



# Valuing Involvement

**Strengthening Service User and Carer  
Involvement in NIMHE**

**Good Practice Guidelines for involving mental  
health service users and carers**



**A product of the Making a Real Difference Project (see overview for  
details)**

## Overview

**The Making a Real Difference Project was undertaken in direct response to the HASCAS review of service user and carer involvement in NIMHE. This resulted in the Making a Real Difference Report.**

**The following document is designed to address some of the recommendations made within the report. It provides a guide to the principles and values expected by NIMHE and its staff when they involve people living with mental health problems and their carers in all of its' work programmes.**

### **Who are the Good Practice Guidelines for? ;**

#### **New NIMHE Staff and Volunteers**

- All new staff should fully familiarise themselves with the good practice guidelines to ensure that they have a good understanding of the expectations NIMHE has for all of its staff in relation to involvement. Any queries should be discussed with their line manager.
- All new work programmes should be guided by the principles set out in the good practice guidelines.

#### **Existing NIMHE Staff and Volunteers**

- Existing staff members should familiarise themselves with the good practice guidelines.
- Existing staff should ensure that their work is sympathetic to the values and principles set out within the good practice guidelines.
- Existing staff should ensure that their work practice reflects the values and principles in the guidelines.
- Any new work programmes should be developed to accommodate the Involvement Good Practice Guidelines.
- All existing work programmes should be reassessed to ensure that they are in line with the guidelines. If necessary a plan should be developed to achieve the principles and values in the document.

#### **People Sharing Their Expertise to Inform NIMHE's Work**

- All people should be made aware of the expectations within the good practice guidelines so that they are clear about what to expect when they are involved with NIMHE and its work programmes.

#### **NIMHE Boards, Commissioners and Performance Managers (including external stakeholders)**

- All NIMHE work programmes and headline management plans (HMP's) should set out plans to achieve the principles and values in the good practice guidelines.
- All NIMHE work programmes should provide regular feedback with regard to performance against the guidelines.
- All monitoring and evaluation of work programmes should include measures of performance against the guidelines.

## Acknowledgements

The good practice guidelines were developed and written by the South West Making a Real Difference Work Group 2 Working Group, on behalf of the Making a Real Difference Project.

The steering group were;

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The make up of the steering group was as follows;

Designation	% of group
CSIP Staff	30%
People with experience of using mental health services	40%
People with experience of caring	30%

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Paddy Cooney	Ross Hughes
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David Goodban	Sally Prescott
Linda Parker	

The South West Making a Real Difference consultation event was attended by approximately 110 people.

This document was informed by the expertise of people from the following groups and organisations;

Advocacy in Somerset	Carers Support North Wiltshire
Anchor Project	Care Services Improvement
Avon & Wiltshire Mental Health Partnership NHS Trust	Partnership (CSIP) North East, Yorkshire and Humber Regional Development Centre
Bath and North East Somerset Council	CSIP South West Making a Real Difference Workgroup
Bath and North East Somerset Primary Care Trust (PCT)	CSIP South West Black and Minority Ethnic (BME) Network
Battle Against Tranquillisers (BAT)	CSIP South West Mental Health Reference Group for Avon, Gloucester & Wiltshire
Bristol PCT	
Bwerani Multicultural and Inclusive Resource Library	
Carers and Relatives Mutual Support (CARMS)	

CSIP South West Mental Health Reference Group for Devon & Cornwall	Purbeck District Council
CSIP South West Mental Health Reference Group for Dorset & Somerset	Realisation Training
CSIP South West Staff	Rethink - Stroud
Devon County Council	Rethink - Taunton
Devon Drug and Alcohol Action Team	Richmond House Carers Group
Devon Partnership NHS Trust	Royal Devon and Exeter Foundation Trust
Dorset Advocacy	Samaritans
Dorset Mental Health Forum	Saplings
Dorset Primary Care Trust	Self-Injury Self-Help Group
East Devon Mental Health Self Advocacy Project	Somerset County Council
East Dorset Mental Health Carers' Forum	Somerset Partnership NHS & Social Care Trust
Ethnic Minority Achievement Service	Somerset PCT
Exeter Community Initiatives	Somerset User Participation Service
Exeter Mental Health Service User Group	SouthWest Devon Service User/Carer Network.
Exeter Mental Health Service User Project	Speak Up Somerset
'Friend'	Speakout Gloucestershire
Fromeside Service Users	Stepping Out Theatre
Gloucestershire First	Sun International
Gloucestershire One-2-One Support Service	Swindon Carers Centre
Hear Our Voice	Swindon PCT
Make A Difference Café	Taunton & Somerset NHS Trust
Mendip District Council	Teignbridge District Council
Mid Devon PCT	The Care Network of Carers Organisation
MIND – South Somerset	The Princess Royal Trust Carers Centre
MIND - Taunton & West Somerset	Together: Working for Wellbeing
Mosaic	Torbay Council
Nation Institute for Mental Health in England North East, Yorkshire and Humber	University of the West of England
Nightlink	Voluntary Organisations Standing Conference on Urban Regeneration (VOSCUR)
North Somerset PCT	West and North Dorset Mental Health Advocacy Forum
Plymouth City Council	Wiltshire County Council
Plymouth Forum	Wiltshire PCT
Plymouth Teaching PCT	Wiltshire Racial Equality Council
Poole Mental Health Service Users Forum	Wiltshire Young Carers
	Wincanton Community Venture
	Womankind – Bristol
	Worcestershire Acute Hospitals NHS Trust

