

Sharing our experience

Compiled by Bec Hanley and Kristina Staley



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. 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.

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).

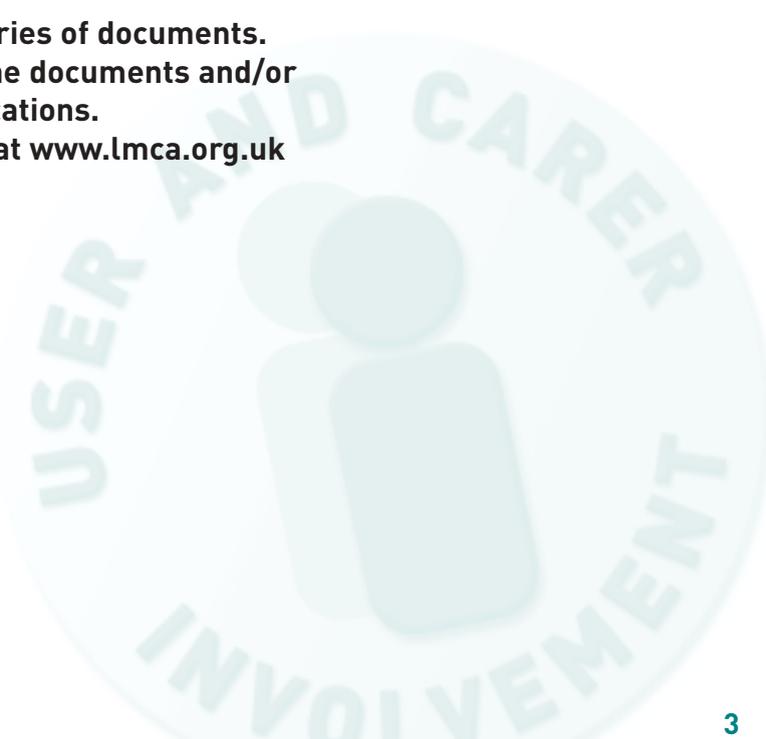
Therefore every organisation will face its own particular issues around user and carer involvement, depending on its history and current stage of development. But at all stages, every organisation, large or small, will always have room for improvement. We hope these resource documents will be as valuable 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**



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.

The case studies in this document were selected to include the experience of LMCA member organisations of different sizes, covering different conditions and in different geographical areas. We did not select them because we thought they were the 'best' at involving service users and carers – but we did think each had valuable experience to share.

We talked to one member of staff and one service user or carer in each organisation, using a standard list of questions developed in partnership with service users and carers, drawing on some of the literature about user involvement in voluntary organisations. We wrote up the notes from each of these interviews as a case study, and sent these to the people we interviewed for checking.

The views contained in these case studies are not necessarily representative of all of the service users, carers or staff in the organisation – each contributor shared his or her individual experience of involvement.

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. In it, people offer tips, advice and experience in response to a series of questions. Via the case studies, people offer tips, advice and experience covering a wide range of issues you might want to think about in your organisation. They may also help you to prioritise one particular topic for action – you don't have to do everything at once. Nor is there a single 'right way' to involve service users and carers; 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.

Case Study 1



We talked with Ffion Heledd, the Patient Network Manager and Mel Clark, a member of Hearty Voices and chair of the Harrogate Heart Support Group, who is also a member of the BHF's Patient Advisory Group.

Background

The aim of the British Heart Foundation (BHF) is to play a leading role in the fight against heart disease, so that this condition is no longer a major cause of disability and premature death. It funds research, education and care, and employs 1,640 staff. The headquarters are in London. There are no regional staff teams apart from fundraisers and communication staff – this creates challenges for user and carer involvement.

BHF isn't a membership organisation – so can't seek user and carer involvement through its membership. The organisation therefore had to think about different ways to ensure it involves its users. The patient network team leads on the user involvement work. This small team has been in existence for about two years.

FFION'S EXPERIENCE

Why does your organisation involve users and carers?

A combination of reasons – new people from different backgrounds joined the organisation – including a new head of department. They had a real interest in user and carer involvement. We were also influenced by the government agenda, which has made patient and public involvement a priority. One of our strategic committees identified a need for patient involvement in our work. We realised that the benefits of patient involvement include bringing reality into our work, making sure we're responsive to needs and improving quality of services. Ultimately of course there's the potential of reducing health inequalities in the long term.

Who is involved?

We involve a mixture of users and carers. It's mainly people with heart disease, but carers are very active too.

How are users and carers involved?

We've been working to involve users and carers for about three years. We do this in a variety of ways, including:

Hearty Voices

Hearty Voices started in spring 2002. This was partly in response to the fact that BHF kept getting requests for 'expert patients' to sit on various working groups, talk to the press and so on. Our list of people who could do this was fairly ad hoc and we wanted to be more systematic. So we linked with the College of Health Voices in Action programme, and learned a lot from Macmillan's CancerVOICES training.

Hearty Voices aims to develop a UK wide network of heart disease patient/carer representatives, give these people access to training and support, and to establish and develop user involvement in the work of BHF at all levels. We also aim to work with other agencies to bring about change wherever this is possible.

Case Study 1: The British Heart Foundation

We piloted Hearty Voices training with heart support group members. The training was delivered by an external trainer. This proved to be really popular – 80 people wanted to take part in the training. So the momentum grew. In May 2003 we launched the Hearty Voices programme nationally and we now have 300 people involved. We've just launched it in Scotland, and will launch in Northern Ireland soon.

“We had to be really honest with the patients and carers involved, that it had to be a work in progress.”

We recently developed an update session, which was held for the first time at our national patient conference (see below). We're currently doing research on what people are doing as a result of Hearty Voices. There's a Hearty Voices newsletter, with a section on opportunities to get involved. Hearty Voices people are involved in many different projects within and beyond BHF.

National patient conference

We held our first national patient conference in November 2003. The second was held in September 2004. The conferences include workshops, speakers, information sessions and Hearty Voices update training. Patients are involved in planning and running the conference.

Involvement at strategic level – the Patient Advisory Group

On the back of Hearty Voices we set up the Patient Advisory Group. The Group was established to ensure that the BHF's work is relevant to the public and firmly focused on raising standards of patient care. It also ensures that the patient and public perspective is represented within BHF.

We didn't want it to be a talking shop. We've made it an advisory group that links to our medical division strategic committee (this

isn't a board level committee). We had to be really honest with the patients and carers involved, that it had to be a 'work in progress'. We didn't have an exact idea of what we should be doing – it's difficult, as we've got nothing to compare to, nothing to follow. We wanted to evolve the Group in partnership with the users involved in it. The Group has space for 8 – 15 members. Currently there are 12. We recruited through advertising through the Hearty Voices newsletter. We got a really good response, and interviewed 20 people for membership. They came for a day, had lunch, talks, and visited our information centre.

The first PAG meeting was in July 2003. The PAG will meet twice a year, in line with other BHF strategic committees. The group has elected a chair and a vice chair and agreed terms of reference. People serve for 2 years.

The chair has started doing a newsletter for members between meetings to keep them up to date. This has been really useful.

Involvement in service delivery – Heart Support Groups

There are 300 heart support groups in England and Wales, which are run by and for heart patients. The support groups are affiliated, not members, so BHF can't tell them what to do, only suggest and encourage best practice.

It's early days for user involvement, which gives us permission to try things out and take risks, make mistakes. We've grown – there were 4 staff in our team, now there are 5 and we're still growing. We've adopted the slowly, slowly model.

User involvement isn't completely an integral part of our culture yet. The Medical Division is leading by example, and elsewhere we're getting there.

