



# How to develop a strategy

Compiled by Kristina Staley and Bec Hanley



# 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](http://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](http://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. Regrettably 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](http://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 2012 (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](http://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 the resource document *User and Carer Involvement: A Good Practice Guide*.



# 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

# 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.

This document aims to provide your organisation with practical advice on how to develop a strategic approach to 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 how they have developed their involvement strategy
- 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 involved in this project, contact details can be found on page 27. Further information can also be found in the Useful Reading List on page 28.

## 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 developing a strategy, and suggests a wide range of issues you may want to think about. You may choose to prioritise one particular topic 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.

# Why is developing a strategy important?

Developing a strategic approach to user and carer involvement is vital to its success. Organisations that develop strategies are able to link user and carer involvement to existing priorities and ways of working. This is essential to managing change. It requires commitment from the top and a whole organisation perspective. A lack of a strategic approach is a major barrier to effective involvement.

## What do other LMCA members do?

**The British Heart Foundation** took a strategic approach to achieving their aim of involving service users in all their work at every level. They reviewed existing involvement, looked at how they would develop the infrastructure for involvement and thought about what training and support they would need to provide.

**Macmillan Cancer Relief** developed a five year plan in 2001 which stated that one of its major corporate aims was to 'promote and embed user-involvement within Macmillan and with our partner organisations and to support post-holders to work in partnership with people affected by cancer'. They also produced a user involvement strategy (see Appendix 1), an implementation plan and guidelines aimed at staff on involving users and carers (see Useful Reading List). Since then they have been taking further steps to become an increasingly user-centred organisation.



# How will a strategy help?

A strategy will help you to be clear about:

- **why** you want to involve service users and/or carers
- **who** to ask to get involved
- **where** and **when** to involve them
- **how** best to do it
- **what** you hope to achieve.

It will provide a clear sense of purpose and direction.

Even if you are already involving service users and carers, a strategy will help you bring this work together and identify how to move it forward across the whole organisation.

The process of developing a strategy will help you generate a shared vision of what you want to achieve, with the input, backing and support from people inside and outside your organisation.

Once you have developed a coherent strategic approach you will be better able to:

- identify what user and carer involvement means to different people at the various levels and in different parts of your organisation
- identify where user and carer involvement can be integrated into your organisation's core activities to influence the mainstream agenda
- identify where user and carer involvement could have the most impact and lead to change, as well as how to make this happen
- identify who will be responsible for taking user and carer involvement forward, with clear roles and lines of accountability for all involved
- allocate resources to this work
- identify what training, information and/or support will be needed by staff, trustees and volunteers to effectively involve service users and carers
- identify what training, information and/or support will be needed by service users and carers to help get them involved

“If your organisation is truly involving then your user involvement strategy and your organisational strategy will be very much the same”  
Jane Bradburn, Macmillan Cancer Relief



# Who can help you develop your strategy?

## Learning from others

Before getting started it is worthwhile talking to another organisation like yours to see if they have developed a strategy. See the list of useful contacts in Appendix 4. You might also find other contacts on the LMCA website ([www.lmca.org.uk](http://www.lmca.org.uk)).

## Engaging all stakeholders

You should try to be inclusive when developing your strategy to create a sense of ownership for all involved. This means engaging with stakeholders (the people who have an interest in the success of your organisation) right from the beginning – giving them opportunities to shape the agenda early on and to agree how best to proceed. Bringing people together will enable them to share their values and interests, reflect on current practice and negotiate common goals. This will help to build better relationships and create the right conditions for an ongoing exchange of ideas.

There are many ways you can do this. For example, establish a small think-tank with a range of stakeholders or run a series of workshops for more extensive consultation. Try to ensure you obtain a diversity of views and seek input from:

- Staff from different levels and departments in your organisation
- Trustees
- Volunteers
- Activists
- Service users
- Carers
- Professionals
- People who may be marginalised

## An ongoing process

Discussing your goals shouldn't just be a starting-point but more of an ongoing process of reflecting on what you do.

Genuine involvement will require a process of negotiation from the outset. You will need to respond to the input from service users as you go along – so you may not always be able to predict exactly where you'll end up (see the report by Anderson, Florin, Gillam and Mountford in the Useful Reading List). In some cases, it may not be possible to get everyone to sit down and agree a set of aims. But setting goals will still be important. It will show commitment at the outset and will help you assess what impact user and carer involvement is having.

