INVOLVE

Briefing notes for researchers:
public involvement in NHS, public health and social care research

About this report

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Overview

This is a new edition of the briefing notes for researchers. Whilst some of the content is drawn from earlier editions this document is substantially different in both its format (available as an online resource) and its content, reflecting the changing environment since the original briefing notes were written in 2004.

The number of resources for public involvement in research have increased substantially, including those provided by INVOLVE such as the online Evidence Library and Putting it into Practice Database, those available through other National Institute for Health Research (NIHR) funded initiatives, and through the Research Councils and various research charities.

Public involvement in research sits in a changing and evolving environment. There is now a greater commitment to the importance and contribution public involvement can make to research and there are far more organisations and individuals supporting public involvement. There are also many more researchers and research commissioners working alongside the public for the first time. We have restructured some of our thinking about the framework for public involvement in research. In the past we have used the terms consultation, collaboration and user controlled to describe different levels of involving people in research. Over time it has become clear that in practice researchers can use a combination of these three and it is more helpful to describe them as approaches rather than levels.

This publication aims to provide an introduction for those new to public involvement. The briefing notes have been developed as part of a larger online resource which includes more detailed information in the form of supplements, examples and templates. Within this publication briefing note three will help you to think through your framework for public involvement and briefing note five provides practical information for planning your public involvement.

This report should be referenced as: INVOLVE (2012) Briefing notes for researchers: involving the public in NHS, public health and social care research. INVOLVE, Eastleigh

Let us know what you think

We welcome your comments and feedback on the briefing notes and please send us copies of your case studies and templates.

To feedback your comments, information and resources email: briefingnotes@invo.org.uk

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A full list of those who contributed is in the Appendix of the report.

The web links in this publication were updated September 2014.

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Briefing note one: Introduction

The briefing notes for researchers link to a larger online **resource for researchers** on how to involve members of the public in research. This is available in the **Resources section** of the INVOLVE website www.involve. nihr.ac.uk/resource-centre/resource-for-researchers

The online resource holds supplements of detailed information on public involvement in specific types of research and on specific involvement activities.

There are also case studies showing how members of the public have been involved in research projects and templates of useful documents such as job descriptions and terms of reference for committees and steering groups.

Who are the briefing notes for?

These briefing notes are for researchers new to public involvement in research and just starting to consider how best to involve members of the public in their work. They will also be of interest to researchers with experience of public involvement in research who are looking to update and 'refresh' their knowledge and skills and helpful to others interested in public involvement in research.

The briefing notes explain the different ways that members of the public are involved in research. They will help you to **plan**, **resource** and **support** public involvement in your research.

How to use the briefing notes

You can download the briefing notes from the website, read them online or use them as an index to find out what other resources are available for researchers. The online resources will be updated and further information and new case studies will be added.

Keep up to date by visiting the online resource for researchers on our website www.involve.nihr.ac.uk/resource-centre/ resource-for-researchers/

Briefing note two:
What is public involvement in research?

INVOLVE defines public involvement in research as research being carried out **'with'** or **'by'** members of the public rather than **'to', 'about'** or **'for'** them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants.

When using the term **'public'** we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

What public involvement in research is not

Researchers and others use different words to describe public involvement, for example words such as engagement and participation. In this publication when we use the term 'public involvement' we are not referring to researchers raising awareness of research, sharing knowledge or engaging and creating a dialogue with the public. We are also not referring to the recruitment of patients or members of the public as participants in research.

However, these different activities – involvement, engagement and participation – are often linked and although they are distinct can complement each other. For example, the public can and do play a valuable role in advising on recruitment of patients as participants and on ways of engaging with the public.

INVOLVE uses the following terms to distinguish between the different activities:

Involvement

Where members of the public are **actively** involved in research projects and in research organisations.

Examples of public involvement are:

- as joint grant holders or co-applicants on a research project
- identifying research priorities
- as members of a project advisory or steering group
- commenting and developing patient information leaflets or other research materials
- undertaking interviews with research participants
- user and/or carer researchers carrying out the research.

Participation

Where people take part in a research study.

Examples of participation are:

- people being recruited to a clinical trial or other research study to take part in the research
- completing a questionnaire or participating in a focus group as part of a research study.

Find out more

about participation in trials:

UK Clinical Trials Gateway
www.ukctg.nihr.ac.uk/default.aspx

NHS Choices information on clinical research
www.nhs.uk/Conditions/Clinical-trials/Pages/Introduction.aspx

Engagement

Where information and knowledge about research is provided and disseminated.

Examples of engagement are:

- science festivals open to the public with debates and discussions on research
- open day at a research centre where members of the public are invited to find out about research
- raising awareness of research through media such as television programmes, newspapers and social media
- dissemination to research participants, colleagues or members of the public on the findings of a study.

Find out more

about engagement:

National Coordinating Centre for Public Engagement
www.publicengagement.ac.uk

Briefing note three:
Why involve members of the public in research?

"No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well."

Professor Dame Sally Davies
Chief Medical Officer
(Foreword in Staley, 2009)

As well as the practical benefits of helping to ensure research quality and relevance, the underlying reasons for involving members of the public in research are also informed by broader democratic principles of citizenship, accountability and transparency. The reasons for involvement might not always be clearly defined and at times will overlap each other. However understanding **why** you want to involve members of the public in your research will help you think **who** you want to involve and **how** you want to involve people.

Democratic principles

It is a core democratic principle that people who are affected by research have a right to have a say in what and how publicly funded research is undertaken. Public involvement is an intrinsic part of citizenship, public accountability and transparency. In addition public involvement in research can lead to empowering people who use health and social care services, providing a route to influencing change and improvement in issues which concern people most.

Research quality and relevance

Providing a different perspective

Members of the public might have personal knowledge and experience of your research topic or be able to provide a more general perspective. Even if you are an expert in your field, your knowledge and experience will be different to the experience of someone who is using the service or living with a health condition.

Improving the quality of the research

This might be by:

- making the language and content of information provided more appropriate and accessible (for example in questionnaires and patient/participant information leaflets)
- helping to ensure that the methods proposed for the study are acceptable and sensitive to the situations of potential research participants
- helping to ensure that research uses outcomes that are important to the public
- increasing participation in research through:
  - making the research more appropriate and acceptable to potential participants
  - improving the information provided so people can make informed choices
  - helping to include seldom heard groups.

"As healthcare professionals we mustn't assume we know more than anyone else does! You have to recognise that other people are experts and accept that other people have skills that will make your project work."