What about users and carers from groups or communities that are often marginalised?

We're beginning to develop the way we involve people from marginalised groups, but there is

a long way to go. The Asian community, women and young people are represented on our Patient Advisory Group but more work needs to be done in reaching marginalised communities in the wider sense. The Hearty Voices project seems to attract more younger people than our traditional patient support projects and that is a good thing. We will also be piloting a training the trainer course, so that the Hearty Voices training can ultimately be cascaded through users themselves to reach a wider range of people.

Did you have a plan or strategy to involve users and carers?

The key aim for my team is to develop support networks and programmes and information for heart patients and carers, so that they are able to maximise their health and be less anxious and better informed about their condition. Supporting the involvement of users both within BHF and in other organisations is a key part of this. So the strategy was at an operational level rather than a board level. Although it's now becoming a board level issue. We also have a plan for taking forward Hearty Voices.

How are users and carers supported in their involvement?

We try to support people in a variety of ways. We offer the initial Hearty Voices training. People said they didn't want any follow up courses, but we are piloting training the trainer so that we can cascade the course and reach more people. We send everyone a Hearty Voices newsletter.

We pay people travel expenses to come to training and to come to meetings. We also provide lunch. But we don't pay people a fee. The PAG get feedback at their next meeting and they get minutes of other meetings to show what has happened as a result of their input.

What difference has user and carer involvement made? What are the benefits?

I think the main impact users have had has

been in a massive cultural shift across the organisation. We now always have input from patients when we are developing new resources. Patient involvement is now at the forefront of people's minds, you can talk about it without having to explain it all the time.

It will take a while for tangible examples to come out of it. But we have a database, so if we get a request for involvement, it's much smoother. That's good business practice for the organisation. In time it will benefit the organisation much more, as we'll be seen as a much more friendly and approachable organisation, less stuffy.

How do you convince people in the organisation who may be sceptical about the value of user and carer involvement?

Have a measured approach. Don't scare them. Explain it can mean a lot of different things. Have a rigorous system in place for recruitment, support, and record keeping. Make sure you have clear, realistic and achievable plans.

What makes user and carer involvement work well in your organisation?

- The team – it was definitely to our advantage that we were new.
- A measured approach – in this organisation, any other approach wouldn't have worked.

Case Study 1: The British Heart Foundation

- Support from the top to get on with it. I feel that we have permission to do it and to shout about it.
- Patient patients! It's good when users understand that things can't be changed overnight, but by working together we can start to make a difference.

What's the main thing you've learned about involvement? What would you do differently if you could start again from scratch?

The main thing I've learned is that it can be very frustrating! You can get disillusioned very quickly if you don't watch it. You need to expect people to challenge you and complain you're not doing more when you're working really hard – so keep reflecting on what you've achieved. Other lessons:

- Learn from others – we've learned loads from CancerVOICES.
- You could get really swamped by it all. Choose what you're going to do and do it well.
- Get lots of people involved, get them on your side – spend lots of time on this, otherwise it won't work.
- Get perspectives from all levels in the organisation and try to make it work for everyone. Try to get a balance between what people at the top want and what's achievable at the grass roots.
- Think carefully about in what capacity you want to involve patients, when and why.
- Give people options about where they can get involved and when. Give people a dip in, dip out option – don't just offer opportunities that require long-term commitment.
- Have a structured way of finding people who want to get involved, even if you can't involve them immediately.
- Don't be too ambitious – don't try to do it everywhere in the organisation all at once – focus on quality and impact. Give people somewhere to move on to next – think about options.

MEL'S EXPERIENCE

What made you want to get involved with the BHF?

I had a heart bypass, and that got me interested in how people with heart disease are cared for, and how they recuperate. I had been a PT instructor, so I was really interested in exercise and the cardiac rehab process. The provision and delivery seemed disjointed – no uniformity nationally and no nationally agreed standards.

I was fired up by the enthusiasm of the people I came into contact with, particularly the cardiac staff funded by the BHF.

How are you involved with the BHF?

In 1996 I found there was a Heart Support Group in Harrogate, where I live. These groups are supported by the BHF, but they aren't BHF groups. I got involved in the exercise group. I joined the executive committee in 1997, and became chair of the group in 1999.

Then I got more interested. I want the best quality of life I can for as long as I can. So I studied more, and built relationships with BHF and hospital staff. They realised I was genuinely interested in what was going on and that I wanted to help their cause from a patient perspective. In the first instance I was viewed sceptically. People shouldn't see you as your condition. You have a history of work experience, life experience.

I had no thoughts of becoming part of BHF. But the more I read about cardiac rehab, the more I got a sense of the divergent views about what constitutes cardiac rehab. It was too academic – I wanted to look at what's happening now.

It was Ffion who got me involved – in 2000. She was the first connection at BHF I had. They were just setting up Hearty Voices training. I wanted to get onto it, as I wanted to take on NHS people, and to do that I needed to understand the NHS structure.

I became a member of the Patient Advisory Group 18 months ago, when it started.

I don't consider myself a heart patient. That's the myth we're trying to dispel. We're getting on with our lives.

What happened when you first got involved? Did you receive any training or written information?

I was one of the first people on the Hearty Voices training course. It was good, but I felt it was too involved for the type of people attending. There was too much covered in one day – too much theory and method. I felt we needed something more practical that you could understand and implement. Notwithstanding, it helped me to become part of the local PCT group and we have a strong voice in the CHD (coronary heart disease) process as a result.

When they developed the Hearty Voices training manual, I made lots of comments. I'm not sure how many of these have been taken on board.

How does the BHF support you to stay involved?

As chair of the Heart Support Group I've received a lot of support from the BHF nurse at the hospital, who's great. And we get a

Hearty Voices newsletter. I believe that the accessibility of BHF staff in London is also a major factor – it gives a feeling of inclusiveness.

Do you think that the BHF is good at involving users and carers?

Yes. They've got a zeal for it. They honestly believe the patient is important. There's no other reason for them to exist. They want to eradicate or alleviate heart disease. I'm impressed with all of the staff I've met – their enthusiasm, commitment.

“People shouldn't see you as your condition. You have a history of work experience, life experience.”

Do you think the involvement of users and carers has made a difference to the work of the BHF?

With the Patient Advisory Group, it's too early to say. But some comments we've made about strategy have been implemented. Sometimes you don't get any feedback. 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 that whoever has been involved with the Patient Advisory Group seems to be listening – at a management level they are listening. But sometimes you need time to discuss and consider things properly at meetings, and we don't always have that time – we meet only every six months. I also genuinely believe that users/carers do make a difference, and comments and suggestions will motivate BHF staff to examine themselves and be more circumspect about their role in BHF.

It was a bold step for the BHF – they've created a monster in their midst. It has potential, but it will take years to really see what impact we might have.

If a new user or carer was going to get involved in the BHF, or another voluntary organisation, what advice would you give them?

Find out about the organisation and what they actually do. If you believe in what they're doing, get involved. They need foot soldiers to spread the message. There are few people who can encourage and enthuse others.

You have to care about the patient and carer and understand what the organisation is trying to do, the philosophy of the organisation. If you don't, you can't make an active contribution.

Hearty Voices gives people who have a bit of initiative the courage to go and do something. If there are enough of us, we can change things.

What advice would you give BHF or other organisations about the best way to involve users and carers?

Encourage the prospective candidate sensitively. Pay attention to the advice we give. We have your interests at heart...

What's the main thing you've learned from your involvement?

I've learned a great deal about BHF, what they do, why they do it. It's a great deal more than a charity that raises money for research. BHF is the leader in almost every aspect of heart disease, and without their immense effort there would be very little impetus or beneficial developments.



