

Getting it right
for **service users** and **carers**

Getting it right
for **research**



**How to decide whether to help
researchers find people to take part in
research**

Guidance for research staff working in health
charities

Compiled by
TwoCan Associates

welcometrust

About TwoCan Associates

TwoCan Associates carry out R&D and provide training and support to help voluntary and statutory organisations involve people who use services in their work. For further information visit www.twocanassociates.co.uk or email us at info@twocanassociates.co.uk

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Foreword

Charities and voluntary health organisations play an important role in bringing researchers, service users and carers together to pursue research which will advance our understanding of disease and help develop ever-better therapies and treatments.

The experience of many charities is that service users and carers want to participate in studies that could help improve their condition, even if they themselves may not be the direct beneficiaries. Having lived the experience, many service users and carers have an altruistic desire to improve the quality of life and wellbeing of others in the future. They often contact health charities in the hope of finding new research projects to take part in.

Researchers will often follow a similar pathway, turning to charities in the knowledge that these organisations offer the most direct route to the insights and experiences of service users and carers, and one of the most effective means of recruiting people to their study.

To make this relationship between service users, carers and researchers work well, the role of charities and other voluntary health organisations must extend beyond that of simply the dispassionate broker. They must also become active partners in the relationship. Inherent in this role is a responsibility – primarily to their service user group – to ensure that the research is of high quality and of direct benefit, that its conduct reflects service users' interests and concerns, and that the expectations of both parties are realistic.

It is a role which encompasses many elements – from information provider to gatekeeper to quality assurance – and is not without its challenges. However, this guidance put together by TwoCan Associates working in partnership with service users, carers and staff from four health charities – Asthma UK, The Neurofibromatosis Association, Rethink and The Stroke Association – provides a flexible model by which charities can navigate these challenges and make appropriate decisions about whether they should help researchers by promoting opportunities to take part in research – or not.

Given the increased impetus for clinical research in recent years and the Government's stated desire to ensure that service users and carers can easily access information about opportunities to take part in research, all charities – large and small, local and national – will play an increasingly important role in this area in future. *'Getting it right for service users – Getting it right for research'* aims to help these organisations fulfill this role – in a way which ensures that researchers and service users and carers travel the research pathway together, working in partnership to deliver genuine 'patient benefit'.

Simon Denegri
Chief Executive, Association of Medical Research Charities (AMRC)

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Introduction

This guidance aims to help your organisation make decisions about whether to help researchers find people to take part in their research.

It was developed by TwoCan Associates working in partnership with service users, carers and staff from four health charities – Asthma UK, The Neurofibromatosis Association (NfA), Rethink and The Stroke Association. The project was funded by the Wellcome Trust.

In designing this project we purposefully selected four very different organisations to work with us. We hoped this would ensure that the general lessons would be relevant and useful to a wide range of health charities.

Who is this guidance for?

This guidance has been written for people in health charities who are asked to make decisions about whether to help researchers find people to take part in research. It aims to help you make these kinds of decisions in a more robust and systematic way. In large organisations, this may be staff working in research departments. In smaller organisations, this may be a trustee, a paid member of staff, a volunteer, service user or carer or anyone else with an interest in research. Throughout this guidance we have referred to all of these potential users as 'research staff'.

How was the guidance developed?

Each pilot organisation set up a small working group to develop their policies and procedures. These groups were made up of around 4-6 service users and carers and a member of staff or a Trustee. Each organisation worked independently to:

- Develop a set of criteria to judge the quality of research projects
- Develop a process for making decisions about which projects they will support
- Consult a wide range of stakeholders on the new policies and procedures
- Improve the ways they inform service users and carers about opportunities to take part in research

Service users, carers and staff from all four organisations also came together for two workshops to:

- Share learning
- Reflect on their experiences
- Draw out the general lessons for other organisations

They helped draft this guidance and commented on early versions. A Steering Group made up of researchers, funders, people with expertise in user involvement in research and representatives from the pilots provided valuable input throughout the project.

A note about terminology

We have assumed that people reading this guidance will be familiar with basic research terms. Some useful definitions can be found in the INVOLVE publication *'The Public Information Pack: Booklet 4: Jargon Buster'* (Download from www.invo.org.uk).

We use the term '**service user**' to describe people who use (or wish to use or have used) health and/or social care services. Some organisations prefer the terms 'patient', 'user', 'public' or 'person'.

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

Why help researchers? – Benefits and risks

This section talks about why a health charity might want to help researchers find people to take part in research.

What are the benefits to health charities?

Researchers often ask health charities to publicise their research projects. The type of researchers (and the type of research) varies enormously, and includes:

- Undergraduate students who want to carry out a small project as part of their degree
- Postgraduate students, for example those doing a masters degree
- Researchers working in the not-for-profit sector (for example universities or NHS Trusts) who are undertaking clinical studies – large scale clinical trials or smaller pilot studies
- Health services researchers who are undertaking qualitative research – for example projects that ask detailed questions about people’s health experiences
- Social care researchers who may be undertaking qualitative research – for example about people’s experience of living with a particular condition
- Laboratory based researchers who want people to donate blood or tissue samples
- Pharmaceutical companies, where researchers may want help to recruit people to take part in pilot studies or larger clinical trials
- Companies that manufacture medical devices, who may want people to take part in research to test products
- Researchers working for companies that develop products which they want to market to particular groups of people – for example companies that make special mattresses or vacuum cleaners may want to recruit people with respiratory conditions to test their products
- Market research companies, who want to recruit people to take part in research which asks for their views on a range of topics

Many health charities are keen to help researchers as this effectively promotes the research that may benefit their members. It is often in line with their overall mission to ‘*find the cause, cure or care*’ for a particular health condition. For smaller organisations, this may be the only way they can promote research in their area, particularly if they haven’t sufficient resources to fund research themselves. By helping researchers, health charities can build better relationships with relevant research institutions. They will also provide a valuable service to their members by helping service users and carers find research projects they can take part in.

Perhaps most importantly, by setting conditions on *when* they will help researchers, health charities can help shape the direction of research, as well as *how well* it is carried out. For example, they can state they will only help researchers who demonstrate they will respect and value research participants – this means the projects will better meet the needs of the people taking part. They can also state that they will only publicise a project if they believe it addresses an important and relevant topic – this makes it more likely that research will genuinely reflect the interests of service users and carers.

“Research gives people hope and moves us forward. It’s important for service users and carers to have a stake in setting the agenda.”

Rethink member

What are the benefits to researchers?

Researchers can find it difficult to find people to take part in health and social care research. Some projects fail because they cannot recruit enough people (for example in 2003 less than one third of clinical trials conducted in the UK managed to recruit within their planned timescale¹). Delays in recruitment can lead to increased costs and low morale. Researchers therefore have a lot to gain from working with health charities.

¹ See Pharmaceutical Industry Competitiveness Task Force Competitiveness and Performance Indicators 2005 Crown Copyright 2006

In the first instance, they are likely to gain quicker and easier access to large numbers of people affected by a particular health condition. This can help to speed up recruitment. More importantly, because health charities are often well-respected and trusted sources of information, having the support of a health charity can make a research project more appealing to people thinking about whether to take part.

“As a researcher, I feel my research project has got more credibility because it’s got the support of Jo’s Trust².”

Claire Vale,
Medical Research Council Clinical Trials Unit

Research projects are also likely to be more credible and more successful with the support of health charities. For example researchers working on a clinical trial for Paget’s disease found that working with The National Association for the Relief of Paget’s Disease not only helped them to find participants more quickly, but also meant that the people who took part were more committed to the trial. The participants were therefore more likely to complete the questionnaires and also stay to the end of the trial. This helped to improve the quality of the data that was collected.

² Jo’s Trust is a charity supporting people affected by cervical cancer.

What are the challenges for health charities?

For health charities, deciding which projects to publicise to their members involves judging whether research proposals are good 'quality'. This is not an easy assessment to make. Judging the 'quality' of a research project is a complex task because so many different aspects need to be considered. It includes deciding whether the research is:

- important and relevant to service users and carers
- likely to make a difference to people's lives
- novel and original
- scientifically robust
- using appropriate methods
- being carried out by researchers with the necessary skills
- ethically sound

Different stakeholders will also have different perspectives on these issues. Some are better placed than others to make judgements about the specific aspects of a research project. This can make the decision-making process much more difficult.

