

# **Finding out about the priorities of users and making them count**

**A report for  
Macmillan Cancer Relief**

**Final report**

**TwoCan Associates  
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## **Executive summary**

This report is about a project to explore:

1. The ways and the extent to which other charities and health and social care organisations currently elicit user priorities and involve users in priority-setting and decision-making
2. Examples of where cancer services users themselves have developed ways of eliciting user priorities
3. Ways in which Macmillan can develop a system for eliciting user priorities at a regional and national level and involve users in prioritisation of users' needs

This project was undertaken by TwoCan Associates and involved three phases: background research, interviews and a workshop.

### **Finding out about users' views**

Many different methods are used to find out about users' views on priorities. Three methods that have been used most frequently within the voluntary health sector are:

#### ***Surveys***

Surveys can be cheap to carry out, and provide quantitative data based on large numbers of people that is considered to be robust. However, they also come under the greatest criticism for lack of depth, and for failing to allow people to develop an informed view about an issue.

#### ***Group discussions***

These can take a number of forms – including workshops, conferences and focus groups. Group discussions are often non-directive. They enable people to share experiences, and to develop a consensus. However, the success of this method is very dependent on the skills of the facilitators. There may also be problems of 'generalisability', and of power imbalances within a group.

#### ***Panels and advisory groups***

These can be of varying sizes but are usually large so they can be thought of as representative of a wider group. Some panels can be long-standing, whilst others are temporary and brought together to discuss a specific issue. Members build up knowledge and experience and are therefore able to engage in more in-depth debate. However, panels can be resource intensive to maintain. New panel members may need to be recruited on a regular basis and this can be expensive and difficult if the panel needs to be representative.

#### ***General lessons***

- To be able to select the most appropriate method in any given context, it is essential to adopt a strategic approach. This means being clear about what information is needed, when, why, who it is for and how

much it will cost. It is also important to consider the strengths and weaknesses of different methods and how well they will meet the organisation's requirements.

- The involvement of people affected by cancer as co-researchers improves the quality and quantity of the evidence that's gathered. It's important to involve users as partners in the development and selection of methods as well as enabling them to lead on consulting their peers.
- Accessibility is an important feature of any method used to seek users' views, and not every method will be accessible to everyone. Therefore, when seeking to identify users' priorities it is important to use one or more methods that will enable everyone in the target group or population to have their say.
- The importance of representativeness depends on why users are being asked for their views. It may not be important if all that is required is a detailed picture of the users' perspective – in which case seeking a diversity of views may become more important than seeking views from a representative sample.

### **Involving users in priority-setting**

The people we interviewed thought there was only one clear way to make users' views count - that is to integrate users into decision-making structures at different levels within an organisation. If users are involved at all relevant levels where priorities are agreed, they can ensure that users' views are translated into priorities for action.

The different methods we identified to involve users in priority-setting include:

#### ***Involvement in governance structures***

Some organisations have chosen to involve users and carers in governance structures to ensure that their views count (and are seen to count) within the organisation. This usually means that a number of places are set aside on each committee responsible for governance, at local, regional and/or national level. This includes involvement at Board level.

#### ***Recruiting users to groups that make decisions about priorities***

Other organisations have chosen to involve users in groups that make decisions about priorities outside the formal governance structure. This might include planning meetings and advisory groups making decisions at lower levels in the organisation. These may or may not report to the Board.

#### ***Asking separate user groups to identify priorities***

Some organisations have chosen to ask groups of users and carers to set priorities. Sometimes their conclusions are fed into decision-making at the level of the Board or at another appropriate level in the organisation. Otherwise, these groups may act on an advisory basis only. In these

instances, the groups' advice is not binding on the organisation and it may be sidelined or ignored if it does not fit with other agendas.

### ***General lessons***

Whatever method is used to involve users in priority-setting, it must be transparent and accountable – and both users and staff should receive feedback about any action taken (or a decision not to take any action) in response to their views.

### **Making it happen**

In order for Macmillan to ensure that the organisation listens to users' views and makes them count in the organisation, it will be important to:

- Develop a strategic approach to listening to the views of users and making them count
- Improve feedback and communication
- Gather information on what is already known about users' priorities in a systematic and accessible way, which complements other existing and planned systems within the organisation that gather the views of a range of stakeholders
- Think ahead about how to balance the views of different groups
- Providing training and support for users and staff

A full list of recommendations is included in chapter 5 of the full report.

# Thanks

## Thanks to

### **Steering group members:**

Ayesha Owusu-Barnaby, Juliet Bouverie, Jane Bradburn (chair), Jessica Corner, Venetia Franglen, Gwen Harlow, Margaret Johnson, Gillian Lord, Huw Meredith

### **Reference Group members:**

Mitzi Blennerhassett, Diana Robinson, John Sharplin, Beth Tracy, Jenny Walton

### **People who agreed to be interviewed:**

Denise Barker, Graham Barker, Jane Bradburn, Andy Caswell, Cath Dillon, Jim Dunn, Neil Formstone, Lynn Hamson, Gwen Harlow, Stephen Hood, Alison Hopkins, Robert Meadowcroft, Cath O'Brien, Joanna Owen, Damyanti Patel, Pauline Proud, Wendy Sandell, Mary Sayers, Neil Thomas, Nazira Vizram, Richard West, Janine Woods, Allison Worth, David Wright

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# **Chapter 1: Introduction**

## **1.1 Background to the project**

Macmillan Cancer Relief has a clearly stated commitment to listen to the voices of people affected by cancer, and wants to ensure that the views of a wide range of people are heard. To do this, the organisation wants to develop a systematic way to listen to the priorities of people affected by cancer and to ensure that their views count. Macmillan wants to learn about how other organisations have gone about this. A short-term research project was therefore commissioned to address this question.

## **1.2 Project aims**

The aims of this project were to identify:

1. The ways and the extent to which other charities and health and social care organisations currently elicit user priorities and involve users in priority-setting and decision-making
2. Examples of where cancer services users themselves have developed ways of eliciting user priorities
3. Recommendations for ways in which Macmillan can develop a system for eliciting user priorities at a regional and national level and involve users in prioritisation of users' needs

## **1.3 Who wrote this report?**

TwoCan Associates were commissioned to undertake this research and write the report. TwoCan Associates is a small company that specialises in promoting and supporting user and carer involvement in health and social care.

## **1.4 Steering the project**

TwoCan's work was overseen by a steering group, which was chaired by Jane Bradburn, Macmillan's User Involvement Adviser. A reference group of people affected by cancer made comments on progress reports by email.

## **1.5 Overall approach**

This project involved three key phases:

- Background research
- Interviews
- A workshop to develop recommendations

## **Background research**

We undertook a phase of background research to address two key questions:

- How do organisations outside cancer involve service users and carers in priority-setting and decision-making?
- How have cancer service users elicited user priorities?

This research involved a brief review of published and grey literature identified via internet-based searches of Google, Medline and the Electronic Library for Social Care. A list of the key reference documents is attached as Appendix One.

In common with other studies we found that there are few published papers on user involvement in priority-setting. Formal evaluations that explore or compare different approaches are rare. Most reports are based on individuals reflecting on their particular projects and these are more commonly found in the grey literature. However, this evidence still provides valuable lessons on user involvement in priority-setting. Collectively, these studies represent an enormous wealth of experience. In this report, we have focused on drawing out the important points for Macmillan - rather than producing an exhaustive review of the literature.

We also contacted individuals and organisations that we knew were carrying out relevant projects or who were recommended to us by Macmillan staff. Through emails or web-based notices sent to members of the Long Term Medical Conditions Alliance (LMCA), the Health Voice Network and INVOLVE we invited a wide range of voluntary and statutory sector organisations to share their experience in this area.

We attended a meeting of Macmillan's Planning User Reference Group, who helpfully identified a range of projects seeking the priorities of people affected by cancer, including a number of projects where users took the lead. Macmillan staff also helped to identify relevant Macmillan projects.

In all we identified a list of 53 relevant projects.

## **Interviews**

The project steering group worked with us to identify 15 projects to interview. Wherever possible we interviewed staff and service users from each project/organisation to ensure we captured both perspectives. A list of the projects we interviewed is attached as Appendix Two.

We were pleased that so many people agreed to see us, despite holidays, an understandable reluctance to travel to London after the bombings in July and the number of commitments many people had.