Case Study 2

The logo for Epilepsy Action, featuring the words "epilepsy" and "action" in a white, lowercase, sans-serif font. "epilepsy" is on a grey rectangular background, and "action" is on a black rectangular background.

We talked with David Streets, Epilepsy Action Council member and Simon Wigglesworth, Epilepsy Action's Deputy Chief Executive.

Background

Epilepsy Action is the working name for the British Epilepsy Association. The Association was set up in 1950 and is member-led. Epilepsy Action has over 17,500 members. Around 800-900 of these are professional staff. The remainder are people affected by epilepsy.

Epilepsy Action aims to be the premier community based organisation for epilepsy, taking action to meet the identified needs of all people with epilepsy and those with an interest in the condition.

Epilepsy Action provides advice and support for people with epilepsy, as well as raising awareness about epilepsy. Services include a helpline (which takes 25,000 calls a year), publications and a website with information on epilepsy. Specialist epilepsy nurses, based on the model developed by Macmillan Cancer Relief, are provided. The organisation also campaigns on health and social care issues for people with epilepsy.

One of Epilepsy Action's objectives is to "encourage and enable the active involvement of its members and other stakeholders in meeting its aims."

DAVID'S EXPERIENCE

What made you want to get involved with Epilepsy Action?

1 in 130 people has epilepsy – it's more common in children and young people, and in older people. In the UK around 80 people are given a diagnosis of epilepsy every day. Our oldest son was diagnosed with epilepsy about 24 years ago. At that time, the help you got from the hospital was very poor. I was a teacher, so I had some experience of epilepsy, but my wife and I joined Epilepsy Action to get more information. Then about 16 years ago we got a letter inviting us to a public meeting about setting up a branch in Sheffield. About 6 people went to the meeting, and 3 of us agreed to get involved. I was the treasurer, and later I became the branch chair.

Then I became an accredited volunteer – I was trained by Epilepsy Action, and gained more information about epilepsy. That meant I could offer advice to others. The training got me more involved with the national office of Epilepsy Action. I got to know some of the staff, and the regional services manager, Sue Blake, encouraged me to stand for election to the Council of Management – the Board of Trustees. I stood about 18 months ago, and was elected.

How are you involved with Epilepsy Action?

I'm responsible for PR at my branch and am an accredited volunteer. As an accredited volunteer, I offer support and advice to people on a one-to-one basis in the Sheffield area, give talks and so on.

I'm also one of 16 Council members. The Council is elected by Epilepsy Action members. We make the strategic decisions on behalf of the charity; decide where we should be going. As a Council member, I visit other branches, go to meetings, attend seminars, and represent Epilepsy Action.

There are lots of people involved in doing similar things to me. All branches are

Case Study 2: Epilepsy Action

encouraged to raise awareness of epilepsy, challenge prejudice and support people with epilepsy and their families.

People from black and minority ethnic communities are not well represented – in the Council, through our membership or within the staff. We haven't ignored that. We've recently done some work in Bradford to look at attitudes to epilepsy, and that's led to a new branch being set up.

We have groups to support parents of children with epilepsy. They often support parents of children who have learning difficulties and epilepsy.

What happened when you first got involved? Did you receive any training or written information?

I received training to become an accredited volunteer. You can now do an NVQ. I get regular updates – sometimes in person, sometimes through distance learning. As an accredited volunteer, I have to do a quarterly report on what I've done over the past three months.

As a Council member, I have a one-day training course every year.

How does Epilepsy Action support you to stay involved?

I get the two magazines produced by Epilepsy Action, and I access the website.

For the Council, there's an appraisal system – individuals appraise the work that the Council does and their own work as Council members. That's made me look at the work I'm doing, and how we're doing as a group.

“You need to be involved with other people – it broadens your views and gives you knowledge of other people's experiences.”

We get tremendous support from the chief executive and deputy chief executive. They also give us updates about what's been done in response to things that have been discussed by the Council.

Branch members are supportive too – if you're supported, you're able to support others.

Do you think the involvement of users and carers has made a difference to the work of Epilepsy Action?

Yes. A lot of things have been done because members have asked for them. For example, we've just produced a new publication, called 'Epilepsy in later life'. This was produced in response to demands from members.

And we've gone from one national conference to a series of regional conferences, as that's what members have asked for. We've had an audit of sudden unexplained deaths from epilepsy – again because members said that was a priority.

At local branch level, people have got new nursing services set up, supported by Epilepsy Action.

If a new user or carer was going to get involved in Epilepsy Action, or another voluntary organisation, what advice would you give them?

Start at branch level – you need to be involved with other people – it broadens your views and gives you knowledge of others' experiences. You have to feel there's something for you to do – I wanted to challenge prejudice.

What advice would you give Epilepsy Action or other organisations about the best way to involve users and carers?

They need to support people at a regional level – so individual members and branches don't feel isolated – Epilepsy Action needs to do more of that.

What's the main thing you've learned from your involvement?

About the variety of activities Epilepsy Action is involved in and why they're necessary. We need to improve the quality of life of people with epilepsy and their families.

SIMON'S EXPERIENCE

Why does your organisation involve users and carers?

Epilepsy Action's mission statement is to be the premier community-based organisation for epilepsy. We take action to meet the identified needs of all people with epilepsy, and those with an interest in the condition. So we need to know what those needs are.

Epilepsy Action has always been a membership organisation, and Trustees have always been drawn from, nominated by and elected by the full membership.

Who is involved?

All Trustees are members of Epilepsy Action. They are elected every three years. Approximately six of our Trustees are people with epilepsy and two or three are relatives of people with epilepsy.

How are users and carers involved?

The Trustees set the strategic direction for the organisation, but our membership are asked for their views on priorities for the work of the organisation. We do this mainly through surveys of our members.

Our surveys – and calls to our Helpline – inform the content and topics of our publications. For example, we are currently writing a book for men with epilepsy. This has been prompted by calls to our helpline and we are currently surveying our male members to ensure the contents reflect the particular issues they face.

Users are also involved in campaigning at national and local levels. Our campaigns are

informed by research into problems faced by people with epilepsy. We check whether the issues we are addressing continue to be important to people with epilepsy using regular mini-surveys.

Our branches are entirely user-led. The branches deliver support in the community and carry out local campaigning and fund-raising.

Each branch has its own model, decides on its own activities and programme and is then given regional support to deliver that. We also evaluate branches to see if they are meeting needs of users.

What about users and carers from groups or communities that are often marginalised?

One of our objectives is to become more inclusive and representative of all people with epilepsy – so we're working on becoming a more diverse organisation. We use Language Line to take helpline calls in over 150 languages other than English and produce some leaflets in Urdu, Punjabi, Bengali, Hindi and Gujarati.

We have commissioned research into epilepsy in black and minority ethnic groups. This has informed our work in Bradford, where we are extending services into Asian communities in particular and are setting up a new branch.

Our regional support managers are extending their work with people from black and minority ethnic communities to support and involve them in local branches.

Regional support managers are also working to promote the involvement of people with learning disabilities in local branches.

Did you have a plan or a strategy to involve users and carers?

Not specifically for user involvement. Our business plan is based on Trustees' strategic objectives.

“One of our objectives is to become more inclusive and representative... so we’re working on becoming a more diverse organisation”

How are users and carers supported in their involvement?

We train our volunteers – some of the training is accredited through the Open College Network. Volunteers have a good understanding and knowledge of epilepsy. They go into communities, schools and employers advising people about the condition and its impact. We’re currently developing a section of our website to provide information and advice to our accredited volunteers. We also have a dedicated member of staff to support recruitment and training of accredited volunteers.