We would also like to say thank you to the service users and carers who did not necessarily belong to any of the above groups but who also contributed to this document.

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## Introduction

**Good practice guidelines for involving people with experience of mental ill health and their friends and families who care for them.**



We have used the symbol of a tree for this Good Practice Guidance. The roots represent our principles, which are the ground from which we work. The strong trunk represents our relationships with one another and this allows the tree to flourish.

The leaves and fruits of the tree are what we achieve – together. If any of these elements are missing, the tree will not thrive.

The growth of service user and carer involvement has seen people actively involved in many areas including committees and boards, recruitment, training, consultation, research, and monitoring and evaluation. We have developed this guidance to inform people about best practice, and to grow and nourish service user/carer involvement within NIMHE and across the health and social care communities.

This document has headings of key principles with guidance points underneath.

- **Be clear**
- **Be inclusive**
- **Treat people equally**
- **Have a positive attitude**
- **Ensure good communication and information**
- **Have good physical accessibility**
- **Adopt a good procedure**
- **Ensure support is available**
- **Have resources available**
- **Create meaningful involvement**
- **Consider all practical issues – before, during and after**

## **Be clear**

- Clarify the reason for involving or inviting service users and carers and ensure everyone understands the purpose of the work or activity and the payment policy.
- Discuss, agree and make clear the roles, responsibilities and expectations of everyone involved. Clarify the authority of any decision making. Produce role descriptions and specifications to recruit people.
- Explain clearly to everyone what will happen to any information that people give about themselves and have an agreed understanding of confidentiality.

## **Be inclusive**

- Involve service users and carers at the earliest opportunity of a project or programme and ensure they have equal influence over its direction and the way it is carried out.
- Have an open, democratic and transparent process when inviting people to be involved. Be clear about any application and selection process.
- Give priority to involve people on their own territory, at times that suit them and in ways that are acceptable to all parties.
- Encourage all people to contribute – be supportive and give people time to express their views, without pressure.
- Give due consideration to the differences within the community which is served. For example include people from minority ethnic communities, people who speak a different language, people who have specific religious beliefs, those with nationality issues, people of migrant status, those with a criminal history, children and young people, older people, men and women, gay, lesbian, bisexual and transgender people, working people, people in rural and urban areas, people who are physically disabled and people with differing mental health problems.
- Explore different and non-traditional routes for sharing information and engaging with people who might not ordinarily be involved and are often marginalised. For example, outreach work drawing on expertise of community workers, writing information in magazines that are not specifically aimed at health and social care, holding community meetings, going to places people socialise, using surveys or translating publicity material. (See NIMHE Standards for Involving Diverse Groups)
- Recognise the variety of perspectives amongst service users and carers.
- Every effort should be made to involve more than one service user or carer in each area of work and you should aim to have equal numbers of service users and carers.

## **Treat people equally**

- Offer appropriate remuneration, learning and development opportunities to enable service users and carers to actively participate.
- Offer learning and development opportunities to support staff awareness and responsibility for, and involvement in, developing service user and carer participation.
- Generate ideas together.
- Be aware of likely power differentials and the impact this might have on people. For example feeling intimidated.
- Ensure the Chair is well briefed about who is in the group or meeting and offers encouragement to enable all voices to be heard.

