A good practice guide

Compiled by Bec Hanley and Kristina Staley

USER AND CARER INVOLVEMENT

LMCA
alliance for health

About LMCA

LMCA, the Long-term Medical Conditions Alliance, is the umbrella body for national voluntary organisations working to meet the needs of people with long-term health conditions.

Our vision is of a society in which people with long-term health conditions have control over their lives and can live them to the full. We aim to:

- gain recognition of their needs and ensure adequate resources are available to meet them
- campaign to achieve change in areas where LMCA member organisations have common concerns
- find and promote solutions to shared problems
- develop effective partnerships between those who plan and provide services and people who use them
- promote participation by individuals in their own care and treatment and greater control over their lives
- support member organisations to help them develop strong voices and effective services

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About TwoCan Associates

Bec Hanley and Kristina Staley of TwoCan Associates have compiled three documents on user and carer involvement at the request of LMCA. TwoCan Associates provide advice, training and ongoing support to help voluntary and statutory organisations involve service users and carers. For further information visit www.twocanassociates.co.uk or contact us:

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About this series of documents

This is one of a series of three resource documents that aims to help voluntary health organisations involve service users and carers in their work. The other two documents in the series are:

- A good practice guide
- How to develop a strategy

All three publications are available from the LMCA and can be downloaded free of charge from our website (www.lmca.org.uk).

The three topics for the resource documents were selected by asking LMCA members what they wanted to know about user and carer involvement. We are very grateful for all of the contributions we received. In particular we'd like to thank the people from the 13 member organisations (staff, service users and carers) who kindly agreed to share their experience of user and carer involvement. Regretfully we had neither the time nor the space to include more examples. However, if you would like to share your experiences or find people in other organisations working in this area, please visit the LMCA website at www.lmca.org.uk.

Why involve service users and carers?

Over the past ten years or so there have been increasing moves to involve people who use health services in the planning, delivery and monitoring of these services. The impetus for this has come from a variety of places. Service users and carers have themselves demanded more of a say. Government policy has stressed the importance of involving service users and carers in the NHS. This is now enshrined in law in Section 11 of the Health and Social Care Act 2001(See the Department of Health publication 'Strengthening Accountability' in the Useful Reading List).

Research has shown that user and carer involvement can improve the quality of information, services and research as well as making them more relevant to people's needs (see the paper by Crawford, Rutter, Manley et al. in the Useful Reading List). It can improve service users' confidence and self esteem. It can also help to motivate staff.

Why have we written these resource documents?

This series of documents has been written in response to requests for help with user and carer involvement from LMCA member organisations. Some members have historically always involved service users and/or carers – other organisations were set up by people who had a real desire to help a particular group. But wherever you start from, involving service users and carers across an organisation can be difficult – and there are no quick fixes or set recipes.

For voluntary organisations that are run by service users, user and/or carer involvement may be simply taken for granted, or deep-rooted within

the organisation's constitution and values. For organisations that were set up for service users rather than by them, making this cultural shift may be more of a challenge. This may also be true of service user-led (or carer-led) organisations that have grown and needed to recruit 'professional' staff. These organisations may well have struggled to keep service user control or maintain this focus in their aims and objective (see the paper by Crawford, Rutter and Thelwall in the Useful Reading List).

Therefore every organisation will face its own particular issues around user and carer involvement, depending on its history and current stage of development. But at all stages, every organisation, large or small, will always have room for improvement. We hope these resource documents will be as valuable to the people who are just starting to involve service users and carers as it will to the people who are looking to get better.

Who are these documents for?

This series of documents has been written for people within voluntary health organisations who are taking forward user and carer involvement. They may be a trustee, a paid member of staff, a volunteer, a service user, a carer or anyone else with a particular interest in this topic. Many of the ideas are transferable to other organisations including those in the statutory sector.

For voluntary health organisations there are particular challenges in involving service users and carers – because people who use services may be unwell and their carers may be overburdened by their responsibilities. So any involvement needs to be planned with interested members in order to take proper account of their needs. It must also be flexible enough to adapt to changes in people's circumstances.

**We would welcome your feedback on this series of documents.
We will use your feedback to help us update the documents and/or decide on topics for future publications.
Please contact the LMCA or visit our website at www.lmca.org.uk**

A note about the terminology used in this document

We have used the term '**service user**' in this series of documents to describe people who use (wish to use or have used) health and/or social care services. We do not mean all users of an organisation's services, as this may include, for example, health professionals. Some organisations prefer the terms 'patient', 'user', 'public' or 'person'.

We have used the term '**carer**' to cover family members, partners or friends who have some responsibility for caring for someone who uses health or social care services. We do not mean professional carers, such as home helps or personal assistants, for whom caring is a paid job.

When we talk about **user and carer involvement**, we mean the active involvement of service users and carers, not their passive involvement as recipients of services or information. Involving is often described as doing things **with** or **by** people, rather than **for** or **to** them. User and carer involvement needs to be integrated into all aspects of an organisation's work rather than being seen as an optional extra.

'**Involvement**' covers a range of activities, from consulting service users and carers about their views or wishes, through to working in partnership with them to develop projects or services, right up to service users or carers leading projects, services or organisations. These three different levels of involvement are discussed in more detail in this document.

Foreword

In recent years the voluntary sector has had much opportunity to tell others how they should be doing more to involve the public and service users in their work. In this guidance we set out how the health voluntary sector goes about involving service users and carers in our own work.

This project shows the voluntary sector at its best. First, the project showcases the excellent work on user involvement done by organisations of all sizes. Second, the very valuable guidance on good practice has been built from the freely-given contributions of LMCA member organisations. Third, the project demonstrates how much the voluntary sector can do with a modest amount of funding – in other sectors where I have worked this project would have cost five times as much!

I hope voluntary health organisations will find the guidance gives them ideas about how to improve the ways they plan for user and carer involvement. I expect others outside the sector could also read it and find wisdom that could be translated and used for their work, too.

The guidance documents might seem long and readers might find that off-putting – but I hope you will find that this is because the ideas are well-presented and described in sufficient detail for real, practical use. And people should feel free to pick and choose those parts of the guidance that address their own situation. LMCA will itself be using this guidance in future, but we will not expect to reach "best practice" standards in all areas overnight.

So, I am very pleased to offer our special thanks:

- to the Lloyds TSB Foundation, for providing the funding grant,
- to Bec Hanley and Kristina Staley, for crafting a clear set of publications from a kaleidoscope of ideas and suggestions,
- to the staff, service users and carers from LMCA member organisations, who have helped design the project and have made their good practice available to all, and
- to Sheila Dane, who led this project when she worked at LMCA.

We would welcome your comments. I hope we will be able to publish further work in this area.

David Pink
Chief Executive
LMCA Alliance for Health

1. Introduction

This document is one of a series of three produced by LMCA on user and carer involvement. More information about this series can be found on page 2.

The aim of this document is to provide your organisation with practical advice on how to develop good practice in user and carer involvement. We have tried to ensure that the advice is:

• Useful and relevant to voluntary health organisations
• Based on sound evidence
• Informed by the lessons learnt by LMCA members

This document was therefore developed and written by:

• Asking service users, carers and staff within a range of LMCA member organisations what they thought the document should cover and what constitutes good practice
• Bringing together other people with extensive experience of user and carer involvement to agree what this document should cover
• Reviewing research and other guidelines on user and carer involvement from both the voluntary and statutory sector

If you'd like to find out more about the user and carer involvement in any of the organisations included in this document, contact details can be found on page 34. Further information can also be found in the useful reading list on page 35.

How to use this document

This document aims to be a useful reference – a resource to be dipped into, rather than read from cover to cover. It contains hints, tips and advice about what might constitute 'good practice' in user and carer involvement and suggests a wide range of issues you may want to think about. You may choose to prioritise one particular topic covered here for action – you don't have to do everything at once! There is no single right way to involve service users and carers, and you need to be prepared to take risks, and make mistakes. You may find it easier to start small, to do something simple, quickly and well – and then set your sights higher.

There are two main sections in this document – preparing your organisation for involvement (section 2), and involving service users and carers in practice (section 3). Key points are included at the end of each section.

2. Preparing your organisation for involvement

2.1 Being clear about why you want to involve service users and carers

It's important to have a strategy to take forward user and carer involvement before you start. You can read more about developing a strategy for user and carer involvement in one of the companion documents in this series – *User and carer involvement – how to develop a strategy*. Some of the information in that document is summarised below.

Why a strategy is important

Even if your organisation is already involving service users and carers, it's a good idea to have a clear plan about why you want to do this, what you hope to achieve through this involvement (your 'vision') and how you'll go about it. Not having a plan will be a barrier to your success. It's best if you can develop this plan in partnership with service users and carers.

Why involve service users and carers

There are lots of different reasons for involving service users and carers in the work that you do. Some of these are listed in the box below.

Once you are clear about why you want to involve service users and carers, you can think about who you want to involve, where and when to involve them, how best to do it and what you hope to achieve. This will

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Why involve service users and carers in the work of voluntary organisations?