We undertook almost all interviews in person, rather than over the phone. This enabled us to build up better relationships with people we interviewed, and therefore to gain much richer insights into how the projects had worked.

## **Workshop**

We held a short workshop, where we invited people affected by cancer and staff to give their views on our initial recommendations, to share their thoughts about how users' views should be gathered and analysed, and to think about how Macmillan could ensure these views count within the organisation. We have included the views of workshop participants in this report.

## **1.6 How this report is structured**

This report has been written so that people can choose to read the chapters that are most relevant to them – we appreciate that this report is long and that some people may not wish to read all of it. It is structured as follows:

- Chapter 2 looks at the different ways used to gather people's views and the advantages and disadvantages of different methods. We have also included some general lessons that apply whatever method is chosen.
- Chapter 3 looks at the different ways to involve users in prioritising the views of their peers. Again, we look at the advantages and disadvantages of different methods and some general lessons.
- Chapter 4 describes what needs to happen to ensure that any system of gathering users' views is valuable to an organisation and can have a genuine impact on decision-making. This includes developing a strategic approach, being clear about purpose, training users and staff and ensuring good communication about outcomes.

In each chapter we provide case studies from Macmillan and other health and social care organisations – these case studies are in boxes.
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At the end of each chapter we summarise the key lessons for Macmillan.

Finally in chapter 5 we outline our recommendations to Macmillan.

## Chapter 2

# What are the best ways to listen to the views of people affected by cancer?

### 2.1 Introduction

There are very many different methods that are used to find out about users' views on priorities. These include:

- Surveys – including face-to-face structured interviews, postal, telephone or web-based questionnaires
- Group discussions - focus groups, workshops, development days, brainstorming sessions and email discussion groups
- User diaries/log books
- Storytelling
- Participatory appraisal – this combines review of documents and interviews with user involvement
- Community profiling
- Panels and advisory groups

Amongst the 53 projects identified through our initial phase of research, there are three methods that have been used most frequently. These are surveys, group discussions and panels / advisory groups. We discuss these in more detail in sections 2.2 to 2. 5 below. Whichever method is chosen, there are some general issues that need consideration. These are discussed in section 2.6. Finally in this chapter, we look at the lessons for Macmillan. These are covered in section 2.7.

### 2.2 Surveys

#### ***What are surveys?***

Surveys can be undertaken face to face, by telephone, through the Internet or on paper. They usually involve asking a number of fixed questions, many of which have 'closed' answers (yes or no, a scale of 1-5 etc.).

#### ***What are the advantages and disadvantages of surveys?***

The advantages of surveys are that they can be cheap to carry out and they provide quantitative data based on large numbers of people that is considered to be robust and 'good quality evidence'.

Surveys are one of the most frequently used methods for seeking users' views, but they also come under the greatest criticism. The problems appear to be:

- Getting the sample right, and ensuring that the responses reflect the target population – even large population-based surveys can still result

in groups of the population (such as young people and people from economically-deprived areas) being under-represented.

- Getting the questions right – people usually complete surveys without any support or guidance, so if any question isn't easy to understand or phrased incorrectly – the survey won't provide useful answers.
- Surveys provide a very shallow understanding of people's views because there are limits to the depth of question that can be asked, and because there is little opportunity to find out why people hold a particular opinion.
- There is little opportunity to provide information or allow discussion and debate, so surveys may not allow people to develop an informed view, and instead capture people's 'immediate reaction'.
- Surveys often have low response rates.

***An example of a survey: RNID***

RNID is the largest charity representing the 9 million deaf and hard of hearing people in the UK. As a membership charity, RNID aims to achieve a radically better quality of life for deaf and hard of hearing people. Its work involves campaigning and lobbying, providing services, training, products and equipment, and undertaking medical and technical research.

The RNID has a Technology Department, which applies technology and scientific research to improve the lives of deaf and hard of hearing people. The Department has a long history of involving users throughout the process of developing new products and technologies. In 2002 the staff team decided to carry out a survey to get reliable evidence of what users really wanted, to help set priorities for the future. They changed their approach from asking for comments on existing ideas and products – to actually asking people about their life experiences.

So they developed a survey that asked people about their lives – for example what they found it difficult to do. They also asked people to describe their 'dream products'

They chose a survey because they wanted a large number of responses. The survey was developed in-house (RNID has a team of people who help other staff do this kind of work). It was piloted with deaf and hard of hearing people. Sign language interpreters were also involved in commenting on drafts. They went through over 30 versions of the questionnaire during the development phase.

When it was ready, the survey was sent out with the RNID's bi-monthly magazine, which goes out to the approximately 30,000 members. The team also wrote a big article about the survey in the main part of the magazine, to tell people more about it and why it was important. RNID outreach workers went to deaf clubs to encourage people to complete the survey. The team

also worked with SAGA to encourage older people to complete the survey views.

Over 10,000 people completed the survey. The team wrote an article in RNID's magazine about the results. The information gained through the survey has been used in different ways by different teams and people within RNID – and although the survey was done in 2002, RNID staff are still using the data in different ways. For example, RNID has recently produced a new smoke alarm, and often went back to the data while they were developing this.

Neil Thomas of RNID comments: *The survey has affected lots of things in small ways. It has given us new ideas for projects, set priorities for work and added weight and credibility to a lot of what we do – it has become a key part of our evidence base.*

## 2.3 Group discussions

### ***What are group discussions?***

Group discussions can take a number of forms – including workshops, conferences and focus groups. Within group discussions there is often an attempt to reach a consensus, and to develop an understanding about why people hold particular views.

### ***What are the advantages and disadvantages of group discussions?***

Group discussions offer the following advantages:

- They are non-directive (i.e. they allow participants to discuss their own issues in a manner that is not heavily influenced by the researcher)
- They enable a full and sensitive investigation of the experiences of participants
- They allow experiences to be shared whilst providing an opportunity for consensus to be reached within a small group setting

There are some disadvantages to group discussions, however. These include:

- There may be problems of 'generalisability', especially as limited budgets may mean that only a small number of group discussions are run.
- The success of this method is very dependent on the skills of the facilitators. Otherwise, a small number of participants may dominate, or the bias of the facilitators may influence the group.
- If the group also includes health professionals, there can be a power imbalance. For example, users may feel that they are 'troublemakers' if they raise any concerns about services.

- People from marginalised communities may not be recruited, or if they are recruited, their voices may not be heard.

***An example of discussion groups: Cancer Care Research Centre, University of Stirling***

The Cancer Care Research Centre aims to work with people affected by cancer to find out more about what they think of the treatment and care they have had. The researchers want to look at people's priorities for improving cancer care, as well as their priorities for cancer care research. In 2004 they got funding from the Scottish Executive Health Department to set up a series of local advisory groups across Scotland.

The first group was set up in Stirling. It was made up of people who the researchers had already had contact with. The next two groups, in East Kilbride and Wigtown, involved working with existing support groups. They have invited the researchers to join their meeting every three months. Other groups were set up in Dundee and Perth. Here, the researchers advertised through the local paper and radio for members. They had 40 responses and set up three groups, which meet on different days and at different times.

There are now 10 on-going groups and other groups that meet occasionally. Some groups are co-facilitated by people affected by cancer. The project has good geographical spread – for example there are two groups in the Western Isles. The researchers have also tried to listen to the views of people who are often marginalised. For example, they have visited a group of Chinese people affected by cancer with the Macmillan Chinese linkworker. They're also working with a young people's group, and with a group of deaf people affected by cancer.

The researchers write a summary of each discussion group and send this to everyone who attended. Once it has been approved, it is sent to all of the other groups. This has been a real springboard for discussion.

This project is at an early stage, but some common issues are already starting to emerge. These may not be shared across all the groups. For example, access to benefits is a big issue for most groups but not an issue at all for others. But issues like the need for early diagnosis and treatment, and inequity between how people are treated are shared by all of the groups. Some ideas generated by the groups have already been developed into research projects, and some group members are getting involved in working with health professionals to improve services and training.