Your strategy will need to be flexible enough to value all outcomes. It may be best to think of it as a 'living document' so that its objectives and priorities are worked on and monitored continuously, revisited often and updated when necessary.

### What do other LMCA members do?

**Macmillan Cancer Relief has recently reviewed its approach to user and carer involvement. They are now calling it 'user support and involvement' as this seems to reflect more accurately what the organisation does – it encompasses the work around supporting self-help groups and more importantly, recognises that if service users and carers are going to get involved, Macmillan will need to give them support. They have decided that it's important to separate their self-help groups from their user involvement groups – so that the self-help groups don't get swamped with requests for involvement.**

# What should your strategy aim to cover?

There is no simple formula or off-the-shelf package to help organisations develop a strategy for user and carer involvement. What needs to be done depends on the organisation – the services it offers, its history and size, and the models for involvement that already exist. However, there are valuable lessons from the extensive user and carer involvement work that’s been done to date (see the Useful Reading List). Thinking through the following issues will help you to develop a strategic approach that’s tailored to meet your organisation’s needs:

## What’s your vision?

Developing a shared vision will help you to be clear about your organisation’s goals for user and carer involvement and how they relate to your overall mission. Publishing a set of core values and beliefs will demonstrate your commitment to this work.

## Why do you want to 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 right.

Being clear about why you want to involve service users and carers is essential to planning the work and answering all the other questions about how, when and where to get users and carers involved. It will also help you plan what to do with the results. Many initiatives fail because there is nowhere for the findings to go. If you decide what or who you need to influence from the start, you can take the right steps to ensure change really happens.

## What have other LMCA members done?

Macmillan Cancer Relief has developed a set of principles for service user support and involvement (some of which have been taken from the National Cancer Task Force Paper *User Involvement in cancer services* April 2001). Macmillan’s principles state:

**We will work in partnership with people affected by cancer to ensure that:**

- We involve a diverse range of people with direct experience of cancer.
- The views reflected come from a wide constituency of people.
- Our structures and processes are open, accessible and diverse.
- The partnership is sustainable and meaningful – not tokenistic.
- Their views are independent and their groups are autonomous.
- By supporting user groups and other community initiatives, we demonstrate our commitment to sharing experiences.
- Their involvement is championed at a senior level.
- They are involved at all levels – so their priorities guide our priorities.
- We support and equip them to be effective influencers.
- Their involvement is adequately resourced and supported.

### 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 involved 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.

### What have you done already?

Carrying out a mapping exercise to assess the user and carer involvement initiatives already in place will help your organisation to identify:

- where user and carer involvement is working well – from the perspectives of service users, carers and staff
- what has made it work in the past
- which factors may act as a barrier in the future
- gaps and weaknesses in your current performance
- what people inside and outside your organisation want and expect from user and carer involvement
- links between user and carer involvement and your wider organisational goals

This will help you to be clear about:

- the gap between where you are now and where you want to get to

“You have to be clear about why you’re involving users and carers. There is no point in setting up forums and networks if there isn’t a mechanism for them to have some effect on what the charity does. We’re planning that our new networks will have close links with governance”

Mary Taylor, Trustee, Rethink

## How to develop a strategy

- the obstacles to be overcome
- priorities for action in terms of strengthening or extending existing work and identifying areas for future development

You may want to commission an independent researcher/consultant to carry out this exercise and ask service users and carers to evaluate existing practice. This is important to challenge your organisation's view of how well it is doing.

### What do other LMCA members do?

**About three years ago the trustees at Rethink agreed that the organisation needed to involve more service users. They therefore appointed a user involvement worker who was herself a service user. She scoped what was happening with user and carer involvement across the organisation, and made a series of recommendations about how service users could be further involved. There were 26 recommendations. For example, one of the recommendations was that the staff induction training on user and carer involvement and mental health awareness should be led by service users and carers. The report went to the board of trustees. People across the organisation are now working to put these recommendations into practice. It's not just seen as the responsibility of the user involvement workers, but the responsibility of all staff.**

### Where else can service users and carers get involved?

There are many different ways for service users and carers to get involved in the work that you do, in every department and at every level. Engaging service users and carers throughout your organisation can ensure that user and carer involvement becomes 'the way you do things' rather than an optional add-on. Involvement in different areas opens up new opportunities for joined-up working and ensures support for service users and carers throughout the organisation.

To ensure user and carer involvement has a real impact, you should look to involve service users and carers in the organisational structures where the real power lies. This will mean inviting users and carers to join key groups/committees and ensuring that any service user or carer groups are more than 'advisory' by being given some authority – and if appropriate resources.