The reason most voluntary health organisations exist is to provide services and support to users and carers. Involving service users and carers in all aspects of your work will ensure that:

- your organisation learns from the people who receive your services - people with different perspectives who are on the 'outside looking in'
- your work is relevant to service users and carers - money and resources aren't wasted on services that have little or no impact
- users and carers get better services that genuinely meet their needs
- you campaign on the right issues
- you get help with delivering services and reaching users and carers who may be marginalised, such as people from black and ethnic minority communities
- service users and carers feel empowered to

bring about change and improvement in the areas that concern them most
- service users and carers feel valued and more in control, and get pleasure from 'giving something back'
- your staff feel more motivated and also get more job satisfaction
- your organisation meets the requirements of funding bodies and government organisations – user and carer involvement is increasingly a condition of contract
- service users and carers are likely to feel personally committed to your organisation
- your organisation demonstrates respect.

So user and carer involvement will benefit both the organisation and the individuals involved. Many people also believe that service users and carers have an unquestionable right to have their say in any organisation that claims to represent their interests.

inform your strategy and give you a clear sense of purpose and direction.

What makes a good strategy?
A good user and carer involvement strategy will:

- have been developed in partnership with stakeholders (including staff from different levels and departments, Trustees, volunteers, service users, carers and professionals) and will be widely endorsed and supported
- have tangible goals that mean something to staff, service users and carers
- provide direction, register commitment and give a sense of purpose
- provide a rationale and business case for the work
- be rooted in reality and make links to existing organisational goals and ways of working

- take account of current work, building on existing initiatives to develop greater capacity to take this work forward
- identify clear objectives, measurable targets and realistic actions
- identify the resources needed to carry out the work and clear roles and responsibilities for staff at all levels
- build in support and training for staff that meets their expressed needs as well as mechanisms to share learning across the organisation
- build in support and training for user and carers that meets their expressed needs and provides opportunities to build better relationships
- build in responsibilities for monitoring user and carer involvement, evaluating its success and feeding back to all stakeholders
- include quick wins and long-term goals
- be seen as a work in progress, needing regular review and updating

2.2 Being clear about who you want to involve

Service users or carers?
Both user and carer involvement are important – but they aren't the same thing. Although carers have the interests of the person they are caring for at heart, the priorities and needs of service users and carers will not always be the same.

Existing activists or new recruits?
It's best to strike a balance between continuity and bringing in new people – try not to rely on the same people all the time, but also make the most of the people who have invested time and effort in being trained and acquiring new skills to get involved. At the beginning it may be difficult to involve a wide range of people – but don't let this put you off. Existing activists can inspire and motivate others to get involved, and may well help to gain commitment from staff if they are already known within the organisation. Be aware that service users and carers may choose to move on once they have achieved their goals.

What do other LMCA members do?
Inspirability is a small user-led organisation that aims to improve the quality of life for people disabled by a chronic condition. They always try to involve family members, friends and anyone else in a service user's support network – because they think it's important to try to improve the quality of life of carers too. They see big advantages in being user-led: their organisation has real empathy, a knowledge based on experience, and is always non-judgemental. But they also understand that service users can't always give their full support if they are ill. They recognise how valuable it is to have the involvement of carers as well. As Inspirability expands, they plan to keep their service user focus by making sure that the split between service users and carers amongst volunteers and staff is always 50:50.

What do other LMCA members do?

The Multiple Sclerosis Society has set a limit of 3-year membership of all committees, with an option to extend if the individual and organisation both want to. This ensures that more people have a chance to get involved. The Society has tried to reach non-members by putting information on its website and running special events, for example research days and events geared towards a younger audience.

The IBS Network has hardly any family members involved because the basis of the organisation is self-help. It's run by people with IBS for people with IBS. Some people with IBS who run self-help groups are also Trustees.

2.3 Ensuring you have the appropriate policies and procedures in place

Although it may sound bureaucratic, having the right policies and procedures in place before you take user and carer involvement forward can make a big difference to its success. Developing these policies and procedures at the start can help to identify areas of disagreement or differences in perception within the organisation. It can also mean that service users and carers feel supported from the beginning.

Some of the policies and procedures you should think about developing include:

- A policy statement which recognises the importance of involving service users and carers
- A database for keeping the contact details of service users and carers who want to be involved, as well as details on what they are interested in doing.
- A payment or expenses policy (see section 3.3)
- Training and support for staff, service users and carers (see section 3.3)
- A policy on confidentiality, if service users and carers are to have contact with information which is confidential

It's important to develop these policies in partnership with staff, service users and carers and to communicate them widely across the organisation.

What do other LMCA members do?

One of Macmillan Cancer Relief's key strategic objectives is to "promote and embed user involvement within Macmillan and with our partner organisations and support postholders to work in partnership with people affected by cancer." This means that everyone across the organisation, as well as those outside it, knows that Macmillan is committed to this work. Macmillan holds a database of people affected by cancer who want to get involved, and what they are interested in doing. The organisation also has a clear policy on payment of expenses and where appropriate, payment of fees. Training on involvement is available for all staff and for people affected by cancer.

2.4 Resourcing involvement

Involving service users and carers costs time, money and other resources, and you need to be prepared for this before you start. You should also think about the potential costs of not involving service users and carers – for example you may end up providing services, products or information that are not relevant to the needs of service users and carers. It's impossible to say exactly how much user and carer involvement costs, but you should consider budgeting for:

- A database to hold the details of service users and carers who become involved in your organisation
- Travel expenses and personal assistant/carer costs as a minimum, thus ensuring that service users and carers are not out of pocket as a result of their involvement
- Any additional payments that are covered in your payment policy (see section 3.3)
- Translators and/or interpreters – for people who do not speak English, who use sign language or Makaton

- Any equipment you might need to make your premises or meeting venues more accessible – induction loops, ramps, stairlifts and so on, or a budget to rent accessible meeting rooms
- Training for service users, carers and staff
- Independent facilitation to support service users and carers, if this is appropriate
- Production of newsletters for service users/carers who become involved (email could be used to reduce costs)

You should also think about how you will build in staff time for involvement. Involving service users or carers in a piece of work can often mean that the work will take longer, but it will also mean that the work is of higher quality, and more relevant.

Service users and carers find it helpful if there is a named individual with responsibility for involvement who they can contact if they have queries or concerns. This individual should have the power to take decisions on a day-to-day basis, and to feed into executive level decision-making.

2.5 Challenging people's attitudes and beliefs

If you want to involve service users and carers in your organisation, you may come up against resistance – and possibly hostility. Staff and trustees may have different ideas about user and carer involvement based on their own experience/beliefs. Introducing or developing user and carer involvement can therefore be very threatening. In preparing your organisation, you will need to think about how you will encourage people to change their attitudes, beliefs and/or behaviour.

Some of the ways you may do this include:

- Involving staff at all levels from the beginning of the process – in planning how

user and carer involvement could be taken forward within your organisation
- Showing that this work need not be frightening or threatening, and will lead to benefits for everyone
- Encouraging staff to share their learning about user and carer involvement
- Identifying champions at all levels of the organisation and offering them support
- Starting small and demonstrating success as you go
- Recognising and valuing good practice across the organisation
- Using external levers, such as the requirements of some funding bodies to involve service users and carers, or the

What do other LMCA members do?
Macmillan Cancer Relief has a shared learning group on user involvement. Its terms of reference are to:

• Create a safe environment to facilitate shared learning within the group

• Undertake user involvement projects as case studies for shared learning

• Share our experience of user involvement with each other, learning from one another

• Promote and champion user involvement within Macmillan

• Develop models of good practice for user involvement within Macmillan

• Ongoing monitoring and review of user involvement principles and good practice within Macmillan

• Provide a safe and supportive network to nurture other individuals or groups undertaking user involvement

The group meets monthly and has been responsible for developing guidelines on user involvement for staff and volunteers (see the useful reading list).

increasing requirements within the NHS for user involvement

• Being prepared to take risks

Have robust systems in place for recruiting service users and carers, providing support and record keeping. Be prepared to explain how this has all worked to other staff in your organisation so you are ready to answer questions and respond to criticism. Show that you have been thorough in your approach.

Encouraging staff to share their learning

It's important to encourage staff to reflect on the development of user and carer involvement. This shared learning should involve staff at all levels, as well as service users and carers. It will provide people with opportunities to share their experiences, test out new ideas in a safe environment and come to a common understanding about user and carer involvement. Shared learning can be a subtle way of changing attitudes/culture, and can lead to the development of further, more meaningful involvement. 'Doing' user involvement will mean different things in different roles/departments. Shared learning will help people find out what it actually means for other staff in practice. This sharing of learning can take time – you need provide opportunities for discussion and reflection, and to deal with concerns and worries.

Identifying champions

You can't 'do' user and carer involvement on your own. If it's to be successful, user and carer involvement needs to be owned across the organisation and become part of the culture. It can be helpful to identify and support 'champions' who will promote this work. These champions may be service users, carers or staff.