Swithenbank 2010 page 15

Making the research more relevant

For example through:

■ identifying a wider set of research topics than if health or social care professionals had worked alone

■ suggesting ideas for new research areas

■ ensuring research is focused on the public's interests and concerns and that money and resources are used efficiently

■ helping to reshape and clarify the research.

The involvement of the National Association for the Relief of Paget's Disease (NARPD) in the PRISM clinical trial

The NARPD worked closely with the PRISM team from the beginning of this study and their involvement was integral. They were involved in peer review, where members of the trial steering committee provided advice to participants, and promoted the trial amongst Paget's disease patients. Most importantly all the participants gained a sense of ownership of the trial. This led to very high response rates to questionnaires which improved the quality of the trial data. The partnership also helped to improve recruitment and the quality of patient information sheets. However, there were resource implications for both parties.

Langston et al. 2005

In addition to these principles there is a growing interest in public involvement by research funders and research organisations as well as the commitment to public involvement in health and social care policy.

Interests of research funders and research organisations

Several funding bodies, as well as research ethics committees ask grant applicants about their plans for public involvement with an expectation that if they are not involving members of the public in the research then they need to have thought through why they have made this decision and explain the reasons.

For example, the National Institute for Health Research (NIHR) have developed a standard application form to be used by all their research programmes, including individual training awards. One of the sections on the form asks applicants to describe how they have involved the public in the design and planning of their study as well as their plans for further involvement throughout the research and if not, to explain why. Applicants are also asked to provide details of the budget they have allocated for public involvement in their research. Responses to these questions will be considered by the reviewers, research panels and boards (which increasingly include members of the public) and will influence funding decisions.

The National Research Ethics Service (NRES) will ask about the plans for public involvement in your research if you apply for ethical approval, and it will be part of their assessment process. NRES expects the involvement of the public in research, as it can help ensure that research planned is ethical, relevant and acceptable from a public perspective.

The Medical Research Charity Alzheimer's Society, has a Research Network of volunteers who play an integral role in their research programme. Their duties include:

- setting research priorities
- prioritising and commenting on grant applications
- sitting on grant selection panels
- monitoring on-going projects funded by Alzheimer's Society

www.alzheimers.org.uk

National Institute for Health Research (NIHR) funded Programme Grants for Applied Research involves members of the public in several ways such as:

- peer reviewing research applications to assess the level of public involvement in the application and the potential for public benefit in the proposed research
- sitting on commissioning panels which assess and shortlist research applications
- writing guidance for researchers
- evaluating public involvement through site visits to ongoing programmes

www.nihr.ac.uk/get-involved/public-involvement-at-ccf.htm

Find out more

about public involvement and research funders:

NIHR National Evaluation, Trials and Studies Coordinating Centre, (NETSCC)
www.nets.nihr.ac.uk/ppi

NIHR Central Commissioning Facility (CCF)
www.nihr.ac.uk/get-involved/public-involvement-at-ccf.htm

NIHR School for Social Care Research (SSCR)
http://www2.lse.ac.uk/LSEHealthAndSocialCare/aboutUs/NIHRSSCR/home.aspx

Asthma UK
www.asthma.org.uk/volunteer-help-us-with-our-research

Multiple Sclerosis Society
http://live.mssociety.org.uk/ms-research/get-involved-in-research

Health and social care policy commitment and initiatives

There have been a number of NIHR health and social care research initiatives that emphasise the importance of public involvement and health policy documents that demonstrate the commitment to public involvement.

In the foreword of the 2009/2010 NIHR Annual Report Earl Howe, Parliamentary Under Secretary of State for Quality, comments:

"Moreover, in a healthcare system in which patients and the public come first, the Government is committed to supporting the emphasis that the NIHR puts on patient and public involvement in research."

The commitment to research and public involvement in research is referred to in the Government's White Paper Equity and Excellence: Liberating the NHS published July 2010:

"This [shared decision-making] is equally true of the partnership between patients and clinicians in research."

Para 2.3

Research organisations such as the National Institute for Clinical Excellence (NICE), Social Care Institute for Excellence (SCIE) and the Association of Medical Research Charities (AMRC) member charities are establishing public involvement in their work.

Find out more

about commitment to public involvement in research:

National Institute for Health Research (NIHR)
www.nihr.ac.uk/get-involved/
shape-research.htm

NIHR Research Design Service (RDS)
www.rds.nihr.ac.uk/

National Institute for Clinical Excellence (NICE) Patient and Public Involvement
www.nice.org.uk/about/nice-communities/
public-involvement

Association of Medical Research Charities (AMRC) – Natural Ground Project
www.amrc.org.uk/publications/natural-ground-
paths-patient-and-public-involvement-medical-
research-charities

Find out more

about the development of an evidence base for public involvement in research:

INVOLVE online Evidence Library holds a collection of references that consider the impact of public involvement in research
www.involve.nihr.ac.uk/resource-centre/
evidence-library

Exploring the impact: examples of public involvement in research
www.involve.nihr.ac.uk/resource-centre/
examples/

Including the following reviews:

PiiAF – The Public Involvement Impact Assessment Framework and Guidance (Popay, Collins et al 2013)
http://piiaf.org.uk/

Exploring impact study: public involvement in NHS, public health and social care research (Staley 2009)
www.involve.nihr.ac.uk/resource-centre/
publications-by-involve/

PIRICOM study: a systematic review (Brett et al 2010)
www.ukcrc.org/patients-and-public/patient-
and-public-involvement-in-clinical-research/
evaluation-of-ppi-in-research/

Service user involvement in nursing, midwifery and health visiting research: A review of evidence and practice (Smith et al 2008)

Briefing note four:
Why members of the public get involved in research

Members of the public get involved in research for a variety of personal and social reasons. For some, these are linked to personal experiences of health or social care services and a desire to bring about change in the quality of care or to improve treatments either for themselves or for others with a similar condition. For others it might be a way to have a 'voice' and influence the processes that affect people's lives or it might be to influence research by giving something back and helping others through their involvement. Well planned and resourced involvement in research can also be valuable to those involved by increasing their confidence and knowledge and helping them to develop new skills.