We publish reports on surveys of our members on our website and on paper.

Our Trustees are also doing a self-appraisal for the first time – to see if there are skills gaps or training needs within the Council. Council members are also offered training.

We meet all expenses for work done on behalf of the organisation.

What difference has user and carer involvement made? What are the benefits?

Our stakeholder survey confirmed our strategic direction is the right one.

What makes user and carer involvement work well in your organisation?

Our chief executive took charge of the stakeholder survey. The whole organisation has always been member-led – so it’s hard to imagine things any differently.

What’s the main thing you’ve learned about involvement? What would you do differently if you could start again from scratch?

Finding volunteers is difficult. Some people who are not too badly affected want to forget they have epilepsy. Others who are so severely affected that they can’t work have the time, but may need a lot more support to run support groups.

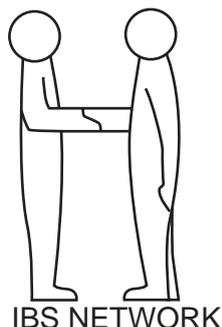
Finding people who have the time, skills and ability to run a branch is difficult. It would be good to have more resources to provide more support to the people who need it.

It’s difficult to strike a balance between meeting the needs of an individual and those of the community of people with epilepsy. If branches are struggling because people can’t run a group themselves – then we have to step back and let it fold.

If I could start again from scratch, I would try to build a more diverse group of Trustees, but this has to be balanced against the democratic nature of our Trustee body. I would also like to have more groups working in marginalised communities.



Case Study 3



We spoke with Shelagh Grey, who has IBS and is a Trustee of the IBS Network, and Penny Nunn, the Network's part-time Development Director.

Background

The IBS (Irritable Bowel Syndrome) Network started in 1991. Two women who had IBS looked around for a self-help group. They couldn't find one, so they decided to set one up. The Network gained charitable status in 1996. It offers help, support and information. There is a helpline run by nurses, a regular journal, befrienders, a penfriend scheme, local self-help groups and other initiatives. Paid staff are all part time, two in the office, plus the nurses who answer calls on the helpline and the Editor of Gut Reaction (the Network's journal). The Network is based in Sheffield, and is entirely funded through donations and subscriptions from its 2,500 members.

Because it is a small organisation, much of the work is done by users – so thinking about user involvement is very different to the thinking in some of the bigger organisations featured in this document.

SHELAGH'S EXPERIENCE

What made you want to get involved with the IBS Network?

I've had IBS for about 30 years, but it was only diagnosed about 12 years ago. I wanted to find ways to help myself, and I read a book about IBS, which had the contact details of the IBS Network in the useful addresses section. I didn't contact them for a while, but then I got worse, so I wrote off for information. They said that there were self help groups – but there wasn't one in Yorkshire, my area. So I decided to set one up – that was about 8 years ago.

How are you involved with the IBS Network?

I'm still running the self-help group I set up. People come from a long way to the group – there's core membership of about ten, and other people come in and out.

Every year the Network has an AGM – you get an invitation in the members' magazine. If you go to represent your group, the Network will cover your train fares. IBS can be very lonely, and I felt quite isolated, so I decided to go, to put faces to names. I had spoken to Penny, the development director, on the phone. At the AGM, they said they wanted Trustees, and I was persuaded to stand. I'm one of the Trustees who are there to represent people with IBS and the self-help groups. The Trustees meet 2-3 times per year. Being a Trustee has done me a power of good.

We hear a lot about how other people are active in the Network through Gut Reaction, our magazine, and through Penny. And I'm very aware of what other Trustees are doing. Each Trustee who is a self-help group leader supports a number of other self-help group leaders – I am currently mentor to five other group leaders.

What happened when you first got involved? Did you receive any training or written information?

When I realised that if I wanted to belong to a self-help group I would have to start one

Case Study 3: The IBS Network

myself I contacted Penny, our development director. She sent me information on how to set up a group, including advice on advertising and also the names of various books on the subject that I could borrow from my local library. I read these and thought carefully about the best way to proceed.

I decided to start by recruiting people who were already members of the Network. For privacy/security reasons Penny was unable to give me the names and addresses of members in my area but she kindly offered to forward a letter to them from me.

I penned a letter introducing myself and explained that I was hoping to start a local group of the Network. I gave the date, time and venue of the first meeting and invited everyone along for a "taste and see." Penny then forwarded this to all the members who lived within a broad radius of me.

“ Get down to the grass roots... don't do all the planning in offices trying to guess the best way forward.”

About 17 or 18 people turned up and our group had been born. I wrote an article about this first meeting and it was printed in our magazine Gut Reaction, providing further advertising for the group.

From there we have opened out and now seek members from the local community and encourage them to become members of the IBS Network as well as of our local group.

When I was voted in as a Trustee Penny sent me information produced by the Charity Commission about the duties/responsibilities of being a Trustee, but there wasn't any training. In the beginning we got further information by post or at Trustees' meetings. Now we're online, so a lot happens by email.

How does the IBS Network support you to stay involved?

I stay involved because of my local group – we rely on each other for support. And Penny is very supportive.

Do you think that the IBS Network is good at involving users and carers?

It tries very hard to involve its members through the magazine, through the self help groups, the penfriends scheme, the helpline and the phone line. But a lot of members don't want to get actively involved – they want information rather than involvement.

My group is full of people like me, who have IBS every day of every year. Other people who have IBS more mildly, or more occasionally come in and out.

We're open to everyone, but I've never come across a black person in my group, or at the AGM, or amongst the Trustees. So I don't know if we do reach all the different groups of people who have IBS.

Do you think the involvement of users and carers has made a difference to the work of the IBS Network?

Yes and no. As someone with IBS, I bring the views of people with IBS – what's important to us, what we want and need. As a Trustee I can make those views known.

When I talk to people with IBS I bring a human touch, understanding, sympathy, and practical advice about how to manage your life with IBS – I can talk about how I manage my life, and how other people with IBS manage theirs. It's a very isolating complaint – lots of people go through a whole load of tests before they are diagnosed. People who come to us are often exhausted and depressed. When people like me say we understand, we've been there, that's a huge weight off their shoulders.

What I do won't provide a cure for me or for people in my group. But I can help others to manage their condition.

I can suggest all sorts of things to Penny and she'll act on them if it's within her power. For example, if people contact Penny to say they'd like to set up a self-help group, she sends them an information sheet. I've made a series of suggestions about how that information can be improved, based on my experience of setting up a group, and those have been incorporated into the new information sheet.

We've suggested that people setting up new groups have a mentor, someone who has already set up a group. That's happening now, and it works well.

If a new user or carer was going to get involved in the IBS Network, or another voluntary organisation, what advice would you give them?

Go for it with all the energy and enthusiasm you can. Be determined to play an active, not a passive part – the more you put into it the more you will get out of it. Offer to help, don't wait to be asked.

What advice would you give to the IBS Network or other organisations about the best way to involve users and carers?

I'd suggest that they get down to the grass roots – out into the groups at local level – and listen to the users and carers. Ask what they want, what they need, where the glaring gaps are and how their own personal experiences of illness could be used to mutual advantage. Don't do all the planning in offices trying to guess the best way forward.

What's the main thing you've learned from your involvement?

My confidence has increased hugely. Meeting doctors on a level playing field has been very confidence boosting. I've acquired confidence in myself and in my knowledge of my condition – I've realised I'm the expert on my IBS. That's what I've got out of it. You need to be on top of your condition – not a victim of it.