What do other LMCA members do?
User and carer involvement within the British Heart Foundation benefited from the active support of the Medical Director, who talked to staff and external people about the importance of involving service users and carers, and made it clear to members of the Patient Advisory Group at the outset that their contribution was highly valued.

The **Multiple Sclerosis Society** set up a Research Network of people affected by MS. Some of the Trustees joined the network and soon became strong supporters, after getting involved in some of the earliest activities. These people championed the work at a Board level, raising awareness of its impact and benefits with all the senior staff.

Start small and demonstrate success as you go

It's best to begin by involving service users and carers in one area of your organisation, where you know they will be welcomed and where their contribution can have an impact. You can then use this experience to demonstrate the value of user and carer involvement to people in other areas.

Use external levers

Some funders require user or carer involvement as a condition of funding. The Government is increasingly promoting patient and public involvement in the NHS and social care. Other voluntary organisations are also increasingly involving service users and carers. Any or all of these factors might influence staff within your organisation to take involvement forward.

Be prepared to take risks

Be prepared to make mistakes. If you are honest with the people you involve that this is a learning process for everyone, they are more likely to support you, and less likely to criticise you when things go wrong. It's important to build in mechanisms to evaluate the work you do and involve service users and carers in this process as well as allowing time to reflect on the lessons you have learnt.

Be prepared for hard choices. There are risks you may lose people. This makes it all the more important to involve stakeholders from the beginning, find your supporters and allies and give clear messages to staff. If you assess the risks before you get started, don't forget to include the risks of not involving service users and carers.

Be prepared to deal with dissenters. If your organisation has a head office and local branches, think about how you will spread good practice at the same time as preserving local power.

Section 2- key points

- **Be clear about why you want to involve service users and carers**

- **Develop a strategy for involvement in partnership with stakeholders**

- **Be clear about who you want to involve**

- **Ensure you have all the appropriate policies and procedures in place**

- **Identify the resources required to support user and carer involvement**

- **Be ready to constructively challenge people's attitudes and beliefs**

3. Involving service users and carers in practice

3.1 Giving people a choice about how they get involved

Involve people in developing new opportunities

It's best to involve service users and carers in thinking through where and how they may get involved because:

- This can create a sense of ownership
- It demonstrates your commitment to involving people and giving them a choice
- Service users and carers may be limited in how much time they can give
- People have different knowledge, skills, experiences to offer – and may be better suited to one task than another. Asking where and how they want to be involved respects this
- You recruit the people who are interested in and enthusiastic about your particular activity
- Service users and carers are very likely to come up with ideas that you haven't even thought about – not only about where they could get involved but also how practically to make it happen

Offer different ways for service users and carers to get involved

The best place to start is to be ready with some options about where and when people can get involved. Include opportunities for people to get involved on a one-off occasion – don't just offer options that require long-term commitment. Offer these options to people to think about and then ask them to come up with their own ideas. You'll need to be flexible in your responses to their suggestions.

You also need to be prepared to shift the goal posts. Have the confidence to admit that some initiatives may not be successful, and abandon them. Be honest with service users and carers about why. They are very likely to be on your side.

Some of the ways in which service users and carers are currently involved in LMCA member organisations include:

- **Writing or reviewing drafts of information and publications for service users and carers**
- **Putting together newsletters or websites, and contributing to these**
- **Planning new services**
- **Delivering services such as helplines**
- **Running self help or support groups**
- **Offering to share their experience as a user or carer with the press, with staff or with others**
- **Being involved in governance – as a trustee, or on committees/groups at national, regional or local level**
- **Speaking on behalf of the organisation – perhaps through doing presentations or talks**
- **Training staff**
- **Training other service users or carers**
- **Evaluating or monitoring services**
- **Participating in external consultation processes on behalf of the organisation**

Try not to be over ambitious by engaging everyone everywhere at once. It's far better to focus on doing one thing well and really making an impact. Then you can think about developing and expanding user involvement.

It's possible for service users and carers to be involved in any aspect of the work of your organisation. But remember to be clear about why service users should get involved

3. Involving service users and carers in practice

and how they will make a difference. Also be clear to service users and carers that they might not get everything they ask for. It's important to be honest about what's practical.

Help people make an informed choice about where they get involved

Help people to make an informed choice by being clear about what you will expect them to do if they get involved. You can do this by giving them information about:

- Your organisation's policy, principles or agreed contract on user involvement
- Background to the project, group or committee
- The aims of the project or activity, the terms of reference and remit of any group or committee
- What training and support will be available
- Their role and remit – a job description - and statement of the time required
- What kind of skills you're looking for – a person spec

It's best to draw up contracts or write job descriptions by working in partnership with service users and carers – don't just hand them out.

In whatever way people get involved, it's important to support them in their involvement (see section 3.3) and to encourage people to review their involvement regularly (see section 3.7).

Be flexible and creative in the methods you use

There are lots of different ways to involve people. The method you choose needs to be fit for purpose and to meet the needs of the service users and carers you involve. Written questionnaires are good if you want to get feedback on a draft policy or strategy, but membership of a planning group is much better if you want service users or carers to have an active role in developing a plan or strategy.

'Involvement' covers a range of activities,

from consulting service users and carers about their views or wishes, through working in partnership with them to develop projects or services, to service users or carers leading projects, services or organisations.

There are other guides that can help you choose a method (see useful reading list). It will also be useful to think about what level of involvement you think will achieve your goal and then choose an appropriate method. It's important to be honest with service users and carers about what level of involvement you are offering in your organisation.

For simplicity, we suggest that there are three different levels of involvement:

(i) Consulting service users and carers

Consulting people involves asking them for their views and then using these views to inform your decision-making.

Possible methods for consulting service users and carers include:

- Asking service users and carers to comment on drafts of written information
- Setting up service user or carer reference groups or advisory groups to provide comments on and input to a particular project
- Asking service users and carers to complete questionnaires or take part in focus groups or interviews
- Meeting with existing community groups, self help groups or groups of members
- Workshops, seminars or conferences

What do other LMCA members do?

Epilepsy Action carries out a major survey of over 1000 of their members every five years to get feedback on the organisation's overall strategy and direction. They also carry out regular mini-surveys (200-300 people) to identify priorities for campaigns and ensure they are addressing the issues that are important to their members.

What do other LMCA members do?

At the **Multiple Sclerosis Society**, equal numbers of Research Network members (people affected by MS who have an interest in research) and 'professionals' review research proposals, and share their views. This means that research proposals are assessed both in terms of their scientific quality and their relevance to people affected by MS. There are also Research Network members on the Grant Review Panel, the group that makes the final decisions about awarding research grants; and the Science and Development Board, the group that oversees the implementation and development of the Society's overall Research Strategy. This means that people with MS don't just give advice but also have a say in the important decisions.

Breakthrough Breast Cancer has formed a UK wide Campaigns & Advocacy Network which includes individual members and organisations dedicated to campaigning to improve breast cancer services, research and prevention. The work of the Network is directed by a Steering Group of ten women, all with personal experience of breast cancer. The Steering Group provides advice to the Network on all its activities – helping to shape campaigns, events and publications. The views of the Group and the wider membership are sought when Breakthrough responds to National Institute for Clinical Excellence consultations and develops other policy work.

(ii) Collaborating with service users and carers

Collaboration involves more of an active partnership between an organisation and service users/carers. It is usually ongoing, and involves the development of relationships between people.

Possible methods for collaborating with service users and carers include:

- Including service users and carers as members of existing groups or committees, at all levels of the organisation (although this can become tokenism if only one user or carer is involved, or if the service users or carers are not supported in their membership)
- Developing new services in partnership with service users and carers

(iii) User and /or carer controlled work

A user or carer-controlled project is one where the power, initiative and decision making sit with service users and/or carers, rather than with 'professionals'.

This includes:
- Organisations where service users or carers are in the majority at trustee level
- Self help groups or support groups run by service users or carers
- Projects where responsibility for decision making and resources (including finance and staff) have been taken on by service users or carers

What do other LMCA members do?

DANDA (the Developmental Adult Neuro-Diversity Association) is entirely user-led and controlled – you have to be developmentally neurodiverse in order to be a full member of the organisation. If you are not, you can only be an associate member.

Rethink supports a service user network, the Voices Forum. The Forum uses Rethink's name and charity number, but has its own clear identity. Rethink raises the money to employ a worker. Rethink staff only become involved at the request of Voices Forum members. The Forum has representatives on Rethink's Board of Trustees.

What makes it easier for service users and carers to get involved?

A study for ACEVO (the Association of Chief Executives of Voluntary Organisations – see publication by Taylor in the useful reading list) found that the following factors made it easier for service users and carers to get involved:

- Commitment from the top of the organisation
- Peer support
- A belief that user involvement is good for services
- Professional allies
- Anger on the part of service users and carers, which can motivate people to want to bring about change
- Adequate time, support and resources
- Information
- A clear idea of the role they are to play

3.2 Involving people who may be marginalised

Make sure you involve a wide range of people

Are all the service users and carers who are active in your organisation older, white, middle class, able-bodied people? And are the people affected by the condition you support also young, disabled, black or Asian?