Find out more

about why members of the public get involved in health and social care research

Why people get involved in health and social care research: a working paper (Tarpey 2006)
www.involve.nihr.ac.uk/resource-centre/
publications-by-involve

Public Information Pack (PIP) for members of the public interested in getting involved in research. (Buckland 2007)
www.involve.nihr.ac.uk/resource-centre/
publications-by-involve

Briefing note five:
How to involve members of the public in research

Planning and preparation

To help you plan and undertake public involvement in your research we suggest you consider the following points:

- involve people as early as possible
- be clear with the people you want to involve
- be accessible
- resource public involvement in research
- offer training and support
- clarify organisational responsibilities
- document and record public involvement in your research

Involve people as early as possible

Involve people at an early stage so that they feel part of the research and also have a sense of ownership of the research. Consider involving people in the identification and prioritisation of the research topic and the development of the research question. Ethical approval is not needed where people are involved in planning or advising on research, for example as a co-applicant on a research grant, a member of an advisory group or in developing a questionnaire.

Find out more

about public involvement in research and the requirements of research ethics review

Patient and public involvement in research and research ethics committee review (2009)
www.involve.nihr.ac.uk/resource-centre/publications-by-involve/

A statement developed by the National Research Ethics Service (NRES) and INVOLVE.

Public involvement in research applications to the National Research Ethics Service (Tarpey 2011)
www.involve.nihr.ac.uk/resource-centre/publications-by-involve

This publication is currently being updated and a new version will be published Autumn 2014.

Health Research Authority
www.hra.nhs.uk/research-community/before-you-apply/planning-and-study-design/

Be clear with the people you want to involve

It is important that both you, as a researcher, and the people you involve have a shared and clear understanding of what they are being invited to do:

- explain why you are asking people to get involved

- develop a job or role description so that they know what is expected of them

- be clear about the time commitment

- be clear about what they can expect from you, for example in terms of accessibility, mentoring, training or payment

- agree the aims of the research and discuss your expectations for the project and listen to and discuss the expectations of the people you are involving

- discuss at an early stage which aspects of the research have scope for people to influence and how much influence they will be able to have (including where there is no scope to change the research)

- develop terms of reference for any type of advisory group, steering group or committee. **(See also briefing note eight)**

Be accessible

Consider your plans for who you are going to involve and if they reflect the diversity of people or cultures in the research. It might be that you need to take further time to build relationships with organisations and individuals to make sure that you have the breadth of perspective needed for your project. It might also be necessary to make changes in order to support people to be fully involved:

- write clearly and simply using a friendly style and avoid jargon

- ask people how you can meet their specific accessibility needs for, example non-English speakers, people with visual or hearing impairments, learning difficulties or chronic long-term conditions

- make sure that members of the project team have equal access to resources and activities within the project – this might be meetings, support, equipment and library resources

- ensure fees and expenses are paid promptly so people are not left 'out-of-pocket' for long

- consider where you are going to hold meetings and whether the venue is accessible. **(See briefing note eight)**

- do not assume that everyone has easy access to a computer or that they can print out long documents. Offer to post printed copies of information

- allow for additional time for people to read information and paperwork.

"Partners needed access to terminology, steering group meetings, training in research, and funds (e.g. travel expenses). Communication challenges included the routine use of e-mail, conferences, and corridor meetings by professionals to discuss research, all of which could exclude partners. Professionals also e-mailed consultation documents at the last minute and expected rapid responses, whereas partners needed time to review unfamiliar material."

Hewlett et al 2006

Find out more

about accessibility:

Strategies for diversity and inclusion in public involvement: Supplement to the briefing notes for researchers (INVOLVE 2012)
www.involve.nihr.ac.uk/resource-centre/resource-for-researchers

NIHR 'make it clear' campaign
www.involve.nihr.ac.uk/makeitclear/

SCIE Guidelines for accessible events
www.scie.org.uk/publications/accessibleevents/index.asp

Plain English campaign website
www.plainenglish.co.uk

Resource public involvement in research

Think about how you resource public involvement both in terms of budget and the additional time required to involve the public in your research.

Some research funders, such as the National Institute for Health Research (NIHR), will actively encourage and expect public involvement to be adequately costed in research proposals. It is very difficult to obtain funding for public involvement later if it has not been built into your research grant application.

Costs will differ depending on how you are involving people in your research and who you are involving. In preparing your budget you might need to take account of the following:

- travel and subsistence expenses
- childcare and carer costs
- costs for personal assistants
- payment for time and work undertaken
- hire of accessible venues
- additional support such as an independent facilitator
- refreshment costs
- hotel accommodation costs
- translation and interpretation costs
- training and support
- administrative support
- telephone, photocopying and postage
- attendance at conferences and events
- writing publications and journal articles.

It is good practice to offer payment whenever possible to the members of the public you involve in your research. However, receiving payment or a fee can have implications for people receiving any form of benefit. It is very important that people receiving state benefits get expert advice prior to accepting payment.

Find out more

about payment:

To keep up to date with payment issues please visit the payment and public involvement in research page on the INVOLVE website
www.involve.nihr.ac.uk/resource-centre/payment-for-public-involvement/

Budgeting for involvement: a practical guide and cost calculator to plan and budget for public involvement in your research (Mental Health Research Network (MHRN) and INVOLVE 2013)
www.involve.nihr.ac.uk/resource-centre/involvement-cost-calculator/

Payment for involvement: a guide for making payments to members of the public actively involved in NHS, public health and social care research (INVOLVE 2010)
www.involve.nihr.ac.uk/resource-centre/publications-by-involve

What you need to know about payment: an introductory guide for members of the public who are considering active involvement in NHS, public health or social care research (INVOLVE 2011)
www.involve.nihr.ac.uk/resource-centre/publications-by-involve

Involving members of the public in your research will take additional time and this needs to be allowed for. The time might be in respect of additional training and support, negotiation and discussion of roles and research methods, arrangement of meetings at suitable dates and venues or simply for reassurance and progress reporting.

Offer training and support

We suggest you plan for training and support for members of the public **and** the researchers in your team. Individuals might require different types of training and support depending on their needs and the project.

Different types of training might be:

- attending training sessions or courses
- 'on the job' training
- sharing knowledge and experiences with colleagues and peers.

Support might take the form of:

- support from other team members
- a mentor with similar experience
- team meetings or one-to-one meetings with line managers
- informal or formal mechanisms of peer support.

Ask members of the project team about their training and support needs. These may change as the project progresses and people become aware of the skills required.

"Training for co-researchers receiving palliative care services had to be flexible and tailored to meet their specific needs. Training days were short, held over successive days. Remote learning was provided to allow co-researchers to manage their learning in their own time rather than travelling to training events. Sufficient time and resources have to be provided to enable effective training."