In thinking this through it's essential that you ask service users and carers where they would like to be involved and seek their views on practical ways to make it happen. You could also visit other organisations to see examples of effective user and carer involvement in action. Think about how you can work towards diverse, flexible and continuous strategies to involve people.

### Is your organisation ready to involve services users and carers?

Involving service users and carers will and should change your organisation. Taking account of your organisational history can help stakeholders to see this as an opportunity rather than a threat. The history of an organisation explains why it is there and why it has certain attitudes and beliefs. Looking at the historical context can show how these have shifted over time. This can help people to see how new changes are simply part of the organisation's evolution, that organisations are always learning and that nothing is entirely "fixed".

### What do other LMCA members do?

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

- Writing or reviewing drafts of information for service users and carers
- Producing newsletters or setting up websites, and contributing to these
- Planning new services
- Providing services such as helplines
- Running self help or support groups
- Sharing their experience as a service user or carer with the press or with staff
- Being involved in governance – as a trustee at national level, or on committees/groups at national, regional or local levels
- Speaking on behalf of the organisation – through presentations or talks
- Training staff
- Training other service users or carers
- Evaluating or monitoring services

Your organisation's structure and culture may need to change so that it can respond to the views of service users and carers and adapt to new ways of working. If it isn't right, people will get frustrated. Think about putting new policies and procedures in place to create a supportive environment and minimise resistance.

### What has happened in other LMCA organisations?

**At the British Heart Foundation, senior level support proved crucial to taking the patient involvement work forward. A new head of cardiac care department came with a real interest in user and carer involvement and was key to getting things going. The medical director was also very pro and was a valuable ambassador promoting the work.**

“Be aware of tokenism. Your volunteers will become disillusioned if they feel they are not being taken seriously. There's absolutely no point in involving people if you don't believe in it...Keep why you are doing it in the forefront of your mind”

Mary Taylor, Trustee, Rethink

### Do you have senior level commitment? Do you have the support of other staff?

Senior level commitment is essential to:

- provide leadership
- demonstrate the importance the organisation places on user and carer involvement
- make things happen in response to user and carer involvement.

It's important to have senior level commitment before you start, because if people at the top have doubts, they will feed into the doubts of people further down. You will also need a few individual enthusiasts to get things going. But getting commitment across the organisation may take longer. It will only develop as people get exposed to the impact and benefits of user and carer involvement.

“Having commitment from the top has definitely made a difference. I feel I have permission to do it and to shout about it.”

Ffion Heledd, Patient Network Manager, British Heart Foundation

## How to develop a strategy

### How will you get people to think differently?

Some Trustees, staff or volunteers may be resistant to getting service users and carers involved. You will need to think about how you will overcome this (see the report by Taylor in the Useful Reading List). The best way might be just to take it gradually and to show that involvement works. But it might also help to think about:

- creating an involvement culture within the organisation – consulting and involving staff in the development of a user and carer involvement strategy
- supporting and confronting the fears of staff – emphasising that working in partnership with service users and carers has to provide benefits to everyone
- raising awareness and showing how the changes that will ensure effective user and carer involvement will have wider benefits

e.g. making papers and meetings clear and accessible helps everyone, not just service users and carers

- recognising and valuing good practice across the organisation
- bringing service users and carers into the organisation to meet staff and get involved in things – this will help cut through people's pre-conceptions
- using external levers for change e.g. the requirements of funders
- creating champions for this work – service users, carers and members of staff

Successful change in attitudes and behaviour will only come about if the staff have some way of reflecting on their experience of user and carer involvement and learning and developing. You could think about ways to support this process e.g. setting up a learning set.

### What have other LMCA members done?

**Macmillan Cancer Relief** has set up a 'Shared Learning Group' for staff from across the organisation plus two service users. The Group meets every month for two hours and has an open agenda. The meetings are open to anyone who involves service users and carers in their work, or is planning to do so. They were careful about which service users to involve – user involvement staff selected people who were interested in learning and had a partnership approach – in order to support the staff who were feeling unsure at the beginning. This Group generated the guidelines on user involvement for staff (see the Useful Reading List), and is currently developing a welcome pack for service users and carers who get involved with Macmillan.

Having a group like this means that user and carer involvement is based on the lessons learnt through practice. It also means that any policies and plans are better suited to the needs of front-line staff – rather than being handed down from the top.