Think about involving a wide range of people – people of different ages, backgrounds and socio-economic groups including:

- Children and young people
- People with learning disabilities
- People from black and minority ethnic communities, and people whose first language is not English
- Disabled people. Don't forget that some disabilities may be hidden. (See Appendix 1)

What do other LMCA members do?

Rethink's trustees are very keen to ensure that the charity is representative of it's beneficiary group, especially young people and people from black and minority ethnic communities, who are disproportionately represented as users of acute mental health services. So they have linked with existing black and minority ethnic community groups and produced publications specifically aimed towards these groups. Membership amongst black and minority ethnic communities is slowly increasing.

Rethink has also been working to involve young people, targeting colleges, having displays at fresher's fairs, and developing a website for young people: www.rethink.org/at-ease

Trustees looked at barriers to membership and found that the membership fee often put people off. So they introduced a 'pay what you can afford' membership fee.

Macmillan Cancer Relief employs a Black and Minority Ethnic (BME) Community Development Co-ordinator. She has a network of linkworkers and organisations wanting to involve people from BME communities. She has set up a national BME group of people affected by cancer, and is now setting up local groups in each of the cancer networks, and making links with the development workers for each network.

Macmillan has also set up Young CancerVOICES to involve children and young people affected by cancer in the work of Macmillan and the NHS. They have also established a Rarer Cancers Forum and a facilitator has been funded to work with this group.

- Gay men and lesbians
- Homeless people and travellers
- Older people (including people with dementia)
- Refugees and asylum seekers

You can read more about methods for involving these different groups in the Department of Health publication on *Strengthening Accountability* – see useful reading list.

Make an extra effort to include people who may otherwise be marginalised

Some of the best ways to do this are to:

- Work with people from the community you want to involve. They are best at reaching others. You may need to recruit new outreach workers and ensure they receive the necessary support.
- Work with other voluntary organisations or community groups (see Useful Contacts).
- Establish links with relevant community group leaders.
- Offer to meet people on their own 'turf',

and at a time convenient to them. This is important for all service users and carers but may be particularly important with marginalised groups.
- Think about different ways of communicating. Disabled people who may find travelling difficult may be engaged through the Internet, or by phone. Also think about making information available on tape, in large print and in different languages.

Macmillan is now looking at how people who are very ill and who may be at the end of their lives can get involved in the work of the organisation. They have commissioned new research to help plan their involvement.

One of Epilepsy Action's objectives is to become more inclusive and representative of all people with epilepsy. Staff and members have been working to ensure that the organisation becomes more diverse. They commissioned research to look at how epilepsy affects people from black and minority ethnic communities. As a result, they have extended their services for Asian communities.

A significant number of people with epilepsy also have some level of learning disability, and may be living in residential care. The National Society for Epilepsy works hard to ensure that

the voices of these service users are heard and that they are actively involved in the decisions that will affect them. The Society produced an award winning pack aimed at people with learning disabilities, covering the medical, practical and emotional consequences of epilepsy. Service users with learning disabilities were involved at every stage of production and their involvement ensured that the pack met their needs appropriately. The pack combines text, Makaton symbols and photographs of service users, to ensure its accessibility.

Most people who are members of the IBS Network are adults. However, IBS can affect young people. One of IBS Network's younger members, who is 14, developed a junior website, which is aimed at young people of secondary school age.

3. Involving service users and carers in practice

What do other LMCA members do?

The Princess Royal Trust for Carers has produced a good practice guide for involving carers (see useful reading list). They stress the need to consider the pressures and strains in carers' lives. This means that it's important to pay attention to all the usual elements of good practice, but also to:

- Give people extra notice about the timing of meetings – it may take some time for people to make alternative arrangements for the person they care for
- Make the day an enjoyable experience for carers – it may be the only time they have free from the responsibility of caring – e.g. give them a good lunch, time to socialise, offer therapy sessions e.g. aromatherapy, reflexology or classes e.g. surfing the net, tai chi. You will need to budget for these extra activities.
- Involve carers in planning their involvement

- Offer to provide or pay for alternative support for the person who needs care
- Organise transport to save carers' time
- Offer different ways for carers to contribute e.g. by telephone interview or written survey, as some may feel unable to leave the person that they care for

The feedback from carers is that these extra measures make them feel valued, make events feel more balanced and inspire confidence in the organisers. It demonstrates a real understanding of carers' issues.

The Terrence Higgins Trust has produced a guide on involving people with HIV/AIDS. This stresses the importance of remembering that people with HIV are not a homogenous group, and the need for confidentiality (see the useful reading list).

- Use an appropriate style and format. Young people may not respond well to material that's been targeted at an older membership.
- Provide information in plain English – avoid jargon, acronyms and long sentences.
- Offer people practical support to enable them to get involved – carers will be more willing to get involved if the costs of respite care are covered. You will need to think about expenses, transport and accessible venues (see section 3.3).
- Advertise opportunities for involvement widely (for example in the gay press, in community publications) and in different media. Make it clear that there are lots of different ways to be involved, and that support and resources are available.
- Present images that reflect the group you're wanting to involve – so use photos of black service users, gay carers and so on.

3.3 Providing training and support for staff, service users and carers

It's very important to offer support to service users and carers to encourage then to get involved and stay involved. This support can be practical and / or emotional.

Practical support
Payment
As a minimum, you should:

- Pay people's travel costs, and where possible buy train or coach tickets for people in advance so that they do not have to incur large expenses
- Pay for childcare, respite care or for a support worker or personal assistant
- Offer meals, and pay for meals eaten whilst the service user or carer is 'working' for the organisation
- Cover people's costs for stationery, phone calls and other resources they use as part of their involvement

You may also choose to pay people for their time - but if you do, you need to recognise the implications if they receive benefits. Some people may prefer to receive some other kind of recognition. INVOLVE produces guidelines on paying service users and carers for their involvement (see the useful reading list).

It's good practice to develop a clear payment policy that tells service users and carers when they can claim, what they can claim for and how quickly (or otherwise) their claim will be paid. Some organisations buy people's train tickets ahead of time if these are likely to be expensive. Others pay cash for expenses immediately, so that people are not out of pocket for any length of time. Whatever you decide to do, it's important that this policy is in place and explained to service users and carers from the outset.

Access
If you're asking service users or carers to come to you, you should select a venue

> **What do other LMCA members do?**
> **The IBS Network offer to cover the travel costs for one member of each of their self-help groups to attend their AGM. They publicise this clearly in their newsletter before the AGM.**
>
> **Macmillan Cancer Relief pays service users and carers who get involved with Macmillan if they take on a specific task, such as acting as a regional contact for CancerVOICES. Macmillan's user expenses and payment policy is included at the back of this booklet – see Appendix 2.**

carefully. It's might help to ask the following questions:

- Is the venue easy to get to by public transport?
- Does it feel safe? Is the approach dark or very quiet?
- Is there good access for wheelchair users? You need to think about the entrance to the building, access to the room itself and access to toilets, refreshment areas and so on
- Is parking available? Can parking be reserved for blue badge holders?
- Are other communication aids (for example an induction loop for people who use a hearing aid, a signer for people who use sign language) available?
- How do you get there? Sending directions out beforehand can make a big difference to the state of mind people arrive in.
- Will tea, coffee, food be available?
- Is there anything else people might find helpful to know about the venue?

Written materials
Different service users will have different requirements for accessing written information, but as a general rule anything

3. Involving service users and carers in practice

What do other LMCA members do?

The Multiple Sclerosis Society has developed a format for meetings and training events that meet the specific needs of people with MS. Agendas include breaks for people's comfort and need to rest. Meetings start late and end early, so that people have plenty of time to travel to and from the venue outside peak hours. The Society has built in the possibility for virtual involvement for people who are housebound. Events are held in different parts of the country so that people don't have to travel far. The papers for the meeting are emailed ahead of time, but people are also given printed versions on the day. Each folder is named so people can find them easily, and extra staff are there to help carry papers round, collect tea and coffee and provide any other support.

ARMA (the umbrella body for arthritis/musculoskeletal condition user and professional organisations) has recently facilitated a major project to develop user-centred standards of care for people with musculoskeletal conditions. This involved establishing mixed working groups of service users and clinicians to work together to develop the standards. It was vital for the project that the service users were able to participate on an equal footing. However, this was the first time many of the service users and clinicians had worked in this way, and for some service users, the first time they had been involved in policy work. ARMA therefore arranged for the service users to get together in advance of the full group at the meeting to discuss key issues from their perspective. These issues were then presented to the full groups at the beginning of the first meeting, to act as a framework for all future discussions. This helped set the right tone from the outset and placed the emphasis on users' perspectives. It also helped the service users feel more confident about participating.

you produce for service users and carers should be in plain English, with acronyms spelt out. Print should be clear and 12-point font minimum. Don't forget that the Royal National Institute of the Blind produces guidelines on making written information accessible to people with visual impairments. Also think about making information available in other formats – for example on tape, by email, in simple text documents or in other languages. People who speak languages other than English may not read in their native language, so tapes may be more effective.