PENNY'S EXPERIENCE

Why does your organisation involve users and carers?

The Network is run by people with IBS for people with IBS – the basis of it is self-help. We couldn't exist without user involvement. Our whole ethos is about people with IBS being involved in their own care. Our constitution emphasises the importance of involving people with IBS who run self-help groups as Trustees.

Who is involved?

Almost everyone involved has IBS – hardly any family members are involved.

How are users and carers involved?

Because we're such a small organisation, people with IBS do a lot, including:

Producing written information

They're involved in writing articles for our journal. The editor of the journal also has IBS. Members review books and tapes about IBS. Our members decided what our emergency help card should say, and then translated it into different languages. People also contribute to writing the annual review.

We produce factsheets in response to demand from our members. These factsheets are read in draft by our Trustees with IBS to check that they are user-friendly. We have also made some of our publications available on tape.

“I do the personal things that help people feel valued... I phone people to see how they are getting on.”

Providing services

Members with IBS are telephone contacts, befrienders, run self-help groups and are on our media list. Some of the self-help group leaders are Trustees and also act as mentors for new self help groups. Three of our Trustees are local self-help group leaders. We support an email discussion group for members.

What about users and carers from groups or communities that are often marginalised?

The only thing we've done to date is to have our emergency 'can't wait' card translated into a number of community languages. We tell all health professionals about this through events such as the British Society of Gastroenterologists and the Royal College of Nursing conferences.

Some of our members are from black or minority ethnic communities, but we don't have the resources to monitor this.

Our more active self-help groups are run by older people – but younger people use our email discussion group and the website. One of our younger members, who is 14, developed a junior website, which is aimed at young people of secondary school age.

Was there a plan or strategy to involve users and carers?

We had a five-year plan for the whole organisation – this isn't specifically about user involvement, but was developed in partnership with users.

Our Trustees are about to start putting together a new five-year strategy. This will be user led.

How are users and carers supported in their involvement?

The chair of Trustees (not a user) is very active and in regular contact with our Trustees. I do the personal things that help people feel valued – I send birthday cards, Christmas cards, small gifts. I phone people to see how they're getting on. I ask our volunteers what they need and we are open to ideas. The Trustees support each other, too.

We have a mentoring system for people who run self-help groups, run by the Trustees who run self-help groups themselves. We've also agreed that people who are volunteer telephone contacts will offer support to each other.

We ask people to write up their experience of involvement and we publicise it in our journal. This also tells other people what the job would involve (e.g. talking to the media). We cover train fares to the AGM for one person from every self-help group. We also pay expenses for other users to come to the AGM – befrienders, people who are on our media list and so on. We publicise that in our magazine, and it's on the application form to be a volunteer. Trustees get expenses – that's on their job description.

What difference has user and carer involvement made? What are the benefits?

We've involved people from the start, so it's hard to say what difference it has made. Without input from our users, we wouldn't exist. The involvement of people with IBS in our Network has meant that people with IBS get support TODAY – it's not about research to help people in the future, it's about supporting people who live with IBS now. For example, the helpline run by specialist nurses was set up in response to users saying that's what they wanted.

What makes user and carer involvement work well in your organisation?

The self-help groups and almost all of our other services are run by people with IBS. In

our constitution, the only people who can vote at AGMs are registered self-help groups.

What's the main thing you've learned about involvement? What would you do differently if you could start again from scratch?

It's extremely frustrating – our members can say they'll do something and then they'll be ill on the day. But they're really nice people and really enthusiastic, they pull out all the stops and they're fantastic.

Meeting people in the flesh is so important – personal contact is vital.

A lot of it comes down to money. We should maybe have waited until we had raised the money to do things, rather than doing them on a shoestring. But then things would have happened much more slowly, and lots of people wouldn't have had access to support and advice.



Case Study 4



We talked with Jane Bradburn, Macmillan's Support and User Involvement Advisor and Nazira Visram, CancerVOICES member.

Background

There are now over a million people living with cancer in the UK and, if current trends continue, more than five million will be diagnosed between now and 2020. Macmillan Cancer Relief provides the expert care and emotional support that makes a real difference to people living with cancer. It offers a range of innovative cancer services and is at the heart of improving cancer care throughout the UK.

One of Macmillan's corporate 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."

Macmillan supports CancerVOICES, which is a UK wide network of people affected by cancer who are helping to shape the future of cancer care. CancerVOICES supports patient and carer representatives to get involved in local groups of people affected by cancer, to gather views of people affected by cancer via surveys and questionnaires, and to take part in cancer research and in national cancer committees and projects. CancerVOICES offers free flexible training programmes and provides support and resources for the network of representatives, self help and support groups.

JANE'S EXPERIENCE

Why does your organisation involve users and carers?

About two and a half years ago Macmillan developed a new five-year plan for the organisation, focused on the needs of people affected by cancer and building a broader base of support to include health and social care. The merge with Cancerlink (an umbrella organisation supporting over 600 UK wide independent cancer self help and support groups) and CancerVOICES in 2002 enabled Macmillan to broaden its support to include user involvement groups and self help and support groups. Macmillan has been taking steps to become an increasingly user-centred organisation.

Who is involved?

People affected by cancer are able to become involved through CancerVOICES. The CancerVOICES database records people who have direct experience of cancer, and how many are family members, partners or friends. I would say that the majority of those involved have direct personal experience of cancer.

The cancer self-help and support group network is supported separately from the user involvement groups. We think this is important because self-help and support groups can get swamped with requests for involvement when they often only want to provide peer support. However there are still strong links between them. Many people who get involved are or have been members of self help groups. We use the expression 'from support to influence' as this is often a personal journey taken by people affected by cancer who choose to become involved.

How are users and carers involved?

CancerVOICES

We have about 500 people affected by cancer on our CancerVOICES database. This doesn't reflect all of the people affected by cancer who are actively involved with Macmillan –

not all will have registered with CancerVOICES. There are over 100 people affected by cancer working on projects and groups within the organisation's UK office alone.

Involvement at a strategic level

There's currently no involvement of people affected by cancer at Board level – although the Board is reviewing this.

However this year Macmillan has involved cancer service users in its planning process. Initially this was to review its 5-year plan. CancerVOICES members came together to review the objectives set out in the plan. Their comments were fed into the Executive Directors' Team and to the Board.

CancerVOICES have had an ongoing input into the planning process throughout its cycle. They have been involved in planning within the Services Directorate (Macmillan's biggest department). 8 CancerVOICES members will go to the Services planning day and then will continue to feed in to the planning process. We will review this process together with CancerVOICES members to see how we might improve it next time and extend user involvement to the work of our Regional Service Development Teams.

Other types of involvement

Recently we mapped where users are involved across Macmillan. Users are very active in some of our departments beyond Services, for example in Communications and Policy, Planning and Research Departments. There is less user involvement in our IT, Finance and Fundraising departments, although our IT department are beginning to think about how they can involve users, and our Finance department are working towards user friendly, speedy and flexible reimbursement of expenses.

We have a Shared Learning Group, which is made up of staff from across Macmillan, plus 2 users. The group meets every month for

“ Taking account of the history of the organisation is very important when introducing a more user-involvement focus.”

2 hours and there's an open agenda. The meetings are open to anyone who is, or is planning to involve users in their work. This group has generated guidelines on user involvement for staff and volunteers, and is currently developing a welcome pack for users who get involved with Macmillan. The group means that user involvement in the organisation is based on learning through practice, not on information handed down from the top. We are careful about which users we involve in this – it is important that they are interested in learning and have a partnership approach, as staff can feel quite unsure about the 'how' initially.

