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CANCER SUPPORT**

# **Getting involved**

**Practical guidance for organisations**

# Chapter 1: What is user involvement?

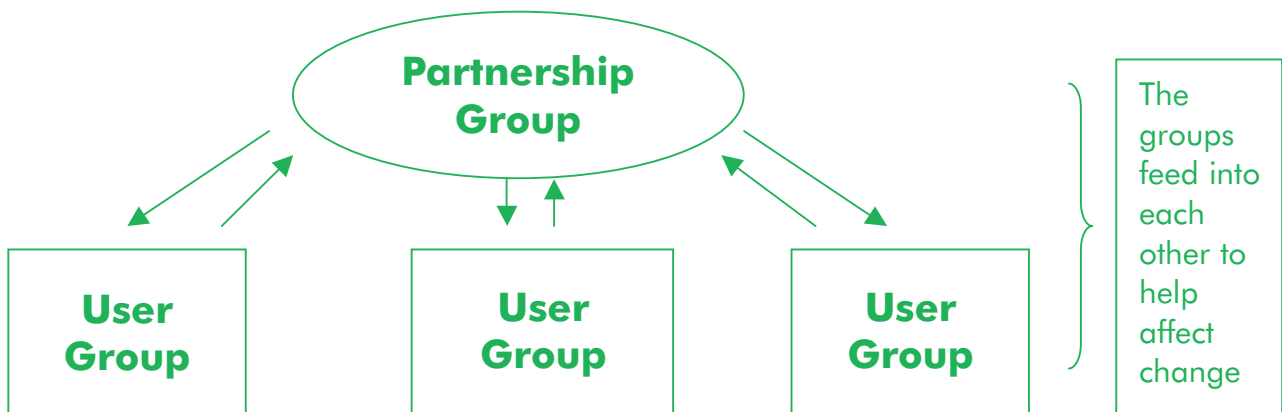
## What the NHS has said about User Involvement

The development of cancer services should be patient-centred and take account of the views and preferences of patients, families and carers, as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional.

(Department of Health (1995), A Policy Framework for Commissioning Cancer Services. A Report by the Expert Advisory Group on Cancer to the Chief Medical Officer of England and Wales – better known as the Calman-Hine Report).

## How the NHS 'User' system works

**The country is divided by the NHS geographically into 34 Cancer Networks.** Each Network has User Groups within it. These User Groups report to the Network's Partnership Group, (called so because the users and health professionals work in partnership with each other to improve cancer services).



## The principles of user involvement – why you should involve users

User Involvement is about people whose lives have been affected by cancer becoming a part of the apparatus for making decisions about future cancer services. Users are people who have used cancer services such as the ones provided by your organisation. By involving users in your projects you are able to gain unique patient input so that the decisions you make can be the most relevant and useful to your future service users. The users you involve can tell you what your decisions are going to look like from the patient/carers point of view.

A person affected by cancer either directly, as a patient, or indirectly, as a carer/relative/friend has a valuable experience of using cancer services, be those of the NHS, charities or any other organisation. By listening to those experiences and drawing on them you can improve the service your organisation provides.

At Macmillan we call all the users involved in our work 'Cancer Voices' because these are people who want to use the voice of their experience to improve cancer care. Macmillan can offer these people training to help them to learn to use their experience to the best possible advantage. Training is also open to the professionals that work with users, and programmes for users and professionals have been very successful. If you, or the users involved in your organisation or project would like to receive Macmillan Cancer Voices training contact Heather Petty, Training Administrator on 0207 091 2010 or email [hpetty@macmillan.org.uk](mailto:hpetty@macmillan.org.uk).

### **Why people may want to get involved in your project as users**

When a patient becomes involved as a user it is important to remember that as well as bringing their patient experience with them, they bring a wealth of other experiences both social and professional. Some users may be unable to return to work full time because of cancer but may be looking to exercise their skills again in a professional environment. Some patients may be looking to achieve something on a personal level from involvement, using their experience to make things better for other people in the same situation.

### **The Aylesbury Vale user group – setting up a new breast prosthetics room**

*The existing prosthetics room was a cupboard, filled with other prosthetics. It was hot, stuffy and cramped without a mirror. Furthermore, representatives from only one company provided the service and the patient may not have met them before their first fitting. In short, it was not a quality, caring service. Breast patients in the group got involved by devising a business plan and case of need to establish a breast prosthetics room across the corridor from the cancer information room. Now there is one room with a wider range of prosthetics from a variety of companies. Swimwear is now available for patients to try on too. The new room is light with heating for cooler days, comfortable chairs and no smell of rubber from other prosthetics. Also, patients can wait in the comfort of the information room with a member of the cancer management team always there to offer a cup of tea and some support. It is a sustainable change and patients really appreciate the changes. The group is now keen to work towards setting up a wig service.*

Bringing new people into your work can seem off putting especially when you think that these people have had negative experiences or may be hostile towards you. User involvement is about working together to improve services; looking forward and using experiences from the past only to make improvements for the future. You and the users you are working with are working towards the same goal – to make things better.

It is natural that there will be concerns on both sides about working together and these may include:

### **Concerns for users**

- not knowing what to do
- causing a problem or getting into trouble if they complain and losing what services they have
- making fools of themselves
- being saddled with responsibilities they're not able to take on or keep up.

### **Concerns for professionals**

- they will be criticised
- the skills they have will no longer be valued
- what power they have, they may lose
- they won't know how to work in the new ways which people want
- there won't be a job or role for them any more.

It is important not to ignore the feelings that come up during your work with users as these may make people on both sides reluctant to be involved. Addressing these feelings and doing your best to put everyone at their ease will make user involvement far more effective. Feelings that may come up include:

- embarrassment
- worry
- anxiety
- suspicion
- nervousness
- depression
- powerlessness
- frustration
- resignation
- fear.

## **Users' questions**

There are lots of potential questions a user might ask and it is best to give them as much information as possible before you start your project so that you do not lose people along the way.