## **Have a positive attitude**

- Foster an atmosphere of encouragement and acceptance among everyone involved.
- Do not include people for tokenistic reasons and ensure everyone is there for a genuine reason with a clear task.
- Be genuine in actions and statements and aim to work as a team in every respect.
- Recognise and value that everyone is different and there may be a range of different opinions. Respect and accurately record people's contributions. For example by acknowledging their help verbally within meetings and credit in documents.
- Be receptive to new ideas.
- Encourage everyone to be realistic, honest and positive
- Acknowledge and give appropriate honest and open feedback to contributions.
- Enable constructive dialogue to discuss and challenge differences of opinion between people.

## Ensure good communication and information

- Communication between service users, carers and the organisation should be open, honest and transparent.
- Keep people informed of developments during and beyond the project or group.
- Ensure all information is accessible and in an appropriate and acceptable format and language. For example give careful consideration to any information to be given to children and young people ensuring they understand. Have access to a braille and large print service, taping service and someone who can put printed material in easy-to-understand language and pictures.
- Check how people like to receive information sent to them (for example email, post, through an organisation, in large print) and follow their wishes.
- Provide a glossary of 'jargon' and 'abbreviations' when used.
- Ensure people understand and encourage questions
- If a person has communication or learning difficulties find out how each person communicates best and take time to get to know the person and for them to get to know you. If necessary seek advice for example from self-advocacy groups.
- If involving children or young people offer coaching to help them listen effectively, present views constructively and to enable them to research information for themselves
- When presenting information use a variety of learning aids to promote understanding. Presentation materials and handouts should be clear and easy to read.
- Ensure all materials are age appropriate
- Recognise the importance of listening and demonstrate active listening (for example, through body language and not interrupting).

## **Have good physical accessibility**

- Consider if a meeting or event is the most appropriate means of communication.
- Ensure all venues are accessible, that meeting times and locations suit service users and carers; such as being near to public transport or making car parking facilities available and comply with requirements of the Disability Discrimination Act.
- Ensure venues are comfortable, as quiet as possible and an appropriate size with adequate ventilation. Consider the most appropriate room layout for those attending. Ensure good circulation space for wheelchair users.
- Have appropriate types of seating available for the length of the meeting or event to ensure comfort.

## **Adopt a good procedure**

- Prior to any involvement discuss and agree with service users and carers the personal resources they may need to enable them to contribute – knowledge, time, numbers of meetings to attend, travel, child care, accommodation etc.
- Be clear from the start about the terms of involvement and give opportunity for each service user or carer to be briefed appropriately and individually.
- Develop an induction check list which should be signed by both staff contact and service user or carer as a record and safeguard of what preparation was carried out.
- Be clear about the commitment and the duration period needed in relation to specific meetings, committees and projects. Recognise young people particularly may only want to be involved for a short, defined period.
- Have flexibility to accommodate people's fluctuating health or mental health needs.
- Provide speedy resolution of problems, concerns and issues, keeping service users and carers up to date at all stages.
- Recognise that endings can be difficult for people so ensure that the ending of a project or group that has met for a period of time is appropriately marked.
- Collect feedback and evaluate the benefits from any meeting or event to ensure it was meaningful for those involved.
- Evaluate outcomes from the work carried out and share with all those involved.

## **Ensure support is available**

- Discuss possible support needs prior to any involvement and make necessary arrangements. For example: personal supporter, specific type of chair, reserved parking space, bringing assistance dog
- Give service users and carers effective support, encouragement and supervision as appropriate in any work they are involved with.
- Be aware of stress factors which may arise through involvement and have an identified person to provide support if necessary. For example asking a participation worker, friend, professional or another person within the group.
- If involving children or young people find out whether adult support is required and if CRB checks are needed.
- Provide administration support where appropriate and do not assume everyone has access to computers or email.

## **Have resources available**

- Ensure an appropriate budget is available to pay for expenses, remuneration, support and training needs.
- If remuneration and expenses are to be paid for participating, make this clear beforehand to service users and carers. A copy of the payment and expenses policy should be given and discussed prior to their commitment to become involved. Mechanisms for payment should be agreed and acted upon quickly.
- Service users and carers must be made aware that fee payments and expenses can impact on their benefit conditions and income tax in some cases. If necessary give information on where to get expert advice and support to ensure service users and carers make an informed choice (for example Job Centre Plus). (See NIMHE 'Valuing Involvement – Service user and Carer Involvement Payment and Reimbursement Policy Guidance')
- Easy to follow guidance and support should be offered to complete any forms

## **Create meaningful involvement**

- Ensure outcomes from service user and carer involvement has influence on the decision making within the organisation.
- Keep service users and carers abreast of any changes that have happened as a result of their work.
- Check that people feel they benefit and enjoy aspects of their involvement.