This guidance aims to help health charities make judgements about the quality of research with input from relevant stakeholders. This in turn will help them make decisions about when they will help researchers by publicising opportunities for service users and carers to take part in research. Importantly our approach is based on involving service users and carers in the decision-making process.

Why involve service users and carers in judging the quality of research?

Service users and carers are the people best suited to judge whether a research project is relevant and important to them. Their involvement is therefore essential to find out whether a research project genuinely reflects their interests and needs.

They are also in the best position to assess other aspects of research projects, for example whether there is appropriate involvement of users and carers and whether the practical aspects of the research design will meet the needs of the participants.

By involving service users and carers in this process, you will also build up a team of people with a highly developed knowledge and understanding of your research area. These individuals can act as ambassadors for your organisation, developing new relationships with the research community and extending the reach of your networks. They can also assist other departments in your organisation, for example using their skills to support your organisation's work around policy and campaigning. Once people become involved in one part of your organisation, it can help to support and encourage involvement in other areas.

What are the risks to health charities?

Based on the experience of the pilots, the risks of this process have proved to be minimal. However, as with all kinds of service user and carer involvement, making decisions based on the views of service users and carers alone can challenge the status quo and upset existing power relations. Deciding not to publicise a particular project may affect relationships with individual researchers, service users, funders and/or commissioners.

This approach will work best if it fosters greater partnership working between service users/ carers and researchers. Health charities have a critical intermediary role to play in this process. They can help build bridges between the different communities and develop mechanisms that support joint decision making. With this approach it is unlikely that projects will be rejected outright. It is more likely that a health charity will find ways to work with the researcher to make changes or clarifications that improve the quality of the research design and supporting information. Researchers often find it helpful to receive this kind of constructive criticism. Working in partnership with researchers is therefore more likely to bring benefits to all involved.

Part 2

How do we do it? Practical advice

Part 2 provides the resources for health charities to develop their own policy and practice in relation to helping researchers to find people to take part in research. It is made up of four sections:

- Section A:** Preparing your organisation
- Section B:** Developing your own policies and practice
- Section C:** Making decisions about when to help researchers find people to take part in research
- Section D:** Advice from the pilots - hints and tips

Part 4 provides templates for all the documents needed to support this process. These are referred to by number throughout this guidance.

Not all organisations will want to follow every part of this guidance, but they can choose to start small, adopting the processes that are most relevant and useful to them.

SECTION A: Preparing your organisation

As with any other project, it's important to be clear what you need to do to make this work for your organisation – and why you want to do it. This section talks about the three key things to think about before you begin to adapt the policies and procedures in this guidance and before you think about recruiting a panel of service users and carers:

- Clarity about why you want to do this
- Resources
- Support

Be clear about why
your organisation
wants to develop
these new policies
and procedures

At the outset, it is important to consider what your organisation wants to achieve by helping researchers find people to take part in research and what role it wants to play. If your goal is to

promote research that genuinely meets the needs of service users and carers, you may decide to be more demanding of research projects and ask researchers to revise their proposals before you agree to support their project. In this case your organisation becomes more of a gatekeeper, only publicising projects that strictly meet the criteria set by service users and carers. Or your organisation may choose to get less involved, simply checking that proposals meet a minimum set of requirements before publicising them to your members. It might be helpful to talk to service user and carer members of your organisation to find out what they expect.

You will also need to consider how much capacity you have to work with researchers to develop their proposals so that they better meet your standards.

You may also want to develop these ideas over time, adapting your policies and procedures to reflect any changes in your organisation's priorities.

"We have some responsibility to service users and carers. The point of this assessment is to say we've looked at this research project carefully and to say 'we think this is good and worth supporting'. We want to use this policy to improve the quality of research, by saying that projects must meet certain standards and help researchers with guidance about how to meet those standards."

Rethink Staff

Ensure you have senior level support

You will need senior level support to take this project forward. Depending on how your organisation works, this might mean gaining the backing of your director of research, research committee, chief executive and/or trustees. They will need to understand what this project involves, what the resource implications are (see below) and the potential risks and benefits (Part 1). Without this support, it will be easy for the procedures you put in place to be undermined or ignored.

Ensure you have sufficient resources

You will need to ensure that your organisation has the resources available to take this work forward. The time and money you'll need will depend on how you develop the project, but it is likely to involve:

Staff time: to work with service users and carers, liaise with researchers and publicise research projects.

Money: to pay for service user and carer involvement in developing and implementing the project. This will include travel, accommodation, subsistence, personal assistant, carer or childcare costs, and possibly some office costs e.g. postage and telephone costs. You will need to ensure your organisation can reimburse people promptly.

SECTION B: Developing your own policies and practice

This section makes suggestions about how you can work in partnership with service users and carers to develop new policies and practice that can help you decide whether to help researchers by publicising their research.

Each of the pilot organisations developed different policies and practices. This was influenced by:

- The size of the organisation
- Its culture and history around user involvement
- Whether the organisation awards research grants
- Whether the organisation has a dedicated research department
- The resources available and capacity of research staff
- Other developments in their organisational policy and practice around user involvement in research

Based on this experience, it seems best for health charities to adapt the material in this guidance to meet their own specific needs. We recommend you do this by working with a group of service users and carers. This will ensure your policies and procedures are informed by the views of your members and are practical and simple for you to use. It will also create a sense of ownership and commitment to taking this project forward.

Alternatively, you may choose to use this material immediately in its current format. All of the information can be downloaded from the TwoCan website www.twocanassociates.co.uk

Working with service users and carers at the start

It might be helpful to hold an initial meeting/workshop with service users and carers very early on to help develop your organisation's thinking. This could usefully involve considering the recommendations in this guidance and discussing:

- Whether the benefits outweigh the risks for your organisation
- The expectations of your members and what they hope will be achieved
- Whether you wish to set up an Advisory Panel of service users and carers to help make decisions about when to help find people for researchers
- How best to recruit people to an Advisory Panel if you decide to go ahead

If you decide against setting up an Advisory Panel, you could also work with this group to adapt the material in this guidance. This would involve discussing and agreeing:

- Whether the general list of criteria used to judge requests from researchers for help with publicising their research (see page 18) will work for your organisation
- How decisions will be made, who will be involved and who will have the final say

What the pilots did

The **NfA** do not have a research department and only 2 staff. They therefore decided to ask a volunteer to provide the admin support for the review process, working from home. They decided not to set up a formal Advisory Panel but agreed that the 5 people who had been involved in this project would continue to act as reviewers. They agreed to make their decisions via email discussions, leaving the final decision to the Chair. They thought this approach would be suitable to manage the small number of approaches from researchers they receive each year.

Setting up an Advisory Panel of service users and carers

An Advisory Panel can help you make decisions about which research projects you will advertise to your members, by offering the perspective of service users and carers.

Setting up a panel involves the following steps:

(i) Recruiting panel members

In order to recruit people to the panel you will need to provide potential members with a clear description of:

- The role of panel members (Template 1)
- Terms of reference for the panel (Template 2)

What the pilots did

Rethink recruited to their panel by sending out an advert to Rethink members who had already expressed an interest in research (Template 3). They also circulated the advert to staff in other departments, who then sent it to the people they knew. The role was also openly advertised in email newsletters.

Anyone who was interested was asked to contact a member of the research team who could answer any immediate questions. They were then asked to write a letter outlining why they were interested in the role and how they met the person specification. Individuals were recruited to the panel following a brief, informal telephone conversation with the project manager. All 9 people who applied were recruited to the panel.

"We were lucky with the people we found. They have been interested and engaged from the beginning. We didn't have any difficulties recruiting people."

Rethink staff

(ii) Holding a briefing session for new members

The aims of a briefing session are to:

- Provide background information for panel members on what's involved in recruitment to research and how the quality of research is ensured through research governance (e.g. through peer review of grant applications and research ethics committee approval)
- Provide background information on how your organisation currently makes decisions of this kind, why you have decided to involve service users and carers and the changes you would like to see
- Ensure a shared understanding of what your organisation will achieve through developing and implementing these new policies and procedures
- Review the materials provided in this guidance and change them to suit the needs of panel members and staff
- Ensure a shared understanding of how decisions will be made, for example agreeing how a lack of consensus will be managed and where the responsibility for final decisions lies
- Provide a clear outline of the role of panel members and what is expected of them e.g. in terms of time commitment.