Jim Dunn, a member of the Stirling Advisory Group comments: *People have gained in confidence. We are finding we have shared experiences. I think it has worked well. Everyone is listened to, feels able to have their say. I don't feel anyone dominates. Allison's chairing makes a big difference. A questionnaire wouldn't have given the richness of information. Macmillan should look at information from projects like this and try to co-ordinate it.*

## 2.4 Panels / Advisory Groups

### ***What are panels?***

Panels and advisory groups can be set up of varying sizes but are usually large so they can be thought of as representative of a wider group. Some panels can be specialist e.g. made up of young people or BME groups. Some can be temporary and brought together to discuss a specific issue e.g. a Citizen's jury. Others can be long-standing and regularly consulted on a wide range of issues, through group meetings and/or surveys. A number of voluntary organisations have panels to give advice on particular issues – for example, Breast Cancer Care has a Campaigns Panel.

### ***What are the advantages and disadvantages of panels and advisory groups?***

The advantages of panels and advisory groups include:

- They can be large enough to give their views credibility
- They can be managed by an independent facilitator which gives them independence
- They can be used to provide a quick measure of people's views
- Members can meet regularly to develop a dialogue and reach consensus on specific issues
- Members can be recruited to get involved in any follow-up work
- Members build up knowledge and experience and are therefore able to engage in more in-depth debate

The disadvantages of panels include:

- They can be resource intensive to maintain - members may need training and support
- New members may need to be recruited on a regular basis and this can be expensive and difficult if the panel needs to be representative
- If membership is small, or if members are self-selecting, they may not reflect the broader population of users

In one organisation we interviewed, a panel had been set up which consisted of users with no previous experience of involvement. It was hoped that members of the group would spontaneously come forward with issues and problems based on their daily experiences that could feed into the planning process. This did not happen. Panels and advisory groups need structure, training and support if their views are to be used effectively.

Another organisation brought together the members of their panel for an evaluation day. The group members found it extremely valuable to be able to

meet. They highlighted the following recommendations to improve the way the panel was working:

- The purpose of the panel needs to be made explicit and a shared understanding reached between members and staff
- Members need clarity about their role in terms of how they are likely to be consulted and what further involvement might be required of them
- Members need feedback on how the organisation is making use of the information they provide
- Greater internal publicity for the panel is required, particular in terms of their impact
- Members would like induction training which would help with clarifying staff and users expectations

***An example of a Panel: National Consumer Council***

The National Consumer Council (NCC) was set up by the UK government in 1975 to safeguard the interests of consumers and to ensure that these interests are represented to, and are taken account of, by decision-makers. They are a non-departmental public body, and are independent of any commercial, political or other vested interests.

The NCC set up a consumer network a few years ago because it felt that its role in representing the consumer interest was enhanced by having direct contact with consumers. The network consists of 250 members with experience of being a consumer. Members are surveyed 4 times a year on issues relating to the current work of the organisation and are sent the results as well as other updates in a quarterly newsletter. The network acts as a sounding board to support policy work, provides case studies to illustrate reports with real life stories and are also available to talk to journalists when new reports are launched. They also have an e-network that consists of those network members with e-mail addresses. One of the main advantages of this is being able to get a rapid response.

Network members are also asked to carry out follow-up work. For example when the NCC was working on a project about supermarkets and healthy eating, network members were a given questionnaire to fill out during a visit to their local supermarket.

Alison Hopkins and Wendy Sandell from the NCC have commented that members could do more effective research with further training, *The lack of training has put limitations on what we can expect people to do – and we also had to be careful that we didn't give people leading questions. If the network is to become more effective in this area, the organisation needs to commit more to investing in its development.*

***An example of an Advisory Group: The Disability Rights Commission***

The Disability Rights Commission (DRC) is an independent body established in April 2000 by Act of Parliament to stop discrimination and promote equality of opportunity for disabled people. Its major goal is "a society where all disabled people can participate fully as equal citizens". The DRC gives advice and information to disabled people, employers and service providers; supports disabled people in getting their rights under the Disability Discrimination Act; campaigns to strengthen the law and produces policy statements and research on disability issues.

The DRC has set up a Strategic Enforcement Team to co-ordinate and manage the use of their strategic legal powers, such as the power to conduct formal investigations. Formal investigations are undertaken when there is evidence of systemic bad practice or discrimination against disabled people on the part of businesses, employers or specific sectors. The DRC's two standing advisory groups – the Learning Disability Action Group (LDAG) and the Mental Health Advisory Group (MHAG) – were consulted as part of the process of identifying priority topics for new formal investigations.

The LDAG and the MHAG are made up of users who are representatives of other user-led organisations or self-help groups. Having user representatives is a big advantage, since group members have easy access to wider networks and different communities. Both groups are fully integrated into the organisational structure. They each have a clear role and an established link with the main committee that makes decisions about commissioning future work. It is very clear to all involved how these groups influence the work of the organisation.

Establishing successful groups like this takes considerable time and effort. For example, with the LDAG, it has taken 2-3 years to get the group up and running, to develop trust and get the communication right. Although members of the group came with a lot of 'baggage' and their own agendas, they have been able to work through all of this. This group is now functioning very well and has had a major impact in shaping the work of the organisation.

The MHAG and LDAG both alerted the DRC to the fact that people with mental health problems and learning difficulties die younger and have poorer health outcomes – which they believe is partly due to difficulties in accessing primary care. The Strategic Enforcement Team carried out a literature review in this area and found a lot of evidence to support their views. The organisation therefore decided that it would carry out a formal investigation into the health inequalities experienced by people with learning difficulties or mental health problems.

The investigation is required to meet certain statutory requirements and has three components (1) a large-scale survey, (2) extensive in-depth research within four PCTs (generally representative of the UK) and (3) an inquiry panel review of evidence from organisations with responsibility for addressing this issue. Members of the MHAG and LDAG are involved throughout since they

are regularly consulted about the direction of the research – no major strategic decisions are made without discussion with the two groups.

Joanna Owen from the DRC comments *We got the best feedback on the project from users in meetings set up just for them. Users were then able to be more honest, shared more of their stories and said what they wanted as an outcome – for example people with learning difficulties didn't just want a paper report – they wanted to combine this with other more practical and useful products.*

## **2.5 When is it appropriate to use each method?**

To be able to select the most appropriate method in any given context, it is essential to have addressed the questions in section 4.2. Any method needs to be 'fit for purpose'. This requires clarity about what information is needed, when, why, who it is for and how much it will cost. It is also important to consider the strengths and weaknesses of different methods and how well they will meet the organisation's requirements. A table summarising the advantages and disadvantages of each method is attached as Appendix Three.

## **2.6 General lessons on seeking the views of users**

### ***Involving people affected by cancer in listening to the priorities of their peers***

Involving users right from the start in developing any new mechanism of user involvement is widely agreed to contribute to its success. In the context of listening to people's priorities, this means involving users as partners in the development and selection of methods as well as enabling them to lead on consulting their peers and then empowering them to make decisions.

### ***What are the advantages and disadvantages of involving users in consulting their peers?***

Involving users in seeking the views of other users has the following important advantages:

- In a group discussion, users may feel more comfortable talking to people who share their experiences – because they are willing to be more open and feel more confident in expressing their views, the depth and richness of the data that's collected is enhanced.
- Users may reveal evidence otherwise missed by 'professional' researchers
- In the case of quantitative research, such as a survey, it improves response rates making the results more statistically valid.
- There is often an added commitment from users to follow-up action

- Users may develop new skills and generally feel more ‘empowered’
- Professionals who are committed to listening to the voices of users may be more likely to absorb and implement recommendations

There are also some perceived disadvantages to involving users as researchers. These include:

- It can be time-consuming and resource intensive, as users may need training
- If people are ill, there can also be problems with a lack of continuity.
- The research may not be perceived as independent and objective
- Finally, there may be issues around payment. Users should be paid for undertaking work that a ‘professional’ researcher might otherwise undertake – but this may cause problems for people living on benefits, and may go against an organisation’s policies.

Valuable lessons from research projects interviewed for this study where users were involved in designing and carrying out the research include:

- If users are unable to carry out the research themselves, it is still possible to give them control of the work through allowing them to develop the brief, commission and manage a researcher to collect the data.
- If users are going to carry out the research, then training and ongoing support is essential. User researchers may need:
  - ⇒ Practical support e.g. administration, finance/expenses and travel arrangements, communications
  - ⇒ Research-related support e.g. supervision, de-briefing
  - ⇒ Emotional support e.g. peer support and time to talk through emotional issues and difficulties that may arise during the process of seeking users’ views.
- Severe delays can occur during the process of getting studies approved. These delays are usually caused by Local Research Ethics Committees and NHS R&D committees. They may have a limited understanding of, or be opposed to user-led research. Or there may be organisational complexities that hinder user involvement. It helps to:
  - ⇒ Agree payment issues with other partner organisations *before* people get involved.
  - ⇒ Set up honorary contracts for user researchers, which clarify issues relating to intellectual property, authorship, confidentiality and individual responsibility for personal conduct. These contracts can help to persuade Trusts to agree to user researchers consulting their patients.
- Users may be able to help the research in other ways, such as using

their local knowledge to help with recruitment to projects. One user suggested they could contact key professionals at a local cancer centre to help chivvy along or support the recruitment process if appropriate.