## Consider all practical issues

### Before the meeting or event

- Circulate the details of the person to contact for any queries prior to any meeting or event to everyone attending.
- Provide all information such as agenda, reports etc in advance of meeting. For meetings, under each agenda item include a paragraph explaining what will be discussed, as this will allow people to think about or discuss with their support worker prior to meeting.
- Give service users and carers opportunity to add agenda items.
- Offer service users and carers time to consult with others in their networks if necessary.
- Enable service users and carers to have the opportunity to hold a pre-meeting if required.
- Explain clearly to service users and carers prior to meeting or project what remuneration, if any will be paid.
- Give people any relevant documents and policies. For example, these standards of good practice and the policy on involving service users and carers.
- Ensure everyone has information about directions, public transport and car parking.
- Be well organised and try not to cancel at the last minute. If this is unavoidable, apologise and explain to the service users and carers involved.
- Provide hearing loops, language interpreters and lip speaker when necessary.
- Ensure all entrances are well marked. For example toilets, refreshments, smoking areas and exits.
- It is a good idea if someone can meet and greet people at the entry into a building, especially for a first meeting.
- Identify and cater for all special dietary needs. Label foods clearly and correctly and not mixing vegetarian with non vegetarian.

## **During the meeting or event**

- Make everyone feel welcome.
- Have effective chairing of meetings and events.
- Cover housekeeping, that is, explain where toilets and fire exits are taking into account different people's access needs.
- Develop and use a code of conduct and ground rules.
- Keep to the agenda or programme so people can follow where they are and try to keep to time.
- Discuss and agree adequate breaks and timings within the meeting or event.
- One person should speak at once and the Chair should note who would like to say something.
- Encourage everyone to use plain and simple language with words in full and no jargon.
- Encourage everyone not to talk too fast and not to dominate a discussion.
- Have awareness of, and show discretion, for people with literacy and numeracy difficulties.
- Have awareness of, and show discretion, for people with communication difficulties or different languages.
- Ensure everyone understands what is being discussed and welcome questions and clarification.
- Design and agree with individuals appropriate feedback and debriefing processes.
- Provide refreshments including water, caffeine free drinks and healthy food and drink.

## **After the meeting or event**

- Debriefing at the end of the meeting or event to confirm that everybody understands what has happened and what is going to happen.
- Follow up actions after activities or meetings as required, and be clear about who is responsible for this.
- Record and evaluate any activity or work that follows from the meeting.

## References

NIMHE (2007) Making a Real Difference Involvement Resource Pack.

## Glossary

The Glossary of terms used within the Making a Real Difference Report is;

Carer	Anyone who has a significant role in supporting a friend or family member in managing or overcoming their mental health problems.
Care Services Improvement Partnership (CSIP)	An organization formed in April 2005 to bring together NIMHE with other Department of Health Groups which cover people with learning disabilities, older people and children and young people.
Experts by Experience (EbE)	A national service user and carer group which was part of NIMHE.
Local Implementation Team (LIT)	An organisation made up of stakeholders from different organisations including service users, carers, health and social services staff. Responsible for agreeing the direction for mental health services locally and for implementing national mental health policy.
National Institute for Mental Health England (NIMHE)	Part of the Department of Health, NIMHE was established to support the implementation of mental health policy.
PCT (Primary Care Trust)	Organisations which are based in primary care and responsible for commissioning health services for the local population.
Programme Lead	A member of NIMHE staff responsible for leading a programme of NIMHE's work either at a national or a regional level.
Regional Development Centre (RDC)	NIMHE has eight regional development centres.
Service user	Someone who uses mental health services or has lived experience of managing or overcoming their mental health problems

Other Terms used within this report include;

HASCAS – Health and Social Care Advisory Service	An advisory service working in all aspects of mental health and older peoples services – HASCAS wrote the Making a Real Difference Report
Directors	The senior managers in each CSIP Development Centre
Products	The policies, procedures, guidelines and systems developed during the Making a Real Difference project.
PRINCE2	PRojects IN Controlled Environments, a structured way of managing projects.
Work Group	One of the seven groups that were tasked with developing the Making a Real Difference products.
Project Governance	A term to describe how the whole project was monitored and managed.
Terms of Reference	A description or the responsibilities and purpose of a group – used in reference to the national Making a Real Difference Steering Group.

RATIFYING BODY .....
DATE RATIFIED .....
NEXT REVIEW DATE .....
TO BE APPROVED BY .....