Wright et al 2006 page 826

Find out more

about training and support:

INVOLVE online database for developing training and support
www.involve.nihr.ac.uk/resource-centre/training-resource

Clarify your organisational responsibilities

It is important that you liaise well in advance with the relevant departments within your organisation such as finance and human resources. Explain how you plan to involve members of the public in your research. This will ensure that you are aware and informed of local arrangements for involving members of the public and any issues that finance or human resources may raise about the proposed arrangements. If there are any concerns raised by these departments you will have time to solve problems early on.

Examples of issues you might need to consider are:

- payment and expenses policies
- travel and expenses claim forms
- methods for paying people (including tax and national insurance deductions)
- confidentiality agreements – ask **all** members of the research group to sign a confidentiality statement, not just the members of the public
- health and safety
- honorary contracts/research passport
- insurance and indemnity
- Disclosure and Barring Service (DBS) checks.

We recommend that you:

- have a lead for public involvement in your team so there is a point of contact for all involved. This should be an experienced member of staff who is adequately resourced to carry out the role

- talk to others within your organisation who have involved people in their research

- make sure that people involved know that they can stop being involved at any time

- consider the emotional support you might need to offer people if the research is sensitive or they find some of the information distressing and where to access this

- if asking your own patients, or carers of your patients to work with you on a study consider if this is appropriate and how this might affect your relationship

- where appropriate, discuss in advance what will happen should people become ill for periods of the research

- plan in advance what will happen to the people you have involved at the end of the project, for example opportunities for getting involved in further research, or groups and organisations they can link in with so they can continue to use the skills they have developed.

Document and record public involvement in your research

Think how you are going to track the public involvement throughout your research so you can report and reflect on it as your project develops. Research funding organisations will also be increasingly asking you to report on the impact of your research. Plan to include a record of how members of the public have been involved throughout the study as well as what difference it has made to the research.

For an example

of documenting and recording impact in your research see:

Economic and Social Research Council impact record: www.esrc.ac.uk/impacts-and-findings

Briefing note six:
Who should I involve and how do I find people to involve?

Who should I involve?

In deciding who best to involve it is important to think about the knowledge and perspective that you are looking for from members of the public, and what support you are able to give to people who you plan to involve.

Even if your research is about informing practitioners about approaches to practice, the end user of the research will be the person receiving the practice. In some research projects you will want to consider involving both practitioners and members of the public:

■ You may want input from people who have experience of a specific condition, service or treatment. In this instance a carer might not be appropriate. In some types of research such as childcare the different needs and perspectives of carers, parents and children might be required.

■ Sometimes you might need a more general perspective from a member of the public.

■ Think about whether you are looking for the perspectives of individuals or if you are looking for the collective voice of an organisation or group.

■ You may wish to involve people who have no previous experience of getting involved in research or you may wish to involve those who have experience of working on other research projects or of involvement in other health or social care organisations.

■ It may be useful to prepare a brief 'person specification' to help you think about who you wish to involve, but it is also important to be flexible.

Involve more than one person

Involving more than one person will have the advantage of allowing you to involve different people at different stages of the research process, and allow people to choose how they want to be involved.

It will also help you to:

■ increase the breadth of experience and skills brought to the project

■ provide an opportunity for those involved to support and encourage each other

■ maintain a public perspective within the project if people are unable to attend due to illness or other commitments.

Researchers often ask how they can ensure that the people they involve are 'representative'. However it is more helpful to think about seeking people's perspectives rather than looking for people who are representative. Consider the broad and different views and experiences you will need to include and how you are going to involve people. Try to ensure that you have a variety of perspectives so you get different viewpoints and allow time for those who have the skills you require for the project to network with others.

Members of the public cannot be representative of everyone who uses a particular service or has a specific condition. Equally we would not expect one clinician, for example, to be representative of all clinicians.

For most studies it is not appropriate for people involved in the research to also be participants in the research as that can compromise both the researcher and the person involved. The possible exceptions to this may include some participatory/action research studies where the participants of the research may also be acting as co-researchers, influencing the shape of the study as it progresses.

How do I find people to involve?

Once you have considered who you would like to involve, you then need to think about how to make contact with them. Speak with colleagues and members of the public and ask for their views on how to find the people you want to involve.

Allow time to make contact with organisations and individuals as finding people will nearly always take longer than you think.

Others have contacted people by:

- asking community members or patients about people who might be interested in getting involved
- advertising in GP surgeries, outpatient departments, local newspapers and on the radio
- talking to local or national patient support groups and voluntary organisations
- searching online for relevant organisations
- using online social media such as Facebook or Twitter
- talking to other health and social care professionals such as community development workers, social workers, health visitors, GP practice managers

- contacting the Patient Advice and Liaison Service (PALS) Officer based at your local NHS Trust
- putting details of the opportunity for people to get involved on the People in Research website so interested members of the public can make contact.

"Individuals were recruited through several chronic disease patient groups identified by the patient liaison officer at the local primary care trust (PCT). To maintain confidentiality the prospective members of the public received an information sheet about the research asking them if they would be interested in being part of an advisory group. The information was prepared by the researchers but it was sent out by the patient liaison officer to members of patient groups active within the PCT."

Sutton and Weiss 2008 page 233

Spend time developing networks and building relationships. This might involve visiting organisations to hear about what they do and talking to them about your research.

Putting Evidence for Older People into Practice in Living Environments (PEOPPLE)

In the PEOPPLE project the School of Health Sciences and Social Work at the University of Portsmouth worked in partnership with key non-statutory organisations that were central to engaging with the local community and would be collaborators on the study.

www.port.ac.uk/research/

Many researchers develop long term relationships with organisations and individuals who continue for many years past the involvement in the first research project.

Be aware that some people or organisations might choose not to get involved in your work. This might be for a variety of reasons but it might be because their aims do not match yours, they do not have the time, or because the practical costs of either getting involved or finding somebody to get involved in your work is too great. Some organisations charge when they are asked to find people to get involved in research activities.

Find out more

about how to find people to involve:

Strategies for diversity and inclusion in public involvement: Supplement to the briefing notes for researchers (INVOLVE 2012)
www.involve.nihr.ac.uk/resource-centre/resource-for-researchers

People in Research – A national resource to help members of the public find opportunities to get involved in research and for research organisations / researchers to advertise involvement opportunities
www.peopleinresearch.org

Involving London has a range of information and opportunities for public involvement in research in London
www.involvinglondon.co.uk

North West People in Research Forum – supporting patient and public involvement and patient engagement in health research in the North West
www.northwestpeopleinresearchforum.org

Patient UK has a comprehensive list of national and local support groups and organisations
www.patient.co.uk

Briefing note seven:
Approaches to public involvement in research

In the past we have used the terms consultation, collaboration and user controlled to describe different levels of involving people in research.