**The Princess Royal Trust for Carers** has found that it's not so difficult to help other organisations understand why they should involve carers, but often there are concerns about how to do it. It seems that people don't argue against the principle of involvement, but because they think it's difficult to do, they find reasons not to do it. To overcome this problem, the Trust has developed a set of good practice guidelines on carer involvement, which they make freely available to all the organisations they work with. (See the Useful Reading List).

The **Multiple Sclerosis Society** set up a network of people affected by MS to get involved in various aspects of its research programme. Some of the Trustees got involved in the earliest activities and soon became strong supporters. These people were able to champion the work with the Board, raising awareness of its impact and benefits at a very senior level.

### What training and support will you give staff?

Your organisation's capacity to support user and carer involvement is the engine driving this work forward. Building your capacity will not only ensure that any structures and systems work properly, but also that user and carer involvement is taken seriously and can lead to change.

Think about equipping staff with the mindset to believe in and practise effective user and carer involvement as well as giving them the skills and competencies. It will help if you:

- raise awareness of the benefits of user and carer involvement to get 'buy in' and ensure all staff understand 'why we are doing this'
- provide service user-led awareness training to improve relationships between staff and service users/carers
- assess what skills staff already have to do this work and build on people's strengths
- develop clear roles and responsibilities for staff so that everyone knows who needs to do what
- ask staff what additional training and support they might need

Working with service users and carers can also affect staff at a personal level. It will be important to find ways for staff to support each other, so that they can continue to provide support for service users and carers and cope better with their own emotional experiences.

### What have other LMCA members done?

**Macmillan's Shared Learning Group (see page 14) provides staff with an opportunity to discuss their experiences of working with people affected by cancer and to offer peer-support. Some of the staff work with people who are very ill. So they may well experience some pain or loss in their relationships with service users and carers. The work can also bring up personal issues for staff, reminding them of their friends' or families' experiences of cancer.**

### Who will you involve?

Voluntary health organisations have different kinds of users: parents and children, people with a condition, carers, volunteers and professionals. The users of umbrella organisations are other organisations. The contribution of each of these different users is important in its own right (see the report by Taylor in the Useful Reading List). Service users are often also members of the organisation and have a right to a say on both counts. In thinking through who to involve it's important to think about who are your current and potential users.



“Who are the experts? Users and carers through their experience have expertise that staff often don't have and we employ staff who have other expertise that we need. It's a partnership that can be really dynamic...”

Mary Taylor, Trustee, Rethink

The first step in deciding who to involve is to think about what range of experiences, perspectives and expertise you will need from people to help you develop a brief person specification. Then think about how to:

- get beyond your most active and articulate service users
- include people who may be marginalised – for example children, people from black and ethnic minority communities and people with dementia or learning disabilities
- include a diverse set of people with a variety of perspectives
- recognise the needs of different service users and carers and ensure empowering one group does not disadvantage another

“User and carer involvement is about partnership, about building relationships. It's really about working with people – that's the most important thing”

Jane Bradburn, Macmillan Cancer Relief

### What training and support will you offer service users and carers?

User and carer involvement is about forming new relationships. You will therefore need to think about activities that help build these relationships and establish a foundation of mutual respect.

The best way to decide what to offer is to find out from service users and carers what they think they need. It may also be helpful to draw up an explicit contract as to what service users and carers can expect from the organisation e.g. to be listened to, supported, have their expenses paid and what you will expect from their involvement.

### What resources have you got?

You will need to think through how much time and money this work will need and how this compares to the resources available. In thinking this through it's important to:

- build in time for developing partnerships right from the beginning
- be realistic about the length of time it will take for attitudes to change; for skills, knowledge and trust to develop and for the necessary infrastructure to be put in place
- budget for service users' and carers' expenses, running meetings and possibly paying people for their time (See the companion document *User and Carer Involvement: A Good Practice Guide for a policy on reimbursing expenses and paying people*)
- consider whether you have the resources to do the work yourself or if you will need to commission others. You may need to budget for independent facilitators or consultants.

If resources are limited, it's best to do something well on a small scale than to be over-ambitious and fail.

### Are you prepared for conflict?

If your organisation is going to genuinely involve service users and carers, it's inevitable that power relationships will change. You will need to think of ways to

### What have other LMCA members done?

When **The British Heart Foundation** first set up their training for service users, they modelled their programme on Macmillan's **CancerVOICES**. They first held 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 and will become a regular feature of their national patient conference. The aims and objectives of the **Hearty Voices** training are summarised in **Appendix 2**.