### **What does user involvement mean in practice?**

It can mean

- membership of local committees which decide about future cancer services
- providing guidance for doctors and nurses on what patients want and need
- helping to train health professionals to design patient information
- being involved in decisions about the design of hospital buildings
- working with health professionals on raising awareness of health issues e.g. Smoking
- helping to design questionnaires which ask patients about their experience of cancer services and being involved in research projects.

### **What is the difference between user groups and self help and support groups?**

User groups are often confused with self help and support groups for cancer patients. Self help and support groups are different – they are more commonly groups of people who support each other through sharing their experiences. For example, in a breast cancer support group they might discuss their views and experiences of breast reconstruction.

User groups are about people influencing and changing services through working with health professionals. User groups usually explicitly say in their publicity that they are not a support group so that people do not come under a false impression. However, user groups will signpost people who need support to local self help and support groups. Equally support groups may decide to act to influence cancer services so there are overlaps.

### **How much time and energy will it take?**

Deciding how much time and energy to commit to user involvement is important. For individual members this will mean working out how much free time is available and deciding how much they are prepared to offer to user involvement activities. This may vary over time – so be prepared to be flexible. New members can talk to existing members of the group about time commitment and come to an agreement on what they can manage. Make sure there is understanding that they may be unable to attend meetings or input into projects or discussions, due to personal circumstances. It is important to schedule meetings and deadlines to take account of members' time requirements. It helps for groups to plan their meetings in advance, so that members can make arrangements to attend.

### **How much money will it cost?**

Generally, a user group member will spend money on: travel (to meetings, on visits etc.); subsistence (drinks and food while travelling to meetings etc.), and overnight stays when attending conferences. You must decide what your user expenses policy will be. Macmillan has a sample user expenses policy which you may find a helpful guide. NHS user groups normally have a policy on paying user representatives for their time or expenses but if there is no policy, suggest that the issue is discussed at a meeting.

### **What about personal issues or complaints?**

Personal issues and/or complaints should be dealt with separately from user involvement work. In an ideal world, any complaints about the care received personally or by a relative or friend, should be made before moving into user involvement.

### **NHS**

The local Patient Advice and Liaison Service Officer (England), Community Health Councils (Wales), Local Health Councils (Scotland) should be able to help users to work out what to do about complaining on specific personal matters.

### **Other organisations**

Ensure that the users (and professionals) within your group or project team understand how the complaints procedure of your organisation works.

## Chapter 2: How do we involve users?

User Involvement in your organisation might mean running a user group, or it might mean having users involved in the different projects your organisation is working on. At Macmillan, users, or Cancer Voices, are involved in lots of projects, from being on newsletter editorial teams, to being part of a stakeholder group in our small grants team. We are striving to embed user involvement in every aspect of our work at Macmillan, because we know the Cancer Voices we work with can give us the benefit of their knowledge and experience as people affected by cancer. In doing so they can help us to make our services as relevant as possible to other people affected by cancer.

### **How do we set up a user group within our organisation or for our project?**

There are different ways of involving users, setting up user groups is one of these ways. A user group is a group with both professionals from an organisation and users working within it. The NHS has set up lots of user groups and normally begins the process by holding a group development day.

### **Good planning is the key to setting up a successful user group**

A development day is an opportunity for everyone to find out about how they can get involved and decide whether they want to set up a group. Planning a user involvement development day with small groups of professional colleagues and other service users will ensure that the new group benefits from both perspectives. Staff need to support the idea before you start. They should be able to answer the following questions:

- why do you want to set up a users' group?
- do you have the support of your senior colleagues?
- do you have financial resources to support the group?
- do you have time to support the group?

It is important that the professionals are aware of the resource requirements, time and impact the group could potentially have. Involving users will mean a change in the way in which they work. Holding a workshop for staff to explain user involvement where there is scepticism or concern can help to remove the fear some professionals have about working with users.

## **People you should consider inviting to the development day for the user group you are trying to set up**

- self help and support group members
- patients and carers
- black and ethnic minority community members
- cancer service user representatives who may already sit on committees
- relevant members of your organisation
- staff from organisations affiliated to yours or with an interest in your work
- clinical nurse specialists (for NHS user groups)
- cancer network lead clinician, nurse, manager and leading member of staff for service improvement (for NHS user groups)
- patient forum members
- public and patient involvement staff/members
- local service improvement facilitator
- GP specialising in cancer
- key communications person and/or Strategic Health Authority partnership manager (for NHS user groups).

## **What makes a successful development day?**

- advertising – through local radio, newspaper, leaflets and word of mouth
- planning a long way in advance
- finding an easily accessible venue
- choosing a day of the week people can make – Saturdays are often best so that those who work can also be involved
- providing information packs
- providing refreshments
- planning lots of time for discussion in the programme for the day
- making people feel welcome
- making sure there is a trained counsellor on hand to provide individual support if required
- fixing a date for the next meeting before everyone leaves and make sure people are aware of what will happen next
- recording the day and feedback to everyone who attends
- recording names and addresses of participants, perhaps through the use of a response card, which also records a participant's future interest.

Macmillan Cancer Voices can help with setting up a new user group. Cancer Voices works with health professionals and users who are planning to set up user groups. We will be able to help and support the planning stage and will provide materials and jointly facilitate a user involvement development day.

## **What makes a successful group?**

### **Support from the 'powers that be' within the NHS**

Is the cancer network behind the setting up of a user group? Each cancer network has a board or steering group and is led by a lead clinician, lead nurse, member of staff responsible for service improvement and lead manager. It is important to have the active support of these key people. The staff member responsible for primary care for the cancer network is important too because the group will need resources and primary care trusts fund cancer services including user involvement.

### **Outside the NHS**

It is important to have the support of some key members of your organisation because your groups will need resources and possibly funding from them. Having the full support of your organisation will also indicate to the users you work with that the organisation takes their involvement seriously and that is it not just tokenistic.

### **Resources**

Money to support the group is vital. Groups will need to be able to pay for travel expenses, venue, publicity materials, attending conferences, hosting workshops and other costs. It is anticipated that on-going NHS funding will demonstrate a real commitment to listening to user views.

### **Awareness of emotional issues and knowing how to emotionally support users**

For some users the experience of being involved can bring back difficult memories and it is important that your organisation knows how it can support the users it works with through this. The users you work with may already be part of a support group, but if they are not then you should be able to refer them to one where they can talk about their feelings. A support group is where anyone affected by cancer can meet other people in a similar position to talk and support each other.