Template 4 is an example of a programme for a briefing session. This example session runs for a day. If your organisation works with service users who would find it difficult to attend an event which lasts for a day, this event can be split into two shorter sessions held on separate days.

"It was important to have a development day that involved developing the basic tools. It allowed us to get involved and make decisions about the way forward... being involved in developing the processes you feel you have ownership of it."

Rethink member

"The format and whole approach to the briefing day was important. It helped that it was open and we knew we could comment if we wanted to – but there was no pressure. Through that we got the sense that we were being listened to."

Rethink member

(iii) Piloting your process

Test your new processes with one or more dummy requests for help from researchers. Provide all panel members with the same information from researchers and ask them to assess the requests as if they were real. Use the feedback from this exercise to make any final changes to your documents and procedures.

"The whole structure of the panel must be open and honest. You must be committed to transparency and listening to people's views. Otherwise it won't work. So it's not just about setting up a panel - but about setting it up in the right way. It means endorsing an approach that is empowering."

Rethink staff

(iv) Planning regular reviews

After your panel has been in place for some time and all members have had an opportunity to review at least 2 or 3 requests from researchers, it may be helpful to bring the Advisory Panel back together for a review. You can use the feedback from this event to troubleshoot any problems and revise your procedures if necessary.

A regular annual review could help the panel develop its way of working as well as providing an opportunity to share learning and experiences with new members. Template 6 gives a suggested programme for a review session.

You will also need to think about how to keep all of your panel members up to date with the work that's been done. For example you could provide a quarterly email update summarising how many requests for assistance have been reviewed and how many have been approved.

Finally you will need to think about when you will recruit new members to the panel.

"We plan to recruit further members to the panel every two years. Then we would have a combination of experienced panel members working in conjunction with new members, so that one group can learn from the other."

Rethink staff

Working with other stakeholders

Once you have worked with service users and carers to develop your policy and practice, it is important to ask for constructive feedback from other stakeholders (e.g. other staff and researchers) to help improve your processes and raise awareness of the changes.

Based on the lessons from the pilots, this is best done through discussion face to face. Many people are unfamiliar with how people are recruited to research projects and will want to ask questions.

Staff in other departments

It is important to inform staff in all relevant departments about your new policies and practice to ensure they are applied consistently across the organisation.

"Not all requests for help have gone through the research department so it's important to let the rest of the organisation know about this process to ensure consistency. We want to make sure that no one agrees to help researchers without going through our Advisory Panel. So we also need the buy-in and agreement from other teams in the organisation..."

We communicated directly with other departments, so that they all know this is the new way of doing things. We also put information in a newsletter sent by email to all staff. We're thinking about how to make this information more accessible on our web pages. We also worked with staff from the membership department which was very helpful."

Rethink staff

Researchers

It is important to advise researchers of changes to your procedures and ask for feedback as to how well the changes work for them. You can provide a written policy statement to send to all the researchers you already know as well as any new researchers who come to you for help (see Template 5).

What the pilots did

Staff at the **Stroke Association** decided to develop new policy and practice to assess requests for help with recruitment, as well as requests for funding. They wrote to a number of researchers who had received grants from the organisation in the past. They told the researchers about their new policy and asked them for comments. The response was broadly positive. The Stroke Association's guidance included help with how to structure a plain English summary of research proposals, and some researchers said that this was particularly useful.

Asthma UK developed a generic application form for researchers to cover a wide range of requests – from asking service users and carers to comment on an application for funding right through to taking part in clinical trials.

Other stakeholders

You might also want to consult your trustees and other members of your organisation about these new processes. You can also make more public statements of your intention and commitment to this process – e.g. via your website, or at your AGM.

What the pilots did

Service users and staff who worked on this project at **Asthma UK** were concerned that people would think that Asthma UK had a responsibility for the quality of any research it publicised. They therefore ensured that they discussed draft policies and procedures with Trustees. The new procedures included a disclaimer to make it clear about Asthma UK's role and responsibilities.

SECTION C: Making decisions about when to help researchers find people to take part in research

In this section we describe a process for managing the assessment of researchers' requests for help with recruitment, based on a model where an Advisory Group of service users and carers works with research staff to make decisions. This model can be adapted and modified to suit your organisation.

Making a decision about whether to support a particular research project involves the following steps:

- 1: Responding to requests from researchers
- 2: Assessing research proposals
- 3: Negotiating with researchers
- 4: Telling service users and carers about opportunities to take part in research

Step 1: Responding to requests from researchers

Ensuring clear communication

When your organisation receives a request for help from a researcher you will need to:

- Clearly explain what you can do to help find people to take part in their research and what your organisation will expect in return

- Clearly explain how your organisation makes decisions about whether to help
- Ask the researcher to explain their research in more detail, providing all the information you need to decide whether it meets your agreed criteria

This means sending them written information about your policy and procedures (see Template 5) and asking them to complete and return a simple application form (see Template 7).

"We try to be clear to researchers that we can't guarantee that our members will take part in their research. We can advertise the project very widely, to a lot of people – but then it's up to them if they want to take part."

Rethink staff

Since the requests for help are going to be assessed by service users and carers it is essential that the application form asks for a clear summary in plain English. Some researchers may appreciate some guidance as to what needs to be covered (see Template 8).

Clarifying who has responsibility for research governance

It is important to be clear that by publicising opportunities to take part in research, your organisation is in no way responsible for research governance i.e. how well the research is carried out. This needs to be understood by researchers and potential participants. Your application form therefore needs to include a disclaimer that states that your organisation is not responsible for ensuring the research is carried out in line with the current regulatory framework (see Template 7). This remains the responsibility of the sponsor and chief investigator.

“Ultimately it is the researcher who is responsible for making sure the research is done well and participants are treated with respect and supported. If something goes wrong it is not the responsibility of Rethink. BUT because through this process Rethink will be giving a ‘stamp of approval’ to research projects, it does have responsibility to check that there are systems in place to support people if they do become distressed when they take part in research. We include a clause explaining the exact limits of our responsibilities.”

Rethink staff

If you are concerned about any possible risk to your reputation, you may wish to specify what kind of research you will publicise. So for example, Asthma UK has limited the range of research it will advertise to service users and carers.

“When we embarked on this project, our panel members (both service users and staff) were concerned that people might think that Asthma UK was responsible for the quality of any research we might publicise (i.e. that the charity was taking on some responsibility for research governance). We checked this out by undertaking a survey of a small number of service users and carers active within Asthma UK. They thought that if Asthma UK was publicising a research study, then it must be of a high standard. Therefore we decided that one of our criteria should be that research we publicise must have ethical approval and must be funded by a ‘reputable’ source. This includes research funded by the NHS, the Medical Research Council and research based in universities.”

Asthma UK staff

Charging for your services

You may decide to charge researchers for your services in order to cover admin costs and staff time. This might involve setting different rates for different types of project e.g. you may want to charge more for help with large scale clinical trials than for small scale student projects, or decide not to charge students at all. If you do decide to charge researchers, you will need to provide them with details of your charging policy.

Step 2: Assessing requests from researchers

Assessment criteria

The four pilot organisations developed very similar sets of criteria to assess whether a research project is good quality, even though they work with people affected by very different health conditions. This suggests that a general list of criteria would be relevant for a wide range of health charities (see Box 1). However, we still recommend that you review this list with a group of service users and carers to check whether they agree with all the criteria, or want to make changes or add new ones.

There are two very different types of criteria in the general list. Some take the form of simple checks, for example ‘Has the project received ethical approval?’ These are best assessed through an initial screening carried out by a member of research staff.

Applying other criteria involves making a more subjective assessment, which may vary from project to project. For example, judging whether

General criteria for assessing the quality of research proposals

Aims and purpose of the research

1. The research must be in line with [health charity]'s mission to support people affected by [health condition]. It must have the potential to lead to genuine benefits to people affected by [health condition]. The outcomes should be relevant and meaningful to service users and carers.

