Involving Consumers in Research & Development in the NHS:

BRIEFING NOTES FOR RESEARCHERS

• Bec Hanley
• Jane Bradburn
• Sarah Gorin
• Marian Barnes
• Clare Evans
• Heather Goodare
• Marcia Kelson
• Alastair Kent
• Sandy Oliver
• Jan Wallcraft

At the planning stage we added a charming consumer extension which let in a lot of light and additional perspectives.
Information advice Support

We commission and undertake research.

We produce pamphlets.

and organise Seminars.

Help for Health Trust in Winchester
In this report we use the term ‘consumer’ rather than ‘user’ or ‘lay person’. We define consumers as patients, carers, long-term users of services, organisations representing consumers’ interests, members of the public who are the potential recipients of health promotion programmes and groups asking for research because they believe they have been exposed to potentially harmful circumstances, products or services. We recognise, however, that there is no single acceptable term used by these groups of people to describe themselves. We also recognise that there are many different definitions of the term ‘consumer’.¹

We are all potential consumers of health services. However, consumers who get involved in R&D and do not have other, ‘professional’ roles (such as doctor, nurse, researcher etc.) often have a distinct and complementary role to play in the research process.

By ‘consumer involvement’ in research we mean an active partnership between consumers and researchers in the research process, rather than the use of consumers as the ‘subjects’ of research. Many people describe consumer involvement in research as doing research with consumers rather than to, about, or for consumers.

Consumers have been involved in research and development (R&D) for many years and in many different ways. This involvement can occur during any or all of the processes involved in R&D - setting the research agenda, commissioning research, undertaking research, interpreting research or disseminating the results of research.

There are different levels of consumer involvement (see the section on page 9).

The NHS defines ‘research & development’ as:

- work designed to provide new knowledge, whose
- findings are potentially of value to all; that is, generalisable.

It includes service development only if it is linked with new knowledge. It does not include service development concerned with local implementation of research findings.²

The Director of R&D in the NHS set up Consumers in NHS Research³ in 1996. This advisory group aims to ensure that consumer involvement in research and development improves the way that research is prioritised, commissioned, undertaken and disseminated. The Group is supported by the Consumers in NHS Research Support Unit - a small team based at the Help for Health Trust in Winchester. The Support Unit:

- provides information, advice and support to consumers, researchers and those working within the NHS
- commissions and undertakes research about the involvement of consumers in health research
- produces publications and reports
- organises seminars, workshops and conferences on consumer involvement in health research.

Please contact the Support Unit (contact details are on the back cover of this booklet) for more information.

² This definition is taken from the draft Strategic Framework for the use of the NHS R&D Levy. NHS Executive (1999)
³ Formerly the Standing Advisory Group on Consumer Involvement in the NHS Research and Development Programme.
Section 1: INTRODUCTION

1.1 This booklet

1.2 Why involve consumers in research & development?
   - Reasons that are given by some professionals for not involving consumers in R&D - and some responses...
   - Why consumers choose to get involved in R&D

1.3 Types of consumer involvement in R&D
   - Consultation
   - Collaboration
   - User control
   - Which type of involvement is best?

Section 2: BEFORE YOU START...

2.1 Who should I involve?

2.2 How can I identify consumers? Building relationships
   - Involving consumers from marginalised communities

Section 3: INVOLVING CONSUMERS AT DIFFERENT STAGES OF THE R&D PROCESS

3.1 Is it best to start by involving consumers at a particular stage of the R&D process?

3.2 Involving consumers in identifying topics for research
   - Options for consumer involvement in identifying topics
   - Consumers are consulted about research topics
   - Consumers collaborate with researchers to identify topics for R&D
   - Consumers identify topics for research

3.3 Involving consumers in prioritising topics for research
   - Options for consumer involvement in prioritising topics
   - Consumers are consulted about prioritising R&D topics
   - Consumers collaborate with researchers to prioritise topics for R&D
   - Consumers prioritise topics for R&D

3.4 Involving consumers in commissioning research
   - Options for consumer involvement in commissioning research
   - Consumers are consulted about which research to commission
   - Consumers collaborate with research funders to commission research
   - Consumers commission research
3.5 Involving consumers in designing research
• Options for consumer involvement in designing research
• Consumers are consulted about the design of a research project
• Consumers collaborate with researchers to design the research project
• Consumers design the research project

3.6 Involving consumers in managing research
• Options for consumer involvement in managing research
• Consumers are consulted about the management of research
• Consumers collaborate with researchers to manage research
• Consumers manage the research for themselves

3.7 Involving consumers in undertaking research
• Options for consumer involvement in undertaking research
• Consumers are consulted about the research process
• Consumers collaborate with researchers to carry out research
• Consumers carry out the research themselves

3.8 Involving consumers in analysing and interpreting the results of research
• Options for consumer involvement in analysing and interpreting results
• Consumers are consulted about the analysis of research results
• Consumers collaborate with researchers to analyse and interpret the results of the research
• Consumers analyse and interpret the results of research

3.9 Involving consumers in disseminating the results of research
• Options for consumer involvement in disseminating results
• Consumers are consulted about disseminating the results of research
• Consumers collaborate with researchers to disseminate the results of research
• Consumers disseminate the results of research

3.10 Involving consumers in evaluating the research process
• Options for consumer involvement in evaluating research
• Consumers are consulted about evaluating the research process
• Consumers collaborate with researchers to evaluate the research process
• Consumers evaluate the research process

Section 4: CHECKLISTS

4.1 Involving consumers in committees: a checklist

4.2 Budgeting for consumer involvement in R&D: a checklist

Section 5: • DRAFT JOB DESCRIPTION

• USEFUL REFERENCES

• ABOUT THE AUTHORS
Section 1: INTRODUCTION

1.1 This booklet

This booklet was developed by a group of consumers and researchers who have a commitment to, and experience of, consumer involvement in health research. Seven people took part in a workshop led by Jane Bradburn to develop this booklet, and then made comments on drafts. A draft was also sent to a number of other consumers and researchers for comment. The drafts were written by Bec Hanley, and edited by Sarah Gorin. Information about all of the authors is included at the end of this booklet.

This booklet aims to give researchers working within the NHS some guidelines on how best to involve consumers in their work. Although we have written it primarily for researchers who receive funding through the NHS Research and Development Levy, we believe that this booklet will also be of use to other health researchers. We hope that it will be read by consumers who are involved in R&D in the NHS, so that they know about the good practice that we are suggesting researchers follow.

Consumers take part in many different types of research. They have been involved in the design of randomised controlled trials, commissioning biological studies about the causes of particular conditions and in the evaluation of specific clinical interventions. As far as possible, we have tried to make this booklet relevant to all types of health research.

The guidelines we offer here are not set in stone - they are suggestions based on our experience and on the experience of others. This booklet has been produced as a consultative document, so that we can build on it in the future. If you would like to make a comment on anything included within this booklet, please get in touch with the Consumers in NHS Research Support Unit - contact details are at the back.

The booklet begins by looking at why it is important to involve consumers in R&D and offers suggestions about overcoming some of the barriers to consumer involvement.

We then look at the different types of consumer involvement in R&D, and ask you to think about whether you want to consult consumers, collaborate with them or ask them to take control of a research project.

Next, we offer some general guidelines on involving consumers in R&D - who to involve and how to involve them.

We then talk about how to involve consumers at the different stages of R&D, beginning with the identification of research topics and ending with an evaluation of the research process.

Finally, we include some checklists about the practicalities of involvement, particularly in relation to committees and resources.

Throughout the booklet, we have tried to address the questions that researchers most frequently ask the Consumers in NHS Research Support Unit.