### **Links**

Groups should be linked to local community groups and self help groups. Self help and support groups members often join user groups in order to make sure the views of their members are heard. Their involvement is key to the success of a user group. Make sure that you have invited all your local self help and support groups to attend the user involvement development day.

## **Champions**

Finding people who can act as champions for the group can help it to start to influence local services. Health professionals from the local trusts, primary care trusts (PCTs) and network management groups should be invited and included. This will also help the group to recruit other allies who can help to spread the word to other health professionals and users.

Find champions within your own organisation who can help to promote the work of your user group or user involvement project.

## **Information**

Information is needed to help people to make informed choices and give their informed consent. Information needs to be readily available, accurate and equally accessible to everyone. Health professionals are an important source of information. Making good relationships can ensure groups know what is going on locally and help them gain more local influence.

## **Equal access and opportunities**

Groups need to involve as many people with different views as possible. Sometimes we talk about groups needing to be 'representative' of a wide range of views. The views of marginalised groups such as black and ethnic minority views and those who feel unable to participate for physical, emotional, social or economic reasons should be recognised. A black and ethnic minority national network of Macmillan Cancer Voices has been set up with members across the UK. For further information contact Damyanti Patel, Black and Ethnic Minorities Communities, Macmillan Cancer Support's User Support and Involvement Team on 020 7091 2004.

## **What makes a successful meeting?**

The following points should be considered before holding a meeting. This can help to ensure that the meeting is conducted well and achieves a positive outcome.

### **Arrangements**

The setting and arrangements for service user and carer involvement meetings are very important and will make a big difference to their success or failure. The following considerations cover all types of meeting, including training events.

### **Venues**

Venues should be comfortable, light and airy with efficient air conditioning, adequate access for disabled people and good acoustics so that everyone can hear.

### **Pace**

Meetings should be well paced. Meetings where people have different communication needs are likely to take up more time than many people are used to. Timed items can help avoid a rush towards the end.

### **Thoughtfulness**

All contributions to the meeting, including presentations and discussions need to take full account of non-professional representatives. Remember to use plain language, straightforward explanations, real-life examples and avoid jargon.

## **Respect**

All those attending a meeting need to feel respected, listened to and confident that their contribution is valued. Quiet attention to all contributions is needed. Any disrespectful comments and discriminatory language must be firmly discouraged.

## **Location**

As far as possible the location of any meetings should be convenient for all participants. Thought should be given to whether public transport provision is good and to the access requirements of any disabled people who want to attend.

## **Timing**

Ask people what time of day they would like to meet and whether it should be week days or weekends. Daytime meetings and week days might mean that people have to take time off work. Early evenings or Saturday mornings can be popular times. If there is no agreement, alternate times so that everyone can have a chance to be involved.

## **Working with health professionals (in the NHS)**

Some groups choose to involve health professionals more than others. The advantage of working with health professionals is that they are part of the system the group is trying to influence and can help to change services and keep the group informed.

Working together, however, means understanding and respecting everybody's point of view. Sometimes users come with bad experiences of using health services and express their anger towards all health professionals. Equally health professionals can have negative perceptions of users. Finding ways of working together is vital. One way is through the Macmillan Cancer Voices training that helps users and health professionals to explore their perceptions. The following is an example showing how service users and health professionals have negotiated ways of working together.

### ***South West London cancer network partnership group – changing the attitudes of health professionals***

*This group undertook some work with health care professionals over their attitude towards user involvement and produced a set of guidelines. In any formal meeting where user representatives and health care professionals are working together there will be an agreement that the following will be observed by all those present:*

- *confidentiality will be agreed and respected*
- *one person will speak at a time – and will be listened to*
- *there will be respect for everyone's opinion and point of view*
- *experience in whatever capacity will be valued*
- *everyone will be given an opportunity to participate*
- *if something is unclear clarification will be requested and provided*
- *it is acceptable to disagree but this will be done within the parameters set out above.*

## **What to do at the first meetings**

It is important to follow up a user involvement development day with a first meeting as soon as possible to show that you mean business. Too often users find they have given their views and then nothing happens. Meeting regularly, especially in the early stages, is important in building the group and maintaining momentum and interest.

## **Terms of Reference document**

First of all, groups need to agree on a role and purpose as well as being clear about rights and responsibilities. It's also important to decide which people should join. Drawing up a document called a Terms of Reference, setting out the reason why the group exists and its job description, is a good place to start.

The following case study shows the Terms of Reference document written by one cancer network partnership. New groups may find that some of the aims are similar to their own. They can therefore create their own Terms of Reference based on this group's document.

### **South West London cancer network partnership – Terms of Reference**

*The South West London cancer network partnership is a group of people with an experience of cancer who work together to improve the provision of local cancer services.*

*We aim to:*

- 1. maintain an overview of user involvement in South West London*
- 2. provide a forum and focus for all aspects of user representation*
- 3. be a conduit for the exchange of ideas and information between statutory and voluntary cancer service providers and users*
- 4. identify and voice a broad range of user views*
- 5. implement real improvements to local cancer services and assess the quality of those changes*
- 6. ensure that health care professionals and users meet as equal partners*
- 7. ensure that partnership members can contribute to research and education programmes.*

*We aim to do this by:*

- 1. increasing health care professionals' understanding of the users' perspective and vice versa*
- 2. overcoming barriers to user involvement*
- 3. improving communications between users and providers*
- 4. working in partnership with other organisations providing clinical, education and support services.*

## **Mission statement**

It is important to have a clear mission statement. This is a concise and meaningful paragraph or a few paragraphs which sum up the underlying ethos and overarching wishes of the group. Further information is available from Macmillan Cancer Support's Community Networks Team.

## **Decide how the group will be chaired**

The chair has responsibility for coordinating the group and managing the meetings. Ideally the chair should be a service user. Having the right chair helps to make meetings run smoothly. It is important to elect a chair early on and make decisions about how chairing should be organised. There are various options. A chair could be appointed for a fixed period of time. Alternatively, the group may decide to rotate different chairs or split the role between a health professional and service user. Good practice suggests that service users should take on the role of chairing in some way.

