.
- To act as a source of advice or information about Patient Involvement issues in cancer services both locally and nationally.

Examples of what CaSE Wales members have become involved in are:

- Representatives on CSCG Patient Forum and some of the CSCG All Wales Advisory Groups e.g. Breast and Lung and All Wales New Cancer Drugs.
- Chair of CaSE Wales sits on the South East Wales Cancer Network Board.
- Patient representative on PET Scan Steering group.
- Two members are on the Macmillan Cancer Support User Involvement in Wales Steering group.
- Patient representative on the Macmillan All Wales Patient Information Project.
- Patient representative on South East Wales Cancer Network Urology Group.
- Patient representative on South East Wales Cancer Network Upper G I Review.
- Part of a Brunel University Focus Group on the impact of getting patients and carers involved.

Patient involvement is slow but steady work as we try to build up the relationships between patient and carers and the health professionals so that patients can become involved at the decision making process from the outset rather than just as a cursory “tick in the box”. It is about working together to share experiences from both sides of the service - those that provide it and those that receive it.



Receiving feedback and responding appropriately:

Service providers are responsible for acting on advice of service users and carers, and providing explicit feedback on action taken. Feedback should be given demonstrating how service users' views have been acted upon and if recommendations are not taken forward then the reasons for this need to be explained clearly. Like all communication with the participants, the feedback should be given in an appropriate way for the individual.



Partner Example: Welsh Kidney Patient Association

Patients are not always in a position to convey their views on the provision of their care. They often feel vulnerable and are reluctant to express their views. This is sometimes because of fear of retribution or causing difficulties for their immediate carers who they rely on for the provision of their care.

In the situation where patients attending a dialysis unit were becoming increasingly concerned about the unreliable patient transport service it was seen to be more appropriate for their concern to be taken up by their patient representatives.

The patient representatives were able to discuss the difficulties with the appropriate branch of the service and the matter was resolved quickly to the satisfaction of all concerned.

The availability of knowledgeable patients' friends or representatives fulfils an important link in the ability of individual patients to contribute to their care. It is clearly advisable for there to be good feedback to inform the patient of the action that has been taken or to explain the reasons for not taking it, as appropriate.



Service User and Carer Involvement Principles

The User Representative's Role

User representatives are users of NHS services who work in partnership with health professionals and present the service user and carer viewpoint on health services.

The role of the user representative is very important and should be seen as a fully integrated and valued member of the team. There needs to be collaborative working within the improvement project or group between the organisation and the user representative. The user representatives are not expected to represent all service users accessing the services, but to provide a service user perspective.

It is vital that a good relationship is developed between the organisation and the user representatives. Staff involved in the group should not see the user representative as a threat, but as a person working with them to achieve an excellent service in the best interests of those involved in delivering and receiving the service. Organisations may consider some form of 'bonding' exercise to enable staff to get to know user representatives. This will also allow individuals the opportunity to share feelings and concerns openly so as to clear any misconceptions.

A suggested outline of the user representative's role may be to:

- Contribute to maintaining and continually developing effective public and service user relationships in the organisation.
- Support, consider and review emerging findings from studies carried out by the organisation.
- Develop contacts and good working relationships with a range of organisations, service users and communities, which make up the local public.
- Provide a source of service user and carer views in dealing with particular issues that may arise.
- Reflect on the experiences of people as services users and carers as well as their wider views on health and social care.
- Enable the voices of excluded and vulnerable people to be heard and facilitate the involvement of people who are not part of traditional networks and groups.
- Work in a transparent way in all activities with clear accountability.

Selecting and Engaging User Representatives

To produce the greatest benefits from service user and carer involvement, organisations must firstly be clear about what they are trying to achieve before deciding who to involve and how to engage them. Consideration should be given to:

- Those who have direct experience of the service;
- Members of the wider public; and
- Those who represent geographic or community interests.

Organisations should seek to ensure that service user and carer involvement is inclusive and reflects the diversity of the communities served. Organisations should actively promote the involvement of people who experience barriers to participation. Equality monitoring and evaluation frameworks should be used to identify any gaps in representation and to target seldom heard groups where appropriate.