---

4 The NHS R&D Levy is used to support NHS service providers to undertake and support research. For more information about the NHS R&D Levy see Hanley B, on behalf of Consumers in NHS Research (1999) Research and Development in the NHS: How can you make a difference? NHS Executive: London.
1.2 Why involve consumers in research & development?

There are many reasons for involving consumers in R&D. We outline some of them below. Being clear about why you want to involve consumers will help you to identify who it is appropriate to involve and how best to involve them.

Consumers can help to ensure that issues which are important to consumers and therefore to the NHS as a whole are identified and prioritised.

We know that consumers can identify research topics that have not previously been identified by researchers or clinicians. It was the mother of a young woman with vaginal cancer who first suggested that this might have been caused by the drug she had been prescribed during pregnancy. Consumers in the HIV/AIDS field, as well as in many other areas, have identified and helped to prioritise research topics that would not otherwise have been researched.

The involvement of consumers can help to ensure that money and resources aren't wasted on research that has little or no relevance to the NHS.

At Mount Vernon Hospital in Middlesex, researchers found that involving cancer patients in the design of a trial changed their original hypothesis. They had originally designed a protocol to address the problem of over-burdened outpatient clinics, hypothesising a shift to primary care as the answer. However, the women commenting on this study said that they did not realise that there was such a problem. They said that they generally had more confidence in their hospital consultant and suggested their own solutions.

Consumers can help to ensure that research doesn't just measure outcomes that are identified and considered important by professionals.

Sometimes, researchers can fail to identify outcome measures that are important for consumers. For this reason, many researchers involve consumers in the development of outcome measures, or ask consumers to develop outcome measures for themselves. The Shaping Our Lives Project at the National Institute of Social Work, for example, is developing consumer perspectives on the debate about outcomes in community care.

Consumers can help with the recruitment of their peers.

Some consumers are suspicious about researchers’ motives and may be unwilling to become involved in research. Often, the involvement of a voluntary organisation or self-help group can assist in recruitment. This was the case in the MAIN trial, where the National Childbirth Trust worked in partnership with the National Perinatal Epidemiology Unit to recruit women to join the trial.

---

5 London: Department of Health.
Consumers can access people who are often marginalised, such as people from black and minority ethnic communities.

Researchers who undertook a project on behalf of Consumers in NHS Research found that the involvement of black and minority ethnic consumers had significant benefits for researchers and research funders. One of these was that people from these communities were able to access others from their community more effectively than other researchers.

Consumers can disseminate the results of research and work to ensure that changes are implemented.

Many voluntary organisations carry summaries of the latest research in their magazines, written in user-friendly language. Voluntary organisations also work to ensure that people receive care based on the latest research evidence. For instance, the UK Breast Cancer Coalition designed a leaflet for consumers that highlighted certain items of best practice that had not been widely implemented, thus giving them a tool for accessing a higher standard of care.

The involvement of consumers is also becoming an increasing political priority.

Whilst this is unlikely to be a reason given by researchers for involving consumers in their work, it is important to be aware that policy documents such as The New NHS: Modern, Dependable (1997); A First Class Service: Quality in the New NHS (1997); Our Healthier Nation (1998) and the new Patient Partnership Strategy all advocate the importance of involving patients, carers and others.

Reasons that are given by some professionals for not involving consumers in R&D - and some responses...

If you’re already convinced of the value of involving consumers and you don’t need to convince others, please skip this section. If, however, you come across opposition to consumer involvement, you might find this section helpful.

“One or two consumers can’t be representative of all consumers.”

It is not reasonable to expect one or two consumers to be representative of all consumers. But then it’s not reasonable to expect one doctor to be representative of all doctors either. It might be helpful to think about seeking consumer perspectives rather than consumer representatives.

If you want a range of perspectives, involve a range of consumers, and give the consumers you do involve the time and resources to network with other consumers.

---

11 UK Breast Cancer Coalition (1998) Save this leaflet and it could save your life.
“Trained or ‘professional’ consumers can’t reflect the views of ‘typical’ patients.”

It’s important to think about your reasons for involving consumers. If you want consumers to sit on a research steering group, you will want to be able to involve people who are willing and able to participate in meetings, are supported by a consumer organisation, and who are able to put their views across to a variety of people. These people may not be ‘typical’, but they will be able to contribute important insights from the consumer perspective and will also be able to access and present a range of consumer views.

“Consumers won’t understand the research.”

Many consumers have been involved in research projects that have addressed complex issues or used challenging methodology. For example, people from the HIV/AIDS community have been involved in the design and management of a number of complex randomised controlled trials. Some users of cancer services have designed research projects to look at a variety of treatments and interventions.

“There are too many problems about confidentiality.”

There are issues about confidentiality that you will need to address when you involve consumers in health research - but this does not mean that there is a need to exclude consumers from the research process.

If you are looking at patient records, agree a confidentiality policy to cover all of those involved - consumers and researchers. It is important that consumers understand the confidentiality policy and what is expected of them. They may feel compromised during the research if they are required to keep research findings confidential whilst also remaining accountable to other consumers.

Some researchers worry that research may expose poor practice. Again, this is no reason to exclude consumers. They are more likely to be motivated to ensure poor practice is addressed, as it is in their direct interests to do so.

“Health professionals can act as consumer advocates - that’s their job.”

In fact, research shows that consumers and professionals often have different priorities for research. Even when health professionals are patients they may have a dual agenda. For example, in Australia the National Breast Cancer Centre carried out a study to discover the views on priorities for research in breast cancer as seen by various stakeholders, both researchers and ‘consumers of research’. They found that women with experience of breast cancer saw priorities differently from researchers. They made ‘risk factors’ their highest priority for research, a topic that came fairly low on the scale for clinicians, researchers and policy makers.13

“How can research be objective if consumers who are emotionally engaged with the topic of a study also take part in the research design or research process?”

No one is entirely objective or neutral. Consumers bring a particular knowledge based on their experience of the issue. Many researchers have found that consumers keep research focused on the fundamental reasons for undertaking a research project, and ensure that it remains relevant to the needs of those at the receiving end of services. They do not find that involving consumers compromises the ‘scientific’ value of the research.

However, everyone involved in a research project, including consumers, should be encouraged to consider where they might turn for support if the work they are involved in is personally upsetting.

Why consumers choose to get involved in R&D

Consumers may have a number of reasons for wanting to get involved in R&D:

- to improve treatment services for themselves and those who come after them
- for many consumers research may be a means to an end and they are likely to want to know what will happen as a result of research
- to identify problems related to the treatment or service they are offered through the NHS
- to influence the research agenda in a way that makes research more effective
- to identify gaps in knowledge related to specific treatments or conditions which they feel need research
- to ensure that the issues which are a priority for consumers are addressed
- to ensure that future R&D is relevant to the needs of a specific group of consumers
- to identify existing research which is not being disseminated or implemented, which could improve treatments or services
- to ensure that R&D is undertaken in an ethical way

When you seek to involve consumers in a research project, it is important to understand their reasons for wanting to become involved, as well as explaining your reasons for wanting to involve them.
In this booklet we describe three types of consumer involvement in R&D, which can be seen on a continuum:

- consultation
- collaboration
- user control

We recognise that there is a role for each of these types of involvement within R&D in the NHS. We describe what we mean by these terms below. We use them throughout the rest of the booklet to help you to decide how much you want to involve consumers.

**Consultation**

When you consult consumers about research, you ask them for their views and use these views to inform your decision-making. For example, funders of research might hold one-off meetings with consumers to ask them about their priorities for research, or write to consumers in accessible terms about a research proposal and ask for their views. They will not necessarily adopt consumers’ views, but they may be influenced by them.

**Advantages of this type of involvement**

- It enables you to obtain consumers’ views without having to commit yourself to acting on them.
- It can be fairly quick.
- If you’ve never involved consumers before, this can feel quite a ‘safe’ way to start.