Meeting the needs of service users and carers

2. The information given to people deciding whether to take part in the project (the patient information sheet) must be clear and easy to understand. It must consider the communication needs of the people taking part. It must include a lay-friendly explanation of the purpose of the research and the expected outcomes.
3. The researcher must be clear about how he/she will recruit people to take part, how they will check people have the capacity to consent and how they will ask for it.
4. The researcher must clearly explain how participants' personal information is kept confidential. People must be told they can leave the project at any time without it affecting their care or treatment.
5. There must adequate support in place for people who may become distressed by taking part in the project.
6. The participants must have their expenses (e.g. travel and carer costs) reimbursed promptly.
7. The research should try to actively involve service users and carers in a meaningful way at all stages of the project (where this is appropriate and feasible). For example, service users and/or carers could be members of the steering group overseeing a project and/or they may have been involved in developing and testing the research tools e.g. questionnaires. There should be a budget for any service user and carer involvement in the study.

Quality of the research proposal

8. The project must have ethical approval from a Research Ethics Committee.
9. The proposal must have been through a process of scientific peer review.
10. The researcher must have experience of working in this field with people affected by [health condition]. Students or researchers who are new to this field, must have access to advice and support from a supervisor with relevant experience.

a project has an appropriate level of user and carer involvement will depend on the nature of the project and the resources available. Assessing whether a particular project meets these kinds of more complex criteria therefore requires a more detailed review by both service users and carers and research staff. It's best if a number of people are asked for their views, with the aim of reaching a consensus to inform the final decision.

"We agreed that assessing whether a research project meets our criteria is important to answer the question 'Is this good for us? Is it worth us investing our time in this project?'"

Rethink Staff

Initial screening

The initial screening involves checking that a research application has met some of the basic requirements. It involves checking whether:

- the application form has been completed properly and all additional information (e.g. the patient information sheet) has been supplied
- the proposal has been through a process of peer review
- the research is taking place at a reputable organisation (e.g. a university)
- the proposal has received ethical approval

In addition there may be other screening questions that your organisation wishes to include - for example, some of the pilot sites decided to ask:

- Is the project genuine research that will benefit service users and carers or simply market research that will mostly help commercial companies?

You will need to consider how you will respond if the application fails this initial screen. This could involve:

- asking the researcher to supply missing information, or for example, to justify why ethical approval has not been obtained
- asking your medical/scientific advisers to review proposals that have not been peer reviewed
- asking the researcher to obtain an ethical review from their Local Research Ethics Committee (LREC) (LRECs will consider all requests to review research studies).

"It means that we say no to companies who want to do interviews within a week for instance. This would be unrealistic and unethical - so it's good to have this policy in place."

Rethink staff

Assessments by an Advisory Panel and research staff

A request for help to publicise a research project must have passed the initial screening before it is sent to the Advisory Panel. A suggested process for assessment by an Advisory Panel is outlined below.

1. Each request for help is sent to a minimum of three panel members.
2. Each panel member is sent the completed application form, a comment sheet (see Template 9) and list of the criteria being used to assess projects (see Box 1).
3. Panel members are asked to comment on whether they think the project meets the various criteria, what changes would help

the project to meet the criteria and a final conclusion as to whether the project should be promoted.

4. A research staff member considers the views of all three panel members and makes a final decision as to whether the organisation will help the researcher. This decision may also be influenced by other factors, for example whether there is capacity within the organisation to provide the help the researcher needs.
5. All comments are sent to the researcher as well as a clear list of any changes required before the research project will be promoted. This may require further negotiation and correspondence with the researcher.

Based on the experience of the pilots, it is not necessary for the panel members to meet to carry out these assessments or to reach a consensus. All of these steps can be carried out by email (or post) and by phone.

However you will need to think about how you will respond if your panel members cannot reach a consensus on an application. The Rethink Panel agreed the following:

1. If two or more panel members have concerns about an application, then it is rejected.
2. If one of the three reviewers has concerns, then the three reviewers will hold a telephone conference and try to reach a consensus.
3. If they still can't agree, the concerns are sent to the researcher who is given an opportunity to respond.
4. Three NEW reviewers see the revised proposal and aim to reach a consensus. They do not see the initial comments from the first three reviewers.

5. If there are still concerns, from any of the new set of reviewers, then the application is rejected.

6. All six reviewers are told about the outcome.

How quickly can decisions be made?

This decision-making process clearly requires some time, in particular to ensure that panel members have sufficient time to review projects. You will need to inform researchers when they first contact you as to when they can expect a final decision.

Your panel members may be willing to give you a quick decision in urgent cases, but you will need to agree this way of working with them beforehand. You will also need to agree what's an acceptable timeframe for assessing proposals under normal circumstances.

There may be concerns about researchers asking for an urgent decision, as this may show a lack of forethought and planning. One way round this is to ask researchers for an explanation as to why they need a quick decision and ask the panel members to make a judgement as to whether this can be justified.

"We agreed to consider each urgent request on a case by case basis. So for example, we might decide to make an exception for a student if they cannot wait for a month for a decision. We want to support them because they need to be encouraged to carry on in a research career in the mental health field."

Rethink member

Other options for assessing research proposals

You may wish to consider including other forms of assessment as and when required. For example, **Rethink** members were concerned about how they would assess researchers' attitudes and awareness of mental health issues. In an ideal world they would have liked to have interviewed all researchers proposing to work directly with people affected by severe mental illness, but recognised this would be expensive and time-consuming. They concluded they might consider this option for large-scale or long-term projects.

If your organisation also awards research grants, you might also consider merging the process of peer review with the assessment of requests for help with finding participants for studies (see right).

You may also wish to engage other stakeholders in this process, for example asking your medical and scientific advisers for their view on the scientific quality of a proposal.

What the pilots did

The **Stroke Association** asks all researchers to complete an application form whether they want help to find people to take part in research, or want to apply for a research grant. The form asks a series of questions that were developed by people affected by stroke. This ensures that the researcher answers the questions that people affected by stroke think are important. All forms are reviewed by an Advisory Panel. (The form and the questions can be found on the Stroke Association website www.stroke.org.uk/research/index.html). If an application is for funding, the panel's views are forwarded to the lay representatives on the Stroke Association's Research Awards Committee. If the researcher only wants help with finding participants, the panel's views are considered by the research team, who then liaise with the researcher.

Asthma UK is using a generic application form for researchers to complete if they want help with recruitment to research studies. This covers a wide range of projects from asking service users and carers to comment on an application for funding right through to taking part in clinical trials. This is different to the form that researchers complete if they want to apply to Asthma UK for funding.

The **NfA** decided they would ask their Medical Advisory Board and their Specialist Advisers to review the scientific quality of research proposals.

Step 3: Negotiating with researchers

Panel members are likely to recommend that changes are made to research proposals. It is important to clarify whether they think these changes are essential or whether these points can simply be provided as feedback to the researcher.

You will need to be prepared to negotiate with researchers on essential changes. So far the experience of the pilots suggests that most often these changes are about making details of the proposal clearer and more accessible to a lay audience.

“The researchers have been fine about the feedback. No one has had any issue with the points we’ve made.”

Rethink staff

“During the discussions with stroke survivors, it was clear that they wanted the whole review process to have teeth. Consequently we have implemented a process by which plain English summaries of projects that are of poor quality or that are not understandable are returned to applicants. If subsequent drafts are still of poor quality, the application is rejected.”

Stroke Association staff

Getting feedback on the results of research

Getting feedback on the results of a research project is extremely important to service users and carers who take part in research, and an aspect of the research process that is often overlooked. Simply providing a copy of an academic paper is not satisfactory, because it's not understandable to most people. All results should be available in plain English.

You could make it a condition of helping researchers that they produce a plain English summary of their results. This can be given to the participants who have said they would like to hear about the outcome of the research. It can also be used by your organisation to make the results more widely available to your members through your website, newsletters etc.

What the pilots did

Based on the findings from this project, the **Stroke Association** decided to link the requirement for a lay summary of the results of research with their conditions for funding:

“Stroke survivors said they really wanted feedback regarding the outcomes of research. Consequently, we will require a plain English summary of the research results and conclusions. We are planning to introduce a new policy which states that we will not pay researchers’ final invoices until we have received an acceptable lay summary.”

Stroke Association staff

Step 4: Telling service users and carers about opportunities to take part in research

Who to tell and what to say

Before you start publicising opportunities to take part in research to service users and carers, you will need to decide who you will tell and what you will tell them. Do you want to tell all service users and carers you have contact with about every research project? Or do you only want to tell people who have said they want to hear about opportunities to take part in research? Two of the pilot organisations decided to tell to everyone and two decided only to tell people who had expressed an interest.