There are many ways to engage service users and carers to become user representatives and the following list may provide some guidance and new ideas to help:

- advertising on the organisation's website;
- posters in waiting rooms, clinics and GP practices;
- linking with the voluntary sector, and their newsletters / networks;
- advertising in local community groups, support groups, leisure groups and libraries;
- linking with Patient Panels and the Community Health Council who can offer advice on who can help;
- advertising in local press and on local radio;
- linking with the Expert Patient Programme;
- clinical staff who have daily contact with patients to recruit; and
- link with contacts within local communities e.g. health care staff.



Buddying

Buddying is an approach which may be considered when integrating a new user representative into an improvement project team or group within an organisation.

A buddy, as the name implies, establishes a less formal relationship with the individual than a line manager or a mentor. A buddy is to act as an informal point of contact for the new user representative, ensuring a warm welcome. Buddies will help to put the user representative at ease and support them whilst they develop their confidence in their new role. Objectives of a buddy may include:

- To assist new members to understand the organisation and working processes of the department. Buddies will also help the new user representative to understand what their new colleagues do and their relationship with that person and post.
- To help the new member from their first day of joining/participating, ensuring that they are introduced to their new colleagues.
- To help the new member understand the culture of the organisation. Highlighting (especially for those that are younger or less confident) that they are not expected to 'know everything', that asking questions of others will be quite expected and that other developers, although busy, will be happy to assist.
- To help them recognise other activities that they could be doing to support their understanding of their new role and the organisation: relevant reading; browsing 'InfoZone' and 'SHOW', etc. and explain the essentials of getting started.
- To show their new member where all the essentials can be found and where to go for further assistance.
- A buddy will be ready to help in unfamiliar situations.
- Involve the new member as soon as possible in the social aspects of their department i.e. arrange a team lunch during their first week.

A new user representative should ideally have a buddy for between 3 to 6 months.



Working Effectively - The 4Rs of Working Together

Adapted from *Hearty Voices Manual: Putting forward the patient's point of view*, British Heart Foundation, and *A Guide to Good Practice: Elective Services*, National Leadership and Innovation Agency for Healthcare.

To ensure that effective working is achieved between the organisation and the user representatives every member needs to keep the 4Rs of working together clearly in focus. The 4Rs are:

- **Role**
- **Remit**
- **Relationships**
- **Responsibility**

Role

Members of a group are there because of their particular experience and abilities. The following questions need to be asked:

- Is each member clear about his/her particular role?
- What contribution does each member think they are able to offer?
- What do other members think your role is?

Remit

To accomplish change, the group or team needs to have a clear aim or reason for existing. The remit of the group is covered by its terms of reference. The following questions need to be asked:

- Does the group have clear terms of reference?
- Does every member have a copy?
- When were they last revised?
- Has the meaning been discussed so that everyone has the same understanding of what they do?
- Is there a common understanding of the group's purpose?

Relationships

A clear remit and defined personal roles will help develop relationships, team working and the efficiency of the group. The following questions need to be asked:

- Do group members know each other as people, or are they strangers joined by their roles?
- Does each group feel like a working team?
- Do members share a common purpose and goals? Have they ever been discussed?
- What links does the group have with other agencies and/or groups within and outside the NHS?

Responsibility

This refers to both the responsibility of the group and the individuals within it. The group's terms of reference should address what it is responsible for and its accountability. The following questions need to be asked:

- What is the group responsible for and to whom?
- Is the group clear about issues of responsibility, or is it all left to the chairperson?
- Is there a shared responsibility for the agenda, ensuring everyone's views are addressed?
- Is there enough background information available to inform discussion?
- How are decisions implemented?
- Is the group clear how decisions that they make are fed into the wider change agenda?
- Who has responsibility for feeding back on the group's progress to all interested parties?

Rights and Responsibilities

Effective service user and carer involvement relies on good communication. The emphasis should be on building partnerships based on mutual trust and respect. The partnership between the user representative and the organisation requires some basic terms of reference, which assume certain rights and responsibilities:

User representatives involved have the right to:

- Receive a clear explanation of the work involved and their contribution at the start.
- Be given an indication of time commitment required from them.
- Be introduced, as soon as possible, to other members of the group.
- Be involved throughout every stage of the work.
- Be communicated with in their preferred way to enable effective communication
- To reasonable adjustments to be made to meet the requirements of their communications needs
- Be involved in all discussions of the group.
- Have an identified point of contact within the organisation that will answer any questions and discuss needs.
- Receive feedback regarding the quality of their contribution.
- Receive sufficient and timely accessible communication.
- Have clarity regarding payments and expenses, including the process of claiming.
- Have their contribution valued.