**Disadvantages**

- Some consumers find it frustrating to be asked their views without any commitment to act on them. This may mean that it is difficult to develop effective partnerships in the long term.
- Some consumer organisations may decline to get involved in consultations, arguing that it is a waste of their time if they are not seen as partners in the research process, particularly if their views have been ignored in the past.

---

**Example: Consulting consumers about research and development**

At United Bristol Healthcare Trust (UBHT) a two stage programme has been initiated to begin involving consumers in R&D, clinical audit and quality initiatives.

The first stage - *Information Giving* - aims to give consumers background information about all these activities using:

- A short explanatory leaflet distributed throughout the Trust’s many sites;
- Articles about all these activities in *Feedback*, the Trust’s patient news sheet; and
- A free standing display that travels around the Trust’s sites.

The second stage builds on the first and includes a leaflet with a ‘how you can get involved’ section. This explains what consumers can do if they wish to enquire about, or get more actively involved in any of these activities.

The consumer involvement initiative at UBHT aims to take into account the needs of the consumer for information before they can become involved in R&D and the needs of professionals in R&D - and to ensure that an adequate mechanism exists to begin dealing with consumer involvement. Ideas for projects, requests for involvement in projects, or requests for more information will be dealt with in the first instance by the leads for R&D, Audit and Quality who will ensure the consumer’s ideas or needs are directed to those who are most able to respond.

This ‘umbrella approach’ reflects the Trust’s dual commitments to integrating audit, quality and R&D to achieve clinical effectiveness as well as consumer involvement.
• **Collaboration**

Collaboration involves active, on-going partnership with consumers in the R&D process. For example, consumers might take part in a steering committee for a research project, or collaborate with researchers to design, undertake and/or disseminate the results of a research project.

**Advantages**

• By involving consumers you increase the likelihood that the outcome measures, assessment criteria and evaluation are relevant to research participants
• Consumers can help to access research participants
• Consumers can help with recruitment and informed consent
• Consumers can help to interpret and understand data
• Consumers are likely to feel more ownership of the project and therefore of the results. This means they are more likely to actively disseminate them.

**Disadvantages**

• Collaboration of any kind can be time consuming
• Collaboration can involve extra cost - for example in the payment of travel and other expenses for consumers to attend meetings
• This type of research involves an active commitment from the researcher to collaborate. This means that some control over the research will be lost.

---

**Example: Collaborating with consumers about research and development**

The Forum for Collaboration with Users in Research (Folk.us) is a unique, innovative partnership between users, lay people, academics, clinicians and managers that promotes and supports collaborative and participatory research in the fields of health and social care. Folk.us aims to:

• Promote research that is relevant to the real concerns and priorities of people who use health and social services.
• Encourage a research/practice culture influenced by users, carers and professionals in which research findings are actively put into practice.
• Ensure that those who are frightened to speak are encouraged to do so and listened to.

To date, Folk.us has organised a successful regional conference, run training events and supported the development of a number of successful research projects.
**User control**

In user-controlled research, consumers design, undertake and disseminate the results of a research project. ‘Professionals’ are only involved at the invitation of consumers. To date there has been very little user-controlled research that has been funded by the NHS; more often, research of this kind has been funded through charitable trusts and has taken place within social care. For more information about user-controlled research and how to support it, see Evans and Fisher in the ‘useful references’ at the end of this booklet.

**Advantages**

- Increased involvement of consumers who are often marginalised
- The research is likely to address questions which may not have been considered important by researchers
- There will be commitment from consumer organisations to disseminate the results of research, and to influence change in practice
- The development of research skills among ‘professional’ researchers, clinicians and consumers.

**Disadvantages**

- This type of involvement requires researchers to hand over the ownership of a project to consumers. Some researchers find this difficult or unacceptable.

---

**Example: User controlled research by Wiltshire and Swindon Users Network**

Wiltshire and Swindon Users Network obtained funding of £20,000 from Wiltshire Social Services to carry out user-controlled research into users’ views of the Wiltshire Independent Living Fund, a scheme enabling users to purchase their own social care.

A steering group of users designed the research, collated, wrote up and disseminated the findings. They organised training with the assistance of an ally experienced in research to enable disabled people to design the research questionnaire and carry out the reviews.¹⁴

**Which type of involvement is best?**

There is no single right answer to this question. Different types of involvement will be most appropriate for different research projects. This will depend on the researchers, the consumers, the research method and the requirements of the funding body. In any single research project, you might consult, collaborate with, and ask consumers to lead different stages of the project.

---

¹⁴ Copies of the report *I am in Control* are available from Wiltshire and Swindon Users’ Network, 7 Prince Maurice Courts, Hambleton Avenue, London Road, Devizes SN10 2RT.
You’ll also need to think about the broad topic area that you hope to address. If your research project relates to people affected by Alzheimer’s Disease, for example, you should contact the local and national Alzheimer’s Society.

Consider that some consumers may choose not to become involved in your work - because their aims do not match yours, because they do not have the time, or because the emotional or practical costs of involvement may be too high.

### 2.1 Who should I involve?

This booklet is all about the importance of building good relationships with individual consumers and consumer organisations. Once you have developed relationships, you will have a clearer knowledge about priorities and ways of working, which should make ongoing collaboration more effective.

To address the question about who to involve, you first need to think about the aims and objectives of your R&D programme or project. Prepare a brief ‘job description’ to enable you to think more clearly about who you might involve. (See section 5 for an example job description.) It is usually better to involve more than one person so that a consumer does not feel isolated in a group of professionals. The best way to start is often to go to consumer groups to hear their views collectively.

Remember that there are different types of consumer organisation - self help groups, voluntary organisations that provide services, pressure groups, advocacy groups and so on. There are also different ‘types’ of consumers:

- patients
- long term users of services
- carers or parents
- ‘representatives’ or advocates of patients, for example people working for consumer organisations
- community groups.

You’ll need to think about what ‘type(s)’ of consumers you want to involve. For example, you may want to have input from consumers who have experienced a particular condition or treatment, in order to ensure that the issues you are addressing in your research project are relevant to consumers. It would therefore be more appropriate to involve people with direct experience of the condition, rather than carers, or workers from a voluntary organisation.

### Example: Identifying skills and expertise to recruit consumers

An acute Trust in receipt of NHS R&D funding decided to involve two consumers in their research committee. They agreed that they needed to recruit consumers who:

- could take a broad view of a variety of topic areas and research methods
- had the confidence and experience to take an active part in committee meetings.
- had the time and confidence to read research proposals and reports
- were prepared to reflect the views of consumers at committee meetings
- would be able to access the views of a wide range of other consumers.

The secretary to the committee approached the local Community Health Council and Council for Voluntary Service with this job description. He also wrote to all of the self-help groups and patient liaison groups that had links with the Trust. Two consumers were identified - one from the CHC and one from the Maternity Services Liaison Committee, who was also a member of the National Childbirth Trust.

2.2 How can I identify consumers? Building relationships

Before you contact consumers remind yourself about the aims and objectives of your project and the ‘job description’ of the consumers you’d like to involve (see section 5). You’ll find that having to explain your research in user-friendly terms can help clarify your own thinking.

You may need to contact a number of different consumer organisations. Possible sources of contacts for local and national consumer organisations are:

- the Help for Health HelpBox 16
- your local Community Health Council
- your local Council for Voluntary Service
- the Health Information Service17
- the World Wide Web
- NHS organisations - NHS R&D Regional Offices, GPs surgeries
- College of Health Self-Help Group Directory18
- local libraries
- NHS Direct Online
- Race Equality Councils
- database of research involving consumers19
- patient and local community networks
- advertising through local media and newsletters

You’ll also need to think about the different communities who might have an interest in your research area. For example, will your research affect elderly people? If so, you should think about contacting local elderly people’s organisations. Similarly, if you are planning to carry out research in an area where there is a significant minority ethnic population, make links with these communities.