Over time it has become clear that, in practice, research projects can include a combination of these three and also that the boundaries between them are not clear cut. It is therefore more helpful to describe them as approaches rather than levels. Within these approaches there are many different ways of involving members of the public during the various stages of the research. For example, you might work with one or two service users or carers as co-collaborators throughout a research project, as well as consulting with a wider group of service users on a specific aspect of the study or members of the public might lead on one stage of the research.

How you involve people will depend on the nature of your research, as well as the different activities people decide they would like to get involved in.

If it is the first time that you have involved people in research consider where public involvement will be most effective in your research. This might be in a relatively modest way at first, perhaps in just one activity or at one stage of the project. Build on the skills and experience you develop in future projects.

Consultation

Consultation is when you ask members of the public for their views and use these views to inform your decision making. Consultation can be about any aspect of the research process – from identifying topics for research through to thinking about the implications of research findings.

You might, for example, hold one-off meetings to ask people's views on the importance of a study and areas that it is important to measure within the study. Research funders may consult members of the public by asking for their views on research grant applications.

If this is the first time you have involved people in your research, it can be a good starting point. It can also be a way of getting the views of a larger group of people. However, think carefully about what you are asking and what you will do with the information. You might find that people are frustrated at being asked for their views without a commitment from you that you will act on them. There is a danger of 'consultation fatigue' for individuals and organisations who have been consulted before and think that their views have been ignored in the past.

If you decide to consult with people on your research we recommend that you:

- give them enough time to respond
- feedback on the actions you have taken as a result of the consultation
- ask if they would like to hear about the findings of the research.

> **Consulting parents about the design of a randomised controlled trial of osteopathy for children with cerebral palsy**
>
> Semi–structured interviews were carried out with 20 parents of children with cerebral palsy and other neurological conditions, asking them to choose between four trial designs, to talk about noticeable changes in their child's condition and their views about payment for trial treatment. By consulting parents about the design of the research, the subsequent trial achieved excellent recruitment and retention rates.
>
> Edwards et al 2011

Benefits of consultation:

- it enables you to find out people's views
- it can be useful when exploring sensitive and difficult issues
- you can get a wide range of views
- you can involve people in discussion and debate.

Challenges of consultation:

- you might not get the broad views you hope for
- people might have previous bad experiences of consultation where their views were not listened to
- you might require an experienced facilitator.

Working more closely with members of the public, returning to ask them for further information, and developing an ongoing relationship with them, will take you towards collaboration.

Collaboration

Collaboration involves an ongoing partnership between you and the members of the public you are working with, where decisions about the research are shared. For example, members of the public might collaborate with the researchers on developing the research grant application, be members of the study advisory group and collaborate with researchers to disseminate the results of a research project.

This is a broad approach that can be used in a wide range of different research activities and at many different stages of the research project. Some of the ways researchers have collaborated with members of the public are captured in the following examples:

> **Endometriosis and cultural diversity: improving services for minority ethnic women**
>
> This study involved community facilitators, representatives from the communities and representatives from two voluntary organisations in the following ways:
>
> - the Endometriosis UK and the Endometriosis SHE Trust were consulted on the need for the project
> - community facilitators from the ethnic groups represented in the study were recruited and trained by the research team to organise and conduct the focus groups, and were involved in the development of the interview schedule
> - representatives from the target communities were recruited to the project advisory board
> - the community facilitators and the advisory group members were asked to comment on and adapt the themes that emerged from analysis of the focus groups, adding rigour to the analysis of data
> - the community facilitators and interviewees from the five communities were actively involved in the production of resource materials, in particular contributing to the language and cultural sensitivity of the information.
>
> Denny 2011

Collaboration requires commitment, openness and flexibility and it is important to plan and prepare adequately (see **briefing note five** on planning and preparation).

Benefits of collaboration:

- helps to ensure research remains focused and relevant
- skills and perspectives of the public and the researchers can complement one another
- helps to ensure the research is ethical
- can help with recruitment and informed consent

Challenges to collaboration:

- time consuming and involves additional cost
- researchers and the public may require training or support
- researchers need to be flexible and willing to share the control of the research.
  (See also briefing note eight)

**Involving men affected
by prostate cancer**

A project which examined the reasons for the timing of men's diagnosis with prostate cancer and investigated the profile of men diagnosed in Greater Glasgow over a two-year period (2008-9) involved service user advisors in:

- selecting and prioritising research projects
- developing the research method (including suggesting the involvement of male interviewers to put patients at ease)
- reviewing / assessing the study paperwork (such as survey and interview questions)
- commenting on the results and conclusions.

The service user advisors believed that more men answered the survey (they had a 70% response rate) because of the involvement of those affected by prostate cancer, which helped to ensure the survey asked the right questions and was readable / accessible. They also thought that more men agreed to be interviewed because of their suggestion to include a male interviewer alongside the female team members.

Dickson et al 2011

Find out more

about collaborating with members of the public in research:

Public involvement in systematic reviews: Supplement to the briefing notes for researchers (INVOLVE 2012)
www.involve.nihr.ac.uk/resource-centre/resource-for-researchers

Public involvement in clinical trials: Supplement to the briefing notes for researchers (INVOLVE 2012)
www.involve.nihr.ac.uk/resource-centre/resource-for-researchers

NIHR Senior Investigators: Leaders for public involvement in research (INVOLVE 2014)
www.involve.nihr.ac.uk/resource-centre/publications-by-involve/

Exploring the impact: examples of public involvement in research
www.involve.nihr.ac.uk/resource-centre/examples/

Turning the pyramid upside down: examples of public involvement in social care research (INVOLVE 2010)
www.involve.nihr.ac.uk/resource-centre/publications-by-involve

INVOLVE database of research projects involving members of the public in research
www.involve.nihr.ac.uk/resource-centre/research-project-database

User controlled research

User controlled research is research that is actively controlled, directed and managed by service users and their service user organisations. Service users decide on the issues and questions to be looked at, as well as the way the research is designed, planned and written up. The service users will run the research advisory or steering group and may also decide to carry out the research.