***Users as researchers: Teesside Cancer Network***

The Teesside, South Durham and North Yorkshire Patient & Carer Group undertook a survey to find out whether their work was having an impact on the experiences of local service users and to find out if there were local issues over and above those already identified by members of the group. Group members were responsible for designing the survey and writing the questionnaire and received help from experienced researchers in technical matters. They had 295 completed surveys returned, which was a 40% response rate. They believe this is because the involvement of the patient and carer group ensured that the purpose of survey was made clear to patients and was of interest to them. The questions were also easy to understand and it was clear why they were being asked. Because the covering letter came from a group of patients, this also gave the exercise credibility. It has generated a lot of interest in the network.

Stephen Hood, Founder Chair of the Teesside, South Durham and North Yorkshire Patient & Carer Group observes, *Our survey has generated tremendous interest across our network and in other networks. Because it's been so successful lots of people want to know how we've done it. We are happy to share this with them and allow them to use our survey, but it will need to be adapted to suit other networks. If this was done, Macmillan could look to see if common themes emerge and use these to inform their planning.*

***Users as researchers: The Macmillan Listening Study***

Macmillan has funded a large-scale national research project, *The Listening Study*, to find out what people affected by cancer think about research priorities. The Listening Study has had extensive user involvement throughout. Users have been involved on the project steering group, a user reference group has been consulted to help design the study and produce the patient information sheets, users were recruited as co-researchers to plan and run focus groups, have been involved in the data analysis, and will contribute to dissemination.

Data collection has been completed and the study is currently being written up - but the project has already shown the added value of involving users:

- The user co-researchers ran groups extremely well – it seemed to break the researcher/participant divide, participants relaxed very quickly and seemed more confident about opening up.
- The feedback from focus groups participants has been extremely positive – both formally through evaluation questionnaires and informally in letters.
- The user co-researchers were particularly good at attending to the needs of people in the group.

- Participants seemed to feel more comfortable about speaking their minds. The fact that users were help running the study gave the whole project credibility and seemed to give participants more confidence that something would be done with the results

David Wright, the lead researcher on The Listening Study comments *Users were superb at running groups. They seemed to make it easier for everyone – as soon as people entered the room, they seemed to be more at ease.*

Mary Sayers, one of the co-researchers adds: *The fact that users were there gave the whole project credibility. Because we'd given up our time to take part in it – it showed people that we believed in it. It gave people confidence that we would ensure that the information that was gathered would be used, that this was not just a paper exercise.*

### ***Involving people who are often marginalised***

Accessibility is an important feature of any method used to seek users' views, and not every method will be accessible to everyone. For example, web-based surveys are clearly going to exclude people who do not have access to the Internet, and people who are unable to travel will be unable to attend meetings for group discussions. Therefore, when seeking to identify users' priorities it is important to use one or more methods that will enable everyone in the target group or population to have their say.

There are various innovative ways to involve people who don't normally get their views heard. For example, one team of researchers developed a 'Talking Mats' method to enable frail older people with communication difficulties to express their views (see list of references). Such approaches are best developed in partnership with users who are going to be involved.

A consistent message that came through all the interviews is that involving people whose voices are not often heard requires investment in specific methods to engage those groups. Most often it requires employing an outreach worker to go out to communities and involve people on their own terms. It can also mean adapting a method for different audiences. For example, the Disability Rights Commission conducted a survey on the Internet and on paper to seek the views of people with mental health problems and people with learning difficulties (see section 2.4). They also conducted a series of workshops with groups of people with learning difficulties with the aim of supporting individuals to complete the same questionnaire.

However, simply adapting a method may still not be enough to reach a marginalised group. For example, one organisation that ran a survey offered the use of a translation service for people to complete the survey over the phone, but this was not used and so did not increase the number of responses from BME groups. Paper based and web based surveys are often not a good way to reach these groups. They are better served by community-based approaches.

***Involving people who are often marginalised: Macmillan's BME Network***

Macmillan has set up BME forums, which work closely with partnership groups in cancer networks. This means that issues raised by BME forums are fed into partnership group discussions. A BME user and carer reference group has also been set up in one Macmillan region.

There is also a network of 'project workers' who work to support people affected by cancer in BME communities and includes outreach workers, information providers, health professionals, councillors and staff from other organisations with an interest in working with BME groups. Often these people aren't knowledgeable about cancer – so Macmillan provides training on living with cancer, and e.g. how to set up a self-help/support group.

***Northamptonshire Cancer Partnership Group: listening to the views of people nearing the end of their lives***

The Northamptonshire Cancer Partnership Group was approached by the local lung cancer nurse specialist, who wanted to know about the service she provided from the perspective of people affected by lung cancer. She felt that patients might not feel comfortable in being critical to her, as they wouldn't want to rock the boat.

The lung cancer nurse had a list of subjects she wanted to cover, but the Group's ground rule is that professionals can't fix the questions – they can only suggest subject areas. The Group were interested to find out whether people with a short life expectancy and their carers have similar issues to those with a longer life expectancy – as all of the Partnership Group members are living with cancer in the long term.

The Group decided to run two focus groups – one for carers and one for patients. They chose focus groups because they want people to have a chance to interact with each other, and to get some support from meeting other people with similar experiences.

Group members had all taken part in CancerVOICES training, and all did a further one-day training course on running focus groups with people where there might be a lot of emotional issues coming up. This training was developed and funded by Macmillan. Group members have also arranged that counsellors will be available on the day if people feel upset and want to talk.

*See also the RNID case study re listening to the views of people who use British Sign Language (section 2.2) and the Disability Rights Commission re listening to the views of people with a learning disability (section 2.4)*

***Ensuring representativeness***

The importance of representativeness depends on why users are being asked for their views. It may not be important if all that is required is a detailed picture of the user's perspective – in which case seeking a diversity of views may become more important than seeking views from a representative

sample. It should also be remembered that the costs of recruiting a representative sample makes this type of research very expensive.

Representativeness does become important in:

- Regional planning. In this instance, it is important to involve people who are familiar with their area and the issues that are important to the people within it (see the case study on page 26-27, where users were invited to represent a particular geographical area in a prioritisation process).
- Campaigning and lobbying work – when robust quantitative data based on the views of large numbers of people is required to present a reliable national or regional picture.

In our interviews, some organisations told us that they were concerned that surveying their members would not provide an adequate picture of the needs of their user communities as a whole, e.g. if their members tended to be older, white and middle class. Not all organisations were concerned about this issue as some saw it as their duty to be responsive to their members needs.

If different groups are consulted, thought needs to be given as to how to respond to differences in opinion between the groups. For example, one organisation we interviewed combined a membership survey with a parallel piece of market research to find out the views of a representative sample of non-members. They had only thought to use this to check the validity of the results of the membership survey and had not thought about how to respond to differences in the survey results.

### ***National versus local or regional consultation***

Most organisations who have carried out a survey to identify users' views on priorities at a national level have collected data in such a way as to be able to analyse and interpret the results at a regional or local level, for example by asking participants to include the first part of their postcodes.

If different methods are used to listen to users' views at national and regional or local level, care should be taken to ensure that these methods are complementary, and that data can be passed easily between the different levels of the organisation. There should also be a clear and transparent method in place to address any differences in views.

One organisation we interviewed reported that they had run into difficulties by having a number of processes running in parallel. They had introduced a process to obtain users' views to feed into the organisation as a whole, while at the same time different departments were continuing to run their own surveys. This led to internal disagreements based on a lack of shared understanding of the purpose of collecting different types of information. This example highlights the importance of having a clear understanding of why users' views are being sought and who will make use of the information (see Chapter 4).