When you approach consumers to get involved in R&D, be ready to tell them in simple, unambiguous language about:

- the project you are asking them to become involved in and its background
- why you are approaching them
- what you are asking from them (the ‘job description’- see section 5)
- what resources you can offer to enable them to contribute effectively (see the section on resources on page 34)
- what you hope they might get out of it.

In order to understand consumers’ perspectives better, spend time developing a relationship with them. Visit both individual consumers and consumer organisations on their own ground. Look at examples of their work. Ask to see newsletters and annual reports and ask them to explain what they do. Co-operation is more likely if consumers feel that their contribution is respected and valued.

And finally, ask consumers about how and when they would like to be involved. For example, it may not be easy or appropriate for a woman who has recently been diagnosed with breast cancer to become extensively involved in a research project in this area. She may prefer to become involved at a later stage.

---

16 HelpBox is a database which provides consumer health information. It is used by over 400 organisations and contains over 6,000 records covering a wide range of health issues. It includes details of national self-help groups as well as references of self-help literature. More information can be obtained from the Help for Health Trust (Phone: 01962 849100).

17 The Health Information Service is a free confidential service available to everyone. It can provide up-to-date unbiased information about health issues. The helpline is open between 9am and 5pm Monday to Friday (Phone: 0800 665544).

18 College of Health self-help group directory (Phone: 0208 983 1225).

19 This database was commissioned by Consumers in NHS Research and is available from the Centre for Health Economics, University of York (Phone 01904 433648).
Involving consumers from marginalised communities

Researchers often find it difficult to access people from marginalised communities effectively. One answer is to ask the communities themselves to do this, or ask organisations which speak on behalf of these communities, and ensure you resource them to do so.

So, for example, if your research is connected with learning disability, approach the local or national People First organisation (an organisation of people with learning disabilities). These organisations are likely to be able to access people with learning difficulties more easily than you, as they will already have a relationship with them.

You can also contact the relevant national organisations that may have produced guidelines on working with particular groups or communities.

Don’t forget that many marginalised communities are understandably uneasy about having research done ‘to’ or ‘for’ them. They are much more likely to work with researchers who want to collaborate with them on research that has been identified by the community as a priority, or researchers who are willing to support them to undertake their own research (see the section on user-controlled research on page 11).

---

Example: Minority ethnic residents interview Pakistani and Bangladeshi people about perceptions of psychological distress

A project was carried out in a socio-economically disadvantaged inner city area that aimed to promote community participation in exploring perceptions of psychological distress for Pakistani and Bangladeshi people. Thirteen community members were provided with training to conduct qualitative research in the form of semi-structured interviews. They interviewed 104 South Asian people (49 of whom were of Pakistani origin and 55 people of Bangladeshi origin). Most of the respondents located stress within their experience of racism and socio-economic disadvantage.

The training provided the community interviewers with skills that led to a National Vocational Qualification. The research led to practical recommendations about the need for re-orientation and provision of services and changes were implemented.

---

Consumer involvement does not mean that consumers must be involved in every task or at every stage of the R&D process.

Enable consumers to focus their energy on what they can do and what they wish to do, as you do with other members of the research team.

You could probably start by involving consumers at any stage in the R&D process. But we recommend you start by involving consumers at as early a stage as possible and then follow the process through (see diagram below). You are less likely to successfully involve consumers if you merely want them to help you to disseminate the results of your research project.
This is one of the most powerful ways to involve consumers in R&D as it enables consumers (along with others) to have a say about what will be researched. The task of identifying a research topic should be a dialogue. We have found that the best way to involve consumers in identifying topics for research is to talk with them face-to-face. You’ll need to check whether your priorities match those of consumers. Talk about what you each want from research. Be clear about what research can, and can’t achieve. Research alone very rarely leads to change - but sometimes the involvement of consumer organisations can influence the uptake of research.

Recognise that different individual consumers and consumer organisations may have different priorities, just as different researchers and clinicians do.

**Options for consumer involvement in identifying topics:**

- Consumers are consulted about research topics previously identified by researchers
- Consumers collaborate with researchers to identify research topics
- Consumers identify topics for research

**• Consumers are consulted about research topics**

If you have already identified a research topic, it would still be useful to consult with consumers about the appropriateness of the topic to them. You can use a number of different methods to identify research topics with consumers. These include:

- surveys
- brainstorming
- workshops
- outreach work
- peer group interviews
- independent facilitators (to avoid you getting too involved)

You’ll need to consider whether to offer childminding or carer resources, postage costs, travel costs, transport, an accessible meeting space or other resources to make consumer involvement possible.
You may find that some consumers do not have ideas about the research questions that they would like to see addressed. If this is the case, ask about problems that people affected by the condition or treatment in question face. Or ask about the issues important to them in their experience of the NHS: What didn’t work? What could be improved? What are their ideas about their condition or treatment? What about possible side effects?

Don’t make any assumptions in advance, but be prepared to check your ideas out with them. The aim is to generate a dialogue that will enable both you and consumers to learn how to define research questions together.

Ask the questions in a way that shows you are prepared to listen and respond to the answers you get. Some topics may be identified that are not appropriate for research at the present time or are not suitable for research at all. It is helpful to think about who you can refer consumers to if their topics are more relevant to audit, service delivery or service planning. It may also be helpful to talk through how their concerns can be incorporated into research questions.

---

**Example: Using a workshop to explore consumers’ views of research topics**

Researchers at Birmingham University and local mental health professionals were interested in exploring users’ experiences of compulsion under the Mental Health Act. One of the researchers met with users involved in national mental health service user organisations to discuss the usefulness of such research. A local workshop was held involving researchers, professionals and a user representative to brainstorm key issues for the research. A draft proposal was also sent out for user comment. As this project progresses, users will continue to be involved in the design and conduct of the work. More detailed definition of topics to be covered in interviews took place in workshops involving 5 users and 3 researchers. Discussion drew on direct personal experience and on wider experience via some users’ roles as advocates. Users are conducting the interviews and will also be involved in analysing the results.

---

**• Consumers collaborate with researchers to identify topics for R&D**

You can collaborate with consumers to identify topics using the same methods as those outlined in the section above. In one NHS trust midwives have held focus groups to explore women’s priorities for research. This has resulted in a research proposal being put forward on a priority area they have defined.

Using a collaborative approach you may find that the research question you end up with is drawn from the ideas of a number of different organisations and individuals, both professional and consumer. We’ve found it useful to record these influences at the beginning of the research project.

---

**• Consumers identify topics for research**

Groups of consumers may meet to identify research topics that are of interest to them. Organisations representing the interests of consumers may also identify priorities for research through general contact with the consumers, complaints they have received and calls to helplines.
3.3 Involving consumers in prioritising topics for research

Options for consumer involvement in prioritising topics:

- Consumers are consulted about prioritising R&D topics
- Consumers collaborate with researchers to prioritise topics for R&D
- Consumers prioritise topics for R&D

Example: Consumers are consulted about prioritisation of research topics by the National Childbirth Trust

The National Childbirth Trust has run consultation exercises on the research topics its members want prioritised. One such consultation used various methods to reach members including consultation through their quarterly journal, New Generation, at conferences for members and in mailings to local branches of the Trust.

The topics that were recommended for research included a wide range of issues. These ranged from high technology practices, established practices and new ideas, and patient information and support. These were reduced to five key research priorities by a panel of ten members from the National Childbirth Trust.

The final topics which were prioritised were: methods for effective communication and support to meet individual needs; methods for preserving an intact perineum; attitudes of midwives to breast feeding; and withholding food and drink in labour.