User representatives involved have the responsibility to:

- Be clear and realistic about time they are able to commit.
- Inform the organisation, in good time, if they are unable to attend meetings as required or meet timescales previously agreed.
- Accurately share their views, knowledge and experience.
- Respect the views of others.
- Maintain their independence.
- Not allow any personal agenda to influence their contribution or decision making.
- Respect individual and patient confidentiality.
- Appropriately manage issues of corporate confidentiality.
- Strive to work with the organisation and not against it.
- Share information widely with others in their community where appropriate.



Communication

Communication with user representatives needs to be a two-way process. As the user representative is an equal member of the group, the same information that is shared with the rest of the group should also go to the user representative.

Staff should avoid assuming levels of knowledge and understanding when communicating information, and during all group meetings. The use of jargon should be avoided in written and verbal communication, and staff should be expected to be questioned over the use of jargon in communications.

Support, Training and Induction

As an integral member of the group, user representatives should undergo similar induction/introduction process as other members of staff. It is the responsibility of the organisation to be open to provide further training and support where identified by the user representative and the rest of the group. Individuals should have a named point of contact with whom to discuss concerns and ideas (see the section on Buddying for greater detail).

Payments and Expenses

Many service users and carers contribute their time and expertise into improving services, and it is crucial that their contribution and commitment is recognised and valued. User representative involvement provides an invaluable resource to organisations and many participants dedicate a large amount of time and commitment to helping improve services. It is therefore essential to be sensitive to financial arrangements for user representatives.

Service user and carer involvement can be on a voluntary or paid basis. Volunteering is when people give their time and skills for the benefit of

society and the community. As such, organisations must ensure that user representatives are reimbursed for any reasonable out of pocket expenses incurred whilst fulfilling their role. This may include costs such as:

- mileage;
- public transport;
- care costs;
- stationery; and
- overnight accommodation.

Service user and carer involvement may also be on a paid basis. The level and rate of remuneration needs to be discussed with the individual user representative at the outset and procedures must be put in place to ensure that expenses payments are timely. It is important to note that it may be the decision of the user representative not to claim the expenses offered, as they may wish to provide their services on a fully voluntary basis.

Guidance outlining the principles and practice of reimbursing and paying service users and carers for their involvement is set out in *Reward and Recognition (Reward and Recognition 2nd Edition published by Department of Health, August 2006 <http://195.33.107.76/assetRoot/04/13/85/24/04138524.pdf>)*. Although aimed at local health and social care organisations in England, it contains helpful principles and guidance that may be useful for services in Wales. WAG issued a Welsh Health Circular (WHC (2007) 011) highlighting *Reward and Recognition* as well as *Recruiting volunteers: a manual of good practice* published by the Wales Council for Voluntary Action (WCVA).

Confidentiality

It is the responsibility of the organisation to ensure that user representatives are aware of their policy on confidentiality and this can form part of the induction process. The induction/introduction process should also include an explanation and details on whistle blowing and the difference between this and confidentiality. User representatives should be asked to agree and understand that they will be party to sensitive discussions that are confidential and are not to be disclosed.

Feedback and Evaluation

Feedback and evaluation is an essential requirement for user representatives and this should be provided on a regular and on going basis. User representatives volunteer their time and dedication, and they need to know that their time is being used valuably. Feedback should include what improvements have been made and whether these are sustainable. If recommendations are not taken forward then the reasons for this need to be explained.