When the **Multiple Sclerosis Society** set up its **Research Network**, it held a series of workshops across the country for all new members. This allowed service users and carers to help shape the vision of what the **Network** would achieve, to develop a mission statement for the **Network** and to identify what training and support **Network** members would need. Members said they would like training to prepare them for getting involved in specific activities e.g. people who wanted to take part in reviewing grant proposals wanted training in evaluating research. They also said how they would prefer to receive this training. For example, some people who find travelling difficult said they would prefer distance learning.

prevent or creatively manage the conflict that may well result.

There are likely to be tensions between staff and service users or carers. Staff can sometimes see user and carer involvement as a threat. Service users and carers can become frustrated if they don't see changes being made or they don't get feedback about why things aren't being done. It's not genuine involvement if service users and carers are asked just to rubber stamp proposals put forward by staff, and they will feel their time is being wasted.

It may help to think through the consequences of involving service users and carers and where you want to end up. Does your organisation want to become 'user-led' or 'user-sensitive'? (see the report by Taylor in the Useful Reading List). There is no simple answer. What works for one organisation may not work for another. Be aware of the different options, challenge approaches that have been taken in the past, and find the right balance that will work best for you now.

### Are you prepared to take risks?

Be prepared to make mistakes. Find ways of working alongside service users and carers to develop new ways of working. If you're honest that you're learning as you go along, people are more likely to be supportive. It's important to evaluate your work at every stage. Involve service users and carers in this and allow time to reflect on the lessons that you've 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. When 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. You may have to think about giving alternative status (associate membership) to those groups who decide to go a different way.

## How to develop a strategy

### How will you know if it's been a success?

You will need to think about how you are going to evaluate your work right from the beginning. Keep it simple. If you get a clear idea from stakeholders about what you want to achieve, that will help you think how to evaluate it. There are guides that can help you do this (See the report by Barker in the Useful Reading List).

It's important to involve stakeholders in planning and carrying out the evaluation. They can help both to define the measures of success as well as how to measure them. There may be many different ways of defining a successful outcome and therefore there may be many different things you need to measure (see Box below). It is can be helpful to evaluate processes as well as outcomes, but it is most important to assess whether your activity is bringing about significant change.

### How will service users and carers know they have made a difference?

It's important to think about how you'll give feedback to the people who have been involved. They will be very keen to know how and where their input has made a difference. This also helps to build confidence and trust and will help you maintain strong relationships with service users and carers.

“If we're going to be a viable group, we need feedback from various parts of the organisation about what they do in response to our input. My impression is at a management level they are listening”

Mel Clark, Member of the Patient Advisory Group, British Heart Foundation

### What counts as success following an event with user and carer involvement?

- Lots of people turning up
- Attendance by key decision-makers from your organisation
- Critical discussion between service users, carers and staff during the meeting
- Completion of a detailed report
- Trustees reading the report
- Trustees discussing and approving the report
- Changes to organisational policy
- Changes to the way the organisation works
- Improvements in services for users and carers
- Improvements in people's health and quality of life

(see the report by Anderson, Florin, Gillam and Mountford in the Useful Reading List).

### How will you let other people know about your success?

You will need to think about how you communicate your strategy to other stakeholders and let them know about your success. This is important to maintain an involving culture, raise awareness of the benefits of user and carer involvement and to help change 'hearts and minds'.

# What makes a good strategy?

A good user and carer involvement strategy will:

- have been developed in partnership with stakeholders and will be widely endorsed and supported
- have tangible and meaningful goals for 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, trustees and volunteers that meets their expressed needs, as well as providing a mechanism to share learning across the organisation
- build in support and training for service users 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
- build in time for reflection to learn the lessons from past experience that can inform future developments
- include quick wins and long-term goals
- be seen as a work in progress, needing regular review and updating.

You may find it helpful to review the checklist of 'Questions your strategy will need to address' in Appendix 3, to see if you have tackled all the important issues.

# Putting your strategy into action

Your strategy will need an implementation plan that describes exactly how you propose to take the work forward. When drawing this up you may find it helpful to think about the following:

## Where to start

Identify where there could be 'quick wins' – small pieces of work that result in small, but effective changes. This will demonstrate your commitment to action and build up people's confidence to take the work further.

## Timing

Plan your initiatives carefully so that you obtain the views of service users and carers in time for them to influence key decisions.

