

Introduction to the Training and Facilitation Resource

Participant Version

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1. Words and meanings in user involvement

There are no 'correct' words in the user involvement area, although people certainly have words they prefer. Wherever possible 'jargon' will be avoided in the resource, or if used will be clearly explained. However, names and words used by different committees or Department of Health structures will be used at times. You will need to become familiar with these in doing user involvement work. If unfamiliar words are used, tell the trainers or Link Person so they explain what the words mean.

Below is a list of words that are commonly used in this resource. How common these words are depends on your location. For example, 'service user' or 'user' is one of the main words in the UK. 'Consumer' is more common in Canada, USA, Australia and New Zealand, but is still used in the UK - often in research and development. In the mental health area words like 'survivor' and 'ex-patient' are sometimes used. 'Lay people' is used in the UK to refer to non-professionals, both users and carers, and people who do not use health and social services. It is less common in other countries.

Action steps: The specific actions that you will take so that you can achieve the goal that you have set.

Audit: Audit is comparing how well a service is performing against an agreed benchmark of what the service should be doing. Audit work is commonly used to determine the need for service improvement, and to check how well a service has gone with making changes.

Balance of power: This refers to **where** the power lies in being heard and making decisions. Is there an even or uneven balance between health and social service staff or users, carers and the public?

Carer: Usually an unpaid person who cares for people who use services. Some people may be registered as carers and receive a carers' allowance. The people they care for and support could be their child, partner, parent, relative or friend who has a long-term and/or serious mental or physical health problem. The person may also have a disability, be frail or aged.

Collaboration: This happens when people agree to respect each other and work together. They share expertise and resources. They do not always do the same things, but

agree on what each will do. They do not necessarily do an even amount of the work, just what they agree to do that others in the collaboration are happy with. They want to reach a mutually agreed goal that will benefit everyone involved. The people involved may also have different reasons for collaborating. They might hope that the work will help them meet goals that may have a special benefit for them or their organisation.

Development: In the term 'research and development', development means testing and evaluating new ways of doing things in health and social services. It focuses on how well new ideas actually work in practice, including ideas that have been identified through research.

Empowerment: The process that helps people feel that they are important, capable and valuable, and have the ability and confidence to do things for themselves - they feel empowered. It can also include having permission and the confidence to do things or speak on behalf of others. In short, empowerment is when a person feels they can stand up for him/herself, be heard and get things done.

Engagement: Speaking to people and allowing them to answer - showing respect and really listening.

Evaluation: Evaluation is about deciding how valuable or worthwhile a health or social service intervention, project or service is. This includes an assessment of its quality.

Goals: A statement about what you want to achieve in the long-term, e.g. 12 or more months.

Good and best practice: Both of these terms are used. 'Best practice' means the very best way of providing health and social services or an aspect of them. Because there is not always a single best way the term 'good practice' is used to mean a high quality or excellent way of providing services or an aspect of them.

Health and social service staff: People with qualifications and/or training - including on the job training - within the health/social service sector. They may directly provide, manage, or do research in health and social services.

Indicators: The signs used to decide if goals are being met. They are things that health and social service staff and users, carers and the public may see, hear or experience.

Lay person/people: People who are not employed in the health or social service area. This usually includes members of the public as well as users and carers.

Needs assessment: This is finding out about what users, carers and the public believe needs to happen or are priorities for health and social service work. It is often used to help with service planning and improvement.

Outcomes: This is used in several ways in health and social services, including:

- ω what happens because of an action by a health or social service staff member
- ω the results of an assessment
- ω the results of a research project
- ω the results of a change in service delivery

Patient and public involvement: Patients and the public include current users and carers in health and social services as well as past, potential and future users and carers. This term is often used to mean user involvement in the NHS. When people do user involvement work 'user consultants' is a shorthand way of referring to all of these groups.