## **Publicity and marketing**

Publicity about the groups is very important in order to attract new members and make sure that health professionals are aware of the group. Most groups produce their own publicity leaflet that explains their aims and activities and gives contact details. In addition to this user groups might use the local media and press to raise awareness about their activities. Within the NHS, they might do presentations for staff or produce posters to be put up in out-patient clinics or GP surgeries.

## **Welcoming new members**

It is important to make sure that potential members of the group receive a welcome and are fully informed about the purpose and activities of the group. This can be done in a number of ways. Some groups have a welcome or induction pack, others arrange for potential members to be visited or telephoned so that their queries can be answered and they can get to know a member of the group before attending their first meeting. It is a good idea to make sure that new members have transport. Making arrangements for them to be accompanied to their first meeting could also be considered.

## **Central South Coast cancer network – welcome letter for new members**

*Welcome to the cancer network user involvement project*

*We would like to welcome you to the user involvement project in the Central South Coast cancer network. We look forward to hearing from you about your experiences and working with you to look at ways of improving services in this area. User involvement is about patients, carers and health care professionals getting involved in feeding back about cancer services. It can also mean getting involved in the planning and decision making of new cancer services both locally and across the whole cancer network. We have put together a welcome pack of information, which we hope you will find helpful. This includes information about cancer services and what the cancer network is and the area it covers. It explains further what user involvement is and how this has been and is continuing to develop across the cancer network. Also included are: the terms of reference for the network user/partnership group; a work programme; dates of future meetings with a map of the location, and information on expenses.*

*If you have any questions or issues that you would like to discuss please do not hesitate to contact me on 02380 725518 or 01983 534006.*

*We look forward to working with you.*

*Yours sincerely*

*Andrew Gallini*

*Network user involvement facilitator*

## Recruiting new members

This will be an on-going task. This can be done via the group's website, media, local hospital magazine, volunteer and carers' newsletters and the Cancer Voices section of the Macmillan website. Generic public and patient involvement staff can help by taking the group's leaflets to practice managers, GPs and hospital staff. An annual cancer road show or other annual open general meeting is another useful opportunity for recruitment.

## Equal opportunities

Attention should be paid to equal opportunity issues when setting up user groups. Groups should be accessible to all persons regardless of race, gender or disability. To ensure this is the case, groups should consider accessibility issues. For example translation, disability aids and access requirements. Any additional costs relating to equal opportunity issues should be considered in the planning and costing of the group. Make contact with local community groups and ask them how they would like to be involved. Your local PALS or volunteer bureau could help you to identify these groups. In some areas, black and ethnic minority forums are now being set up as part of the National Black and Ethnic Minority Network to enable community members to become involved in their local area. These forums are linked to user or partnership groups. For more information about this initiative contact Damyanti Patel, Black and Ethnic Minority Communities, Macmillan Cancer Support's User Support and Involvement Team on 020 7091 2004.

## What other areas do new groups need to consider?

### What training is needed?

Everyone needs training to increase his or her say and level of involvement. This applies to policy makers, managers, professionals, direct and indirect service users. What's more, service users and others seeking more say have a central part to play in the development and provision of training.

Once the group has met, members may want to take part in the two day Macmillan Cancer Voices training to develop skills together as a group. Experienced facilitators carry out the training and have experience as user representatives themselves. The training is for users, or users together with health professionals. All Macmillan Cancer Voices training is free. The training includes confidence building, understanding the NHS, working on committees and making a case for change. The training is flexible to accommodate individual group's needs for example, help in developing terms of reference or action planning.

Contact Heather Petty, Training Administrator on 0207 091 2010 or email [hpetty@macmillan.org.uk](mailto:hpetty@macmillan.org.uk) for more information.

*'Training is important to make a good user, but don't be trained so much as to take out the openness, reality and passion'. Pat Fairbrother, Peninsula cancer network user facilitator.*

# Chapter Three: Facilitation

## What is a facilitator and does our group need one?

In the NHS the group's facilitator should be accountable to your partnership group via the Chairperson (who should be a user). In other organisations the facilitator should be accountable to the member of staff responsible for user involvement in your organisation.

Depending on local funding arrangements, the group may want to consider whether it wants to appoint a facilitator. Cancer networks across the country have approached this decision in different ways. Some appoint facilitators before a user group is established and other groups wait a while before deciding to appoint a facilitator.

Facilitators can make life easier. They are usually employed to help the group run smoothly and effectively. They have a key role in helping the group develop and in building the crucial relationships with the professionals. Facilitators can also provide an important and valuable sense of continuity by keeping meetings focused and on track.

The facilitator's roles and responsibilities are to support the user/partnership group by:

- providing support to users (patients and carers) on the group and forming an effective relationship with the chairperson
- preparing papers for group meetings
- briefing members before meetings
- taking minutes at meetings
- making other practical arrangements as necessary
- developing the skills and knowledge of users for participation in the group including arranging training for members
- building and maintaining effective relationships with a wide variety of people
- communicating effectively, verbally and in writing.

## Issues to consider when recruiting and selecting a facilitator

### Advertising

Advertise through all appropriate channels including local media and voluntary sector networks as well as NHS networks and other government and public sector channels. Allow as long as possible between placing an advert and the closing date to ensure all appropriate candidates have the opportunity to apply. This should apply to recruitment advertising too. It is important to pay attention to equal opportunities in any advertising.

### **Selection and recruitment**

Users should be actively involved (alongside cancer network representatives) in short-listing candidates against agreed criteria and person specifications. Construct interview panels with a majority of users, supported by a relevant network representative(s), or professional(s) from your organisation. Identify a user chairperson for the interview panels.

### **Induction**

Agree an induction programme for the facilitator where users play a key role in identifying stakeholders and activities to be undertaken.

### **What if the group doesn't feel it needs a facilitator or can't afford one?**

It's up to the group to decide. Individual groups may want to spend resources differently. It's important that the group discusses the pros and cons of whether to seek a facilitator or not.