• Consumers collaborate with researchers to prioritise topics for R&D

This is mostly carried out by involving consumers on committees that prioritise research topics. Before you approach any consumers, think clearly about the aims of involving consumers in the prioritisation process - are you looking for consumers who have access to the views of other consumers, or consumers who can offer their own personal experience of a particular condition or treatment?

You may want to consider equal representation of consumers and professionals on committees to prioritise research.

We suggest you use the checklist on page 34 if you plan to involve consumers in prioritisation through committees.

• Consumers prioritise topics for R&D

To our knowledge, consumers have not been asked to work alone to agree priorities for R&D in the NHS. This doesn’t mean it shouldn’t happen - only that it hasn’t happened to date. Please let us know of any examples you may have.

Example: Consumers are involved in prioritisation of research in the Health Technology Assessment Programme

In 1998 the Health Technology Assessment Programme (a national NHS R&D programme which looks at how health interventions work) set up a pilot project to involve consumers in its work. As part of this project, consumers were invited to join a number of the panels that prioritise topics for research through the Programme.

Staff leading the pilot identified the attributes they felt panel members needed. These included an understanding of the scope of the panel, an ability to contribute to discussions without representing a particular constituent group above others, time to attend two panel meetings, an induction day and a reflection day, and time to prepare for meetings. Consumers came from the Patients’ Association, Age Concern, the College of Health and other organisations. Two consumers were identified for each of three panels. In addition, consumers from condition-specific groups were consulted about the research needs of particular groups. Their contributions were used to brief the panel members who set research priorities.

Consumer ‘experts’ tended to highlight issues about patients’ views, social contexts, information and support needs, long-term outcomes, and dissemination of research findings to consumers. These issues were usually not addressed so much by professionals who tended to focus on scientific and economic aspects of the work.

The involvement of consumers led staff working on the HTA Programme to review the training and induction of all new panel members. For the 1999 round of panel meetings each of the five panels had two consumer panel members and the methodology group had a consumer methodologist. A mentoring scheme has been set up for new consumer panel members. Consumers peer reviewed three topics for each of the five panels and the methodology group. The consumers came from a wide range of consumer organisations and were asked to highlight issues that are important to patients or people using the services.
3.4 Involving consumers in commissioning research

Options for consumer involvement in commissioning research:

- consumers are consulted about which research to commission
- consumers collaborate with research funders to commission research
- consumers commission research

Consumers may be consulted about which research to commission in a number of ways including: sending surveys to consumers to ask their views; carrying out interviews or focus groups with consumers; or going to meetings of consumer groups and discussing research proposals with them. Information should be provided to consumers in user-friendly language, the views of consumers should be taken into consideration and the results of the commissioning process fed back to the consumers.

• Consumers collaborate with research funders to commission research

A number of funding organisations have involved consumers in reviewing proposals for research. They have found that consumers bring a different perspective to the review process. If you plan to involve consumers as reviewers, think about the following:

- Don’t underestimate the abilities of consumers to review proposals - some consumers already have expertise in this area.

- Ask consumers to review the elements of a research proposal that are relevant to them. Some consumers may not feel confident about commenting on the details of methodology, but would be very happy to comment on the relevance of the questions being addressed, whether the research will address quality of life issues, the approach being used and so on.

- Recognise that consumers from national organisations may have different expertise than those from local groups. National organisations may employ researchers or research managers with particular expertise in this area. Local groups will often be dependent on volunteers.

- Consumers may prefer to review proposals as a group. Not only does this help them gather a range of perspectives for the task, it also ensures they can offer each other mutual support.

You can also involve consumers in committees that commission research. You’ll find that consumers can ensure that researchers address issues that are of importance to those affected by the condition or intervention to be addressed in the research study.

Refer to our guidelines on involving consumers in committees on page 34 if you plan to involve consumers on commissioning groups.
• Consumers commission research

Consumers may commission research that is a priority for them. To our knowledge, this has not happened within the NHS to date (with the exception of Community Health Councils) but that doesn’t mean it shouldn’t happen in the future. It does happen extensively in the voluntary and community sector.

Example: Consumers peer review proposals for NEAT

The New and Emerging Applications of Technologies Programme (NEAT) is a national NHS R&D programme. The NEAT committee considers applications submitted to the programme. After an initial meeting in January 1999, the committee met the following September to discuss nearly 300 proposals received in response to an open call. There are 2 consumer representatives on the committee and full proposals are sent to consumer organisations for review. Projects supported through the NEAT programme are required to reflect an awareness of the needs of users, patients and carers.

Example: Consumers commission research

Residents in Corkerhill, Glasgow commissioned a study that examined high accident admission rates of children to hospital. Corkerhill, a large housing estate in Glasgow, has a high rate of unemployment and lone parent households. The residents were concerned that the accident admission rates of children to hospital were twice as high as those for the city as a whole, so they commissioned a group of researchers to look into it. Local people were involved in devising a survey, arranging interviews and acting as a link between researchers and local people. The research found that it was the physical environment in Corkerhill that put children at risk and the researchers called for more investment into the estate.

After the research smoke alarms were installed in all the houses, a ‘dangerwatch’ scheme was set up by a local resident to alert children to dangers and the estate was awarded ‘Safe Community Status’ by the World Health Organisation - not for the changes achieved but for the vision of what a safe community could be like and what would be needed to achieve it.
If you are involving consumers in your research it is helpful to plan this involvement before submitting a proposal for funding. Some research commissioners may ask how you are involving consumers on the application form for funding. It is important that you think through how you are going to involve consumers and the implications of asking people to become involved.

When designing the research you will need to budget for the additional cost of involving consumers (see section 4.2). You should also be aware of any ethical implications for those people you are asking to become involved in the research (see the list of useful references at the end of the booklet for further reading on ethical considerations).

### Options for consumer involvement in designing research:

- Consumers are consulted about the design of the research project

- Consumers collaborate with researchers to design the research project

- Consumers design the research project

### Consumer are consulted about the design of a research project

You can do this by:

- asking for written comments on a protocol
- asking for comments about written information to be supplied for those invited to participate in the research - for example information sheets and consent forms;
- discussing protocols in focus groups;
- recruiting consumers to a research advisory group.
• Consumers collaborate with researchers to design the research project

Many consumers have collaborated with researchers to design research projects. The involvement of consumers in the design of a research project can lead to research that is more relevant to the needs of consumers and which is more likely to encourage consumers to take part.

You can collaborate with consumers at this stage in the research process through:

• committees - see the general guidelines on page 34;

• focus groups or other discussions;

• agreeing with consumers that they will design particular elements of the research project - for example, many consumers have been responsible for producing written information in user friendly language;

• employing consumers as consultants to the research team.

• Consumers design the research project

See our general guidelines on user-controlled research on page 11.

Example: Collaboration between consumers and researchers on the design of a clinical trial

The Consumers Advisory Group for Clinical Trials (CAG-CT) together with the Patient Involvement Unit at the Lynda Jackson Macmillan Centre used focus groups with women with breast cancer to involve them in the design of a national randomised controlled trial of the use of hormone replacement therapy as a treatment for women experiencing menopausal symptoms as a result of treatment for early stage breast cancer.

The various stakeholders in the research, including representatives from each focus group, then met to determine and agree priority issues for consideration in the trial design. Representatives from this meeting were responsible for monitoring agreed action points and ensuring they were considered by clinicians in the design and management of the trial.

The trial highlighted the importance of adequate information for patients upon which to base decisions. As a result the Patient Involvement Unit, with the involvement of patients, produced a booklet for patients - Breast Cancer, Hormones and HRT.
3.6 Involving consumers in managing research

Options for consumer involvement in managing research:

- Consumers are consulted about the management of research
- Consumers collaborate with researchers to manage the research
- Consumers manage the research for themselves

- Consumers are consulted about the management of research

See our general comments on consultation on page 9 if you plan to consult consumers about the management of a research project.