Involving service users and carers in meetings

When planning to involve service users and carers in a meeting, find out how to make them feel comfortable and ensure they feel able to make a full contribution. You may have to change the way you normally run meetings to accommodate service users' needs. It might help to think through the following questions:

- What time will you hold the meeting? Will this be convenient for service users and/or carers?
- How many service users and carers will you involve? Research has shown that only one user or carer in a group of 'professionals' can feel isolated and ineffective. Involve at least two service users or carers in any group.
- Who will chair or facilitate the meeting? The role of the chair is crucial, especially in groups where there are 'professionals' and service users/carers. Is he or she committed to meaningfully involving service users and carers in the meeting? Has she or he been briefed about any special requirements?
- Are there any ground rules e.g. around confidentiality? If there are, service users and carers need to be told in advance or if possible, given an opportunity to develop them and agree them with the group.
- Will the service users and carers know anyone else in the group? How will they be

made to feel welcome and included?

- How long will the meeting last? Do people need short breaks between agenda items for comfort breaks or to help with concentration?
- Where will the meeting be held? Is it easy for service users and carers to get to?
- Will anyone need any additional resources to enable them to participate fully? For example, will they need a signer or an interpreter?
- Ask service users if they need any extra support - for example they might like a pre-meeting to prepare, or they might wish to talk to another member of the group/committee, or to be linked with a mentor, an experienced user or professional from the group.

The involvement of service users and carers may change the way meetings work, so be prepared for this.

Training
Provide different types of training to meet service users' and carers' needs
Service users and carers are likely to want some form of training before they get involved, even if it's only to be properly briefed on what's expected of them. Training can take the form of:

- Induction – giving background information to the organisation, project, group or committee
- Skills training – equipping people with new skills or knowledge to support their involvement e.g. being an effective committee member, media skills, understanding research and so on
- Attitudinal training – helping people to think about their attitudes and behaviour towards disabled people, for example

Training can take place in many different formats, including:

- Workshops
- Ongoing learning sets
- On the job shadowing/mentoring

What do other LMCA members do?
Epilepsy Action trains its volunteers so they have a good understanding and knowledge of epilepsy. They are then able to support families affected by epilepsy and advise people e.g. schools and employers about the condition and its impact. The course is accredited through the Open College Network. Epilepsy Action also provides ongoing support via a dedicated member of staff. A section of their website is being developed to provide further information and support to accredited volunteers.

When **The British Heart Foundation** set up their training for service users and carers, they modelled their programme on Macmillan's CancerVOICES. They first did 3 one-day pilots, hiring an external trainer to deliver the training. This proved to be really popular – 80 people wanted to take part. Gradually the momentum grew. In May 2003 they launched the Hearty Voices programme nationally and now have 300 people involved. The training is still a one-day course, but an update session has been developed, which is offered at the BHF's national patient conference.

Inspirability arranges for service users and carers to attend training courses together, so that it runs together, so that both can feel part of the learning situation. This also gives the carer a greater understanding of what the service user needs or wishes. Inspirability agreed on this after one of their members, who is a service user, encountered problems attending a course where her learning support assistant was told to wait outside until the course was finished.

The National Association for Colitis and Crohn's Disease carefully selects and trains service users to run a telephone-based support and listening service. The service is managed by a group of service users with support from a dedicated member of staff.

3. Involving service users and carers in practice

Training doesn't need to be formal. Think about what method would best suit the type of training service users and carers have asked for – is this a course delivered in a classroom situation? Could it include buddying or mentoring, or distance learning? Who will deliver the training? Is this something service users could deliver themselves? Do service users and carers need to be the only people attending the training? Could it also be offered to staff?

It's important to remember that it will take time and money to develop and deliver any training – so you need to build in these costs in your initial planning. Decide what's practical and affordable before making promises about what training you will offer.

Involve service users and carers in planning, developing and delivering training
It's best to ask service users and carers about what training they want but it's also important to:

- Involve them in developing training
- Ask them to evaluate the training – and make changes based on their recommendations

What do other LMCA members do?
The Board of Trustees at Epilepsy Action includes people affected by epilepsy and professionals. All are members. All Trustees are going through a process of self-appraisal for the first time – to see if there are skills gaps or training needs within the Council.

Some of the lessons on training for user and carer involvement include (see the publication by Lockey et al in the useful reading list):

- Training is most useful when it has a clear aim and purpose and is centred around real problems or tasks that service users and carers face
- Training should involve service users and carers from the start – right from the planning stage
- It's important to allow time for people to exchange and share information
- A 'safe' environment is important – one where people feel their contribution is valued
- Training can really help build service users' and carers' self-confidence

Emotional support
Involvement can bring up painful memories for service users and carers, or can bring service users and carers into contact with professionals who are hostile to involvement. So it's important to think in advance about what support is available to people who get involved in your organisation, and how they can access this. This could take the form of mentoring, where a more experienced user or carer offers advice and support to someone new. You could also set up a peer

What do other LMCA members do?
The IBS Network has a mentoring scheme for people who run self-help groups. This scheme is organised by the trustees who run groups themselves.

support system, or have a named member of staff who service users and carers can talk to if they come up against a difficult situation.

Training and support for staff

It's important to ask staff what would help them to involve service users and carers effectively and to think about how you could involve service users and carers in delivering that training. You could offer to provide sessions on:

- What is user and carer involvement? Why do it?
- Understanding the needs of different groups e.g. through disability awareness and/or equality training
- Understanding how people's lives are affected by a particular condition, or what it's like to care for someone with that condition
- The skills needed to involve service users and carers e.g. facilitation training
- Sharing learning across the organisation

Staff may also want emotional support. It can be very hard if staff build close working relationships with service users who may then become too ill to stay involved, or pass away.

Joint training

Offering joint training to staff, service users and carers could help break down barriers and encourage partnership working. For example, if you set up a new group or committee involving staff, service users and carers, it may be helpful to run a session to get them to agree their terms of reference and how they will work together.

But it's also important to remember that service users or carers who are new to involvement may need to boost their confidence before starting to work with a group of professionals. It's best to ask them what they would prefer.

3.4 Ensuring user and carer involvement has an impact

One of the most frustrating things for service users and carers is when nothing seems to change as a result of their involvement. There's no point in asking people for their views if your organisation can't – or won't - respond to them. So it's essential to ensure that user and carer involvement has an impact.

What can you do to ensure user involvement has an impact?
The key factors that will lead to change are having:

- A strategy to involve service users and carers that makes links to existing user groups, management initiatives and normal ways of working
- Senior management commitment
- Active commitment of staff at all levels
- An organisational culture that places user and carer involvement at the centre of all activities
- Appropriate use of feedback from service users and carers to influence change

The final key factor is that service users and carers must have a say in how, when and where they are involved, and are supported in their involvement. To read more about these factors, see the publications by Taylor, Robson *et al* and the Commission for Health Improvement in the useful reading list.

Things you can do to ensure user and carer involvement has an impact include:

- Map where the power lies in your organisation, and make sure that service users and carers are involved at the crucial places – at the top on the Board of Trustees, as well as on other key groups and committees
- Identify your champions and keep them informed and motivated
- Support service users to stay involved (see section 3.3)

- Ensure that service users and carers do not become lone voices on committees and working groups
- Think about giving more decision-making powers to user and carer advisory groups
- Practice what you preach – involve service users and carers in your own work and tell them and others about what difference it has made to you
- Document the changes that happen as a result of user and carer involvement. Note what difference user and carer involvement makes to decision-making at different levels in the organisation and publicise this.
- Take the results of user and carer involvement to the senior management team. Make sure the lessons are taken on board and their response is widely reported.
- Ensure that someone at a senior level has responsibility for taking user and carer involvement forward and keep them briefed on progress, with good news stories and lessons learned.

3.5 Communication and feedback

It's important to keep all stakeholders (including trustees, staff, service users and carers) informed of the success of user and carer involvement, in order to build up support and commitment and to challenge attitudes and beliefs. You can do this by:

- Writing about user and carer involvement in the organisation's internal newsletter, in magazines or websites for members, and in the annual report
- Asking service users, carers and staff to write or talk about their experiences of working together at conferences, in your organisation's magazines, newsletters or website
- Giving presentations at local branches to encourage the spread of good practice
- Making your policy on user and carer involvement a public document

All of this will also help to keep service users and carers informed of how their involvement is making a difference. It's helpful to ask people how they would like to receive information, so that they don't feel overloaded.

It's important to go back to the actual people who have been involved to explain:

- Where you have responded to their views
- Why you have been unable to respond, if this is the case

Some of the ways you can do this include:

- Routinely sending any reports of user and carer involvement to the people who were involved.
- Sending service users and carers the final version of any publication they have commented on.
- Sending service users and carers the minutes from any group or committee meeting where the results of their involvement has been discussed so they can see what influence it had on decisions.
- Writing a quarterly newsletter for service users and carers who have been involved with updates on progress. You can give service users and carers the lead on producing this.
- Developing a section of the website just for service users and carers who have been involved – this can be password protected if appropriate.