## 2.7 Lessons for Macmillan

The key lessons for Macmillan about gathering users' views are:

- All methods for gathering users' views have advantages and disadvantages – so it's important to be clear about what kind of information you want in order to decide what method to use.
- You may wish to use a range of methods to reach different groups of users. You may need to invest in employing outreach workers to engage groups of people whose views are often marginalised.
- The involvement of people affected by cancer as co-researchers improves the quality and quantity of the evidence that's gathered. You may need to offer training and support to users to ensure that the organisation gets the most from their input.
- Representativeness is not always important – it depends on why users are being asked for their views.
- It's important that the involvement of users in gathering views at local, regional and national levels does not conflict – methods used should be complementary, and it should be easy to pass data between the different levels of the organisation.

## **Chapter 3**

### **Involving users in priority-setting**

#### **3.1 Introduction**

Through the interviews and background research we identified a number of different ways of involving users in priority-setting. In some instances, users are asked to set priorities as part of a separate arm's length exercise. In others, they are integrated to a greater or lesser extent into the existing governance and decision-making structures within an organisation.

The people we interviewed thought there was only one clear way to make users' views count - that is to integrate users into decision-making structures at different levels within an organisation.

The different methods we identified include:

- Involvement in governance structures
- Recruiting users to groups that make decisions about priorities
- Asking separate user groups to identify priorities

We consider each of these methods in more detail in sections 3.2 to 3.5 below. We then go on to look at the general lessons about user involvement in priority setting in section 3.6 and finally some specific lessons for Macmillan in section 3.7.

#### **3.2 Involvement in governance structures**

Some organisations have chosen to involve users and carers in governance structures to ensure that their views count (and are seen to count) within the organisation. This usually means that a number of places are set aside on each committee responsible for governance, at local, regional and/or national level. This includes involvement at Board level.

##### ***What are the advantages and disadvantages of involving users in governance?***

The involvement of users in governance means that the process for ensuring users views are heard and acted upon is transparent – users can see who represents them at Board and at other levels within the organisation. This approach also ensures that users views are not 'tweaked' or amended by staff or other stakeholders to suit other agendas. However, involving users in governance can represent a major change in culture for many organisations, and managing this change process can be challenging and time consuming. Involvement of users in this way can also be resource intensive – users may require training, support and information to ensure they are able to work effectively at this level.

### ***Involving users in governance case study: Rethink***

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. As a membership charity, Rethink encourages the involvement of service users, carers, staff and volunteers in all aspects of its work.

In 2003 Rethink began a process to re-structure its governance arrangements. A working group, which included service users and carers, was set up. Other service users and carers were consulted about the changes proposed by the working group.

The aim of the new structure was to have a good communication of views, from the Board to members, and from members to the Board.

Rethink now has eight regions. Each region has a Regional Reference Group, made up of 12 Rethink members and supported by a user and carer involvement officer.

Each Regional Reference Group nominates one person to sit on Rethink's Board of Trustees. In addition there are two more places on the Board reserved for service users – one for a mental health service user, and one for a user of Rethink's services. There is also a Trustee elected by the membership, and a Trustee from the Voices Forum, a service user network supported by Rethink.

The terms of reference for the Board of Trustees states that the majority of trustees must be service users or carers.

Jan Woods from Rethink comments: *People in the regional groups are saying that they feel the new structure gives them the opportunity to be heard. Users' views are definitely having an impact. We have set up the Clinical Services directorate because trustees and regional reference groups have said this is what's important.*

Lynn Hamson, a service user Trustee comments: *The responsibility is very great. You have to speak up about issues that can be very emotive or personal. The staff have been fantastically supportive – there's support from top to bottom.*

### **3.3 Recruiting users to groups that make decisions about priorities**

Some organisations have chosen to involve users in groups that make decisions about priorities outside the formal governance structure. This might include planning meetings and advisory groups making decisions at lower levels in the organisation. These may or may not report to the Board. For example, the MS Society has recruited people affected by MS to sit on the

Grants Advisory Panel that makes recommendations to the MS Society Board on the funding of research applications every year.

***What are the advantages and disadvantages of involving users in decision-making groups?***

The involvement of users in groups that make decisions about priorities can help to ensure that users' views can genuinely influence the outcome. If the process is transparent, other users will also be able to see how their views are being taken forward.

The importance of involving users in the prioritisation process is illustrated by an example of a consultation exercise in one of the organisations we interviewed. This organisation consulted an advisory group about ideas for future work. They sent the group members an open form, which asked people to identify any issue they thought was a problem and to suggest what the organisation should do about it. What came back was useful, but a lot of the ideas didn't fit with the organisation's existing areas of work.

A team of senior managers was responsible for deciding on priority areas for the organisation without any input of users. The users' ideas that were selected were only headlines and often what was taken forward was not exactly the same as what had been originally suggested. Users' views were also tweaked slightly to fit better with the organisations aims and objectives. What this meant was that users' could not see the impact of the consultation exercise - it seemed as if their views had not made any difference. If users had been involved in the priority-setting process, they may have had more of an opportunity to influence the outcome, and just as importantly would have had a better idea understanding of why certain decisions had been reached, which they could have then communicated to their peers.

However, involving users in decision-making groups has the following disadvantages:

- Meetings take longer, as users may need more time to ask questions to share their views
- Staff may need to spend time before meetings preparing users, so that they can play an effective role – for example offering pre-meetings, training or additional information
- Users views may be drowned out by the voices of other stakeholders, who may have more experience or more influence within the organisation

***An example of where users have been recruited to a group that makes decisions about priorities: Macmillan East Midlands and North of England (EMNE) Region planning***

Each Macmillan region has responsibility for developing services that are in line with Macmillan's objectives and that have service user involvement at their centre. The EMNE Region wanted to demonstrate that the regional

planning process is robust and rigorous by opening it up and allowing users to ask questions and give their perspective on what service development means.

In 2004 two users were invited to the EMNE priority-setting meeting when bids for funding service developments are given a final score. Initial sifting had been done to eliminate the bids that weren't relevant to Macmillan's objectives or didn't meet the right standards (one standard is that all bids should demonstrate how users have been and will be involved).

Staff explained to users how bids were scored on their user involvement. Users challenged the views of the reviewers who were professionals, and their involvement did change decisions about which bids were supported. Some bids were rejected because users were not convinced they would make a significant difference to people affected by cancer.

Importantly, users helped to ensure consistency in applying scoring criteria, by questioning what the staff might take for granted. This meant that any differences between bids were only due to local variations and not inconsistency of approach – an important way of setting consistent standards across the region.

Users also give EMNE team other opportunities to influence and persuade partner organisations. For example, in one area, the Macmillan development manager had tried to persuade the PCT to develop an information service – but the PCT was reluctant to make it a priority. Users learned about this in the priority-setting meeting and then contacted the PCT, applying pressure from a user perspective. The PCT changed their mind.

This year users were again involved in the priority-setting meeting. Three users were invited to represent each of the three patches within the EMNE region. EMNE staff sent the user representatives the paperwork ahead of the meeting. Users were also invited to a pre-meeting to go through the bids and ask any questions of clarification. Other Macmillan regions also now involve users in priority-setting.

Denise Barker, Head of Service Development for the EMNE Region comments *User involvement brings rigour to the process and ensures common understanding around the table of how applications have been interpreted. So it also stimulates debate. It proved so valuable that we now see this as standard way to do things. And if users understand and genuinely support and are enthusiastic about Macmillan projects – they can act as champions in their communities, and help Macmillan achieve what it wants to achieve.*

Stephen Hood, founder chair of the Teesside, South Durham and North Yorkshire Patient & Carer Group, who was involved in the meeting, reflects *Because of my experience I felt quite comfortable giving my views. I think the staff were surprised how valuable it was to them and that it was as positive as it was.*

### 3.4 Asking separate user groups to identify priorities

Other organisations have chosen to ask groups of users and carers to set priorities. Sometimes their conclusions are fed into decision-making at the level of the Board or at another appropriate level in the organisation. Otherwise, these groups may act on an advisory basis only. In these instances, the groups' advice is not binding on the organisation and it may be sidelined or ignored if it does not fit with other agendas.