## Choosing a method that's fit for purpose

Be flexible and creative in choosing the method that best fits with the nature of your work. There are guidelines that can help you (see the Useful Reading List).

## Setting realistic goals

Be very clear about what is feasible with the people you involve. Be honest and realistic about what you can and can't change as a result of their involvement.

## Learning from your mistakes

Be prepared to be challenged, to make mistakes and learn from them. Build in mechanisms to get feedback on your work and to ask service users and carers what it was like to be involved. Find a way to involve service users, carers and staff in trouble-shooting.

## Planning for the long-term

Think about how to develop and maintain a system of involvement that is ongoing. This will ensure user and carer involvement can be part of every new area of work, right from the planning stage.

## Revising the strategy

Build in plans to regularly review your progress, reconsider your aims and revise your strategy when you need to.

You may also find it helpful to read one of the other documents in this series: *User and Carer Involvement: A Good Practice Guide*.



# Appendices

## 1. Extract from Macmillan Cancer Relief's User Involvement Strategy User Involvement Programme Strategic Framework: 2003-2010

### 1. Why do we need a user involvement strategy?

Through its merger with Cancerlink in 2001, Macmillan has acquired complementary activities based around a core ethos of valuing the experience of people affected by cancer. These activities include support for a UK wide network of self-help and support groups and CancerVOICES, a network of user representatives. The CancerVOICES project has played a strategic role in developing effective user involvement in NHS services. Links with the network of over 600 cancer self help and support groups and national patient organisations have been crucial to the development of a robust and sustainable network of user representatives.

Macmillan now needs an integrated User Involvement Strategy to build on existing good practice in this area and develop a coherent approach across the whole organisation.

### 2. What is included in Macmillan's user involvement strategy?

Macmillan's User Involvement Strategy will build on existing good practice developed within the organisation and upon the user involvement initiatives already successfully developed by the Community Networks team. It will include:

- *A strategic approach to user involvement in Macmillan.* User involvement in Macmillan will be developed throughout the organisation at all levels and functions. This will be achieved by:
- Identification and appropriate changes in organisational structure, attitudes, and culture; inform strategic policy direction, research and campaigning; influence resource allocation
- Provision of appropriate support, training and guidance for staff and postholders, to champion user involvement where appropriate
- To offer a phased approach, adopting co-operative inquiry, beginning with a scoping study to ascertain existing initiatives and examples of good practice in the regions, nations and UKO. From this we will develop and agree a strategic framework to implement across the organisation
- *Strengthening grass roots user involvement activity* The Community Networks team plans to regionalise its activities, bringing together its work with self help & support groups and user groups, thus strengthening their input at local level. This approach will provide additional capacity to continue developing support programmes for self-help and support groups as well as further developing CancerVOICES as a diverse network.

- *Broadening the diversity of user involvement* In order to extend the diversity of people involved, advocacy programmes for individuals and 'hard to reach' groups will be developed and stronger links made with other cancer patient and carer organisations particularly for people with rarer cancer types
- *Developing a user involvement evidence base* User views need to be grounded in a robust evidence base. We will enhance the user involvement evidence base within Macmillan, working with the central research function that is to be established in Corporate Planning and Review
- *User involvement in the NHS* Building on this foundation, user involvement in cancer services will continue to be developed through CancerVOICES and the Cancer Partnership Project – a Department of Health/ Macmillan Cancer Relief joint programme to support user involvement in NHS cancer networks in England. Additionally we will also develop other NHS initiatives, including those in Scotland, Wales and N. Ireland.

### 3.0 Implementation

An implementation plan will be produced following agreement of the strategy:

- Lead responsibility for the policy and strategy development will rest with the Head of Community Links and the User Involvement Advisor in collaboration with CancerVOICES and all UKO, regional and national service teams
- Implementation of the strategy will be the responsibility of the User Involvement Advisor and Community Networks Programmes Manager together with senior managers
- Success measures will be established with Macmillan staff and users, against which the implementation of the strategy can be assessed

User Involvement Programme will have implications for all other programmes:

- Planning user involvement will be an expectation across all programmes
- Existing examples of user involvement in other programmes will inform the scoping study and lead to the development of a coherent approach to user involvement throughout Macmillan.