### **On-going support and professional development for facilitators**

On-going training and support is offered by Macmillan Cancer Support's Community Networks Team through a support programme as well as opportunities to meet together with users to share and learn together.

# Chapter Four: Learning from the experience of other groups

Visiting other groups can provide ideas about how other people do things, the pitfalls and opportunities. It can also provide you with friends who will support you as you develop the group because they know what it is like. Macmillan Cancer Support's User Involvement administrator can put you in touch with your local user groups. They also organise regular regional and national events which enable user group members to meet together to discuss issues and learn from each other. The Cancer Voices newsletter is also a good place to find out what other user groups have been doing and the impact of user involvement in other organisations.

## Finding out about other local groups

By finding out what groups exist locally you can compile your own local directory that will be useful for your group, professionals, and users in your area. Local groups you might want to include are: cancer self help and support groups, user groups, branches of national cancer patient organisations, community groups, and interested individual patients and carers.

The Cancer Voices section of the Macmillan website is a good place to look for sharing ways of doing things and learning from the experience of other user groups. Terms of reference and general good practice guidance will shortly be available on [www.macmillan.org.uk/cancervoices](http://www.macmillan.org.uk/cancervoices).

## Learning the Dos and Don'ts from other groups

### Don't

- Assume that partnerships are always well planned
- Rely on previous ways of working
- Assume everyone is involved for the same reason
- Set expectations high at the start
- Expect members of the groups to get along instantly or simply 'slot in'.
- Avoid tackling sensitive issues such as accountability, power and leadership.
- Miss out key people who should be part of the group
- Assume certain people will automatically do all the active work in the group
- Wait to be asked to take an active role
- See communication as only one-way
- Assume people automatically understand what's said
- See other organisations and their practices as 'threats'
- Underestimate the influence of cultural factors.
- Make assumptions about what other organisations do
- Assume other user groups/ partnerships have all the answers
- Get stuck in a rut of business agenda meetings
- Wait for problems to arise before seeking outside help
- Automatically look outside the partnership to solve problems
- Let the user group/partnership become a 'talking shop' (all talk, no action).

## Do

- Be prepared to set aside time for exploring and negotiating relationships first
- Explore new ways of working together effectively
- Establish a clear common purpose
- Set smaller goals initially – ‘little hits’
- Allow time for group members to get to know each other and establish roles
- Work towards establishing mutual understanding, trust and respect based on transparency and honesty.
- Agree who should be included and review this decision regularly
- Explore ways of delegating and sharing active roles within the group
- Offer to take an active role, if that’s what you wish to do
- Listen and demonstrate that you’ve listened
- Avoid jargon
- See making relationships with other organisations and groups as an opportunity
- Address all aspects of cultural diversity and include equal opportunities awareness
- Use opportunities early on to explore and overcome stereotypes
- Keep abreast with good practice in user involvement in other areas
- Provide opportunities for members to explore their individual abilities and aspirations as well as those of the whole group
- Consider whether/how to use consultants and facilitators
- The user group/partnership should be a resource for its own learning and development.
- Ensure the user group/partnership is geared towards making changes in the real world.

## What’s next?

Once the group has set up its ways of working and members have attended Macmillan Cancer Voices training, it’ll be time to get on with making an impact.

## Planning

Good planning is crucial to any user involvement projects. In planning tasks and objectives, account should be taken of the likelihood of a positive outcome – early successes are more likely to give the group confidence and increase enthusiasm. Good planning is about agreeing on goals and timescales and being able to prioritise, keep an eye on progress, and work out how to get things going again if they get stuck. It is good practice to set a plan for a year and to aim to agree three main goals to be achieved during that time. The group is more likely to keep its membership and to keep them motivated and energetic. The group will also find it easier to gain credibility with professionals if it has a clear plan of action. It is important that the group plans a balance of work for the professionals and the users. This is partnership in action and it works.

## Finding shared goals

Group members need to get to know each other. It's important that careful and clear introductions are made and that everyone has time to share experiences and ideas. The next step is to set out goals and make sure that they are 'shared goals'. One member may feel very strongly that car parking is the most important issue to tackle, However, compromise will be necessary if the majority of members decide it's more important to tackle another issue first, such as the urgent lack of readable information on chemotherapy.

## Prioritising the needs of service users

Always try to keep at the forefront the idea that the group is involved in work to make the cancer journey easier for others. This means keeping the needs of service users as a priority. There is plenty of work that has been done on the issue of needs and the research tends to show that this is what people with serious and life-threatening illness want:

- to be treated as a human being
- empowerment
- information
- choices
- continuity of care
- equal access
- to have their physical, psychological, social and spiritual needs met.

An important key to success is to enable users to be involved in tasks as soon as possible. A useful rule to work by is to aim for some 'quick wins' and then develop from there. To achieve quick wins, tackle tasks that are easy to achieve in a short space of time so that the group will be motivated by seeing the results of effective action early on. An example of the sort of issue which can be tackled early to achieve a quick wins is producing some basic information directing patients and carers to telephone numbers of help and support agencies.

## Routes of influence

### Local champions

Groups need to identify the key influencers in the locality. These are the people with the power, control of the budgets and the respect of their peers and staff. There is no point in presenting a brilliant proposal for helping health professionals (for example, on how to break bad news) to someone who may be sympathetic but has no real power or links to people with power. Remember that influencers don't have to be the people at the top who make the final decisions. Someone much lower down the hierarchy who has a good relationship with the key influencer could be just as useful.

In a local GP surgery an influencer might be one of the GPs, a practice nurse or a district nurse. In a cancer network an influencer might be the lead cancer nurse or the Patient Advice and Liaison Service (PALS) officer. There is no substitute for personal contact with these people.

Always bear in mind that people have their own agendas. Be wary of doing the influencer's work for them. However, if what they want and need fits with the group's aims and objectives, doing it may be a powerful way to influence. Never forget that the group is there to make things better for cancer service users like its members.

Developing relationships with influencers needs empathy on both sides. This involves the ability to understand and accept that people and groups are coming from different places, may have different priorities but can also have shared aims. Influencing in this way needs all participants to listen as well as talk.