Challenges of User Engagement and How to Overcome Them

Service User representatives anxieties	Staff anxieties
Views will not be taken seriously	Work will be criticised
Will look foolish	Unrealistic demands to change services
Will not understand what is being talked about	Role and authority might be undermined
May cause offence if they are seen to complain	Staff/service user relationship might be affected
Might affect their treatment in the future	Service users and carers will lose confidence in them as practitioners if seen as vulnerable or not clear
Nothing will change	Will not be able to deliver the user engagement work

Suggestions on how to mitigate these anxieties include:

- Have a clear, written strategy, developed with staff and service users, for involving people.
- Know what needs to be achieved.
- Use the '4Rs of Working Together' so user representatives and staff work effectively and minimise fears.
- Ensure that communication is a two-way process between user representatives and staff.
- Ensure that communication and accessibility needs of individuals are understood and that these are met throughout the process.
- Build partnerships between user representatives and staff.
- Ensure service user representatives and staff have a named point of contact with whom to discuss concerns and ideas.
- Feedback and evaluation is an essential requirement in allaying any fears expressed from both user representatives and staff.
- Agree ground rules at the start. Typical ground rules could include:
 - Arriving for meetings on time.
 - Respect others' views and feelings.
 - Not to interrupt when someone is putting their point across.
 - Not to deviate from the meeting objective/outcome.
 - Not to get personal.

Key Do's and Don'ts

Do	Don't
Involve user representatives from the beginning and at every stage	Use staff members to substitute service user and carer representation
Ensure roles and responsibilities are clearly defined	Use jargon in communications
Provide support, training and induction	Presume the user representative understands all the detailed processes
Be open and honest	Be tokenistic about user representative involvement
Be clear about time commitments	See the user representative as a threat
Be inclusive of all diverse community groups	Assume the user representative understands their role at the outset
Agree payments and expenses at the outset	Assume one user representative will represent the views of all patients using the service
Provide clear and accessible lines of communication	Assume that one form of written communication will be suitable for all participants
Provide feedback and evaluation	Assume that all participants will drive and will be able to get to remote locations
Ensure confidentiality	
Provide a person within the organisation as the contact point for any questions and queries the user representative may have	
Support service user and carer involvement	
Understand that service users need support as they may not always be able to attend meetings due to health reasons	
Provide sufficient resources, human and financial, to sustain the work	
Provide sufficient commitment to make it work	
Ensure involvement is accessible and meets individual needs	

Links

Signposts

'Signposts - A Practical Guide to Public and Patient Involvement in Wales' was published in 2001, the result of a joint initiative between WAG and the Office for Public Management. It provides information and advice to NHS organisations about how to develop in public and patient involvement (PPI) and focuses on both the strategic and operational aspects of PPI.

Signposts 2

'Signposts 2 - Putting Public and Patient Involvement into Practice' was published in 2003 and aims to tackle the challenges of developing PPI practice further into a more mature form. It provides practical pointers for Trusts and LHBs about how to plan for a more sustained and inclusive approach towards implementing PPI, as well as contact details to encourage the sharing of lessons learnt and experience. Signposts 2 identifies the importance of engaging staff to improve PPI capacity and how to monitor and evaluate PPI to gauge the impact it has made.

Cancer and Cardiac Networks

Both the Cancer and Cardiac Networks have developed a range of approaches to user involvement. This and other useful information can be accessed via the website addresses provided in Annex 1 - Information Points for NHS Service User and Carer Information.



Annex 1 - Information Points for NHS Service User and Carer Information

Organisation	Information Point	Postal Address
Diabetes UK Cymru	www.diabetes.org.uk/cymru Telephone: 029 2066 8276	Argyle House, Castlebridge, Cowbridge Road East Cardiff CF11 9AB
British Heart Foundation	www.bhf.org.uk Heartly Voices Enquiries: 0844 576 6333	Greater London House, 180 Hampstead Road London NW1 7AW
Welsh Kidney Patient Association	www.wkpa.org.uk Telephone: 029 2074 2735	Welsh Kidney Patients' Association Lakeside Offices, University Hospital of Wales Heath Park, Cardiff CF14 4XW
The Stroke Association	www.stroke.org.uk southwales@stroke.org.uk Telephone: 0845 303 3100	Unit 8, Greenmeadow Springs Business Park Cae Gwyrdd, Tongwynlais, Cardiff CF15 7AB
South East Wales Cancer Network	www.sewcancer.wales.nhs.uk/ eleri.girt@sewcancer.wales.nhs.uk Telephone: 029 2019 6166	South East Wales Cancer Network 3rd Floor, 14 Cathedral Road, Cardiff CF11 9LJ
North Wales Cancer Network	www.wales.nhs.uk/nwcn/ pat.evans@bsc.wales.nhs.uk Telephone: 01745 589608	North Wales Cancer Network HM Stanley Hospital St Asaph, Denbighshire LL17 0RS