“Alongside this project Asthma UK set up a group of volunteers who are interested in getting involved in research. We have been promoting this group in lots of different ways. We hope it will help bridge the gap between research and people affected by asthma. When we recruit people to the group, we ask them for some basic information so that we only tell them about opportunities to take part in research that are relevant to them and that they are interested in.”

Asthma UK Staff

How to advertise opportunities to take part in research

There are many ways to inform service users and carers about opportunities to take part in research. The most common way is to advertise in newsletters - but this is not always effective. Researchers' timescales may not always coincide with your publication schedule. So you may also want to consider thinking about other ways that are more targeted and proactive. For example:

- Dedicating an area of your organisation's website to advertising opportunities to take part in research – signposted from the home page and/or research pages
- Developing a database of people interested in taking part in research and writing to them about opportunities to take part in projects
- Advertising through any support services or groups that your organisation runs, or through your regional structures
- Sending out email alerts or newsletters

Linking different people to relevant research projects may be time-consuming and you will need to consider how much staff-time you have available for this stage.

What the pilots did

The **NfA** carried out a survey of their members asking people if they were interested in taking part in research and what types of research they would want to take part in. This information has been added to each person's entry on the membership database. NfA plan to use the database to send people information about specific projects. The questionnaire will also be routinely sent to all new members.

Rethink have put details of research projects on their website. They have also put the information in the staff newsletter so that staff in Services and the Membership and Participation teams have the details. Staff in these departments have many contacts and can send the information out to support groups and other local groups. They are targeting appropriate groups depending on where research is taking place, how many people are needed and how quickly they want to recruit people.

Asthma UK is promoting opportunities to volunteer to take part in research through a variety of methods. They have placed newspaper adverts, displayed posters in GP surgeries and asthma clinics, as well as provided details about volunteering in research on their website and in their magazine. When recruiting volunteers, they ask people to fill out a short form and then chat to people over the phone to find out more about them and what kind of research they are interested in. They think this is important, because asthma affects a wide range of people in many different ways, and people have different interests and areas of expertise.

Issues of confidentiality

Whatever method you choose to publicise opportunities to take part in research, you'll need to think about confidentiality and data protection – have service users and carers with whom you're in contact agreed to be contacted for research purposes? If not, does this question need to be asked of service users and carers with whom you're currently in contact, as well as new service users and carers, as part of updating your membership database?

It's important to ensure you remain within limits of the Data Protection Act. It's definitely not acceptable to pass on names and addresses of service users and carers to researchers. The best approach is to pass the contact details of researchers to service users and carers and allow them to contact the researchers directly.

SECTION D: Advice from the pilots

We asked the research staff and service users and carers in the pilot sites what practical advice they would give to their peers who might be thinking of developing new policies and procedures around helping with recruitment to research. They said:

- **Be prepared to make changes to the way you do things as a result of working with service users and carers.**

“User involvement isn’t just something that you do by ticking a box. You have to be prepared to change things. Otherwise there’s no point doing it.”

Stroke Association staff

- **Invest time in planning how you will work with service users and carers.**

“You need to think about how involvement meets the charitable objectives of the organisation. There’s no substitute for sitting down and thinking it through. Talk to someone in a similar organisation who’s involving users, who’s doing it and doing it well. Find people with the appropriate expertise to help you.”

Stroke Association staff

- **Ensure you have sufficient resources to do it properly.**

“You need time and money - a decent budget especially if people have mobility issues. Don’t under-estimate the resources you need to do it properly. Work out a budget then double it.”

Stroke Association staff

“It’s quite labour intensive and you need to have someone who’s able to put that time in.”

Asthma UK staff

“Small charities should not be put off because they do not have the administrative or financial resources to adopt the whole process. It is okay to start small; for example use an initial assessment by one or two people and form a panel as and when viable.”

Neurofibromatosis Association staff

- **Plan in advance.**

“You need to be clear about what you’re trying to achieve, and where your role ends and the researchers’ role begins. You need to know who you’re publicising opportunities to and exactly what those opportunities entail – in order to facilitate the provision of better information and ensure better experiences for people taking part in research.”

Asthma UK staff

- **Practice what you preach.**

“Make sure you know enough about the health condition you’re working with and the practical implications of living with that condition so that you can anticipate any problems. Ask people if there are things you can do that would help them to be involved.”

Stroke Association staff

How will this help my organisation?

Lessons from the pilots

Based on the lessons from the pilots, there will be benefits to you, your organisation and the service users and carers with whom you work. In this section, the four organisations that took part in this pilot project share their learning and experience.

Asthma UK

About Asthma UK (www.asthma.org.uk)

Asthma UK is the charity dedicated to improving the health and well-being of over 5 million people in the UK who have asthma, including 1.1 million children. We work with people with asthma, healthcare professionals and researchers to develop and share expertise to help people increase their understanding and reduce the effect of asthma on their lives.

Asthma is a condition that affects the airways. When a person with asthma comes into contact with something that irritates their airways, the airways become narrower and irritated, making it difficult to breathe and leading to symptoms of asthma.

Why did your organisation want to get involved in this project?

Before this project our research team made judgements about whether to publicise research projects that people affected by asthma could get involved in. Whilst we made sure that basic checks were made (e.g. they had ethical approval), we didn't have clear guidelines about what should or shouldn't be accepted. We were also looking to promote greater lay input into our research programme, and we thought this project could complement our activities in this area.

What has the project achieved for your organisation? What process do you have now for dealing with approaches from researchers?

We have developed a generic application form for researchers to complete if they require assistance from us. We are offering a wide range of help – from finding service users and carers to comment on a funding application right through to finding people to take part in clinical trials. We have also developed an internal checklist for our staff to use to assess applications. We check whether the applications meet our key requirements before we agree to help. Finally, we've developed some guidance for people affected by asthma, outlining what they can expect if they are considering taking part

in research studies advertised through Asthma UK. We also produced a glossary of terms. All of these forms and documents were developed in partnership with service users and carers.

Alongside this project, we have been setting up a cohort of volunteers who are interested in getting involved in research, from shaping our research programme through to taking part in a clinical trial. We have been promoting this volunteering opportunity in a variety of ways. We ask people for some basic information so that we only tell them about opportunities to take part in research that are relevant to them and that they are interested in.

What has been the impact of this project?

● On you and your work

We are more aware of the breadth of asthma research being carried out and where in the UK it is based. Researchers are also approaching us about studies that are not just specifically about asthma but are looking at broader issues that affect people with asthma as well as people with other long-term conditions. This research may well relate to other work the charity is doing.

We've also been asking for feedback from people with asthma who have taken part in research projects we've publicised. We've learnt a lot from them about how their experience could have been improved, for example in terms of the language used by the researchers or the way researchers have interacted with them. All of these lessons are valuable for us, to help us think about how asthma research should be carried out in the future and how to widen the scope of this project.

● On your organisation

As Asthma UK develops its new strategic plan, there is an increased drive across the organisation to involve people affected by asthma in all sorts of activities that we do, including research. This project has added another dimension to involvement in our research programme – it's not just about lay involvement in funding decisions. It could end up giving Asthma UK more influence over what happens in the wider research environment and bring real benefits to people affected by asthma.

● On the service users and carers involved

Generally we have had a positive uptake when we have made people aware of opportunities which fit with their areas of interest. For most opportunities, we have been able to directly match people with the research that interests them and we have helped recruit the necessary numbers of people. We are still waiting for feedback from some people, but where we have had feedback it has been positive.

● On researchers

We asked researchers how they found filling in the generic application form, and overall the feedback was positive. However based on this feedback, we plan to produce slightly different versions of our form for different types of research (e.g. clinical trials versus steering group participation). This will make it easier for the researchers.

The Neurofibromatosis Association

About NfA (www.nfauk.org)

The Neurofibromatosis Association aims to provide help, support and advice to those affected by Type 1 or Type 2 Neurofibromatosis (NF), their families and the professionals working with them. We provide information, fund research, run activity holidays for children and adults and raise general awareness of the condition.

NF is a common genetic disorder, affecting 1 in every 2,500 people. It mainly affects the nerve tissue and can cause benign tumours to form anywhere in or on the body at any time. There can be other complications including specific learning difficulties and behavioural problems, high blood pressure, problems with bone development, speech problems, increased risk of epilepsy and hearing defects - all of which can lead to serious difficulties for those affected.

Why did your organisation want to get involved in this project?