### **Northern cancer network partnership – a variety of ways of influencing**

- *Chair and vice chair are full members of the network strategy board*
- *Requests from network professional groups for panel members to work with them ie. national cancer research network steering group*
- *Links with patients advice and liaison services within the network region to advise the panel of trends in concerns raised around cancer services*
- *Developing links with member trusts, patients forums and strategic health authorities patient and public involvement activities.*

### **Community networking**

User involvement can be developed across a network by:

- *establishing networks and contacts with all relevant local/community groups and individuals*
- *developing methods of communicating with a network of users and potential user representatives, including leaflets/newsletters/local media to encourage participation in the group*
- *supporting the development of a network of cancer user and support groups across the cancer network*
- *working with community groups including ethnic minority groups.*

### **Health professional training (NHS)**

This can be achieved by:

- *developing the awareness of health professionals in the cancer network about the work of the group*
- *developing the skills and knowledge of health professionals for participation in the group.*

Successful user involvement requires training for staff and users. Groups are involved in staff training in a number of ways included the development of a curriculum for oncology nurse training at local universities.

### **Manchester patient user partnership (PUP) – influencing through raising awareness**

*The PUP group ran a seminar for healthcare professionals about user involvement in cancer services, which was very successful.*

*The reasons why the PUP group ran the event was to:*

- *raise awareness of user involvement within the network*
- *educate healthcare professionals*
- *identify some ‘champions’ within the network*
- *promote the development of the PUP group and advertise the development day.*

*What the PUP group did:*

- *used the Christie NHS Hospital Trust Education Centre because it was familiar to professionals and free of charge*
- *invited all staff responsible for cancer services and primary care trust and trust boards from across the network*
- *Macmillan Cancer Voices team of regional contacts gave presentations*
- *gave opportunity for questions/concerns to be raised*
- *gave information of how the PUP group would operate within the network.*

*Was it a success?*

- *good attendance*
- *evaluation report completed which showed the seminar met its objectives*
- *identified some 'key contacts' and 'champions'*
- *helped distribute information which directly resulted in more contact from patients and professionals.*

### **Links with key NHS initiatives**

Links with patient and public involvement and other key NHS initiatives are an important way of strengthening and consolidating a group's influence. It's important to keep an up to date working knowledge of NHS initiatives and opportunities to influence change.

User representatives should be supported to participate in these other bodies and facilitate effective two-way communications between them and the group. For example, group members could represent the group as part of public and patient involvement forums (PPIFs) or staff from these bodies could be invited to come to group meetings.

### **Initiatives within other organisations**

As well as staying up to date with NHS initiatives, you should try and stay in touch with like minded organisations to your own, or one's whose agenda may overlap with yours, such as social care charities and citizen advice bureaux. Making positive changes in cancer services is your common goal and you may find overlapping work or research helps you with your projects. It may also help you to see how user involvement is making a difference in other organisations and give you ideas for your user group/project.

### **Influencing through meetings and presentations**

Invite people to come and speak to the group. There is no substitute for meeting people with influence directly and impressing them with the group's plans, commitment and willingness to work in partnership. Some groups choose to invite health professionals from key committees or organisations to come to their meetings as an alternative to their members sitting on a wide range of health committees. Attending local and national cancer conferences and meetings are other ways to meet people with influence.

## **West Anglia cancer network patient user partnership – influencing through presentations**

*In order to maintain the profile of the partnership numerous presentations have been made to local primary care trusts, relevant meetings and to national conferences. The partnership members have decided, as a group, who should make these presentations (all by users). They have mainly been done by the chair, the vice chair and two particularly keen user members. As a result the partnership is seen as a respected and important forum. Users across the network have the opportunity to have their views listened to and respected and acted upon where possible. The partnership has influence within the NHS and in the fact that there is patient representation at the executive board and on the policy board. Members are invited to key meetings within the network and at conferences as and when they occur.*

*Personal accounts of both cancer and treatments can influence the way services are offered and also the patient/clinician consultation. Some service users have enlisted the help of local MPs as a way of harnessing political weight to their activities.*

## **Influencing through committee membership/representation**

Users are now being asked to sit on wider cancer service committees. Most groups have user representation on network boards and tumour site specific groups. Mapping out the committees and groups which the group might influence is a useful exercise. However caution should be taken not to overstretch the ability of members to attend all the meetings.

Membership of groups at local level can often lead to the opportunity to become involved at national level. Committees and project groups are often set up for national cancer initiatives and require user involvement. Macmillan Cancer Voices informs groups about these opportunities through the website and newsletter as well as through regular mailings to groups.

# Chapter Five: We want to involve users, but we don't want to set up a user group

Other ways to get users involved

- fielding questionnaires about users' views or needs
- getting on the Cancer Voices section of the Macmillan website and other websites and inviting users to put their views across through web based discussions or surveys
- involving users in initiatives such as training health care and other professionals
- encouraging users to express their views and experiences in other ways such as through art, writing or theatre.

These activities are often part of the support offered through community resource centres, community groups, self help and support groups and day hospices. It is important that user groups find ways of getting the views of a broad range of people especially those who might not be able to come to meetings. Users can be involved in any way that suits their personal circumstances.

# Chapter Six: Measuring Success

This section concentrates on two key elements that should be part of any work in progress – monitoring progress and evaluating success.

## What is monitoring progress?

Monitoring is a method for answering the question: ‘how are we doing?’ It is used to keep an eye on progress while a process is ongoing.

It is important to monitor so that

- changes can be made to the timetable or tasks if necessary during the course of a project
- lessons learnt can be fed into later projects
- it’s part of managing the project
- it helps ensure that projects aren’t abandoned and forgotten about.

## What is evaluating success?

Evaluating success is a method for answering the questions: ‘how did we do?’ / ‘what did we change?’. It is an assessment of the impact of a particular change that has been introduced. It is generally undertaken at the end of a piece of work or at a key point in the lifetime of a project that is agreed at the start.

Evaluation focuses on whether a piece of work has achieved its aims and objectives, as set out in the group’s strategy. The purpose is to determine what has worked and what hasn’t and to develop a work planning process that builds on past experiences.