Some service users make no distinction between the terms user controlled and user led, others feel that user led has a different, vaguer meaning. They see user led research as research which is meant to be led and shaped by service users but is not necessarily controlled or undertaken by them. Control in user led research in this case will rest with some other group of non-service users who also have an interest in the research, such as the commissioners of the research, the researchers or people who provide services.

In an INVOLVE report (Faulkner 2010) exploring seven examples of user controlled research, service users highlighted several key reasons why user controlled research is important for them:

- a commitment to changing or improving the lives of their community of service users
- frustration with traditional research and services which exclude them
- frustration with mainstream research in failing to capture their needs or to research things they feel are important

As a researcher, you might get involved in user controlled research in several ways such as:

- training or supporting a group of service users who are undertaking their own research
- supporting user controlled research in a specific part of your research
- a user controlled organisation might commission you to carry out research under their direction.

Find out more

about user controlled research:

Changing our worlds: examples of user-controlled research in action (Faulkner 2010)
www.involve.nihr.ac.uk/resource-centre/publications-by-involve

User Controlled Research: its meanings and potential (Turner and Beresford 2005)
www.involve.nihr.ac.uk/resource-centre/publications-by-involve

Publications, examples and videos of user controlled research are available on the INVOLVE website
www.involve.nihr.ac.uk/find-out-more/user-controlled-research

Briefing note eight:
Ways that people can be involved in the different stages of the research cycle

Members of the public are getting involved in a whole range of research activities. These include helping to develop the research question, applying for funding and ethical approval, sitting on advisory groups, carrying out the research and disseminating the research findings. This briefing note considers the different ways members of the public can get involved in the stages of the research cycle.
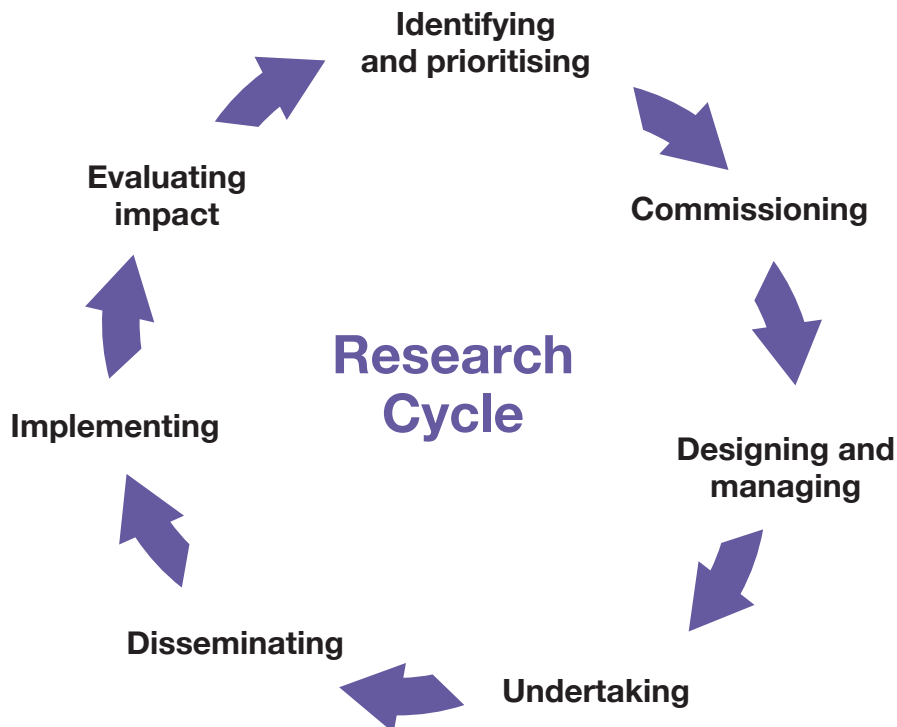
Getting started

You have considered **why** you want to involve people and **who** you want to involve. You now need to consider **how** these people are going to be involved in the different stages of the research cycle. For many this will involve organising a meeting, for example for project advisory groups, public events, reference groups, or workshops.

How you plan these meetings can make a huge difference to how people feel about the research and how much they are able and want to get involved in your work. Holding a meeting is only one of the ways to involve people and you may decide that this is not the best approach for your research.

"I research long term health conditions, particularly respiratory problems. I don't hold a meeting if I want to involve people in my research – instead I go to their meetings and work with people at the local Breathe Easy club. I regularly attend meetings of the club, often not discussing my research and have built a strong relationship with the people who attend."

Researcher 2012

Things to think about if you are organising meetings

Planning for meetings

- Explore opportunities for meeting people in their own environment, such as by attending a regular meeting of an organisation or group.

- Consider venues that are on neutral ground. Venues such as hospitals or Local Authority departments might be associated with difficult experiences.

- Organise meetings at times and in places that are easy for people to get to. Those who are working, have young children or who are carers might need to meet outside office hours. Make sure that there is parking and public transport nearby.

- It is often better to plan for a mid-morning or early afternoon start to the meeting. This makes it easier for people if they have to travel some distance to the meeting or if they need additional time in the mornings because of their disability or health condition. In some situations, you might need to offer overnight accommodation, in which case check if they have any special requirements for an overnight stay.

- Make sure meeting places, hotels and facilities are accessible to all those attending, for example if you are inviting a wheelchair user to join your committee, meet in an accessible meeting room with parking nearby and fully accessible facilities.

- Where possible, visit the venue in person in advance of the meeting, and ask to be shown around to check its suitability and access to all rooms, dining area, disabled toilets and the stage speaker area (if required). Don't rely on the venue telling you that it is accessible as you might find that this is not the case or that the complex routes of access are not acceptable to the people needing access.

- Ask people if they have any special dietary requirements and let them know what refreshments you will be providing.
- Be mindful of practical matters such as microphones and hearing loops for people with hearing impairments or large print for people with visual impairments. Think about whether you will need interpreters for people from different ethnic groups or for sign language.
- Provide clear information about the meeting, timings and directions for getting to the venue well in advance and in a relevant format. Ask people if they require information posted to them or if they would like to receive it by email.
- Plan and prepare a budget for your meeting. **(See briefing note five)**
- Develop terms of reference for the meeting so that those attending know why the meeting is being held and the responsibilities of those attending.