#### ***What are the advantages and disadvantages of asking separate groups of users to agree priorities?***

This method of involving users in priority-setting has the following advantages:

- It provides a safe space for users, particularly those groups who are often marginalised (for example people from BME communities) to work together to identify their priorities before taking these into other forums.
- Users can take all the time they need to ask questions and gather information

However, there are a number of disadvantages:

- Users views may be ignored or distorted once they move to an environment where there is no longer any user involvement
- It may become unclear how users views move through the organisation – this can lead to frustration amongst staff and users
- Users may feel dis-empowered or marginalised, feeling that their involvement is limited by the organisation

#### ***An example of asking a separate group of users to agree priorities: Macmillan's Planning User Reference Group***

Macmillan set up a Planning User Reference Group in 2004. Staff wanted to set up a group of informed users, who could work effectively at the centre of the organisation. The Group was initially asked to give an input to Macmillan's mid-term review of its 10-year plan. Members looked at the mid-term review and gave comments on the gaps. This information was fed to Macmillan's Executive Directors' Team and the Board. There was then feedback to the Group.

Members chose to keep meeting after the mid-term review to offer an input to Macmillan's planning at departmental and strategic levels. The Group has given views on a range of plans, and some members have worked with Macmillan's regions to inform planning at a regional level.

Members of the Group come from various Cancer Networks. Staff ensured that people come from both rural and urban areas, and that there is a balance

of men and women. Efforts were also made to ensure that perspectives from people from Black and Minority Ethnic communities were included.

Members of the Group are involved in self-help groups and partnership groups. They talk to a range of users. And CancerVOICES training encourages them to focus on representing the views of others, not just on their own priorities.

This group offers staff an opportunity to test out ideas and plans. Jane Bradburn comments *The Group has had impact at different levels. It has generated ideas that are now used by the organisation - for example the integrated care project. You can't track back to show the ideas originated from the Group. The group has had an impact in other ways. For example, staff said that Neil Formstone's talk at the planning day last year was very helpful and very grounding.*

Neil Formstone, a member of the Group adds: *The things we have influenced have been significant. We've made a difference to how Macmillan operates. I've seen lots of changes – minor and major. From simply the way people talk to us to the way in which we have been involved in a number of major projects – from planning to implementation. On a personal note, I really feel like a team member in Macmillan. The work we get involved with has proved to me Macmillan's commitment to examining any issue from all sides. And in the end this will lead to constructive proposals that will enhance the excellent services that the organisation already provides, which in turn will mean a better life for people affected by cancer.*

***An example of asking a separate group of users to agree priorities: The Parkinson's Disease Society***

The Parkinson's Disease Society is the leading charity dedicated to supporting all people with Parkinson's, their families, friends and carers. It has 30,000 members, 19,000 supporters and over 300 branches and support groups throughout the UK. The Society provides support, advice and information to people with Parkinson's, their carers, families and friends, and to health and social services professionals involved in management and care.

The Society aims to involve people affected by Parkinson's across the organisation, and in key decision-making. In 2004 the Society began to think about how it could involve people more effectively in priority setting at the AGM, which is attended by representatives from branches, trustees and other stakeholders. About 300 people attended the AGM last year.

People with Parkinson's can have difficulty communicating, and staff wanted to find a way to involve as many people as possible and to get quick feedback on key questions for the Society.

Staff came up with a short list of questions to ask at the AGM. These were approved by the senior management team. At the AGM, people were asked to take part in an interactive session, chaired by the chief executive and the

director of policy. Everyone at the AGM was given a remote control handset. Questions were shown on a large screen, and people were asked to press a button on the handset to vote. Results were then shown on the screen.

There were warm-up questions, and lots of humour. People were asked what region they came from, so that answers could inform regional planning. Then for each key issue, there was some background information. A question then came up on the screen and people were asked to vote. After each question there was a discussion, so that people could raise issues that were important to them. The Society also has an Open Forum slot between each of the topics so that members can ask questions and comment more generally on any issue that concerns them.

One of the questions asked was: *Thinking about the group you represent, which are the most important priorities to improve in 2005 and beyond?* There was a list of options, including 'other', so that if people had specific priorities they could add them.

The top five priorities were adopted as the Society's campaign priorities for this year. A report of the session was sent to all members in the Society's magazine.

Robert Meadowcroft, the Society's director of policy, campaigns and information comments: *Members enjoyed taking part in this new approach and were pleased to have the chance to input in this way. And staff were very positive. This method gives us a chance to get quick feedback, to gather evidence. We are doing it again at the AGM this year -we'll recap on what has happened since last year and then ask people for their views about research, to inform our research strategy.*

### **3.5 When is it appropriate to use each of these methods?**

The method any organisation might choose to involve users in priority-setting is likely to be informed by the organisation's philosophy, aims and structure. It will depend on:

- Whether an organisation is committed to working in partnership with users or to being user-led
- Whether an organisation wishes to make its decision-making processes transparent to users
- How users wish to be involved – some may prefer to take part in separate user forums to discuss priority-setting, others may wish to be part of an organisations formal decision-making structures

These different approaches are not mutually exclusive, and an organisation may choose to use all or some of them at different levels or at different times in its development.

### **3.6 General lessons on involving users in priority-setting**

#### ***Transparency and accountability***

An important feature of any priority-setting exercise is that it is open and transparent to all stakeholders - to ensure accountability and earn widespread support. This also means that the process needs to be simple and easy to understand. A good system of priority-setting will be objective and clear about expected outcomes, rather than being based on subjective decision-making. It will also ensure that whatever the outcome, it is communicated to all stakeholders with a clear explanation of how and why any particular decision has been reached.

#### ***Involvement at all relevant levels***

If users are involved at all relevant levels where priorities are agreed, they can ensure that users' views are not 'distorted' as they move through the system, and that they are translated into priorities for action. If this doesn't happen there is a danger that:

- Users' views will be 'tweaked' to fit better with the opinions of staff or organisational goals, in which case users will no longer recognise that the work reflects their input or meets their expressed needs
- Ideas or projects may be 'hijacked' by staff, sidelining users who therefore don't receive any recognition for their contribution.

One of the users we interviewed identified an important advantage of involving users on all the various committees where decisions are being made. If encouraged to work together, these users can forge links between different projects, when lack of communication in an organisation or departmental boundaries may prevent staff from doing so. In addition because users have no vested interest in any particular department or professional role, it is possible for them to say the things that other people feel they can't.

#### ***Issues about capacity***

Some people have questioned the competence or expertise of users to be involved in organisational decision-making. They believe users are going to make irresponsible decisions because they won't consider the legal, funding or other organisational constraints. However, this is an argument for integrating users into existing decision-making structures, and providing them with the information and support they need to ensure their decisions are fully informed.

### **3.7 Lessons for Macmillan**

The key lessons for Macmillan about involving users in prioritising are:

- Whatever method is used, it must be transparent and accountable – and both users and staff should receive feedback about any action taken (or a decision not to take any action) in response to their views
- The method chosen depends at least in part on an organisation's philosophy and structure
- Whatever method is chosen, users should be involved in setting priorities as well as in giving their views

## **Chapter 4**

### **Making this happen**

#### **4.1 Introduction**

In this chapter, we outline some of the building blocks Macmillan will need to think about putting in place to ensure that the views of users are listened to and acted upon. These are:

- Developing a strategic approach to listening to the views of users and making them count
- Improving feedback and communication
- Gathering information on what is already known about users' priorities
- Thinking ahead about how to balance the views of different groups
- Providing training and support for users and staff

#### **4.2 A strategic approach**

Developing a strategy to implement any form of user involvement is vital to its success. A lack of a strategic approach is a major barrier to user involvement having an impact. In the context of listening to users' views and making them count, this means addressing the following questions:

- Why do we want to know about users' priorities?
- What do we already know about what users think is a priority? What more do we want to know?
- What information do we want to collect?
- What will we do with users' views once we have them?
- What decisions will users influence? What weight will be given to their views?
- Who in the organisation needs to take account of these views? Are these people committed to taking account of user views?
- Have we got the commitment of people who are able to make change?
- Are we prepared to take action as a result of what we learn?
- Who will have the final say over decisions?
- Are we prepared for the consequences if there are changes in the balance of power amongst our stakeholders?
- What resources in terms of time and money are we prepared to give to this work?
- When do we need this information – at what point in our planning cycle?
- How will we ensure all our stakeholders are aware of this work?
- How will we know if we've been successful?
- How will users know their involvement has made a difference?

### ***A strategic approach: Diabetes UK***

Diabetes UK is the leading charity for people with diabetes. Diabetes UK funds research, campaigns and helps people to live with the condition. Its mission is to improve the lives of people with diabetes and to work towards a future without diabetes. Diabetes UK is a membership organisation with a regional structure. Only a tenth of people with diabetes in the UK are members.