Evaluation will focus on whether the group has achieved its aims and objectives in bringing about change. It is a crucial part of the improvement process to demonstrate benefit and also to ensure that the changes that have been introduced can be maintained.

By monitoring and evaluating work, the group can constantly review its practice and ensure that it is achieving the goals it set itself. This information can be used to:

- review and appraise the group, its effectiveness and the way it is facilitated and supported
- help future planning identify any difficulties, problems or gaps and quickly implement solutions/recommendations
- demonstrate to funders how their money is being used and how it is making a difference.

## Setting clear objectives and goals

The key elements of monitoring and evaluating are the group’s objectives and goals. If the group doesn’t have a clear agreed work plan, there won’t be anything to monitor and evaluate! Objectives should progress gradually in terms of difficulty and scope. Be wary of being too ambitious too quickly. Objectives should also be ‘SMART’ (specific, measurable, achievable, realistic and timed).

## **How does the group take this forward?**

From the outset it is important to be clear about what it is that you want to evaluate. These are some of the questions the group needs to address:

### **What are we evaluating?**

In all cases the focus should be on the aims and objectives defined for the work before or during the planning stages of the process. For example, it might be useful to measure how things have altered as a result of introducing a change (a piece of patient information or a new piece of equipment designed to improve patient dignity and respect, for example).

### **How were things before?**

In order to move forward with this, it is desirable to have a clear view of how things were before the change was introduced. However, in user involvement it is not always easy to quantify things in this way. Something like maintaining or increasing the numbers of user representatives on a group can be easily tracked from before a piece of work started until it is finished. It is a simple measure of counting. Something like changing the attitudes of consultants is much more difficult to assess.

### **Was it successful?**

To measure success, the group will need to look at the process of the work carried out as well as the outcomes or results.

### **Look at the process**

The process is important and to evaluate it the group can ask the following questions:

- how did the dialogue happen?
- how did people feel at the end of it?
- did people feel that they had been given the opportunity to express their views, to contribute and influence thinking?

### **Outcomes/results**

But for most people – staff, patients and the public – it is the outcome or results of the discussions or the changes that happen as a result of their involvement that are most important. Even if it is the most inclusive process, if nothing changes as a result of patients and the community talking to the NHS they will have their doubts about whether it is worth doing again.

### **Internal evaluation and monitoring forms**

These are ways of getting views from group members about how well they think user involvement is working. All user representatives could be encouraged to complete the form but this shouldn't be compulsory. It is important to stress how valuable feedback is and that the forms are completed anonymously.

### **Telephone interviews**

A group facilitator, chair or an interested health professional from outside the group, could be asked to carry out a small telephone survey of peoples' views on the effectiveness of the group and its activities.

## Speaking to participants

Ask participants (committee members/staff/other service users):

- whether the groups' involvement made a difference?
- how could the group have worked to utilise members' skills and experience more effectively?

Some common ways in which monitoring and evaluation can take place are through:

- questionnaires
- focus groups
- shadowing
- one-to-one interviews.

Approach these with caution! They can be labour intensive and may not be the best use of the group's time.

## Making use of the results

### Capturing learning

As a group one of the aims of the evaluation process should be to capture the learning that is part of the process. Ask:

- what went well?
- what didn't work so well?
- what would we do differently if we were doing it again?

As a by-product of being involved in work which has properly included monitoring and evaluation, members will be part of a group of more skilled people with more confidence. Members will then be able to help lead and perform even better in the future.

### Sharing learning

Make sure that you advertise your successes. The ideal place for this could be on your group or organisation's website or on the achievements section of the Macmillan Cancer Voices website, [www.macmillan.org.uk/cancervoices](http://www.macmillan.org.uk/cancervoices), in local newsletters and press. This will not only show the effectiveness of user involvement to a wide audience, but will give the users you are working with more confidence in their own ability to make changes happen.

It can also be helpful to produce a sort of annual report, showing all those who have been involved in your projects the differences that have been made over the year. This can also be helpful for gaining future funding, for keeping a record of the progress of your group and helping you to plan for the next year.

## The Northamptonshire cancer partnership

*The Northamptonshire cancer partnership undertook a patient satisfaction survey in the local oncology department. Talking to current patients they identified three things that were thought to be working well and three areas that could be done differently.*

*This work was then presented back to the department by the users. The group have subsequently been asked to undertake similar surveys for other hospital departments.*

# Chapter Seven: Challenges and solutions

## Helping each other

### Difficult behaviour

**Challenge:** Person has unresolved personal issues.

**Solution:** Clarify that group is not a support group and give options for obtaining relevant support elsewhere.

**Challenge:** Facilitation of group is weak.

**Solution:** Discuss and offer training opportunities.

**Challenge:** Group members do not understand responsibilities to others.

**Solution:** Make contact with Cancer Voices training coordinator and arrange training for the group.

### People use the group as a support group

**Challenge:** Purpose of group is not clear.

**Solution:** Ensure publicity clarifies that the group is not a support group/explain and explore differences between user involvement and support with membership.

**Challenge:** Some members may need a support group.

**Solution:** Ensure that members have information about local support groups and where they are not available, work with health professionals to make more available.

**Challenge:** Discussions raise emotional issues that need to be dealt with.

**Solution:** Make sure that emotional issues are addressed – either within the group or through contacts with local counselling services.

### Members do not want to be actively involved

**Challenge:** A few people are doing most of the work.

**Solution:** Discuss this with the membership. They may not be aware of the burden this can place on a few people.

**Challenge:** Members are not well/over-committed.

**Solution:** Review workload of the group to make sure it is realistic. Actively seek to recruit more members who have time and energy to work for the group, including health professionals.

### Losing members through death

**Challenge:** Members do not know how to deal with this.

**Solution:** Discuss and agree ways in which group wishes to approach this, for example through an acknowledgement and celebration of the person's contribution to the group.

**Challenge:** Key member, the chair for example, dies.

**Solution:** As above, plus discuss how duties of chair can be covered by the group until you are ready to appoint a new person.

## Working with health professionals

### Group is not accepted by local health professionals

**Challenge:** Health professionals do not understand user involvement/role of the group.

**Solution:** Contact the Macmillan User Support and Involvement Team for information on user involvement training courses for health professionals.