- Consumers collaborate with researchers to manage research

This is usually undertaken through a committee or steering group (see our guidelines on involving consumers in committees on page 34).

You will need to think about issues of confidentiality before you ask consumers to take part in steering groups or committees to oversee a research project. For example, if your committee will be looking at patient notes, does the organisation’s confidentiality policy allow a consumer to be involved in this? Some consumers have been asked to leave the room when discussions like this take place in steering groups for research. If this is likely to be the case, advise the consumer beforehand.

You can also collaborate with consumers to recruit researchers for your project. Consumers can bring a useful perspective to the selection process - particularly if you are recruiting researchers who will need to build relationships with research participants to access data for the research.

We believe that it is not usually appropriate for research participants to also act as managers or advisers. People can find it compromising to be both the ‘subject’ and the researcher, particularly if the research is about relationships.
Example: Involving consumers in developing a guidebook

Staff at the National Primary Care Research & Development Centre have worked with consumers to develop a guidebook of evidence-based medicine for people with ulcerative colitis. It is designed to empower patients and enable them to make informed choices about their care.

Consumers were active partners in the development of the guidebook - they were involved in the recruitment of the researcher, the selection and co-ordination of other consumers, the discussion of issues in focus groups, and individual assessment of the guidebook. 22

• Consumers manage the research for themselves

See our section on page 11 about user-controlled research.

Options for consumer involvement in undertaking research:

- Consumers are consulted about the research process
- Consumers collaborate with researchers to carry out research
- Consumers carry out the research themselves

**3.7 Involving consumers in undertaking research**

- **Consumers are consulted about the research process**

  Meetings may be used during the research process to let consumers know that the research is being undertaken and what it is about. This is particularly important if the topic is a sensitive one.

  As well as informing consumers about the research, meetings can also help with response rates to questionnaires and make the first contact if interviews are to be carried out.

  Researchers involved in clinical trials may use meetings with patients or voluntary organisations during the research to keep them up to date about the progress of the trials.

- **Consumers collaborate with researchers to carry out research**

  We have already pointed out that consumers and consumer organisations have links with other consumers. They will therefore be able to help you to access particular communities, help with consent, gather data, and so on. If you are collaborating with consumers to undertake research, ensure that you:

  - are clear about the role you are asking people to undertake - a job description is helpful here (see section 5).
  - are as explicit as possible about the research. Ensure that the research questions and the research method are clear.
  - offer training to consumers in the research methods you are adopting, if they do not have experience in this area.
  - offer payment to consumers. Some consumers may be happy to volunteer ‘free’ time, but this should not be assumed.
Consumers carry out the research themselves

Consumers may take a variety of roles in undertaking research. They may design the research instruments, (that is, the questionnaire or the interview schedules).

They may also carry out the research themselves. This may take the form of surveys, interviews, focus groups, gathering or reviewing documentary evidence, or undertaking library based research.

If consumers carry out the research themselves it is important to make sure they have the right skills and that training is provided for those who need it.

Example: Consumers are involved in carrying out research

In June 1998 the National Eczema Society published an article in the Society’s magazine, Exchange, calling for volunteers to become involved as consumers in the newly registered Cochrane Collaboration Skin Group. Twenty-two people replied.

The National Eczema Society worked with the Cochrane Skin Group to develop an induction pack and run a one-day seminar in November. Here, people signed up for hand searching of journals, focus groups and other activities.

Example: Consumers undertake research on the prevalence of smoking

In 1997 a project was set up which aimed to look at the prevalence of smoking amongst residents in a socio-economically deprived area in South Tyneside.

The project recruited and trained local residents to undertake a door to door survey about smoking. Residents were responsible for both undertaking and analysing the research.

They received training on issues such as security; confidence; reflective listening; confidentiality and data analysis techniques. One of the main aims of the research was to actively work with members of the community to provide them with new skills.

The study found that such involvement provided people with higher scores on the Huskin’s Personal/Social Skills Assessment, that the recruits found the experience enjoyable and informative and that there had been positive benefits in terms of self-esteem and improved interpersonal skills.
3.8 Involving consumers in analysing and interpreting the results of research

Options for consumer involvement in analysing and interpreting results:

• Consumers are consulted about the analysis of research results

• Consumers collaborate with researchers to analyse and interpret the results of research

• Consumers analyse and interpret the results of research

Consultation with consumers about the analysis of research results may take the form of meetings with those involved or interested in the research. Consumers can also be consulted by providing them with draft copies of the analysis for comment. They may be able to advise on which areas of the findings are of most interest to them and which they would like to be analysed further or featured in reports to be produced.

• Consumers collaborate with researchers to analyse and interpret the results of research

You can involve consumers in analysing interim results of research. This can result in feedback or comments, which aid analysis and interpretation. You can also hold a participative conference to check your initial findings.

• Consumers analyse and interpret the results of research

Consumers may be experienced in analysing and interpreting the results of research or they may benefit from some guidance from a researcher.
In research undertaken by the Wiltshire and Swindon Users’ Network (see footnote 5 on page 5) a researcher was asked to advise on how users could best analyse qualitative research. The proposal that was made involved two processes:

- Firstly, two members of the group read all the transcripts to acquire an overall perspective. Using two people was thought to minimise the likelihood that one perspective would dominate.

- Second, members of the group were asked to read particular sections of the interview and write summaries of what the users were saying, using direct quotes.

A series of workshops were then proposed where specific and overview perspectives could be co-ordinated. Additional workshops were provided to train people in systematic analysis.
Options for consumer involvement in disseminating results:

- Consumers are consulted about disseminating the results of research
- Consumers collaborate with researchers to disseminate the results of research
- Consumers disseminate the results of research

Consumers can influence the implementation of research findings, particularly if these have implications for service delivery. They will be able to raise the research in different forums; often those to which researchers do not traditionally have access.

Consumers are much more likely to disseminate the results of research to their peers if they have been involved in the research from an early stage. You can involve consumers in reviewing draft research reports. This is particularly helpful if you want to produce a report that is accessible - consumers are very good at identifying jargon. If you involve consumers in this way, see section 3.4 on consumers collaborating with research funders to commission research.

Consumer involvement in dissemination can also lead to other activities, such as the development of guidelines for future practice.

- **Consumers are consulted about disseminating the results of research**

It is often useful to consult with consumers about how they think the results of the research should be disseminated. They may have views about how best to reach other consumers and may be able to suggest other networks and publications that could be used to disseminate results. Consumers often have their own informal networks. Consultation about the results of the research is also likely to lead to informal dissemination.

- **Consumers collaborate with researchers to disseminate the results of research**

It is worth producing brief progress reports or newsletters to keep people informed of progress throughout a research project, rather than waiting to the end to produce a report for dissemination. You should ensure you feed back the results of research to research participants, if you have agreed to do this.
Report positive and negative results, not just the ones you think people (or funders) will want to hear.

It is important that you tell everyone involved in a research project about the results before you publish anything in the media. There is nothing more likely to alienate consumers than reading about your research project in a newspaper or journal before knowing about it first hand. This is vital if the results of the research have direct implications for the health of participants or their families.

The publication of the study undertaken by the Institute for Cancer Research of women with breast cancer attending the Bristol Cancer Help Centre caused much distress to participants when the interim results were widely publicised without informing the women themselves in advance. Participants heard that those who had attended the Centre were twice as likely to die and three times as likely to relapse as women who had not been to the Centre. These findings were later discredited, but the damage had already been done.