## 2. British Heart Foundation: Lay Representative Training ('Hearty Voices') – Review of Proposals and Update on Development

### Aims of project as originally stated:

1. To set up a network of lay representatives for Coronary Heart Disease and provide adequate training and support for those people, ensuring that they are well informed, confident and effective in their role
2. To establish patient involvement in the work of the BHF at all levels

Objective	Status
1. Training to be developed with the College of Health. Adapted from the 'Voices in Action' resource book. Must be relevant to heart patients/carers.	<ul style="list-style-type: none"> <li>• Training developed during summer 2002. Condensed version of the Voices in Action 2-day training course. Contains information specifically relevant to those affected by heart disease as well as more general topics and skills.</li> </ul>
2. Map interest within Heart Support Groups	<ul style="list-style-type: none"> <li>• Initial letter sent September 2002. Resulted in over 100 names on the register. Response from a wide geographical area (in England and Wales only). Numbers steadily increased to 180 (March 2003).</li> </ul>
3. Keep interested people up to date with a regular newsletter	<ul style="list-style-type: none"> <li>• First newsletter June 2002</li> <li>• Bi-monthly thereafter</li> <li>• Received positive feedback from both patients and health professionals</li> <li>• Newsletter to be developed (produced by external printers) from January 05</li> <li>• Public Affairs to have regular column</li> </ul>
4. Run three pilot training days (location depending on interest but to cover a wide geographical area)	<ul style="list-style-type: none"> <li>• Three days held in Autumn 2002</li> <li>• Locations were Cheadle (Manchester), Cardiff and London</li> <li>• High response rate</li> <li>• Positive feedback</li> <li>• On the day evaluation forms completed. Positive response overall</li> <li>• Continuous quantitative evaluation of database data on a monthly basis using structured monitoring forms</li> <li>• Exploratory qualitative research on impact and further training needs completed Autumn 2003</li> <li>• Survey of all database participants to ascertain level of involvement/long term impact of training</li> </ul>

Objective	Status
6. Offer training on a wider scale to Heart Support Groups	<ul style="list-style-type: none"> <li>• Continue to offer basic training courses – deliver at least 6 in 2004</li> </ul>
7. Expand training to include ‘training the trainer’	<ul style="list-style-type: none"> <li>• Patient Network Co-ordinators and Cardiac Services Manager to attend ‘training the trainer’ day – April 2003</li> <li>• Pilot training the trainer course for lay people – Spring 2005 (with lead up campaign)</li> </ul>
8. Launch the project on a wider scale to anyone affected by Heart Disease	<ul style="list-style-type: none"> <li>• National launch completed in May 2003</li> <li>• Publicise project to health professionals and patients/carers in all areas</li> <li>• Continue to promote in Scotland</li> <li>• Expand training opportunities and resources – re-write the training manual by April 2004</li> <li>• Develop additional resources for training, such as information cards, jargon busters and NHS ‘jigsaw’</li> </ul>
9. Establish focus groups for use across the BHF	<ul style="list-style-type: none"> <li>• Project participants have taken part in focus groups for BHF (e.g. patient newsletter review with external researcher) and communications work (e.g. women and heart disease campaign)</li> </ul>
10. Establish Patient Advisory Group for BHF	<ul style="list-style-type: none"> <li>• Recruitment took place March-May 2003</li> <li>• First meeting end July 2003</li> <li>• Further meetings twice a year (Autumn and Spring)</li> <li>• Need to target marginalised groups and continue to develop the group</li> </ul>
11. Develop resources to support lay reps and develop more options for training	<ul style="list-style-type: none"> <li>• Use evaluation data and collaborate with Cancer Voices, Diabetes UK and other agencies to produce relevant resources and look into training needs (adapting current training and developing others as necessary and as resources allow)</li> <li>• Participants are currently given a contact list of all those attending their session. Consider developing other networking opportunities</li> <li>• Ensure newsletter and training booking forms are available on the website</li> <li>• Consider establishing key lay ‘regional contacts’ for virtual network</li> </ul>
12. College of Health input to be phased out so that BHF runs project on its own	<ul style="list-style-type: none"> <li>• Autumn 2003 – Spring 2004 -joint delivery of training with Gillian Fletcher</li> <li>• Autumn 2004 – BHF staff delivering training</li> </ul>