What do other LMCA members do?

At the British Heart Foundation, the chair of the Patient Advisory Group produces a short, regular newsletter to keep members up to date.

The Princess Royal Trust for Carers gives carers written or verbal feedback shortly after they have been involved and then AGAIN 6-12 months down the line, so that people know what the follow-up has been over time.

3.6 Involving service users in measuring the success of user and carer involvement

User and carer involvement costs time and money. So it's important that it makes a difference to the work of your organisation, and offers real value for money. For this reason you should plan to evaluate the success (or failure!) of your work. It's important to do this when you first develop your strategy for user and carer involvement and to ensure that you:

- Ask service users, carers, staff and other stakeholders what successful involvement would mean to them, and what difference user involvement might make
- Involve service users, carers and staff in thinking about how to measure success in the way that they have defined it

Once your organisation has been involving service users or carers for some time, think about asking service users and carers to evaluate the impact of their involvement. Do they feel their voice is heard? Do they feel their contribution is taken on board and makes a difference? What went well during

What do other LMCA members do?

In partnership with service users and carers, Rethink has developed a user involvement checklist for use by its local services. This checklist will help staff to reflect on how they are involving service users, and what they could do to develop this involvement (see Appendix 3)

their involvement? What's difficult? What would they change if they could?

You should also ask staff and other stakeholders (for example trustees) about the impact of user and carer involvement. What are the benefits? And the drawbacks?

You may undertake this reflection through informal discussion, questionnaire, focus group, workshop or by commissioning a formal evaluation. It will all help to improve your processes in the future. It's also important that you share your findings with all stakeholders.

Section 3- key points

- **Give service users and carers a choice about how, when, where and how often they get involved**

- **Think about the level of involvement you want – consultation, collaboration or user control**

- **Ensure you involve a wide range of people – make special efforts to involve people who may often be marginalised**

- **Provide training and support for service users, carers and staff – think about expenses and payment, training, access issues, information, involvement in meetings and emotional support**

- **Ensure user and carer involvement has an impact**

- **Keep all stakeholders informed of the success of user and carer involvement**

- **Involve service users and carers in measuring the impact of user and carer involvement**

Appendices

Appendix 1: Involving people with hidden disabilities or multiple disadvantages

Most organisations are very aware of the specific access issues for their beneficiary group - for example, the Multiple Sclerosis Society has given a lot of thought to the access needs of people with MS. But service users may have other disabilities that are not related to their condition. Some of these may not be immediately obvious.

Adrian Whyatt from DANDA, an LMCA member organisation that is user led and controlled, has contributed the following advice on involving people with hidden disabilities and/or multiple disadvantages.

Neuro-Diversity includes developmental dyspraxia, dyslexia, Asperger's Syndrome, attention deficit (hyperactivity) disorder (AD(H)D), dyscalculia, Tourette's syndrome, Dyspragia and related conditions. All are very common, and grossly under-diagnosed, especially amongst adults.

The characteristics of hidden disabilities:

- Dyspraxia (Difficulty in planning and carrying out complex movements such as drawing, writing, buttoning) and dyslexia are the most common lifelong disabilities – they are about twice as common as the obvious sensory and motor impairments.
- Dyspraxia and dyslexia tend to overlap and co-occur with Asperger's syndrome, attention deficit disorder and other neurological conditions – collectively known as neurodiversity.
- Most people with dyspraxia do not know they have it.
- Neurodiverse people tend to have a jagged profile – often to an extreme. They can be brilliant on one area and have great difficulties in another area – having a post-graduate degree – but unable to find their way around town.
- People do not 'grow out' of these conditions.

- People's problems are not widely recognised – they tend to face ignorance or disbelief. Neurodiversity is often mistaken for other things such as deliberate rudeness, laziness and depression.

Involving people with hidden disabilities
General difficulties experienced by neurodiverse people include:

- Over or under-sensitivity to light or noise
- Difficulty multi-tasking or sequencing
- Short-term memory problems
- Great difficulty in open plan environments – offices, trains, buses
- Clumsiness
- Writing by hand
- Getting from A to B – in terms of following directions, maps
- Hand eye co-ordination – may cause problems using office machinery/equipment
- Tendency to fall/trip
- High distractibility
- Often extreme attention span problems
- Hyper or hypo sensitivity to hot or cold
- Organising their work
- Following instructions – written and oral
- Social problems – use of tone, may interrupt people, use different body language

You will need to think about supporting neurodiverse people in their involvement to make them feel comfortable and able to make a full contribution.

Involving people with multiple disadvantages
- People can be disadvantaged in more than one area – maybe in many different areas – their needs require more attention and may not be met by single issue groups/organisations.
- Black disabled people often complain that their combined disadvantages are ignored by the black and disabled communities –

this is also true for people from religious minorities
- Some groups have recognised this problem and provide more tailored support e.g. the Asian deaf group.

You will need to think about supporting people to overcome multiple disadvantages and to ensure that the action you take to involve one group does not exclude another.

Appendix 2: Macmillan user payment policy

User support and involvement is one of Macmillan's key strategic programmes. It supports the principle that people affected by cancer should not be out of pocket for user involvement activity (associated with Macmillan) – for example, requests to attend conferences, seminars, events, meetings or working parties and in addition, that in specific circumstances they should receive appropriate payment in recognition for time, energy and expertise spent on this role.

The policy acknowledges that for people affected by cancer their involvement may be affected by issues such as fatigue which will need to be taken into account when making travel and accommodation arrangements, financial considerations e.g. living on low incomes, benefits, and pensions or being self-employed. Also the fact that involvement takes people away from their normal domestic life which may mean they prefer to travel with a companion or family member.

It is recognised that the policy should be subject to periodic review to reflect developments in user involvement, developments within Macmillan including budgetary constraints.

1. Out-of-pocket expenses
Many people will not have the means to pay for travel, accommodation or meal expenses in advance.

1.1 Rail, plane, coach, taxis
Travel fares should be booked whenever

possible in advance by Macmillan staff on behalf of the user representative. If a user representative has to book their own travel then their expenses will be covered in full, though standard fares and discounted rates for example Apex or Supersaver should be used whenever possible.

1.2 Car mileage
For some people affected by cancer there will be a clear preference to drive when requested to attend meetings or events. This may be because they need to be in control of their journey e.g. for toilet stops, to avoid feelings of claustrophobia on public transport (a hidden side affect of radiotherapy for some) or to avoid numerous changes of transport and the carrying of bags and luggage and generally to ensure a comfortable and stress free journey.

Where it is the most appropriate form of transport for the user representative, car mileage should be reimbursed to take account of wear and tear to a vehicle, the recommended rates are:

- Car engines up to 1000cc 28p per mile
- Car engines up to 1001 – 1500cc 35p per mile
- Car engines 1501 and above 40p per mile

1.3 Accommodation and meals
Accommodation requirements need to be taken into account where early starts or late evenings are required to avoid unnecessary fatigue.

Accommodation should be booked by Macmillan staff on behalf of the user representative whenever possible. A single, twin, family or double room should be booked within Macmillan maximum rate limits as requested by the user representative.

Currently these are:

- £90 (inc VAT) for Central London
- £70 (inc VAT) elsewhere With maximum use to be made of Travel Lodges etc at c. £50 per night.

In addition, whenever possible, the hotel booking should allow for an evening meal and breakfast. Where it is not possible to include this in the booking, user representatives should claim their own personal expenses within the current Macmillan maximum rate limits (see below) and provide receipts:

- Breakfast £12.50 in London, £10 elsewhere
- Lunch £12.50 in London, £10 elsewhere
- Evening meal £17.50 in London, £15.00 elsewhere

2. Additional out-of-pocket costs

2.1 Accompanying carers
If a user representative requires the support of a carer then carers costs will be covered in line with the above guidelines on travel, accommodation and meals.

2.2 Caring responsibilities
User representatives include carers of people affected by cancer whose ability to attend an event or meeting may depend on having someone to sit with or care for their relative.

If a user representative has adult caring responsibilities then reasonable carer's expenses will be reimbursed at the discretion of the manager concerned.

When it is a necessity for someone without a

normal childcare role or responsibility to mind a child/children reasonable expenses will be covered at the discretion of the manager concerned.

2.3 Accompanying companions/family members
Any accompanying companions/ family members are welcome to travel with user representatives as long as this does not incur any additional costs in line with the above guidelines. If costs are incurred these must be met by the user representative.

This excludes cases where the accompanying companion/ family member is the carer. User representatives should ensure they clarify the position with their Macmillan contact regarding any of these additional costs prior to any booking.

2.4 Administration expenses
Reasonable administration costs for activities undertaken will be reimbursed where there has been prior agreement for example to cover the costs of phone calls, printing cartridges, stationery and postage.

3. Reimbursement
Reimbursement will be made from the budget of the Macmillan team or department requesting the user's involvement. User representatives should be aware who their key Macmillan contact is and who can advise about what expenses and fees will be covered.