Consumers may also be involved in dissemination by producing research summaries in user-friendly language for circulation to other consumers and those in the NHS.

Example: Consumers collaborate with researchers and clinicians to disseminate the results of the first trial for HIV therapy

The first drug trial for HIV, the Concorde trial, began in 1988 and lasted for over four years. The trial compared AZT (zidovudine) to placebo and aimed to discover whether the drug could postpone or prevent the onset of HIV-related disease. The results showed that there was little difference between using the drug in the early or later stages of the HIV infection.

It was clear that the results of the trial were going to be controversial and that they had very significant implications for those who took part in the trial and the rest of the HIV community. It was therefore very important that those involved in the trial were explained the results prior to press releases and were told whether they had taken the drug or the placebo. It was also important that nurses and clinicians understood the research and its implications so they were able to provide support and advice to people with HIV. Nick Partridge, the Chief Executive of the Terrence Higgins Trust was a member of the trial steering group. He was involved in meetings with community based groups and these meetings continued for several months after the release of the results, in order to ensure that people fully understood the results and were not misled by inaccurate media reporting. A regular newsletter was used throughout the trial to inform participants about progress and a community representative was also on the panel that was responsible for breaking the results.

• Consumers disseminate the results of research

Consumers can disseminate the results of research by producing articles in their newsletters and talking about the research at their meetings and conferences. For example, The Multiple Sclerosis Society produces summaries of research in a newsletter that is distributed to people with MS. Listening to a consumer report research findings and their experience of the research process can be a very engaging and effective means of disseminating information. They will be able to summarise the results of research in user-friendly language. You should ensure you fund photocopying, postage and other costs if you are asking consumer organisations to disseminate the results of research.

Options for consumer involvement in evaluating research:

- Consumers are consulted about evaluating the research process
- Consumers collaborate with researchers to evaluate the research process
- Consumers evaluate the research process

Whether consumers do the research themselves, collaborate with researchers or are consulted about research, it is important that the research process is evaluated after completion. Consumers who have been involved in research should be involved in this evaluation and reflection process.

This is the time at which both researchers and consumers can consider what went well during the research, what did not work so well and what they would do differently if they were to do the research again. It is important that consumers feel able to share their experience of the research process and their involvement in it openly and honestly. Through an open exchange between researchers and consumers, both parties can learn from each other.

Evaluating the role consumers play in the research process provides useful information and encouragement for other researchers wishing to involve consumers in their work. It can also help you to involve consumers more effectively next time.

The involvement of consumers in evaluation can result in the identification of new research topics, thus completing the cycle of R&D.

- Consumers are consulted about evaluating the research process

It may be useful to consult with users who have been involved in the research when undertaking evaluation, particularly when considering how the process of involving consumers worked.

Consumers who were involved in the research may have very different insights about the process of involvement and how they experienced it. It is useful to include their perspectives in an evaluation of the research.
• Consumers collaborate with researchers to evaluate the research process

Consumers may be involved in undertaking the evaluation. They may complete evaluation forms or rate their own skills before and after the research in order to ascertain the ways in which they think being involved in the research process has affected them. Alternatively, they may meet with researchers to evaluate the research process on a more informal basis.

• Consumers evaluate the research process

Consumers may also evaluate research themselves. This may take the form of commenting on the research before or after it has been published.

Example: Consumers comment on a published review about a treatment for early breast cancer

The Breast Cancer Collaborative Review Group of the Cochrane Collaboration published their overview of ovarian ablation as a treatment for early breast cancer in the Cochrane Library in January 1998. It had had no consumer input before publication, but the Comments and Criticisms facility of the Cochrane Library enabled consumers from BREAST UK (Breast-cancer Research Ethics and Advocacy Strategy) to contribute critical comments on the absence of a discussion about the side effects of the treatment, which are significant for women. They also made suggestions for future research in this area.
Section 4: CHECKLISTS

4.1 Involving consumers in committees: a checklist

Who to involve:

- Involve more than one consumer - this avoids tokenism and can mean that consumers can offer each other support and encouragement;
  - Find people who are used to committee work;
  - Consult with consumer organisations in order to identify the most appropriate people. Ideally, you should ask consumer organisations to select their representatives;
  - Ensure that those consumers you involve have links with consumer networks - this means they can consult with others as well as getting support and encouragement when they need it;
- Don’t expect a health professional to sit on a research committee with a former or current patient - it’s unfair to both.

When you approach people...

- Be clear about the task - this will enable people to make an informed choice about whether they want to participate;
- Be clear about the basis for involvement on a committee - are you looking for a personal perspective, or will you be asking consumers to consult with their peers or organisations to offer a ‘broader’ view?
- Be clear about the committee’s remit, and what you are likely to achieve - don’t raise inappropriately high expectations;
- Ensure you offer new consumer members some form of induction and training.

Offer resources and support:

- Think about consumers’ emotional support. If you are involving people with cancer in prioritising research topics related to cancer services, this is likely to have more emotional impact on them than on other people on the research committee;
- Think about ongoing support for consumers members on committees, perhaps through a system of mentorship;
- Ensure you can pay travel and carer costs, and make this clear to consumers in advance. If other people are paid through their own or your organisation to be involved in research, ensure you offer to pay consumers for their time too;
- Ensure that consumers have access to information resources. Provide contact numbers for information services and ensure that consumers have access to health care libraries and borrower entitlement.
Before the first meeting:

☑ Provide adequate background information in user-friendly language;
☑ Invite consumer contributions for the agenda before the meeting;
☑ Learn from the experience of other committees which have consumer membership - for example the Maternity Services Liaison Committee, the Local Research Ethics Committee, etc;
☑ Provide training (for consumers and other committee members) if necessary.

Access:

☑ Schedule meetings at times and in places which are convenient to consumers;
☑ Meeting places should be accessible to all participants - so if you are inviting a wheelchair user to join your committee, ensure you meet in an accessible meeting room with an accessible loo;
☑ Consider having meetings in the consumers’ venues, and not just where researchers are based;
☑ Think about whether you need interpreters for people from different ethnic groups, somebody to translate into sign language, or translate material for meetings.

During the meeting:

☑ Avoid jargon in written information and in discussion. If you must use jargon, produce a glossary or spend time briefing consumer members before a committee;
☑ The role of the chair is crucial. Ensure she/he supports the involvement of consumers in the committee and makes efforts to include them during meetings;
☑ Think about using an independent facilitator;
☑ Think about different formats for meetings - perhaps work in small groups, have sub-group meetings, have a time at the end of the meeting when you review how the meeting has gone;
☑ Drinks should be made available because people may need to take medication during meetings. Ideally another room should be made available for people to use if they need to during meetings.
☑ Ensure that professionals turn up to the meeting, if they have been invited.

After the meeting:

☑ If you agree recommendations which involve consumers, make sure you implement them;
☑ Provide feedback on outcomes of the committee’s work, even if no actions are taken;
☑ Allow sufficient time between meetings for consumers to consult with their peers or their organisations, if they wish to do this;
☑ Seek feedback from consumers about their experience of involvement in the committee - ask how things could be improved.
Before you involve consumers in R&D, you’ll need to think about budgeting for their involvement. The following list provides suggestions of the types of expenses you may need to think about. The extent and type of consumer involvement in your research will dictate which of these you may need to cover:

- Travel expenses;
- Childcare and carer costs;
- Payment for involvement - particularly if other members of the research team are being paid for their involvement, even if not by your organisation. If you do not pay a fee, think about budgeting for loss of earnings;
- Hire of accessible venues;
- Translation and interpreting costs;
- Payment of an independent facilitator;
- Postage, photocopying and telephone costs;
- Payment towards administrative support.
Section 5:  • DRAFT JOB DESCRIPTION  
• USEFUL REFERENCES  
• ABOUT THE AUTHORS
Background

The Health Technology Assessment Programme is the largest single programme within the NHS R&D strategy and aims to reduce uncertainty about the effectiveness and cost-effectiveness of interventions used in the NHS. The Director of the HTA programme is advised by a number of advisory panels. The role of the panels is to help decide which of the many suggestions received by the programme is prioritised for commissioning.