Conducting the meetings

- Brief the Chair and other committee members to ensure that the members of the public are welcomed and included during the meeting.
- Offer a pre-meeting or telephone discussion for members of the public to discuss the agenda and papers.
- Provide name badges in a large clear text font, and ask people to introduce themselves at the beginning of the meeting.
- Agree ground rules for how you will conduct a meeting so everybody has an equal opportunity to contribute. It is important that all group members including members of the public agree to these rules of mutual respect.
- Make sure that everybody has an equal voice on the group. Encourage the use of clear language, explain jargon and acronyms. Ask the Chair to regularly check that people understand the language used and the content of the meeting.

- Plan for frequent breaks and refreshments as people might need to take medication or find sitting for long periods difficult. If it is possible to have a spare room then allocate this as a quiet room for those who might need to take some time out of the meeting.
- Consider different ways of conducting meetings, such as time in small group sessions as well meetings in a larger group to allow people the opportunity to contribute in different ways.
- Create a mentor or buddy system to support the members of the public you are involving on an ongoing basis.

After the meeting

- Provide feedback on any recommendations or outcomes.
- Allow sufficient time between meetings for people to consult with their peers or their organisations if they wish to do so.
- Ask for feedback from members of the public involved in the meeting and if they have any suggestions for improvement for future meetings.

Find out more

about organising meetings and events:

Patient and public involvement in research groups: guidance for Chairs (Twocan Associates 2010)
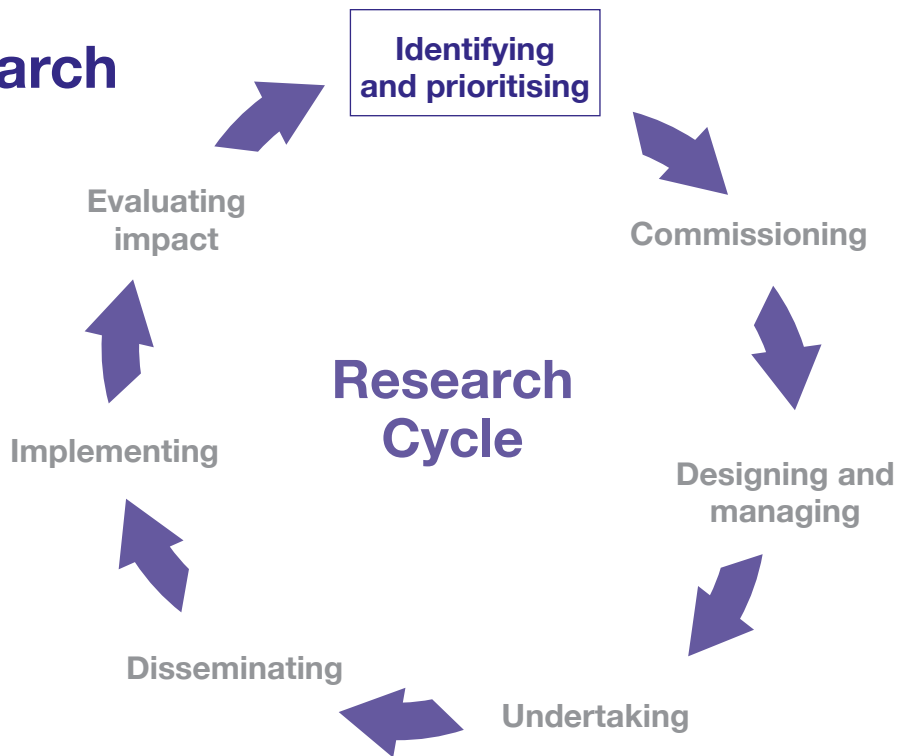www.twocanassociates.co.uk/pubs.php

INVOLVE online resource for researchers has templates and examples of ground rules and terms of reference for groups
www.involve.nihr.ac.uk/resource-centre/resource-for-researchers

Strategies for diversity and inclusion in public involvement: Supplement to the briefing notes for researchers (INVOLVE 2012)
www.involve.nihr.ac.uk/resource-centre/resource-for-researchers

Identifying and prioritising research

Research Cycle

Identifying and prioritising

Commissioning

Designing and managing

Undertaking

Disseminating

Implementing

Evaluating impact

Involving the public in helping to identify and prioritise research is a powerful way to involve people as it allows them to influence what will be researched. Involving people at this stage will allow you to check that your research priorities are the same as those of people who have the condition you are researching or who use relevant services.

Depending on the type of funding call you are applying for topics might have already been decided by the research funder or commissioner. Members of the public might have been involved in the identification and prioritisation of the topics by the research funding organisation.

Individual members of the public and the different organisations that represent them will have different priorities just as researchers and clinicians do. However by working together you can identify a number of research questions. An active partnership will enable you to learn from each other and agree on the research questions together, and the final topic will be a shared decision between the group. Consider recording how the research question was developed and the different influences on the question at the beginning of the project.

Researchers and research organisations use a range of different ways to work with the public to identify and prioritise research. These include:

- discussions with existing reference groups and networks
- inviting people to an event or holding a workshop or focus group
- attending meetings held by service user groups
- peer group interviews
- surveys and interviews
- asking organisations who support the public about the feedback they get from people who use services
- using an independent facilitator (this reduces the risk of researchers influencing the agenda too much).

Sometimes it is difficult for people who are unfamiliar with research to identify research questions. It may help to first discuss problems that people experience using services or with their treatment or condition, before discussing how these might be turned into research questions.

Involving burn survivors in agenda setting on burn research

Burn survivors and professionals worked together to prioritise their 15 most important research topics. There was considerable overlap between the research priorities of survivors and professionals particularly with respect to wound healing and scar management. However burn survivors put more emphasis on psycho-social after care and quality of care. New research topics were introduced by burn survivors such as itching and oedema.

Broese et al. 2009

Several of the programmes of the National Institute for Health Research (NIHR) Evaluation Trials and Studies Coordinating Centre (NETSCC) encourage individuals or organisations to suggest a topic for research.

Find out if others have worked with members of the public to identify research topics

In several areas of research including cancer, arthritis and mental health the research topics and priorities of people with these conditions have been explored and published. Find out if research has been carried out to identify the topics most relevant to patients or service users in your area of work to enable you to identify relevant research topics.

The James Lind Alliance, funded by the National Institute for Health Research (NIHR) facilitates Priority Setting Partnerships. These partnerships bring patients, carers and clinicians together to identify and prioritise the treatment uncertainties which they agree are the most important for research.

The Listening Study

The aim of this study was to explore the views that people affected by cancer have about research and to identify their research priorities. Patients and carers were involved as co-researchers and in the design of the study. (Macmillan 2007)

www.southampton.ac.uk/msrg/ ourresearch/completedprojects/core/ macmillanlisteningstudy.page

It's not too late to involve people if you have already identified a research topic – you can still involve the public by asking them if the topic is relevant to them.