User involvement isn't quite embedded within the culture of Macmillan yet – Macmillan as an organisation has a history of supporting Macmillan nurses and grant giving. Taking account of the history of the organisation is very important when introducing a more user involvement focus. There has been some concern among staff that a focus on users will mean less support for professional post-holders, but our aim is to support both and promote a partnership approach.

Macmillan also encourages the involvement of users by their partner organisations including the NHS, Social Care and voluntary organisations. Macmillan actively supports the development of user involvement in NHS cancer services. A joint 3-year project with Department of Health – the Cancer Partnership Project – has resulted in Partnership Groups being set up in most of the NHS cancer networks in England. This has created opportunities for users and carers to become involved in improving cancer care at a local and national level.

What about users and carers from groups or communities that are often marginalised?

We have a Black and Minority Ethnic (BME) Community Development Co-ordinator. She has helped to develop a national network of link workers and organisations wanting to involve people from BME communities. She has set up a national user involvement group of people from black and minority ethnic communities who are affected by cancer, and is now setting up local groups in each of the cancer networks, linking with the development workers for each network.

In response to requests from users and carers, we are just starting a Young VOICES for children and young people affected by cancer.

We have also supported the development of a Rarer Cancers Forum, and have funded a facilitator to work with this group.

We are keen to find appropriate ways in which we can involve people who are very ill, and who may be at the end of their lives. We're funding some research at the moment to help us plan this work.

Other areas are yet to be developed through our 'Barriers to Access' programme, including work with people with learning disabilities who are affected by cancer.

Did you have a plan or a strategy to involve users and carers?

Macmillan has a vision, aims and objectives – user involvement is key across all of these. It's about a whole system approach. For example, Macmillan had a five-year plan for the organisation as a whole, agreed in 2001. One of the key objectives within this plan is "to promote and embed user involvement within Macmillan and with our partner organisations, and support post holders to work in partnership with people affected by cancer".

We produced a user involvement strategy and an implementation plan. Our approach is one of 'learning through doing' and this enables staff and users to learn together about what real partnership means in the context of the organisation. This is underpinned by guidelines for staff on involving users, which include examples of good practice, and staff shared learning.

How are users and carers supported in their involvement?

We know that recruitment and retention is an issue for CancerVOICES members. Some people choose not to stay involved for long, and we're not yet sure of the reasons why. Partly in response to this, we have reviewed our approach to user involvement and are now calling it user support and involvement, as this seems to reflect more accurately what we do. This encompasses the work we do to support self-help groups, but more importantly it recognises that if you involve people, you need to support them.

We offer CancerVOICES training to groups of people affected by cancer who want to get involved. This training lasts for 2 days, and is usually delivered by people affected by cancer who have experience as user representatives. We do not offer the training

to individuals, as we have found that it is more effective if people are already part of an existing group which has routes of influence. We offer training for chairs of user involvement groups. And we are now also offering training for people who sit on NHS site-specific groups (cancer network groups focusing on a specific cancer e.g. breast or urological cancer). We train professionals about user involvement too.

We have a CancerVOICES newsletter and a CancerVOICES website which enables people to hear about opportunities to become involved.

We give feedback to users about what has happened as a result of their input. But we do not routinely ask people how they feel their involvement went – we don't have a formal way of doing this yet, although we are planning to hold a 'reflective day' to review how well users think we are working together.

We have an expenses policy so that people aren't out of pocket as a result of their involvement. Committee or reference group members receive expenses. If users are running training or teaching/presenting they get paid for their time.

What difference has user and carer involvement made? What are the benefits?

Users helped the Macmillan Grants team redesign their patient information. So the way that this team presents itself is now much more patient friendly.

Users have been involved in our buildings programme, making sure that the buildings we fund are as user friendly as possible.

Macmillan has traditionally monitored its progress using numbers and quantitative measures. User involvement has stressed the importance of 'process' and has encouraged us to use some more qualitative measures.

The biggest impact is that users say they feel transformed through their involvement, and staff can feel transformed too. User involvement has made the organisation feel even better about itself. Users say that they get more of sense of self-worth. It makes a more diverse environment –so we're not just working with people who support the organisation as donors who give us financial support or as volunteers who give their time and skills but also as users and carers who give their experience to improve cancer care.

How do you convince people in the organisation who may be sceptical about the value of user and carer involvement?

We offer awareness raising training for staff. Practical examples really help – you need to show where people are involved already. This makes it less scary. The most powerful way is to bring people affected by cancer into the organisation – they're actually in the office, meeting people, doing things with the staff. That way you cut through people's pre-conceptions.

Staff often expect to be criticised by users – so when users praise them and give them positive feedback, that really helps. We encourage an ethos of partnership working and shared learning.

What makes user and carer involvement work well in your organisation?

Since I've joined Macmillan, I've been impressed by the staff – Macmillan has a genuinely caring culture, where people are helpful to each other. That's a really good start. The support from Peter Cardy, our chief executive and senior members of his team has also been critical.

Most of all though, making user involvement work depends on the generosity of the users and carers. The users are amazingly committed – they are prepared to see this as a long-term culture changing exercise and stick with it.

What's the main thing you've learned about involvement? What would you do differently if you could start again from scratch?

I've learned that this work is about creating a culture that stresses partnership, and building relationships. Otherwise it becomes about questionnaires and focus groups and can be quite hands off. It's really about working with people – that's the most important thing.

Putting the infrastructure, procedures and processes into place is really important too – e.g. an expenses policy so that people get paid quickly.

Looking after users in a whole sense is vital – they might be ill, or they might get upset. You have to go through the pain with them – some of our most active users are quite ill at times.

If I could start over again, I'd try to do more collaborative thinking – more group work and building a consensus with staff at a grass roots level right at the beginning.

NAZIRA'S EXPERIENCE

What made you want to get involved with Macmillan and CancerVOICES?

I stumbled into CancerVOICES through a bad experience during my cancer journey. I was writing to and emailing different people to see if I was the only person in my situation. CancerVOICES responded to my email. I've been involved since January 2003.

How are you involved with Macmillan?

I've got caught up in a whole range of issues. For example, I spoke at the Labour Party conference last year, on behalf of 20 cancer charities. I've done interviews for BBC radio to promote awareness. I'm featured in Macmillan's annual review and have been involved in representing users' views on the future direction for Macmillan.

I'm involved in the Black and Minority Ethnic Reference Group, in the review of patient grants and am now delivering CancerVOICES training. I run a support group and am a member of my local user partnership group. At present I am working jointly on developing a self-management programme for Asian communities.

Through experience, I have now learnt not to get involved in projects if I feel there's no prospect for change. It can at times be scary to get involved in certain projects – I am aware it's scary for all concerned. The difference is as a patient I've got to continue using these services.

What happened when you first got involved? Did you receive any training or written information?

None that made sense. I just went in headfirst when CancerVOICES was in its infancy. But I know that users are better informed now about various training to help them get started.

Recently, through my involvement, I've suggested that we put together a welcome pack for new users. This will clarify any

questions they may have on what to expect and also what Macmillan expects of them. We're working on the pack now.

How does Macmillan support you to stay involved?

I go to workshops and conferences to keep me updated. Networking is important, as it's not just my views I'm representing. By listening to the views of others, I can represent them more effectively.

I've attended various CANCERVOICES training.

We're planning a reflective day for users who have been involved at Macmillan's UK Office. I suggested that. We want to understand what people want to get out of involvement, what makes them stay involved and why they leave.

Do you think that Macmillan is good at involving users and carers?