Partnership: When people agree to work together on a task or project that all parties agree is important. Everyone is committed to doing a fair share of the work - this is usually discussed and agreed together. Partnerships may have formal or informal arrangements. Informal partnerships work best when the project is specific and can be achieved relatively quickly: the purpose is clear and outcomes achievable. Where the task is complex and long term then it is wise to formalise the partnership through a written agreement. This provides a structure for decision-making and agreeing ways of working.¹

Research: The NHS defines research as work that aims to provide new knowledge. This knowledge should be:²

- ω potentially of value to those facing similar problems elsewhere
- ω open to critical examination
- ω accessible to all who could benefit from it

¹ Based on: Wilcox, D. (1994). *Guide to effective participation*. Available online at: <http://www.partnerships.org.uk/guide/index.htm>

² Based on: Royle, J., Steele, R., Hanley, B. & Bradburn, J. (2001). *Getting involved in research: A guide for consumers*. Winchester: Consumers in NHS Research Support Unit. Available online at: <http://www.invo.org.uk/pub.htm>

Research and development cycle: There are six main stages to this cycle:

- ω **Consulting about research** - working out what topics could be researched and what are the priorities
- ω **Commissioning research** - deciding who gets funded to do the research
- ω **Doing research** - being involved on the project team who does the research, analyses the information and writes it up
- ω **Managing research** - registering the project within the health or social service organisation, supporting ethics approval and keeping a watch on the research process to make sure it goes smoothly
- ω **Disseminating research** - getting the research outcomes out to people who need to know about them
- ω **Evaluating research** - checking how well research was done and also, drawing lots of people's work together to see what has been found out so far

Service planning and improvement: Service planning is when you develop and describe a vision of what you want health and social services to be like. You create goals and action steps to achieve that vision. Service improvement is when

you develop health and social services to improve the quality of services and how much service provision is available. Both service planning and improvement include the overall planning you do, how you put your plan into action, how you check on (review) your progress and how you evaluate the outcomes achieved.

User or Service User: A person who uses or has used a health or social service.

User consultant: A person who takes on a user involvement role in a health or social service. They may be a user, a carer or a member of the public. They may be representing his/her community, forum, support group or user network. Sometimes they may only be representing themselves.

User involvement: When users, carers and the public are involved in discussing and making decisions in a genuine partnership with health and social service staff about:

- ω their own health or social care
- ω service planning or service improvement
- ω research and development activity

It is more than advising or being consulted by staff, or participating in a pre-set process. It may mean having independent control over health and social service delivery and decision-making. However, it often means working **with** health and social service staff. Other terms are also used to mean the same things, such as consumer involvement or patient and public involvement.

A glossary is included in the Introduction sections of Themes 1 and 2. It may include some terms that are specific to those units that are not used in the Core units, as well as some of the above terms.

2. The training and facilitation resource

2.1 Why has this resource been created?

This resource has been created for several reasons:

- to help people learn more about user involvement
- to link people directly with health and social services
- to identify people who can train others in user involvement
- to learn about the impact that training in user involvement has on people's skills, confidence and opportunities to do user involvement work

The resource will help users, carers and the public learn more about user involvement in health and social services. While it was initially developed with a focus on the NHS, it can also apply to health or social service agencies or organisations in the private and voluntary sector.

A key feature of the resource was designing it to link users, carers and the public directly with health and social service organisations. This is what the 'facilitation' part of the name means. By connecting to the 'real world' of services, as a participant you can start building relationships where you may do user involvement work. This is important because stand-

alone training may not be effective, particularly if you do not have existing or strong links with a service. Rather than wait for a phone-call to be invited into user involvement work, the direct linking creates opportunities while you are still training that can carry on once the training is finished.

The resource will also make it possible to identify people who would like to train other people in user involvement. This will increase the number of users, carers and the public who feel able and are available to do this important work. This opportunity may interest you.

Finally, it is vital to continue evaluating user involvement work and learn about what is working, what is not working and why. This resource includes evaluation tools that can track your experiences as a participant before, during and after the training, and any shifts in your knowledge, skills and confidence. This contributes to the evidence base for user involvement in general. It also creates a baseline that any organisation or group can use to compare the outcomes of user involvement training and activity as part of long-term evaluation.