A consumer is someone who uses a service. The service, in this case, is the NHS and its consumers are patients (or potential patients), carers, long term users of services, organisations that represent these people’s interests, and other groups affected by the service they receive from the NHS. They come from all sections of the population.

The HTA has been at the forefront of developing consumer involvement in NHS research. In June 1999 a strategy was agreed for integrating consumer perspectives into the HTA programme. The strategy states that each panel will have two consumer members.

The consumer members are required to take a broad view of a variety of topic areas and research methods and have the confidence and experience to take an active part in the panel meetings. The main duties will involve having the time and confidence to read briefing papers (vignettes) and being prepared to reflect the views of consumers at the panel meetings without representing a particular constituent group above others.

Example provided by the National Coordinating Centre for Health Technology Assessment (NCCHTA)
**Principal Responsibilities**

1. **To attend an HTA Programme Briefing**  
   This is held before the panel meetings each year and is an introduction to the work of the HTA programme.

2. **To attend a number of panel meetings a year**  
   Meetings are held in London and last most of the day.

3. **To deal with the associated paper work of the panel**  
   To read suggested research topics and review vignettes before the meetings.

4. **At the panel meetings**  
   At the panel meetings to take notes during the discussions of preferences to prepare for voting during the meeting. Also to contribute to the discussion to ensure that the priorities reflect consumer priorities and to ensure that the final questions reflect issues of concern to consumers.

5. **To have a mentor (if required)**  
   A mentor system for new consumer panel members was set up in December 1998. All new consumer panel members will be offered a mentor. Experienced consumer panel members may be asked to act as a mentor in the future.
   
   The guidelines for consumers as to what to expect from their mentor is:
   - to be able to contact their mentor by telephone before and after each panel meeting
   - to be welcomed at the first panel meeting
   - to have questions answered at the panel meeting.

6. **Conflicts of interest - declaration**  
   At the start of discussion of a vignette, panel members are requested to declare whether they could be in a position to benefit as potential applicants were the topic to be taken forward as a priority for commissioning.

---

**Person specification: Consumer panel member**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Essential attributes</th>
<th>Desirable attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qualifications</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td>Experience</td>
<td>Committee experience</td>
<td>Having good links through consumer networks/associations/society</td>
</tr>
<tr>
<td>Special skills</td>
<td>Willingness to familiarise yourself with medical and research language</td>
<td>To keep up to date with current consumer issues via consumer networks/media</td>
</tr>
<tr>
<td>Specialist knowledge</td>
<td>Knowledge of consumer perspectives</td>
<td>To have an understanding of research</td>
</tr>
<tr>
<td>Personal qualities</td>
<td>Good communicator</td>
<td>Self confidence in a mixed group of professionals and consumer advocates</td>
</tr>
<tr>
<td></td>
<td>Ability to listen to others and express own views in discussion</td>
<td>Able to respond to challenging tasks. Willingness to give feedback to the NCCHTA and help develop this area of work. Experience of receiving fairly complex agenda papers and preparing for meetings.</td>
</tr>
</tbody>
</table>
USEFUL REFERENCES


If you want to think further about how to involve consumers in research, the College of Health is running courses on Involving Users in Research as part of its training programme. Contact 0208 983 1225 or email jessica@tcoh.demon.co.uk
**Bec Hanley** is director of the Consumers in NHS Research Support Unit. Bec worked on some of the first citizens’ juries in this country, and was the first patient representative to work in an acute trust in the UK. Her background is in community development, both in the voluntary and public sector. Recent publications include *Involvement Works* (NHS Executive 1999); *Research and Development in the NHS: How can you make a difference?* (NHS Executive 1999) and *Ordinary Wisdom* (King’s Fund 1998).

**Jane Bradburn** is a freelance research and development consultant in user involvement who has undertaken innovative projects involving users in research, primarily cancer service users. She is currently managing the Voices in Action Project for the College of Health. This national 3-year Department of Health funded project aims to provide training and support for lay representatives in the health services. She is completing a PhD on user involvement in cancer services at the South Bank University in London. Jane chairs the Patient Empowerment sub-group of Consumers in NHS Research and is a consumer advisor to the Medical Research Council, Breast UK, and the Knowledge Management for Health Reference Group. She has published a number of articles in consumer involvement and advocacy.

**Sarah Gorin** works for the Consumers in NHS Research Support Unit as an Action Researcher. This involves working with health service users and user groups, researchers and those in the NHS. Previously Sarah has worked in social care research with a particular focus on services for children and families. She is completing a PhD that examines foster carers’ experiences of looking after children with emotional and behavioural difficulties and has co-authored a book entitled *State Child Care: Looking After Children?* (Jessica Kingsley, 1999).

**Marian Barnes** has worked in a research and development capacity on user involvement and citizen participation for nearly 14 years. She has been involved in co-research with older people and with carers, and is currently working with users of mental health services in this capacity. She is Director of Social Research in the Department of Social Policy and Social Work at Birmingham University and is leading on community involvement for the team undertaking national evaluation of Health Action Zones.

**Clare Evans** is a disabled person with a background in social work and education. She was a non-executive director of East Wiltshire Healthcare NHS Trust 1993 - 1997. She was the founder and first director of Wiltshire and Swindon Users Network and is currently manager of the Leonard Cheshire Disabled Peoples Forum. She has written several publications on user involvement.

**Heather Goodare** was treated for breast cancer in 1986/7. Formerly an academic editor, after her cancer experience she trained as a counsellor and works with the cancer support group Crawley Cancer Contact. She represents consumers on the Editorial Board of the British Medical Journal and the Advisory Committee of the Cochrane Cancer Network, and chairs the consumer advocacy group BREAST UK. She is a member of the National Association of Cancer Counsellors, whose newsletter she edits. She has contributed to medical and psychosocial journals and books, translated *An Introduction to Psycho-Oncology* by Patrice Guex, and edited *Fighting Spirit* (Scarlet Press 1996).

**Marcia Kelson** is a Senior Research Fellow at the College of Health, a national charity that aims to promote patient interests in the NHS. Marcia has a national reputation for her work promoting patient, carer and public involvement in the NHS. She is the author of numerous...
policy and practical guidance documents, many of which have been widely circulated and influenced practice throughout the NHS. She is currently collaborating with the National Institute of Clinical Excellence (NICE) to promote effective user and carer involvement in the development of clinical guidelines.

Alastair Kent is the Director of the Genetic Interest Group (GIG) - the UK alliance of charities and support groups for people affected by genetic disorders. GIG’s mission is to promote the development of the scientific understanding of genetics and the part that genetic factors play in health and disease, and to see the speedy transfer of this new knowledge into improved services and support for the treatment of currently incurable conditions. Prior to joining GIG Alastair worked for a number of voluntary organisations on issues concerning policy, service development and disabled people.

For nine years Sandy Oliver brought research evidence to health service consumers and a consumer perspective to health services research as a member of The National Childbirth Trust. Five years ago she joined the Social Science Research Unit at the Institute of Education, University of London where she develops training and support for lay and professional users of research in Evidence-Informed Policy and Practice in Education and Health. She is currently supporting consumer involvement in the NHS Health Technology Assessment Programme and researching how consumers identify and prioritise research topics, and how they peer review proposals. She is an Honorary Visiting Fellow at the UK Cochrane Centre.

Jan Wallcraft works at the Mental Health Foundation.