The organisation has recently made monitoring the implementation of the diabetes National Service Framework (NSF) a key priority. The decision was made at a senior level. Their policy department looked at data from the National Audit Office and Dr Foster (a company that provides data from PCTs self-reporting on the state of their services) and identified five diabetes healthcare priority areas for service development. These five areas are now being prioritised by all departments in the organisation.

They also saw there was a gap in the information in terms of how people with diabetes view current services. They therefore decided to carry out a large-scale survey of their membership to ask people about their experiences of services in the five key areas. They are also asking people about their 'best' and 'worst' experiences of healthcare to find out if there are areas of concern beyond the five chosen targets.

Because they are concerned that their membership is not representative of the UK diabetic population, they have also commissioned a piece of market research to run in parallel. This is asking a representative sample of people with diabetes (1000 people in total) to complete the same survey. The results will be compared to determine how much weight to give to the views of the membership.

The goal is to build up a UK wide picture of the experience of people with diabetes. This will contribute to a 'state of the nation' report that will act as a benchmark against which to measure future progress at national and local levels. The data is being made widely available and people will be able to pull out information that's locally relevant. Those attending local planning meetings, who represent people with diabetes, will therefore be equipped with recent and robust information about current needs. It is hoped this evidence will be very powerful.

This project has been well planned to fit with the rest of the organisation's work on the NSF. They have had a clear, well thought-out process in mind from the start and a strategy as to how to use the data they collect. This has enabled them to explain the project to other staff across the organisation. They have held a number of face-to-face meetings with staff in all the different departments not only to explain what is being done and where it is leading, but also to find out what other staff are working on and to get feedback on how the results of the survey might be useful to them.

It is expected that the survey will reveal gaps in services that will become priority areas of work for the organisation e.g. for the policy and campaigns

team and for the development of education resources for professionals and information for users. Any work taken forward to address the gaps, will be evaluated before dissemination. Its impact on services will then be assessed as part of ongoing monitoring as a whole. So there is a planned circle of activity which is hoped will lead to continual improvements in diabetes services across the UK.

The key lesson is that good planning and communication require a lot of investment but both are essential to the success of the project; they ensure staff buy-in and a shared organisational understanding.

Pauline Proud, the member of staff leading on this project at Diabetes UK, comments: *Your project may not be at the top of other people's priorities. You need to find out what information other people want and when they want it. Be prepared to change what you're doing to help other staff – and make sure everyone is prepared to respond.*

### **4.3 Improving feedback and communication**

Many of the users we interviewed who had worked with Macmillan said that they did not know what happened to their views once they had been expressed. There is therefore a need to improve the feedback given to staff and users about how users' views on priorities have been made use of within the organisation. This will improve the transparency and accountability of Macmillan's decision-making.

But communication needs to be more than one-way (for an example of how an organisation has established a formal mechanism for two-way communication see the example from Rethink in section 3.2). It must be clear as to how feed users views into the organisation as well as how information comes out. Some of users and staff we interviewed within Macmillan said this had been a problem for them - they did not know what to do with the information they had collected on users' priorities.

### **4.4 Gathering information on what is already known about users' priorities**

Macmillan is in a unique position of having access to many robust and reliable studies of the views of people affected by cancer (A list of these potential sources can be found in Appendix Four and the boxes below). Not only is much of this work already being carried out within the organisation, but also there is extensive work being carried out to find out about users' priorities in the cancer networks. Many of these projects share the common goal of generating robust evidence based on the views of large numbers of people, or representative samples, rather than a handful of users. Macmillan has already invested heavily in this work and could do more to reap the benefits.

***Gathering information on what is already known about users' priorities:  
The Rarer Cancers Forum***

The Rarer Cancer Forum, with funding from Macmillan, commissioned a researcher to carry out a rapid appraisal to find out about the unmet needs of people with rarer cancers. This involved reviewing existing information, as well as interviews with Forum members, other people with rarer cancers and professionals. The process was designed and managed by people with cancer to ensure it met the needs of the Forum. The approach proved very successful in giving a firm evidence base to identify gaps in service provision, to strengthen the case for funding from Macmillan and to indicate a clear direction for the work of the Forum. One of the advantages of this approach was the evidence was gathered quickly and cheaply.

***Gathering information on what is already known about users' priorities:  
Macmillan's BME Network***

Users' views on priorities can be obtained very simply at meetings and conferences through informal means. For example, at a Macmillan BME networking event, participants were asked to write up their views on the way forward for Macmillan by adding their comments to a flip chart at any point during the day. Although, certainly not 'robust' or 'representative', this method identified a number of important areas of work not only for the Macmillan BME worker, but also for other parts of the organisation – for example a recommendation to develop training for health professionals to be culturally sensitive in breaking bad news.

Making better use of the information that has already been collected will also address a major concern of staff and users. One of the most common complaints we heard from users and carers was that they were frustrated by being asked for their views on the same issues over and over again – without seeing that their views were making a difference. Staff shared the same concern.

It can therefore be argued that Macmillan already has access to 'evidence' about the needs and priorities of many people affected by cancer. But what it has not done effectively is to establish a process through which this evidence can be gathered together and analysed within the organisation and used to inform decision-making. More systematic ways of collecting this information, routinely employing an organised approach, would help to improve the current situation where the views of some users may be heard on some subjects in a rather piecemeal way. It could also help Macmillan to avoid duplicating effort and to target its resources on filling the gaps in its knowledge.

***Developing a new system to gather information***

The discussions at the workshop began to explore what such a system might look like. Participants highlighted the following issues that will need further consideration:

- There are very many sources of information on users' priorities internal and external to Macmillan (an initial list can be found in Appendix Four). Macmillan may not want to draw on them all - there may simply be too

much information - so it may need to develop some criteria to decide which sources to use. Some of this data is not owned by Macmillan (for example information collected by the network partnership groups), so Macmillan may need to think about establishing agreements with these partners and providing something (e.g. training for user researchers) in return for sharing information. It will also be important to think about how to match up the work being done by network partnership groups on users' priorities with the work being done by regional service development teams.

- Information on users' views is being collected in many different ways – ranging from large-scale regional surveys to small group conversations at conferences. Some judgement may have to be made about the quality of information collected from different sources, in terms of its robustness and how much weight it should be given. However, it will be important not to exclude the 'good ideas' that can come from 'a conversation at the end of the workshop'.
- Some thought will need to be given as to who will actually collect this information and take responsibility for feeding it into the organisation. Workshop participants thought this should be the lead person in any particular project (this might be the staff manager, or the chair or facilitator of a partnership group) and that they should be asked to produce a synopsis of users' views using a standard, simple template.
- Some thought will need to be given as to how to analyse all the information that's been collected and how to distil it down into simple messages. A thesaurus being developed by the Research team to help classify all cancer resources may be useful here. It could provide a list of common terms to help analyse the results. For example, if one survey identifies 'hospital parking' as a priority and another highlights 'lack of public transport to hospitals', they could be classified as issues relating to a standard term 'transport to hospital'. This would provide a means of comparing results across many different consultation exercises.
- The analysis will also need to identify what information is missing, for example if there are particular groups of users who haven't been consulted e.g. people with a rare cancer, people at different stages of their cancer journey etc. Macmillan could then decide to commission additional research to fill the gaps.
- Some thought needs to be given as to *where* all this information will go and *who* will be involved in reviewing it and drawing conclusions on users' priorities. Participants thought that users should be involved in this review process and should help draw conclusions on what the priority areas seem to be. Macmillan could also consider testing out these conclusions with other groups of users if it wanted to test their robustness and generalisability. Users would also need to be part of the decision-making processes where decisions are made based on the agreed priorities. This is essential if users are to remain connected to the issues.
- However this information is collected, stored and analysed, it will be important that this initiative complements the work going on elsewhere in

the organisation to develop knowledge and information management systems. This will help to mainstream user involvement. It will also be important not to develop a complex, unwieldy system.

- In making final decisions on how to respond to users' priorities, some thought should be given as to how to choose between different options. The development of some criteria might help here. For example, one important criterion is whether a particular action is do-able and realistic for Macmillan to take forward. Some issues may be beyond Macmillan's capacity. However, Macmillan could also choose to develop its skills and capacity in new areas in response to users' views.
- As users' views are likely to change over time, some thought will need to be given as to how often to repeat this exercise in order to keep the information current.