The NFA wanted to take part in this project because we had no formal guidelines in place to assess projects submitted by unknown researchers. We wanted more formal policies to help us rate and review applications effectively. We were also keen to work in collaboration with the larger charities so we would be able to hear their different points of view.

What process do you have now for dealing with requests for help from researchers?

As part of this project we carried out a survey

of our members and now know which of our members would be interested in taking part in research projects and what kinds of research they are interested in.

We planned to set up a small virtual group to help with reviewing research proposals. The group was to be made up of the people who were involved in this project and would have made decisions by email. We also planned to ask our Medical Advisers to comment on the scientific aspects of proposals. One of our members was going to provide the admin support working from home. Regretfully, we have had to put these plans on hold due to staff shortages and lack of resources. We hope to be able to put them into action in the near future.

What has been the impact of this project?

● On the staff and the organisation

While we were working on this project, we had direct experience of what can happen if there isn't some discussion with researchers before they carry out research with our members. One researcher carried out some research with children with NF at one of our holiday camps. Some of the parents involved were concerned and some of the children didn't like it. It made us realise that our decision-making processes did need to be strengthened – so we had a better idea of what our members might be asked to do in a research project, before we agree to find people to take part.

Having carried out a survey of our members we have found out that many of our members are interested in research and willing to take part. We've got all this information on file.

● On the service users and carers involved

It was interesting to see how the other organisations were managed and staffed. We realised because they had dedicated Research Departments, they found it easier to put their policies into action. We felt disappointed that we could not continue the work after the pilot because of the lack of resources, but feel that we have learned a great deal from the project. We hope that our policy will be used in the future.

● On the researchers

We don't get that many requests for help from researchers. But this project made us think about how we might promote more NF research. Now that we know which of our members are interested in taking part in research, we've got a way of getting in touch with lots of people to tell them about research opportunities. We think this could be a real resource for researchers. We know that there are a few places in the country where Masters students are working on the social and clinical aspects of life with a genetic condition. If we can offer them an easy way to recruit people, we might persuade them to research NF rather than something else. We would like to talk to staff in the relevant universities to see how best we can take this forward.

Rethink

About Rethink (www.rethink.org)

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

In Rethink severe mental illness is defined as mental illnesses in which psychosis is likely to occur. Psychosis is the medical term used to identify symptoms where the individual experiences a loss of sense of reality, where they cease to see and respond appropriately to the world they are used to.

Why did your organisation want to get involved in this project?

Service user and carer involvement sits at the centre of Rethink's ethos. We were very keen to become involved in this project in order to increase service user and carer involvement in the activities of our research department.

Before becoming involved in this project, the research team made decisions about whether to help external researchers recruit through our organisation. However, we were keen to increase the transparency of this process and ensure that it was informed closely by our members. The establishment of the Advisory Panel allowed us to fulfil these goals.

What process do you have now for dealing with requests for help from researchers?

We set up a panel of 9 service users and carers who review all requests from researchers. We spent a lot of time briefing panel members and working with them to get all the processes clear and the paperwork right. So now everything works smoothly for panel members and for the researchers. The staff carry out an initial screen of all requests. We also consider some of the more technical aspects of the research and also whether we've got time and resources to provide the necessary support. We then send the information to three panel members who come back with their recommendations within three weeks. We've agreed a way of reaching consensus on the final decision. We are very much guided by the views of panel members.

What has been the impact of this project?

● On the staff and the organisation

It's had a really positive impact on the work of the research team and our reputation within Rethink. It has helped us to think about joining up our work with other departments and made the research team more visible to the rest of the organisation.

It's also made us think about our own research practice – we need to ensure we're adhering to the standards that we ask of outside researchers.

The rigor of our new process and the efforts required probably dissuade those who aren't serious about research from submitting an application to the Advisory Panel. It feels like an achievement to have introduced rigor into the process. Outside people are often impressed

that there is a panel. It has brought transparency to our decision-making process.

● On the service users and carers involved

The service users and carers on our panel have said they have gained personally from their involvement:

"I have raised self-esteem from being involved in something important. I'm surprised by how much I feel it and would recommend it to other people."

Rethink member

● On the researchers

Researchers who have had their applications reviewed by the Advisory Panel have commented that it helped to inform their research design and helped them to consider service user and carer involvement in greater depth. The panel's advice on the wording of information sheets and consent forms has been particularly well received.

We've realised that actually we need to start working with researchers as early as possible in the development of a research project. This is the best way to have an influence. For example, if our Advisory Panel wants to make changes to a patient information sheet after a researcher has already received ethical approval, then the researcher will have to resubmit their proposal to the ethics committee to get approval for those changes. It is obviously in everyone's interests if the panel can input into the research project at a much earlier stage and save everyone a lot of time.

So we are starting to develop new forms and processes so we can help researchers much earlier - at the design stage. Although this will

lead to more work and may require us to change our processes, the panel members have said they are happy to do it:

“The changes are easier to make and our input is likely to make more of a difference to the direction of the research project. Then we’re more likely to end up with a research project that fits with Rethink’s mission.”

Rethink member

The Stroke Association

About the Stroke Association (www.stroke.org.uk)

The Stroke Association is the only UK wide charity solely concerned with combating stroke in people of all ages. We fund patient orientated research into all aspects of stroke, including prevention, acute stroke care, rehabilitation and long term care, and applied neuroscience. We also help stroke patients and their families directly through our Rehabilitation and Support Services. We campaign, educate and provide information to increase knowledge of stroke at all levels of society, and act as a voice for every-one affected by stroke.

Every year an estimated 150,000 people in the UK have a stroke. Of all people who suffer from a stroke, about a third are likely to die within the first 10 days, about a third are likely to make a recovery within one month and about a third are likely to be left disabled and needing rehabilitation. Stroke has a greater disability impact than any other medical condition. A quarter of a million people are living with long-term disability as a result of stroke in the UK.

Why did your organisation want to get involved in this project?

User involvement was moving up the agenda in the research department and across the organisation. But within the research department we had had very little experience of user involvement. We hoped that involvement in this project would give us some ideas about how to do it properly. We also saw this project as a good opportunity to access examples of best practice. And we thought it would help us to develop procedures.

What has the project achieved for your organisation? What process do you have now for dealing with approaches from researchers?

This project helped us to involve people affected by stroke in decisions about research grants. We now have a process where we have a separate, plain English application form as well as a standard application form. Researchers have to complete both if they want to be considered for funding. People affected by stroke review all applications for grants and are represented on our research awards committee. These people have attended training on reviewing research proposals and together form a user panel. This panel also deals with approaches from researchers for help with recruitment.

What has been the impact of this project?

● On you and your work

The impact on the department has been huge. The whole research function is now very user-centred, which makes the research seem more meaningful. We’re also thinking about how to get service user panel members involved in

different projects. This illustrates how far we've come, as two years ago we wouldn't have thought to do that.

On a day-to-day basis the research team staff are much more conscious of the needs of stroke survivors. We're thinking more about accessibility and how the way we work will affect people. We have a much better understanding of what people are going through. It has brought the concept of stroke to the forefront of our minds.

● **On your organisation**

We've got a better reputation with stroke survivors. We've given stroke survivors a way into the research department. And it has brought user involvement to the attention of other people in the organisation. Other departments are looking to the research team to find how it should be done properly. We have developed a reputation in the organisation for doing user involvement well.

The other major change that has come about is that we now involve people affected by stroke in a meaningful way in research funding decisions. We used the recruitment to research project as a model for the design of our research grants funding process. If we hadn't got involved in this project, we would have still involved stroke survivors, but we'd have done it more slowly. It would have been more difficult and there would have been more pitfalls.

● **On the service users and carers involved**

They have found it a really positive experience. People said that they felt valued, sometimes for the first time since their stroke. They also recognised the importance of what one stroke survivor called 'the lived experience'.

"[Service users and carers] can provide very relevant insight for researchers who, although experienced and accomplished in their field, may not have had personal experience of their area of interest."

Stroke Association Lay Reviewer

● **On researchers**

Researchers are now obliged to write a decent lay summary. It's driving home to them that the voluntary sector is changing, and that people affected by a condition are having more say in research. We've had very little comeback from researchers. Nobody's complained. A couple of researchers have said it's a good idea. We've been very clear about what we're doing and how we are processing their applications, which has helped.