Yes. Macmillan strongly believes in user involvement and has addressed it corporately. However, it's all still very new, and needs frequent evaluating in terms of consistency and continuity. It's a huge culture change and people have to be constantly reminded.

Do you think the involvement of users and carers has made a difference to the work of Macmillan?

Macmillan are good listeners and responsive to suggestions – for example through the development of the welcome pack and clarifying the expenses policy. We've all learned. We have now started to cut out assumptions and work towards real issues through improved communications. It's helped to demonstrate that users/carers are not a threat but there to work in partnership.

If a new user or carer was going to get involved in Macmillan, or another voluntary organisation, what advice would you give them?

Be open and ask for clear information on the level of involvement, the timescales, what

“ I have now learnt not to get involved in projects if I feel there's no prospect for change.”

kind of things they might be asked to do and how frequently. A decision can then be made on whether or not to commit. Personal contact is extremely important. When I meet people face to face, then people see me as a person and not just a condition. It's less scary and brings down barriers.

What's the main thing you've learned from your involvement?

Be honest – you can achieve more. It's a risk, but it pays off – people respect you.

I can see the other side now – I understand the frustrations, the limitations, and the politics. I say we can address things together – that way we can all benefit. It has to be a WIN/WIN situation if there is to be a positive outcome.



Case Study 5

rethink severe mental illness

We talked with Mary Taylor, Coordinator of the Suffolk Rethink Severe Mental Illness Group and Rethink Trustee and Janine Woods, Rethink's User and Carer Involvement Manager.

Background

Rethink is the largest severe mental illness charity in the UK. Rethink is dedicated to improving the lives of everyone affected by severe mental illness, whether they have a severe mental illness themselves, care for others who do, or are professionals or volunteers working in the mental health field. It is a membership charity.

The organisation was set up over 30 years ago by the father of a man who had a diagnosis of schizophrenia, and now employs over 1,500 staff. Rethink provides 383 community-based services; supports 137 mutual support groups; campaigns for changes to policy and practice that will impact on both local and national levels, and works to raise awareness of mental health issues and challenge the prejudice, ignorance and fear that create stigma.

Rethink encourages the involvement of service users, carers, staff and volunteers in all aspects of its work, from initial planning through to day-to-day and strategic management, both locally and nationally. Rethink's work is overseen by the Board of Trustees, the majority of whom are carers and users.

MARY'S EXPERIENCE

What made you want to get involved with Rethink?

My daughter experiences severe mental illness. During her third episode in hospital, she had a really good consultant who suggested we find our nearest Rethink group. We felt very alone and ignorant, so my involvement came out of a need for information and support.

There was no local group – we had to drive 40 miles to the nearest one, but it was worth it because we got such fantastic support, fellowship and information. After our experiences I didn't want other families (both the person with severe mental illness and the family around them) to go through what we went through in the time before we discovered Rethink. I also realized that we had to fight for better services and to combat public ignorance and stigma, so at a national AGM a few years later I volunteered to set up a local group – that was about four years ago.

I think your experience right at the outset is what influences you to get involved – the first contact you have with an organisation is paramount. Often this contact is with a volunteer – a service user or a carer so I feel very strongly about offering training and support to those volunteers who are the first contact for enquirers.

How are you involved with Rethink?

I'm the coordinator of the Suffolk Rethink Severe Mental Illness Group. We're a campaigning as well as a support group and are for users as well as carers. We do things like mental health information stalls at local events. We try to raise the profile of severe mental illness and talk to people. We talk with statutory services about issues. We're gathering people to us, but it's often hard for people to get to meetings so we have a group newsletter. As coordinator and a telephone link I support people over the telephone, send them information about Rethink, and

about severe mental illness, put them in touch with Rethink services like our National Advice Service and also other local organisations and services that can help.

About three years ago I became a member of the Eastern Area Committee (now the Eastern Regional Committee). Each Regional Committee elects a national Trustee, and I was elected in 2003.

All this demands a big commitment of time. I find myself invited to join bodies like local mental health statutory and voluntary partnerships, give presentations on social worker training courses and to Community Mental Health Teams. Some weeks it is like a full-time job and sometimes I have to say no to things because it all becomes too much.

What happened when you first got involved? Did you receive any training or written information?

I had a lot of support from the Group Development Officer. She came to the first few meetings of our group. I also got a 'group guide' – a really useful book about how to set up and run a Rethink group. It includes draft terms of reference.

How does Rethink support you to stay involved?

I have support from the staff if I have problems or queries, and from fellow committee members and Trustees. When I have a family crisis I also get a lot of support from fellow members. It is important to recognise that volunteers can have family or personal crises that make it difficult for them to carry out their work at times.

As a Trustee there is induction training, and some joint training with staff.

As a local group coordinator I attend an area coordinators' day every year. This is organised by the Group Development Officer. The coordinators from each area get together for training, to exchange views and to discuss concerns. There's also a monthly

coordinators' mailing which is really useful. It includes information about Rethink campaigns, items useful for local newsletters, news about research and services and general news about the charity. Members also receive a national magazine.

I have gained a great deal from going to conferences. I receive email news updates every weekday that cover all media, including medical journals and I find our websites invaluable.

Do you think that Rethink is good at involving service users and carers?

We're pretty good, but we could be better. We're still working at it. For instance, we still don't have good enough involvement in governance at a local level. We want to involve more people. At the moment we particularly want to involve more service users to improve the balance, because both users and carers are beneficiaries of our charity. We also want to reach more people from black and ethnic minority communities. We run a lot of services for mental health service users, and we try to involve them through these local services, but often not very successfully. We are looking at new ways for people to participate in the work of the charity. Not everyone can, or wants to sit on committees, so we are setting up new regional networks of user and carer activists – both to give them support in the work they do locally, and to involve them in Rethink. 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, so we are planning that these new networks will have close links with governance.

Do you think the involvement of service users and carers has made a difference to the work of Rethink?

Yes. Rethink wouldn't have come into existence without it and we had involvement long before we started to run services. We still need it because users and carers are

“ You have to be clear about why you’re involving users and carers.

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our beneficiary group and have personal experience that informs what Rethink does. They also carry out a lot of work. Rethink is a very big organisation now and employs a lot of staff, so there is a danger that users and carers will have less influence and less effect on decision-making.

I could give you many examples of the ways users and carers have made a difference recently but I’ll just name a few.

We couldn’t do a lot of our campaigning work without users and carers who are willing to speak out. We offer training to become a Rethink media volunteer.

In some places Rethink services have been set up where members have seen a local need and opportunity.

At an area coordinators’ day there were concerns about the telephone link scheme run by Rethink. We produced a paper on this for our area committee, and this was then passed to the Public Affairs Committee, which is a sub-committee of the Board of Trustees. We’re now doing a survey to find out how the role of these volunteers may have changed since the scheme was set up, and their present needs. So this is another example of a concern being picked up on.

If a new service user or carer were going to get involved with Rethink, or another voluntary organisation, what advice would you give them?

I would encourage them and tell them that it can be very rewarding, but I’d advise them

not to take on too much to start with and to ask for training and the names of people they should turn to for support.

Within Rethink, I’d find out what their interests are, what sort and level of involvement they want to offer. I’d tell them all the possibilities including details of their nearest group and about joining the Regional Network of activists. I’d suggest they get in touch with the User and Carer Involvement Team.

What advice would you give Rethink or other organisations about the best way to involve service users and carers?