#### **4.5 Balancing the views of different groups**

There are two issues Macmillan may need to address when thinking about balancing the views of different stakeholder groups:

##### ***Balancing the views of different groups of users***

None of the organisations we interviewed had addressed this issue directly. If the aim is to make decisions that reflect the views of the population of users as a whole, it seems there is only one way to do this – to carry out a national survey of a representative sample. This sample will include people from different communities in the same proportions as they exist in the UK population. This means due weight is given to the different opinions according to how many people are likely to hold the same opinion. But this has the disadvantage of obscuring the views of minority groups and even a survey on this scale may not reach all marginalised groups e.g. people at the end of life, or people receiving care in hospices.

More commonly organisations seek the views of marginalised groups through different methods that are appropriate for those groups. The question as to how to weigh up minority views against those of the majority is then a value judgement that the organisation has to make. This judgement will usually be informed by some other evidence e.g. evidence that that a particular group is underserved in some way. For example, one organisation made a public commitment up front to reflect BME issues in their recommendations on priorities for action and have built this into their data collection and analysis.

##### ***Balancing users' views with those of other stakeholders***

Macmillan is in a unique position of working with both a large group of postholders and a large group of active users. What should Macmillan do if their views on priorities conflict? There are a number of ways forward including:

- (1) Macmillan could make a commitment to becoming a user-led organisation in which case the views of postholders could be used to help inform decisions

about *how* to respond to users' priorities and to implement any necessary changes. The implications for decision-making throughout the organisation would need to be made explicit and a shared understanding reached by all users and staff.

(2) Macmillan could continue to engage both as equal stakeholders and seek to find ways of increasing the areas of common ground and encouraging joint-working towards common goals. It may help to break down the barriers by removing artificial boundaries – many users have as much knowledge and experience of cancer services as professionals, and many professionals have personal experience of cancer. One of the organisations we interviewed adopted this policy. They did not see user and professional views as being in competition with each other, but rather as different perspectives that needed to be understood to explain why particular problems exist e.g. such as difficulties in accessing services. Both groups were also seen to be important sources of 'solutions' to achieve the shared goal of improving services.

#### **4.6 Training and support for users and staff**

Macmillan has access to a group of people affected by cancer who have already had training and/or experience of consulting other users for their views. For example, the group of users from the Macmillan Listening Exercise and the Northamptonshire Cancer Partnership Group have been trained in running focus groups, and a number of partnership groups have been trained in developing surveys. Some of these users have expressed an interest in undertaking further research.

Macmillan has already arranged for groups to access this kind of training on request. It may be worth considering offering this kind of training more widely as part of CancerVOICES.

If users become more involved in priority-setting within Macmillan, they may require further training, support and information. Similarly, some members of staff may welcome help in thinking about how to involve users in gathering and prioritising views within their particular area of work.

## **Chapter 5 Recommendations**

We have made a number of recommendations, based on our background research and interviews. Some of these recommendations have been tested out with our steering group and with people who attended the workshop.

- 5.1 Macmillan should develop a strategic approach to listening to the views of users and making them count. This will include being absolutely clear about why Macmillan is seeking the views of users and how it will make use of the information it collects.
- 5.2 Users should be involved in all stages of any process to listen to users' views, to analyse and prioritise them, and to make them count within Macmillan.
- 5.3 The involvement of people affected by cancer as co-researchers improves the quality and quantity of the evidence that's gathered. Macmillan should therefore seek to involve people affected by cancer in gathering the views of their peers wherever possible.
- 5.4 It will be important to think ahead, before any projects to listen to users views have begun, about how to balance the views of different groups
- 5.5 A 'representative' view is important but not always necessary. Macmillan should therefore only invest in seeking the views of a representative sample of people affected by cancer when a strong case has been made that this is necessary.
- 5.6 It is important to consider using a range of methods to reach different groups of users, especially those who are often marginalised.
- 5.7 Whatever method is used, it must be transparent and accountable – and both users and staff should receive feedback about any action taken (or a decision not to take any action) in response to their views
- 5.8 It's important that the involvement of users in gathering views at local, regional and national levels does not conflict – methods used should be complementary, and it should be easy to pass data between the different levels of the organisation.
- 5.9 It's important to bring together information on what is already known about users' priorities – and to do this systematically. The system developed should complement other existing and planned methods of bringing together views of stakeholders.
- 5.10 Macmillan should consider providing further training and support for users and staff who get involved in gathering and prioritising users' views.

## Appendices

### Appendix 1: key reference documents

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

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

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Corner J and Wright D (2003a) *Involving people affected by cancer in setting priorities for cancer research* Southampton, Southampton University.

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Steel R. (2004) *Involving marginalised and vulnerable people in research: A consultation document*. Eastleigh, Hampshire, INVOLVE.

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Macmillan Cancer Relief – User involvement in Macmillan's research programme:

Proceedings of a one-day workshop on 23<sup>rd</sup> May 2005

Murphy J, Tester S, Hubbard G, Downs M & Macdonald C Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats as an interview tool *Health and Social Care in the Community* Vol 13(2) 95-108

ONS (2000) National Statistics other theme Working Group. *User consultation*. London, ONS.

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

Staley K and Hanley B. (2004) *User and carer involvement: How to develop a strategy*. London, LMCA.

## **APPENDIX 2: List of projects interviewed**

### **Macmillan projects**

BME Network – staff member and person affected by cancer  
Planning User Reference Group – staff member and person affected by cancer  
Rarer Cancers Forum – staff member and person affected by cancer  
Listening exercise – staff member and carer co-researcher  
EMNE planning – staff member and person affected by cancer

### **Other organisations**

Cancer Care Research Centre – staff member and person affected by cancer  
Disability Rights Commission – staff member  
National Consumer Council – staff member  
Diabetes UK – staff member  
Rethink – staff member and service user  
RNID – staff member  
Parkinson's' Disease Society – staff member

### **Cancer Partnership Groups**

Teesside, South Durham and North Yorkshire Patient & Carer Group  
Leicestershire Cancer Network Partnership Group - person affected by cancer

### APPENDIX 3: Advantages and disadvantages of the different methods for listening to people’s priorities

Method	Advantages	Disadvantages
<b>Surveys</b>	<p>Cheap to carry out</p> <p>Provide information about large numbers of people</p>	<p>It’s hard to get the sample right – even large surveys can still result in groups of the population being under-represented</p> <p>It’s hard to get the questions right – people complete surveys without any help, so if any question isn’t easy to understand or phrased incorrectly, the survey won’t provide useful answers.</p> <p>They provide a very shallow understanding of people’s views because they are often simple, may have low response rates &amp; the people completing them aren’t usually given additional information or help.</p>
<b>Discussion groups</b>	<p>Allow participants to decide their own issues in a way that is not too directed by the researcher</p> <p>Can give a deeper understanding of issues than surveys</p> <p>Allow experiences to be shared whilst providing an opportunity for consensus to be reached</p>	<p>It may be hard to draw general conclusions from a small group</p> <p>Success is very dependent on the skills of the facilitators.</p> <p>If the group includes health professionals as well as users, there can be a power imbalance.</p> <p>People from marginalised communities may not be recruited, or if they are recruited, their voices may not be heard.</p>
<b>Panels</b>	<p>Can be large enough to give their views credibility</p> <p>Can be supported by an independent facilitator which gives them independence</p> <p>Can be used to provide a quick measure of people’s views</p> <p>Members build up knowledge &amp; experience &amp; are therefore able to engage in more in-depth debate</p>	<p>Can be expensive to maintain (both in time and money)</p> <p>New panel members may need to be recruited on a regular basis.</p>

## **Appendix 4: How are users views currently gathered within Macmillan?**

People who attended the seminar (see section 1.5) identified the following ways:

- Self-help and support groups
- Macmillan website
- CancerVOICES conferences
- CancerVOICES steering group
- Complaints
- Comments
- Thanks
- User Involvement business meeting
- Story bank
- User Involvement Shared Learning Group
- Surveys and other activities carried out by the Partnership Groups
- Various work that has been done to listen to the views of children and young people
- Via postholders (including at postholders' conferences)
- Planning User Reference Group
- Medical Strategy User Group
- Partnership Forum meetings
- Regional meetings with facilitators and users
- National and regional self help and support
- User involvement conferences

We recognised that this list represents only a fraction of ways that users' views can come into Macmillan.