Organisation	Information Point	Postal Address
South West Wales Cancer Network	www.wales.nhs.uk/sites3/home.cfm?orgid=361 helen.dorman@swwcn.wales.nhs.uk Telephone: 01792 607356	North Wales Cancer Network HM Stanley Hospital St Asaph, Denbighshire LL17 0RS
Mid & South West Wales Cardiac Network	www.wales.nhs.uk/sites3/home.cfm?orgid=483 marc.thomas@mswcardiacnet.wales.nhs.uk Telephone: 01792 607353	c/o NHS Wales Business Services Centre Floor 12, 36 Orchard Street, Swansea SA1 5AQ
North Wales Cardiac Network	http://howis.wales.nhs.uk/sites3/home.cfm?orgid=489 julie.green@bsc.wales.nhs.uk Telephone: 01745 589919	Tŷ Livingstone, HM Stanley Hospital St Asaph, Denbighshire LL17 0RS
South East Wales Cardiac Network	www.wales.nhs.uk/sites3/home.cfm?OrgID=490 claire.lewis@sewcn.wales.nhs.uk Telephone: 029 2019 6164	3rd Floor, 14 Cathedral Road, Cardiff CF11 9LJ
Wales Neurological Alliance	www.walesneurologicalalliance.org.uk Telephone: 029 20 68 2140	Wales Neurological Alliance C/o Genetic Interest Group 206b Neuadd Mirionydd Heath Park, Cardiff CF14 4YS
Motor Neurone Disease Association	www.mndassociation.org Telephone: 01604 250505	Motor Neurone Disease Association PO Box 246, Northampton NN1 2PR

Information correct as of 18/12/2009

Annex 2 - Good Practice Checklist and Monitoring Tool

Action	Met	Part Met	Not Met	Action Taken	Monitoring Arrangements	Review Date
Involving user representatives at every stage						
Roles and responsibilities are clearly defined						
Support, training and induction provided						
Being open and honest						
Being clear about time commitments						
Being inclusive of all diverse community groups						
Payments and expenses agreed at the outset						
Providing clear and accessible lines of communication						
Providing feedback and evaluation						
Ensuring confidentiality						
Provide a person within the organisation as the contact point for any questions and queries the user representative may have						

Action	Met	Part Met	Not Met	Action Taken	Monitoring Arrangements	Review Date
Involvement is accessible and meets individual needs						
Not using staff members to substitute service user and carer representation						
Not using jargon in communications						
Not presuming the user representative understands all the detailed processes						
Not being tokenistic about user representative involvement						
Not seeing the user representative as a threat						
Not assuming the user representative understands their role at the outset						
Not assuming one user representative will represent the views of all patients using the service						
Not assuming that one form of written communication will be suitable for all participants						
Not assuming that all participants will drive and will be able to get to remote locations						

Definitions and Other Information

Glossary of Terms

Carer

Is a person who looks after a family member or friend, who are users of health services and who require care, help or support.

Healthcare Professional

Health care professionals include physicians, dentists, nurse practitioners, physician assistants, support staff, nurses, pharmacists, therapists, psychologists, chiropractors, physical therapists, optometrists, paramedics, and a wide variety of other individuals regulated and / or licensed to provide some type of health care.

Patient and Public Involvement (PPI)

The process by which individuals and communities have the opportunity to improve and shape their local health services by offering views and recommendations.

Service Provider

Any organisation providing health services, whether in the public sector, private sector or voluntary sector.

Service User

Defined as patients; unpaid carers; parents/guardians; users of health services; disabled people; members of the public who are the potential recipients of health promotion/public health programmes; groups asking for research because they believe they have been exposed to potentially harmful circumstances, products or services; groups asking for research because they believe they have been denied products

or services from which they believe they could have benefited; organisations that represent service users and carers.