● **On service users and carers affected by the condition you represent**

We have found it reassuring to know that service users and carers have a say in the decision about what research will be funded – we can be confident that we are funding research that is important to the people we support. As this message gets out to stroke survivors and their carers, we hope they will have a better view of us as an organisation.

- 1:** Job Description – Advisory Panel Member
- 2:** Advisory Panel – Terms of Reference
- 3:** Advert to recruit panel members
- 4:** Advisory Panel training session – Programme and guidance notes
- 5:** Information sheet for researchers – Model policy
- 6:** Advisory Panel review session – Programme and guidance notes
- 7:** Application form
- 8:** Guidance for researchers on writing for a lay audience
- 9:** Assessing research projects – Comment sheet for Advisory Panel members

Job Description: Advisory Panel Member

Post	Advisory Panel Member
Duration	Initially for one year and then renewed every two years if agreed between [health charity] and the panel member
Payment	All panel members will have their expenses met, including accommodation, travel and care arrangements to attend training days. The role, however, is a voluntary position and members are not paid to attend events or undertake reviews

Main responsibilities

1. To review lay summaries of research projects.

To assess how well research projects meet [health charity]'s criteria for publicising opportunities to take part in research. You can do this work anywhere - you do not need to travel to the office of the organisation. Each review will take about 1-2 hours. You can do this at anytime that suits you as long as you can meet the agreed deadline.

2. To attend a training day.

A meeting will be held in (add location) and will last for (add length of time).

3. To attend an annual meeting of the panel.

At the annual meeting of the panel, members will be asked to reflect on their experiences of reviewing researchers' requests for help with publicising opportunities to take part in research. This will help develop [health charity]'s policy and practice.

Person Specification

Factor	Desirable Attributes
Qualifications	None essential.
Experience	Personal experience as a service user and / or carer Used to communicating by email (preferred) - but panel members can also communicate by post Used to commenting on documents, and producing written comments
Special skills	An interest in research Willing to respond to requests for comments on research projects within three weeks Ability to keep to tight deadlines Able to give written comments on research projects
Personal qualities	Ability to express own views Willing to give feedback to [health charity] to help develop the Advisory Panel
Commitment	Willing to be a volunteer member of the panel for 12 months Willing to review for the panel regularly (estimated 3-4 times a year)

Advisory Panel – Terms of Reference

Role of the panel

1. The role of the panel is to help [health charity] staff make decisions about whether to help researchers find people to take part in their project or to become partners in research.
2. Panel members will be asked to read and comment on lay summaries of research projects. They will be asked to comment on how well they think a project meets the needs of service users and carers.
3. Three panel members will review each project. Panel members will be given three weeks to return their comments. The work will be distributed as evenly as possible to ensure no individual panel member is overloaded. But this also depends on people's availability, particularly whether they are able to return comments within three weeks of receiving an application.
4. The final decision on whether to support recruitment to a particular research project will be made by TITLE AND ROLE. They will base their decision on the recommendations of the Advisory Panel.

Membership

5. The Advisory Panel is made up of 10-20 people³, selected from a group of [health charity] members.
6. Panel members will join for an initial period of one year while the review process is piloted. After this first year, membership of the panel will be reviewed every two years, and new members recruited on a rolling basis to maintain 10-20 members.

Training and Support

7. All new members will receive training at a briefing day before reviewing any research projects.
8. The panel will aim to meet once a year to reflect on their experience of reviewing proposals. This meeting will help develop policy and practice.

³A smaller number of people may be more appropriate for smaller organisations.

Advert to recruit panel members

New participation opportunity in [health charity]

We are currently recruiting volunteer members for ...

Research Advisory Panel

- Are you a service user or / and carer?
- Are you interested in research?
- Would you be interested in working with the [health charity] research team to select which projects [health charity] becomes involved with?
- Do you enjoy reading reports and providing critical feedback?

Interested? Please contact:

(Add name, email address and telephone number of staff member)

Closing date for expressions of interest: (Add date)

Commitment:

- One day training event
- One year membership to the Research Advisory Panel
- Assessing applications and providing reviews on request

Benefits:

- Contribute to the work of the [health charity] research team
- Meet other people interested in research to share ideas
- Learn more about research

Advisory Panel training session

Programme and guidance notes

In the programme below, guidance notes for the facilitator are in **italic text**.

10.45am Arrival and coffee

11.00am Welcome and housekeeping arrangements

Welcome participants. Go through any practical arrangements (eg break times, meal times, fire exits etc).

11.10am Introductions

Get people to introduce themselves, and make sure everyone knows who you are and what your role is. Explain a bit about the day - what the aims are, and what you'll be covering.

11.20am What's it like being asked to take part in research?

It's good to get people thinking about research in an easy way. In the sessions we ran, we asked people to get into pairs and to tell each other about a time when they had been asked to take part in a piece of research. This could be a piece of market research on the street or on the phone, or a clinical trial – or anything in between. We asked them to describe what the research was and then to talk about why they agreed or declined to take part in the research. We then discussed these reasons as a group and listed them. We reflected on how the reasons given relate to the research about why people say yes or no to taking part in research.

11.45am Why does [health charity] need an Advisory Panel?

Explain the background to this project, why the organisation wants to involve service users and carers and what the organisation hopes this project will do. Allow time for questions and discussion.

12 noon How does a research project get from being an idea to a reality?

Explain how a research project moves from being an idea to being a reality – focus on the approval processes – for example funding committees or other types of peer review, research governance arrangements and ethics committees. This gives people confidence that there are safeguards (even if they aren't perfect) and that responsibility for the quality of a piece of research does not sit with the Advisory Panel. Again allow time for questions and discussion.

12.30pm Lunch

1.15pm Using criteria to decide about whether to help find people to take part in a research project

We sent panel members two 'dummy' applications that researchers had drafted for us. We asked them to look at these before they came to the session. On the day, we worked through one of these as a whole group. Then we split people into two small groups and asked them to work through the second application. We then shared responses, stressing that there is no 'right' answer.

2:15pm How will the Advisory Panel work in practice?

You'll need to allow time to talk about how this will work in practice. For example, how do people want to receive applications – by email or by post? How many do they want to receive in a year? How long do they need to look at them? What will you do if there is no consensus between panel members? What should you do if there are requests for a quick review for some reason?

2:45pm Tea

3.00pm Review of the day and next steps

Ask people how they felt the session went. Do they have outstanding questions or concerns? Explain what will happen next. If you do not expect to receive a request from researchers for some time, you might want to suggest that you send people another dummy application to try on their own at home, while they feel confident and motivated.

3.15pm Close

Information sheet for researchers

Model policy

Our policy

[Health charity] often receives requests from researchers asking for help with finding people to take part in their research. We are always willing to help with these requests, as long as they meet with our organisation's aims and objectives.

[Health charity] needs to be certain that research projects are of good quality and will deliver genuine benefits for service users and carers with whom we work. Before agreeing to help with recruitment to research, we therefore carefully assess each proposal to check it meets our required standards.

Researchers who would like [health charity] to help with recruitment to their projects are asked to provide further details of their project using the enclosed application form.

How we can help you

[Health charity] has access to [add number] service users and carers, including people with direct experience of [health condition] and carers of people with [health condition]. We also run support groups and provide services.

All contact with individuals will be made via [health charity] as we do not release people's details without their permission. We will contact our members to let them know about research projects via our website, publications and membership database.

How decisions are made

Completed application forms are reviewed by a small panel of service users and carers and a member of staff in [health charity]. Decisions about whether to help with your request will be made within four weeks of receiving your application form. Researchers will also receive feedback from the Advisory Panel. We hope that you find this new process helpful and we welcome your comments.

A key factor in making decisions is whether there is capacity and resources within the organisation to provide the support and help that is required. [Health charity] will reserve the right to charge researchers for the support provided where this is appropriate and justifiable. For example, we will not charge students for supporting recruitment to small scale research projects for educational purposes.

What we ask of you

All researchers who receive support from [health charity] are asked to:

- Acknowledge [health charity] in any publications/ reports of the research
- Provide feedback to all participants about the overall findings from the research
- Provide a lay friendly summary of the research for dissemination to service users and carers
- Advise [health charity] on the potential applications of the research results

Advisory Panel review session

Programme and guidance notes

In the programme below, guidance notes for the facilitator are in **italic text**.