Reimbursement will only be made for expenses that have actually been incurred and agreed. Macmillan expense claim forms should be given to user representatives, full details of every claim and all original receipts must be submitted.

Reimbursement should be dealt with as a priority by Macmillan staff and will normally be made by cheque, though small amounts may be claimed through petty cash where this is available.

4. Recognition of time, energy and expertise for additional roles

The Community Networks team are sometimes asked to identify actively involved service users to attend high profile events to promote Macmillan campaigns e.g. the Cost of Cancer campaign at the House of Commons or the Get it Spent Where it's Meant campaign at Party Conferences, and to be available to talk to invited guests.

Many user representatives use annual leave from work to attend special events or if they are self-employed lose a day's earnings. From experience within the Community Networks teams, we know that where reimbursement has been offered to 'selected' individuals it has caused offence, and in general users prefer the principle of an agreed rate being offered to all (even though not all will claim).

If user representatives are asked to take on substantial additional roles over and above normal participation it should be clearly stated the type of input being requested and what additional payment may be offered. This will take into account preparation and follow up required in addition to attendance and role on the day, for example:

- £100 fee for a full day
- £50 fee for a half day

N.B. The Dept of Health pays users approx. £125 per day in similar circumstances. These rates can be used as a guide if substantial additional roles are identified. Where a payment is to be made, the user representative should include this on their claim form (see 5 Reimbursement).

5. Approaches from external organisations for user representatives

The organisation making the request should make it clear what involvement they are asking for and what expenses or payments are being offered.

If the organisation does not have its own policy it will be directed to Macmillan's policy but the organisation will be under no obligation to adhere to it or Macmillan obliged to cover expenses incurred. It will be the responsibility of the user representative concerned to accept or decline the offer to be involved.

6. The position of people dependent on benefits

People affected by cancer will often be dependent on welfare/state benefits of one kind or another. Macmillan contacts will need to make them aware that they need to make their own informed choice about whether or not to accept payments and giving their time to user involvement activities.

Users should be made aware that the Macmillan Money Advice Line offers a free confidential, impartial advice service which can deal with individual issues.

Appendix 3: Rethink's involvement of people who use services: Competence checklist (pilot version)

Element	Check	Achieved? Yes/No or N/A	Action required or comments
1. Information provision	1.1 Does the service provide information on how service users can become involved in planning, managing and maintaining services? 1.2 Is information up to date, relevant to service users and free of jargon? 1.3 Does the information provided have a strong service user input? 1.4 How does the service ensure that information reaches service users? 1.5 Are service users made aware of the complaints procedure when they join the service, and is it explained to them? 1.6 Can the service provide information in languages other than English if required, (through leaflets, tapes or translators)? 1.7 Can information be provided in other formats if needed – for example, Braille, signing for deaf people, computer disc?		
2. Consultation	2.1 Are people who use the service regularly consulted on: a) Quality and review of existing service? b) The planning and development of services? c) The physical environment in which the services are provided, and about any problems in using the service (to ensure they are as inclusive as possible). d) Policies within the service and codes of practice – including who is given information about themselves (consistent with Rethink policies)? 2.2 Does the project hold user consultation meetings? Are they held in a comfortable environment? Has it considered involving users in facilitating these? 2.3 Are transport, expenses, and refreshments considered to enable people to attend? 2.4 Are service users able to have their own meetings and is there a room to meet in?		

Element	Check	Achieved? Yes/No or N/A	Action required or comments
	2.5 a) Does the service make special efforts to ensure service users from all groups within the project are consulted (including ethnicity, gender, physical disability, sexuality) and that any special needs are considered? b) Are the quality and adequacy of the service considered in relation to the population groups and unmet needs within the community served? 2.6 Does the service have budgets to ensure that service users involved in consultation receive expenses and fees (where agreed and in line with Rethink policy) for their work? 2.7 Is feedback given on service user consultations, including on how they have influenced service development (or why they haven't)? 2.8 Are service users consulted about any training they need to become involved? 2.9 Are service users consulted about any training staff require in order to be able to consult effectively with users? 2.10 If questionnaires are used for consultation, is help available to complete them?		
3. Representation	3.1 Does the service ask for representatives from a) current users of service? b) ex service users? c) user groups? 3.2 Has a Service-User Forum been developed from which representatives can be elected (in the absence of 'c' above performing this role)? 3.3 Do user representatives have access to training in committee and representation skills? 3.4 Does the service ensure that user representatives can work with user representatives from other projects to provide mutual support?		

Element	Check	Achieved? Yes/No or N/A	Action required or comments
	3.5 Are user representatives provided with adequate administrative support, including access to means of communication, to enable them to provide an effective link between the service users they represent and the decision-making groups of which they are a member?		
	3.6 Does the service make a special effort to equally attract service users from ethnic minorities and from both genders?		
	3.7 Are service users involved and represented in: (a) Decision making committees (b) Staff recruitment panels (c) Project Advisory Groups and/or Contract Meetings (d) Planning of user-led services and self help groups (e) Quality monitoring groups (f) Formulating and delivering training		
	3.8 Does the service ensure users have access to independent advocacy?		
	3.9 Is there a structure whereby complaints which are upheld are acted upon within policy development?		
4. Participation	4.1 Does your service enable and support service users in routine tasks within the service, e.g. preparing meals?		
	4.2 Are service users provided with training and accreditation if they undertake these tasks?		
	4.3 Does the service facilitate the provision of leisure activities by service users?		
	4.4 Does your service take steps to prevent discrimination against service users and ex-service users who wish to work with your project or in mental health generally?		
	4.5 Does your service provide opportunities for supported voluntary work?		

Useful contacts

The Arthritis and Musculoskeletal Alliance (ARMA)
41 Eagle St, London WC1R 4TL
Contact: Sophie Edwards   Tel: 020 7841 5191
Email: arma@rheumatology.org.uk
Website: www.arma.uk.net

The Breakthrough Breast Cancer Campaigns and Advocacy Network
Third Floor, Weston House,246 High Holborn,
London WC1V 7EX
Contact: Joanna Nunney   Tel: 020 7025 2400
Email: joannan@breakthrough.org.uk
Website: www.breakthrough.org.uk

British Heart Foundation
14 Fitzhardinge Street, London, W1H 6DH
Contact: Ffion Heledd   Tel: 0207 487 7125
Email: heleddf@bhf.org.uk
Website: www.bhf.org.uk

The Developmental Neuro-Diversity Association (DANDA)
46 Westbere Road, London NW2 3RU
Contacts: Mary Colley, Adrian Whyatt
Tel: 020 7435 7891/5443
Email: mary@pmcolley.freeserve.co.uk
or adrian_whyatt_athome@yahoo.co.uk
Website: www.danda.org.uk

Diabetes UK
10 Parkway, London NW1 7AA Tel 020 7424 1000
Email user.involvement@diabetes.org.uk
Website: www.diabetes.org.uk

Epilepsy Action
New Anstey House, Gate Way Drive, Yeadon,
Leeds LS19 7XY Contact: Simon Wigglesworth
Telephone 0113 210 8800
Email swigglesworth@epilepsy.org.uk
Website: www.epilepsy.org.uk

Inspirability
Contacts: Cathy and Nic Holc-Thompson
Tel: 02392 353141
Email: postmaster@inspirability.co.uk
Website: www.inspirability.co.uk

INVOLVE
Wessex House, Upper Market Street, Eastleigh,
Hampshire SO50 9FD
Contacts: Roger Steel, Helen Hayes
Tel: 023 8065 1088 Email: admin@invo.org.uk
Website: www.invo.org.uk

Irritable Bowel Syndrome Network
Unit 5, SCEDU, 53 Mowbray Street,
Sheffield S3 8EN Contact: Penny Nunn
Tel: 0114 272 3253 Email
penny@ibsnetwork.org.uk
Website: www.ibsnetwork.org.uk

Macmillan Cancer Relief
89 Albert Embankment, London SE1 7UQ
Contact: Jane Bradburn
Tel: 020 7840 2013 Email:
jbradburn@macmillan.org.uk
Website: www.macmillan.org.uk

Multiple Sclerosis Society
372 Edgware Road, London NW2 6ND
Contact: Lee Dunster
Tel: 020 8438 0770 Email:
LDunster@mssociety.org.uk
Website: www.mssociety.org.uk

The National Association for Colitis and Crohn's Disease (NACC)
4 Beaumont House, St. Albans,
Herts AL1 5HH
Contact: Elaine Steven
Tel: 01727 830038
Email: elainesteven@nacc.org
Website: www.nacc.org.uk

National Society for Epilepsy
Chesham Lane, Chalfont St Peter, Bucks
SL9 0RJ Contact: Melanie Ekless
Tel: 01494 601 337
Email:
melanie.ekless@epilepsynse.org.uk
Website: www.epilepsynse.org.uk

People First
3rd Floor, 299 Kentish Town Road
London NW5 2TJ Tel: 020 7485 6660
Email: general@peoplefirstltd.com
Website: www.peoplefirstltd.com

The Princess Royal Trust for Carers
142 Minories, London EC3N 1LB
Contact: Peter Tihanyi Tel: 020 7480 7788
Email: info@carers.org
Website: www.carers.org

Rethink Severe Mental Illness
Contact: Janine Woods Tel: 0121 233 2083
Email: janine.woods@rethink.org.uk
Website: www.rethink.org

Useful reading list

We found the following publications to be very useful in developing the content of these resource documents.