The resource covers three main areas:

- core knowledge and skills in user involvement

- user involvement in service planning and improvement
- user involvement in research and development activity

As a participant, you attend training and 'Link Time' meetings in one or more of these areas. These will be explained in the next sections. The trainer will tailor a training programme to meet the needs of the training group based on the units and unit parts that are available. The programme may provide an introduction as a basis for you to start getting involved, or the trainer may choose sections that add to your existing knowledge and experience. In either situation, you will develop knowledge, skills and confidence in the areas of user involvement work that interest you.

2.2 Who is the resource for?

The resource is for any service user, carer or member of the public who believe they would benefit from attending the training. You may be a beginner or you may be experienced in user involvement and want to expand your role. NHS and social service staff may also benefit from sharing the learning experience through shared training. The trainer may decide to do this as part of a training programme.

2.3 Main sections of the resource

The training and facilitation resource has three main sections:

1. The **Training Handbook** - this is for people who conduct the training for participants. These people will be service users, carers or members of the public who are experienced in user involvement. There may be a combination of health and social service staff and service users involved in the training, but most of the trainers will be users.
2. The **Participant Handbook** - this provides information that you will use during the training, including space to write notes on all the different activities.
3. The **Link Person Handbook** - this is for people who hold the Link Time meetings with participants.

The content of each handbook is described in Section 3: How to use this training and facilitation resource.

2.4 What happens in the training and facilitation?

Training units

During training meetings, you join other participants in a group for teaching sessions with trainers. There are five training

units - three core units and two theme units. Each unit will focus on a particular topic and include important information that you need to know about user involvement and health and social services for that area.

Unit 'parts'

Each training unit has been divided into several 'parts.' This gives trainers the option of using a training unit as a whole unit of learning, as each part is designed to build on and expand the previous part in that unit and previous units. Alternatively, they can choose those parts that your group needs to learn. This 'pick and mix' approach allows considerable flexibility in tailoring the training to a specific purpose, and the level of experience and ability of the group.

Each part has one or more training activities. For each activity, there are two or several activity options to add another layer of flexibility. Trainers are provided with recommendations for combining the activity options so that any combination will achieve the learning objective for the training activity. The activity options allow for different levels of interaction between group members, and between you and the trainer. The trainer can choose those options that fit with the style of learning preferred by the group or your level of experience.

2.5 What happens in the Link Time?

Most people will do the training because they want to be involved in a particular health service, social care service, or an agency or organisation from the private or voluntary sectors. The training units provide general information that is valuable, but by themselves they are not enough. You need to know about the specific activities and interests of the service or organisation with which you could be involved. As described above, you also need the opportunity to build a relationship with health and social service staff, and identify possible user involvement activities. This is the focus of the Link Time and is a very important part of the training and facilitation resource.

You will be directly linked into the service or organisation that you want to be involved with. This will happen before, during and after the training. The information in the training units becomes more 'real' through the Link Time meetings as you start applying what you learn.

A person in the health or social service will have the job of being a 'Link Person.' They will meet with you individually or in small groups. During these meetings the Link Person will introduce you to information that helps you understand how to be involved in **that specific** health or social service. This will

include negotiating your user involvement role, the support that can be provided and the different opportunities for involvement. Through Link Time meetings you will build a relationship with the Link Person and other people from the service to whom you are introduced. This can form the basis of an ongoing partnership between you and the service or organisation in doing user involvement work.

2.6 How does it all fit together?

Figures 1 and 2 on pages 17 and 18 provide an overall picture of the three 'core' units and two 'theme' units of the training and facilitation resource, including each of the unit parts. Most units have four parts, but due to the different stages of the research and development cycle Theme 2: Unit 5 has eight parts.

If you have limited knowledge and experience of user involvement and health and social services, then it is recommended that you start with the core units. If you are already doing user involvement work, you may want to do less of the core units and focus more on specific theme units and parts.