Service User Representative

Service user representatives are consumers of the NHS who work in collaboration with health professionals to give voice to service user and carer viewpoints on health services.

References

British Heart Foundation. *Hearty Voices Manual: Putting forward the patient's point of view*. British Heart Foundation

Welsh Assembly Government. *Stronger in Partnership 2: Involving Service Users and Carers in the design, planning, delivery and evaluation of mental health services in Wales*. Welsh Assembly Government, 2008

Cumming A. *A Guide to Good Practice: Elective Services*. National Leadership and Innovation Agency for Healthcare, 2005

Mersey Care NHS Trust. 'Involving Service Users and Carers – The Mersey Care Way', 2007

Crawford MJ, Rutter D, Manley C et al. 'Systematic review of involving patients in the planning and development of health care.' *British Medical Journal* 2002; 325:1263 -1265 <http://bmjjournals.com/cgi/reprint/325/7375/1263>

Useful Resources

Publications

- Making the Connections: Delivering Better Services for Wales
Welsh Assembly Government, 2004
- Beyond Boundaries: Review of Local Service Delivery
Welsh Assembly Government, 2006
- One Wales
Welsh Assembly Government, 2007
- Stronger in Partnership 2: Involving Service Users and Carers in the design, planning, delivery and evaluation of mental health services in Wales
Welsh Assembly Government, 2008
- Signposts - A Practical Guide to Public and Patient Involvement in Wales
Welsh Assembly Government and Office of Public Management, 2001
- Signposts 2 - Putting Public and Patient Involvement into Practice
Welsh Assembly Government and Office of Public Management, 2003
- Designed for Life: Quality Requirements for Adult Critical Care in Wales
Welsh Assembly Government, 2006
- Hearty Voices Manual: Putting forward the patient's point of view
British Heart Foundation
- A Guide to Good Practice: Elective Services
National Leadership and Innovation Agency for Healthcare, 2005
- 'How to Kit': Undertaking Discovery Interviews/Patient Story Collecting Projects
South East Wales Cardiac Network, 2008
- Reward and Recognition (2nd Edition)
Department of Health, 2006
- Welsh Health Circular (WHC (2007) 011). Reward and Recognition
Welsh Assembly Government, 2007
- Recruiting Volunteers: A Manual of Good Practice
Wales Council for Voluntary Action
- Designed for the Management of Adults with Diabetes Mellitus across Wales: Consensus Guidelines
Welsh Assembly Government, 2008
- The Cardiac Disease National Service Framework for Wales
Welsh Assembly Government, 2009
- National Cancer Standards
Welsh Assembly Government, 2005
- Designed to Tackle Cancer in Wales: A Welsh Assembly Government Policy Statement
Welsh Assembly Government, 2006
- Accessible Venue Guidance
Welsh Assembly Government, 2006

Websites

www.nliah.wales.nhs.uk

The National Leadership and Innovation Agency for Healthcare website

www.wales.gov.uk

The Welsh Assembly Government website

www.nhsdirect.wales.nhs.uk

NHS Direct Wales website

www.wales.nhs.uk/equality

The NHS Centre for Equality and Human Rights website

www.bhf.org.uk

The British Heart Foundation website

www.diabetes.org.uk/cymru

Diabetes UK Cymru website

www.stroke.org.uk

The Stroke Association website

www.wkpa.org.uk

The Welsh Kidney Patient Association website

www.wales.nhs.uk/sites3/home.cfm?orgid=338

Cardiac Networks of Wales

www.sewcancer.wales.nhs.uk/

South East Wales Cancer Network

www.wales.nhs.uk/nwcn/

North Wales Cancer Network

www.wales.nhs.uk/sites3/home.cfm?orgid=361

South West Wales Cancer Network

www.nice.org.uk

The National Institute for Clinical Excellence website

Acknowledgements

British Heart Foundation

Diabetes UK Cymru

The Stroke Association

Welsh Kidney Patient Association

Wales Cancer Networks

Wales Cardiac Networks

Bridgend Association of Voluntary Organisations

Wales Neurological Alliance

Motor Neurone Disease Association

The Stroke Association

National Leadership and Innovation Agency for Healthcare

The NHS Centre for Equality and Human Rights