Anderson W, Florin D, Gillam S and Mountford L. *Every Voice Counts: Involving patients and the public in primary care.* (2002) London: King's Fund.

Audit Commission. *Making Connections: Connecting with users and citizens.* (2002) London: Audit Commission.

Barker J, Bullen M, deVille J. *Reference Manual for Public Involvement.* (1999) London: Southbank University.

Buchanan S and Willis E. *Practice Guidance: Involving people in modern public services – why it matters.* (2002) London: Parkinson's Disease Society.

Carr, S. *Has service user participation made a difference to social care services?* (2004) London: SCIE.

Commission for Health Improvement. *Sharing the learning on patient and public involvement from CHI's work. Involvement to improvement.* (2004) London, CHI.

The Community Care Needs Assessment Project. *'Asking the Experts' - A guide to involving people in shaping health and social care services.* (2001) Brigg, North Lincolnshire: CCNAP.

Crawford M, Rutter D, Manley C *et al. Systematic review of involving patients in the planning and development of health care.* (2002) BMJ 325: 1263-1267.

Crawford M, Rutter D and Thelwall S. *User involvement in change management: A review of the literature.* (2004) London: National Co-ordinating Centre for NHS Service Delivery and Organisation.

Department of Health. *Strengthening Accountability. Involving patients and the public. Practice guidance.* (2003) London: DH.

Emmel, N. and Conn, C. *Towards community involvement: Strategies for health and social care providers. Guide 1: Identifying the goal and objectives of community involvement.* (2004) Leeds: Nuffield Institute for Health.

Emmel, N. *Towards community involvement: Strategies for health and social care providers. Guide 2: The complexity of communities and lessons for community involvement.* (2004) Leeds: Nuffield Institute for Health.

Fletcher G and Bradburn J. *Voices in Action Resource Book. Training and support for user representatives in the health service.* (2001) London: College of Health.

Fletcher G and Buggins E. *The Voices Project. Training and support for maternity service user representatives. Becoming an effective user representative.* (1997) London: National Childbirth Trust.

Hanley B, Bradburn J, Barnes M, Evans C, Goodare H, Kelson M *et al. Involving the public in NHS, public health and social care research. Briefing notes for researchers.* (2004) Eastleigh, Hampshire: INVOLVE.

Useful reading list

Keeley B and Clarke M. *Consultation with carers: Good practice guide.* (2003) London: The Princess Royal Trust for Carers.

Kirby P, Lanyon C, Cronin K and Sinclair R. *Building a culture of participation: Involving children and young people in policy, service planning, delivery and evaluation.* (2003) London: Department of Education and Skills.

Lockey R, Sitzia J, Gillingham T, Millyard J, Miller C, Ahmed S, Beales A, Bennett C, Parfoot S, Sigrist G and Sigrist J. *Training for service user involvement in health and social care research: a study of training provision and participants' experiences (The TRUE Project).* (2004) Worthing: Worthing & Southlands Hospitals NHS Trust.

Macmillan Cancer Relief. *User support and involvement guidelines. The full guide to involving people affected by cancer in all Macmillan's work.* (2004) London: Macmillan Cancer Relief.

Merseyside Health Action Zone. *A step-by-step guide to community involvement for organisations. How well are we doing?* (2001) Liverpool: Merseyside HAZ.

NHS Wales. *Signposts: A practical guide to patient and public involvement in Wales.* (2001). London: Office for Public Management, Cardiff: National Assembly for Wales.

NHS Wales. *Signposts Two: Putting public and patient involvement into practice.* (2003) London: Office for Public Management, Cardiff: National Assembly for Wales.

Robson P, Begum N and Locke M. *Developing user involvement: Working towards user-centred practice in voluntary organisations.* (2003) York: The Policy Press in association with the Joseph Rowntree Foundation.

Steel, R. *A guide to paying members of the public who are actively involved in research.* (2003) Eastleigh, Hampshire: INVOLVE.

Taylor M. *Preparing for the Future. Involving users in the running of voluntary organisations.* (1999) Harrow, Middlesex: The Association of Chief Executives of National Voluntary Organisations.

Terrence Higgins Trust. *Practice guidance on involving people with HIV and other long term conditions in planning and developing services.* (2002) London: Terrence Higgins Trust.

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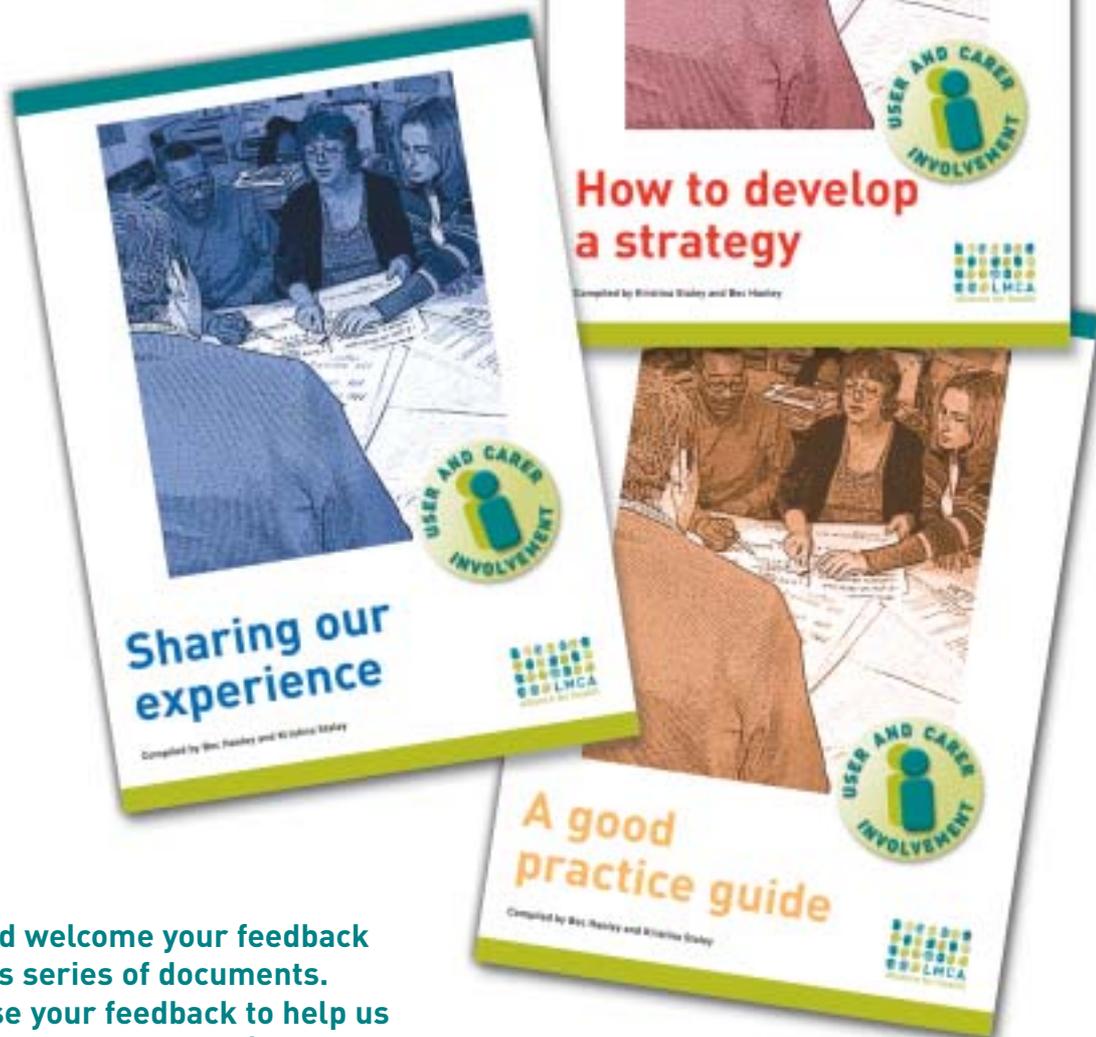**Catherine Wilson**, National Society for Epilepsy

A good practice guide

This is one of a series of three resource documents that aims to help voluntary health organisations involve service users and carers in their work. The other two documents in the series are:
- How to develop a strategy
- Sharing our experience

All three publications are available from the LMCA and can be downloaded free of charge from our website www.lmca.org.uk

How to develop a strategy

Compiled by Kristina Staley and Bec Hanley

Sharing our experience

Compiled by Bec Hanley and Kristina Staley

A good practice guide

Compiled by Bec Hanley and Kristina Staley

We would welcome your feedback on this series of documents. We will use your feedback to help us update the documents and/or decide on topics for future publications. Please contact the LMCA or visit our website at www.lmca.org.uk