Objective	Status
<p>13. Create an efficient and successful mechanism for other organisations to access patient/carer views conveniently, quickly and usefully</p>	<ul style="list-style-type: none"> <li>• Several successful recruitment drives from a wide range of organisations, for example; CHI, King’s Fund, BBC, British Cardiac Society</li> <li>• Publicising the project to other organizations who would benefit, particularly CHD Collaboratives and PCTs in conjunction with communications division</li> <li>• Survey organisations who have requested patient reps to assess level of response/ suitability and helpfulness of HV service</li> </ul>
<p>14. Reach a wide range of people</p>	<ul style="list-style-type: none"> <li>• Currently mainly reaching ‘typical’ heart support group members</li> <li>• Positive number of women attending</li> <li>• Target areas for future development: ethnic minority communities, young people, parents of children with heart disease</li> <li>• Need to develop resources which help those who attend training to learn how to access these communities if they are gathering views</li> </ul>
<p>15. Recognise the potential of the website for networking</p>	<ul style="list-style-type: none"> <li>• Patient section of BHF website developed April/May 2003</li> <li>• Launch put on main page of BHF website in May 2003</li> <li>• Section for Hearty Voices on website and shortcut to publicise in newsletter and on leaflets/posters etc</li> <li>• E-mail used on occasion to tell people about an opportunity to get involved at short notice</li> <li>• Look into possibility of distributing e-mail addresses to start networking facility</li> </ul>
<p>16. Travel expenses to be reimbursed</p>	<ul style="list-style-type: none"> <li>• All travel expenses reimbursed</li> </ul>
<p>17. Training to be delivered by a trained facilitator with experience as a lay rep or together with a lay rep</p>	<ul style="list-style-type: none"> <li>• Need to monitor potential lay reps willing to help out and pilot training the trainer course. Spring 2005</li> </ul>
<p>18. Training to be provided locally</p>	<ul style="list-style-type: none"> <li>• Training provided locally whenever possible</li> <li>• Deliver first course in Scotland in Autumn 2004</li> <li>• Begin to make links in Northern Ireland ready for launch in 2005</li> <li>• Research potential for telephone training and other methods of reaching more people</li> </ul>

### 3. Questions to think about when developing your strategy

**The list of questions below aims to be a useful reminder of the wide range of issues to think about in developing a strategic approach to user and carer involvement. You don't need to tackle them all at once. You may choose to prioritise one area for action – based on where you are now and where you can reasonably get to.**

- Why do we want to involve service users and carers?
- Do we know what other organisations like ours are doing?
- What are we going to do with service users' and carers' views once we have them?
- Who within the organisation needs to take account of these views?
- Who is committed to this work and who is not?
- Have we got the commitment of those who are able to make change?
- What scope is there to make changes or influence decisions?
- Are we prepared to take action as a result of what we learn?
- Who will have the final say over decisions?
- Are we clear about what kind of organisation we want to be?
- Are we prepared for consequences of changing the balance of power between staff and service users/carers?
- Is our organisation run in a way to ensure that all service users and carers are treated with respect?
- Do we know where service users and carers are already involved in our organisation?
- Are our staff committed and equipped with the skills needed to make user involvement work?
- What training/support do we give to staff, trustees and volunteers to ensure user and carer involvement works well? Has this been influenced by service users and carers?
- Is user and carer involvement included in induction training for all new staff?
- What resources in terms of time and money are we prepared to devote to this work?
- Is the timing right?
- Are we clear who our users are?
- Who do we need to involve?
- Are we involving people who might be marginalised?
- Have we asked service users and carers how they want to be involved?
- What support will we give to service users and carers to ensure they can get involved?
- How will we ensure all stakeholders are aware of our user and carer involvement strategy?
- How will we know if we've been successful?
- How will service users and carers know where their involvement has made a difference?

# 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  
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Website: www.breakthrough.org.uk

## **British Heart Foundation**

14 Fitzhardinge Street, London, W1H 6DH  
Contact: Ffion Heledd Tel: 0207 487 7125  
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## **The Developmental Neuro-Diversity Association (DANDA)**

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Tel: 020 7435 7891/5443  
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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  
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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  
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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  
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Website: www.nacc.org.uk

## **National Society for Epilepsy**

Chesham Lane, Chalfont St Peter, Bucks SL9 0RJ Contact: Melanie Ekless  
Tel: 01494 601 337  
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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 Minorities, London EC3N 1LB  
Contact: Peter Tihanyi Tel: 020 7480 7788  
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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.**

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**Ffion Heledd**, British Heart Foundation  
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**Penny Nunn**, IBS Network  
**David Streets**, Epilepsy Action  
**Mary Taylor**, Rethink  
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# How to develop a strategy



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:

- The Good Practice Guide
- 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](http://www.lmca.org.uk)



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](http://www.lmca.org.uk)