**Challenge:** The group is not recognised within the cancer network.

**Solution:** Identify key health professionals who could become 'local champions' for user involvement. Invite them to the group and explore ways in which they could help the group to influence their colleagues.

### Group is overwhelmed by requests from health professionals

**Challenge:** The group is reacting to requests with no clear plan.

**Solution:** Have a clear plan of what the group wants to achieve, which includes 'reacting' to requests but also being 'proactive' on user issues.

**Challenge:** Health professionals have unreal expectations of the group.

**Solution:** Discuss capacity and work load with health professionals and agree a way of working.

**Challenge:** Health professionals just want to 'tick the box'.

**Solution:** Ask health professionals to give reason for involving group (could be filling in a request form).

### Initial appearance of influence has disappeared

**Challenge:** Lack of real commitment from cancer network staff.

**Solution:** Use group representation on network steering group to sustain commitment – make sure there is a user agenda item.

**Challenge:** Change of staff who championed group.

**Solution:** Look for other 'champions' or suggest users are part of recruitment for new posts.

**Challenge:** No evidence of change/influence.

**Solution:** Gather evidence of influence and disseminate widely.

### Disagreements between group and cancer network

**Challenge:** Terms of Reference/aims of group unclear.

**Solution:** Revisit Terms of Reference with cancer network staff. Meet to discuss with an external facilitator.

**Challenge:** Difference in expectations of group.

**Solution:** Contact the Macmillan User Support and Involvement Team for advice.

## Running the group

### Difficulty in finding funding

**Challenge:** Loss of national funding from the cancer partnership project.

**Solution:** Obtain a copy of Funding Advice from Macmillan Cancer Support's User Support and Involvement Team. Make good links with cancer network staff and get involved in local service delivery plans for cancer services (September each year).

**Challenge:** Network makes no financial contribution to group.

**Solution:** Make good links with your local primary care trusts, which fund cancer networks and have user involvement responsibilities.

### Difficulty in recruiting new members

**Challenge:** Group not known about.

**Solution:** Group leaflet/website/cards/hold open meeting.

**Challenge:** Advertising is not effective.

**Solution:** Word of mouth is often best – visit potential members/groups.

**Challenge:** Group does not retain members.

**Solution:** Support new members and make them welcome. Review format of group meetings – talk to people who have left/involve an external person in the group who can give constructive comments.

### All members are from similar social class, gender, ethnic background and cancer type. Not enough disabled people

**Challenge:** Not effective with other social classes, genders, ethnic backgrounds.

**Solution:** Seek advice from Macmillan black and minority ethnic development coordinator.

**Challenge:** Advertising/publicity is not geared towards other groups.

**Solution:** Locate key groups and arrange to visit and discuss how links can be made.

**Challenge:** Issues that group concentrates on or exclude other groups.

**Solution:** Make contact with key contacts for other social groups, ethnic groups, genders and disabled people. Invite them to a meeting to discuss the issue of equal opportunities.

### Carry out study of local issues for excluded groups.

**Challenge:** Members all come from breast cancer support group.

**Solution:** Contact local specialist nurses for other cancers and get their help to recruit people with other cancers.

### We don't seem to be achieving anything

**Challenge:** No clear terms of reference/aims/objectives.

**Solution:** Agree terms of reference and an annual business plan. Make contact with Cancer Voices training coordinator and arrange training for the group.

**Challenge:** Direction lost over time.

**Solution:** Arrange some follow-up Cancer Voices training to refresh and refocus group.

**Challenge:** Lack of feedback about changes.

**Solution:** Ask health professionals to routinely feed back on resulting changes from group's involvement.

### **No one seems to be running the group**

**Challenge:** There is no facilitator. There is no user chair or vice chair.

**Solution:** Discuss with membership role of a facilitator, user chair and vice chair and contribution this makes to group's functioning effectively. If agreed put into effect a recruitment plan.

**Challenge:** The facilitator/chair is ineffective.

**Solution:** Discuss with individual and offer training opportunities.

### **Group is getting too large**

**Challenge:** People do not get a say during meetings.

**Solution:** Think of ways of working together differently to enable everyone to have a say, for example split into groups during the meetings or set up sub groups that work on different issues.

**Challenge:** There are too many competing agendas.

**Solution:** Set up local user groups as satellite groups that remain linked through a representative to the Network level group.

### **We seem to just be 're-inventing the wheel'**

**Challenge:** Do not know what is happening in other partnership groups/networks.

**Solution:** Look on the Cancer Voices website to share experiences. Attend national network development programme meetings and other sharing events.

# Chapter Eight: Useful information

## Contact Information

Cancer Voices Development Coordinator (UK) – Carol Gibbons  
Email: [cgibbons@macmillan.org.uk](mailto:cgibbons@macmillan.org.uk)  
Tel: 0207 091 2007

Community Networks Training Administrator – Heather Petty  
Email: [hpetty@macmillan.org.uk](mailto:hpetty@macmillan.org.uk)  
Tel: 0207 091 2010

## Glossary

User – someone who has used cancer services at any time

User Involvement – in this document ‘involvement’ means anything ranging from information gathering and consultation to having a direct say in decisions to improve cancer services.

Macmillan Cancer Voices – this is Macmillan’s way of describing users, because they are people voicing their cancer experience to help improve cancer services.

Partnership Group – A group of people affected by cancer working together with health professionals to improve cancer services as part of their NHS cancer network.

## Useful publications

NHS confederation (2003), The pocket guide to the NHS. NHS confederation. This is published annually. Separate guides are published for Scotland and Wales.

Department of Health (2001), Strengthening accountability: Involving patients and the public, London, Department of Health.

Department of Health (2005), Now I feel tall – What a patient led NHS feels like, Department of Health.

Tritter J, Daykin N, Evans S, Sanidas M. (2003), Improving cancer services through patient involvement. Radcliffe Medical Press.

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care. One in three of us will get cancer. 1.2 million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.

Macmillan Cancer Support  
89 Albert Embankment  
London SE1 7UQ

Tel 0800 500 800  
CancerLine 0808 808 2020  
[www.macmillan.org.uk](http://www.macmillan.org.uk)

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