I would say to all voluntary and statutory organisations, beware of tokenism. Your volunteers will become disillusioned if they feel they are not being taken seriously. There’s absolutely no point in involving them if you don’t believe in it. If your organisation is staff driven you will need to change your culture. Staff may need training in how to involve users and carers. Be prepared for the fact that your organisation might change as a result of involvement. Keep why you’re doing it at the forefront of your mind: What are your aims and objectives? What’s your vision for the future? Who are the experts? Users and carers have expertise, and staff have expertise. It’s a partnership that can be really dynamic, but it can be very frustrating for users and carers if they are met with unresponsiveness. You must get the governance right, starting at the grass roots. Staff and volunteers working together must be part of the culture of the whole organisation and not just the parts that are specifically about volunteers. There needs to be clarity (guidelines and procedures) about how staff and volunteers can and should work together and there needs to be good two way communication.

If for instance a group of users and carers have worked very hard locally to find funding for a service, it is important that they should still be involved once the organisation is running that service.

You have to get the balance right between what people can do for the organisation and what the organisation does for them. You have to put in support for people who are involved, and you have to find sufficient money to do this properly.

What's the main thing you've learned from your involvement?

I've learned so much that I can't just name one. I've learned that knowledge is power –service users and carers are so powerless in some of the situations they find themselves in. Sometimes you have to demand your rights. You need to become well informed. Rethink can help you with the knowledge you need.

I've also learned a lot about mutual support. We need practical support, but the emotional support is so important too. As a carer, seeing someone close to you experience severe mental illness can be confusing and devastating. It can make you question everything at a deep level. It can also be very isolating, especially as there is such ignorance, stigma and fear attached to this kind of illness. To have someone alongside you who's been through that experience is very helpful.

I imagine this is also the case for people who experience the illness – I can't really speak on their behalf, but this is what some of them have told me. Through Rethink I meet a lot of people who experience severe mental illness and they have added greatly to my personal understanding and my outlook on life.

Standing together we have more power to change things for the better, but we must always evaluate what we have done if we are to learn for the future.

JAN'S EXPERIENCE

Why does your organisation involve service users and carers?

Carers established the organisation and so they have been involved from the start. Our services have always involved the people using them in their running. More recently, we began really trying to actively encourage the involvement of service users, younger people and people from black and minority ethnic communities in all aspects of the organisation. We're a membership charity, so our members are involved in governance at all levels.

Who is involved?

Historically, because we started as a carers' support organisation, we have been most successful at involving carers. But about 3 years ago the Trustees decided we needed to try to be more representative of our entire beneficiary group. Many people first affected by severe mental illness are younger people, and a disproportionate number using inpatient facilities are from black and minority ethnic communities. So we've been working hard to involve these groups. Now about 30-35% of our members are service users.

How are service users and carers involved?

It's important to offer people a range of ways to be involved – from writing a letter to supporting a campaign once a year, to being actively involved as a Trustee or as a member of a regional committee.

Involvement in governance

Users and carers are involved in our governance structures – from area committees through to the Board of Trustees. We have targets for how many users and carers should be involved in individual local services. Local services have advisory groups and these groups include users and carers. Users and carers are also on advisory groups for specific national projects.

“ Involvement needs to be everyone’s job.”

Users and carers are involved as quality auditors to monitor our services. Users and carers are also on interview panels for staff appointments.

Supporting user and carer-controlled projects

We support a service user network, the Voices Forum. The Forum uses our name and charity number, but has its own clear identity. Rethink raises money to employ a Voices Forum worker, and we offer other support when requested. The Voices Forum has representatives on our Board of Trustees.

Most of our mutual support groups are carer focused and run by volunteers, mostly carers themselves, although we are interested in increasing service user involvement here too.

Involvement in policy and campaigns

Users and carers are involved in our public affairs work – as media volunteers and in campaigning. Often our campaigns are developed in response to requests from regional committees. For example, our ‘Discovered Generation’ campaign was generated at the request of our West Midlands regional committee. This campaign highlights the difficulties faced by at least 50,000 service users who are too well to be in constant contact with services, but who need support and encouragement to raise the quality of their lives. We develop policy statements to give advice to people externally about good practice, and users and carers are involved in developing these.

We have two user involvement workers. One is a carer and one an ex-service user. And we’re about to appoint a director of user and carer involvement.

We employ a lot of users and carers – although we don’t have a specific policy on this.

What about service users and carers from groups or communities that are often marginalised?

Our Trustees were very keen to ensure we’re representative of our 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 we’ve been linking with existing black and minority ethnic community groups, and we’ve produced publications specifically aimed towards these groups. Our membership amongst black and minority ethnic communities is slowly increasing. It will take time to build a relationship, to build trust.

We’ve also been working to involve young people, targeting colleges, having displays at fresher’s fairs. We’ve developed a website for young people, www.rethink.org/at-ease/.

We’ve tried to work with groups that are already in existence. We don’t want to compete – we’re aiming to form alliances.

We looked at barriers to membership and found that the membership fee often put people off. So we introduced a ‘pay what you can afford’ membership fee. So now people pay what they can afford to join, rather than paying a fixed fee.

Did you have a plan or strategy to involve service users and carers?

Yes. The Trustees agreed the need to involve more users. My team was set up to support members and mutual support groups. Part of our remit was to promote and increase membership and diversity of membership.

We 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 users could be further involved. For example, the corporate induction training that all staff have to attend includes sessions on user and carer involvement. One of the

recommendations was these sessions should be led by users and carers. There's a mandatory staff course on mental health awareness. Again the recommendation was that this course should involve service users as leaders. In all there were 26 recommendations. The report was considered by the board of Trustees.

People across the organisation are now working to put these recommendations into practice. It's not the responsibility of the user involvement workers. It's everyone's responsibility.

How are service users and carers supported in their involvement?

We offer training – there are two modular courses for carers, and we're currently planning a modular training course for service users. That means if they miss a session they can always catch up later. Often carers who go on the courses tend to stick together afterwards and form a mutual support group.

In each of our regions we run a members day, which is free of charge to members. There we offer information and support. And in each region we run days for the coordinators of local support groups. Here we offer a mixture of training, information and support.

We try to give feedback to users and carers about their input. In campaigning, we feed back through our members' magazine, Your Voice. Regional committees receive reports from staff. In local services, users and carers get feedback locally.

What difference has user and carer involvement made? What are the benefits?

Some of our campaigns have been run in response to users and carers. Often new services are developed in response to requests from local users and carers and the organisation is able to be more responsive to the needs of its membership and beneficiary group.

Breaking down the prejudice, ignorance and fear surrounding severe mental illness is a huge challenge. Our media volunteers' programme, in which service users and carers are supported in telling their stories, has been very successful.

The involvement team are now getting requests from staff who want help to involve users and carers – it's not about encouraging staff to do this. We've developed a user involvement checklist for use by our local services. We're piloting this in one area, and lots of staff in other areas want to be involved too.

How do you convince people in the organisation who may be sceptical about the value of user and carer involvement?

There is very little scepticism about user and carer involvement in Rethink – it's very much part of the culture.

Sometimes users can be sceptical, because they have had bad experiences of involvement in the past.

What makes user and carer involvement work well in your organisation?

Having the support of our Trustees is very important. And we're appointing a director of user and carer involvement, who will be part of our senior management team, so involvement will be on the map at every level of the organisation. The impetus to create this post came from the Trustees.

Users and carers now ask who was involved in a particular project or campaign, so they keep reminding us about this.

What's the main thing you've learned about involvement? What would you do differently if you could start again from scratch?

If I could turn back the clock, I would employ the service user involvement workers earlier. User involvement in governance has made a real difference. They have been able to identify areas where we're weak.

Involvement needs to be everyone's job.

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
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Website: www.breakthrough.org.uk

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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.

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Useful reading list

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Sharing our experience



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



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