10.45am Arrival and coffee

11.00am Welcome and housekeeping arrangements

Welcome participants. Pass on apologies from any panel members who are unable to attend. Go through any practical things (e.g. break times, fire exits etc).

11.10am Introductions and review of agenda

Get everyone to introduce themselves. Explain the aims of the day. Talk through the agenda and check you are covering what people want to talk about.

11.20am Feedback on how it's going so far

Explain how many requests for help have come in, how they've been dealt with. Allow time for questions and discussion.

11.40am Your views on how things are going

Ask people to get into small groups to think about how they have got on. Ask them especially to think about:

- *What they think about the requests for help they have had so far*
- *The paperwork they get - is it enough? Does anything need amending or adding to?*

Then have a whole group discussion.

12.25pm What has happened with the requests for help that you have reviewed so far?

Run through what has happened with the requests for help that have been reviewed, whether any research has started (or been completed) since the panel was set up. Again allow time for questions and discussion.

12.45pm Lunch**1.15pm Dealing with exceptional circumstances**

In the review sessions we have facilitated, we found we needed to allow space on the agenda to deal with issues that had arisen since the project began. In this case, the issue we wanted to address was about how to deal with exceptional circumstances. You may find there are other issues that you want to address.

In this session, we talked about what to do about requests that need a quick turn around, and whether panel members were prepared to look at research projects earlier at the design stage.

1.40pm Other opportunities for getting involved in the [health charity]'s research work

We found it helpful to have a session to talk about other opportunities for involvement in the work related to research in the organisation.

1.50pm What will happen next?

In this final session you need to confirm any actions you have agreed to take as a result of this day.

You should also ask people whether they want to come together again to review progress in a year's time.

2.00pm Close

Application form

1. Title of Research Project (in plain English):	
2. Contact Details of Researcher:	
Name:	Job title:
Address:	
Tel:	
Email:	

3. Research Funding:
Name of funders/partners:
Has this project been through a process of peer review? (Please circle yes or no)
Yes No
If yes, please provide further details:

4. Has this project received ethical approval? (Please circle yes or no)
Yes: I have attached a copy of the approval letter.
No: I have not yet received ethical approval.
Please enclose a copy of the participant information sheet and your approval letter with your application.

5a. How many people do you wish to recruit in total?	
5b. How many people do you wish to recruit through [health charity]?	

6. What is the closing date for recruitment?

7. Plain English summary for service user and carer reviewers

On the next page of the form please write a lay summary of your project (no longer than one-side of A4 in 12 pt Arial) to answer the following questions:

Aims and purpose of the research

- a) What is the research about?
- b) How will it benefit people affected by [health condition]?
- c) How does it build on research that has already been done?

Service user and carer involvement

- d) Have service users and carers been involved in planning the research?
- e) How will service users and carers be involved as the project continues?

Practical issues for research participants

- f) What will taking part in the research involve for participants?
- g) How will you obtain consent from participants?
- h) What support will be offered to participants during the project?
- i) How will you make sure no one is out of pocket by participating in your research?
- j) How will you keep the information you collect about people confidential?

I undertake to provide a lay summary of the results of this research to the research participants and to [health charity] for dissemination to service users and carers.

I will acknowledge [health charity] in any publications or reports from this project.

I understand that by helping to recruit people to this project [health charity] is not taking any responsibilities for the research and is therefore not liable for any claims concerning negligence, harm or oversight that might arise during the course of the research.

Applicant signature _____ Date _____

Please return the form to:

[NAME and ADDRESS]

Plain English Summary of Project

Guidance for researchers on writing for a lay audience

When you write your lay summary of your research, you might find it helpful to think about⁴:

- Your writing style
- The layout and presentation

Your writing style

- **Write as if you are explaining your work to a friend or family member who has no scientific background**

This will help you keep it simple. You will be writing for a mixed audience with a range of reading ages and levels of education. Some may have little medical or scientific knowledge. Those with a better understanding will not be offended by simple and direct language.

- **Talk directly to your reader**

As you are writing, imagine you are talking to your reader and write the way you would speak to them. Refer to the researchers as 'we'. For example, 'we will look for...'

- **Use simple words and avoid scientific jargon**

Your vocabulary should be as simple as possible. Try to use everyday alternatives to jargon. For example, use 'give' instead of 'administer'. If technical terms must be used, then provide a simple definition.

- **Be positive and direct**

Try to write in a positive and direct style. Make sentences short and without too much punctuation. If more than one comma or connecting word seems necessary, then consider more than one sentence or a bulleted list. Make sure your main point is in the first part of a sentence and/or paragraph.

- **Use active verbs rather than passive**

Clear writing describes people doing things, not people having things done to them. Use active verbs not passive ones. For example, use 'we will look for the effects on quality of life' rather than 'the effects on quality of life will be observed'. It's usually clearest to keep 'subject verb and object' in that order.

⁴ Mellor E, Raynor D and Silcock J. (2003) Writing information for potential research participants. In: Manual for Research Ethics Committees 6th Edition. Cambridge University Press, Cambridge.

● Don't turn verbs into nouns

This is often done in formal documents. It doesn't help people's understanding. For example, 'When your blood has been tested, a decision will be taken with respect to your continued participation' could read 'We will test your blood and decide if you should stay in the trial.'

● Test your writing with users and carers

This is the only foolproof way to find out if your writing can be read and understood. Our panel can help by reading initial drafts of your patient information sheet.

Layout and presentation

● Guide your reader

In a long document, a short introduction can be used to highlight important points and guide the reader through detailed text. Make an effort to select and use clear sub-headings. Group related points together under a clear heading.

● Format and style

This is always a matter of personal preference. But since some people may have problems with their sight, it is often best to:

- Use Ariel font, minimum point size 12 or 14
- Use line spacing of 1.5
- Align text to the left (justified text is harder to read)
- Use italic, bold and underlined styles sparingly.
- Highlight headings by additional space rather than underlining
- Leave plenty of clear space in your document – particularly around bullet points and lists

● Useful websites

How to write reports in plain English.

New Mills: Plain English Campaign.

www.plainenglish.co.uk

Assessing research projects – Comment sheet for Advisory Panel members

In the spaces below please write your comments on the following aspects of the research project:

1. Aims and purpose of the research

Is the project...	Yes	No	Don't know
in line with [health charity]'s mission?			
relevant to people affected by [health condition]?			
likely to benefit people affected by [health condition]?			
important in your view?			

Comments:

2. Service user and carer involvement

Have the researchers...	Yes	No	Don't know
involved service users and carers in developing and planning this research?			
planned to involve service users and carers in the remaining stages of the research?			
included enough money in the budget for service user and carer involvement?			

Comments:

Do you think the service user and carer involvement could be improved and if so, how?

3. Practical issues for research participants

	Yes	No	Don't know
Is the researcher clear about how they will recruit people to take part and how they will obtain people's consent?			
Has the researcher outlined clearly how confidentiality will be maintained and stated that participants can leave the project at any time without impacting on care or treatment?			
Is there adequate support in place for people who may become distressed by taking part in a research project?			
Will participants in the research have their expenses reimbursed?			

Comments:

4. Information for participants

	Yes	No	Don't know
Is the information which will be given to research participants (the patient information sheet) clear and easy to understand?			
If there is other information for participants e.g. posters – are these clear and easy to understand?			

Comments:

5. Any other comments:

6. Do you think [health charity] should help with finding people to take part in this project?

Yes – as it stands	
Yes – with changes	
No	
Don't know	

7. What changes would need to be made before [health charity] agrees to help?

Please list the changes below:

- *“Research gives people hope and moves us forward. It’s important for service users and carers to have a stake in setting the agenda.”*

Rethink member

- *“You need to be clear about what you’re trying to achieve, and where your role ends and the researchers’ role begins. You need to know who you’re offering opportunities to and exactly what those opportunities to take part in research entail – to facilitate the provision of better information and ensure better experiences for people.”*

Asthma UK staff

- *“User involvement isn’t just something that you do by ticking a box. You have to be prepared to change things. Otherwise there’s no point doing it... You need to think about how involvement meets the charitable objectives of the organisation. There’s no substitute for sitting down and thinking it through.”*

Stroke Association staff

- *“Small charities should not be put off because they do not have the resources. It is okay to start small...”*

Neurofibromatosis Association member

TwoCan Associates

Website: www.twocanassociates.co.uk

Email: info@twocanassociates.co.uk