Most researchers or research organisations have a range of topics or areas that they would like to research. Members of the public can work with individual researchers, research teams or organisations to decide which topics to focus on first.

Listen, respond and talk through with them how their ideas can be included in your research questions.

Find out more

about public involvement in identification of research topics

The James Lind Alliance and Priority Setting Partnerships
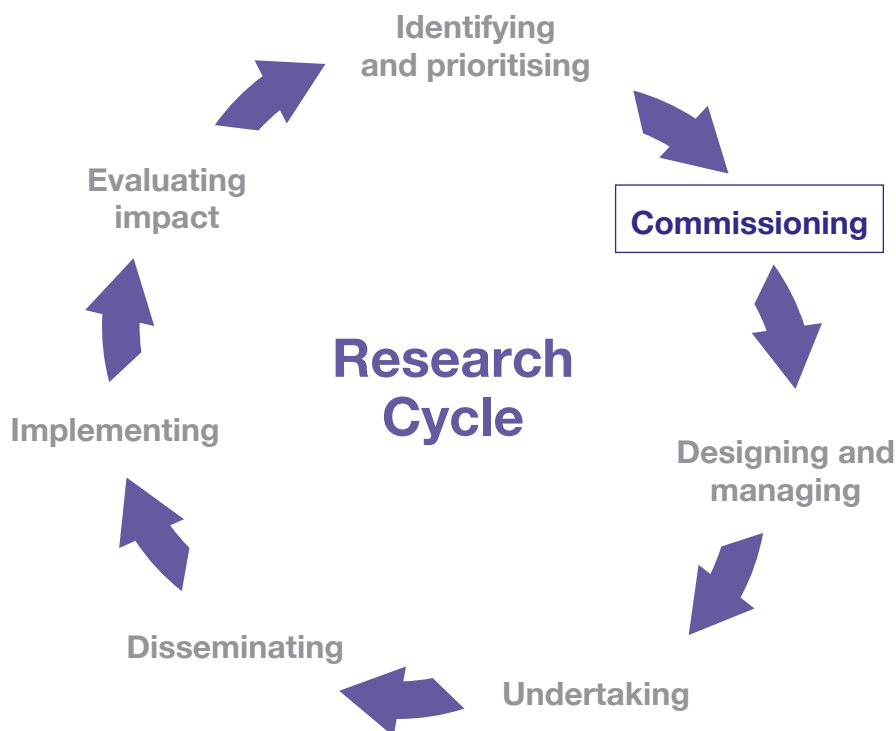www.lindalliance.org

User involvement in research – a route map (Twocan Associates 2010)
www.twocanassociates.co.uk/routemap/ setting-research-priorities.php

OMERACT – Outcome measures in rheumatology
www.omeract.org/

Commissioning research

Identifying and prioritising

Evaluating impact

Commissioning

Research Cycle

Implementing

Designing and managing

Disseminating

Undertaking

Many funding organisations now involve members of the public in commissioning research. This gives a broader perspective to the review process, by considering the issues that are important from a public perspective.

Involvement can be in a variety of ways, including:

- involving members of the public in reviewing research proposals
- having members of the public on research commissioning panels or boards
- involvement in the monitoring process of research, once funded
- user controlled organisations commissioning research.
  (See briefing note three)

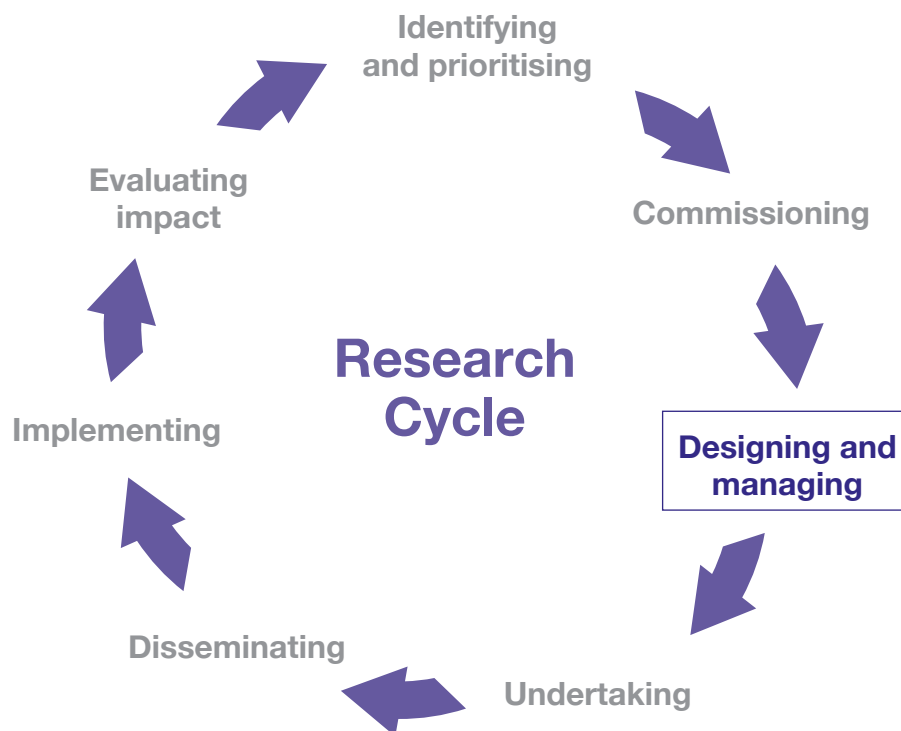You might also be interested in the following resources available on our website:

Information on research commissioning on the INVOLVE website
www.involve.nihr.ac.uk/find-out-more/information-about-research-commissioning

Public involvement in National Institute for Health Research (NIHR) programmes
www.nihr.ac.uk/get-involved/how-you-can-get-involved.htm

Designing and managing research

Identifying and prioritising

Commissioning

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Evaluating impact

Designing

Involving members of the public in the design of research helps to ensure that the research is relevant to the needs of people and also that the research question and outcomes are clear. Outlined below are some of the benefits of involving people in developing research grant applications and research tools and information.

You can also listen to a member of the public speak about their experiences of working with researchers to design a trial on the People in Research website

www.peopleinresearch.org/find-out-about-involvement/what-can-i-do/experiences/helping-to-run-a-trial

Benefits of public involvement in research grant applications

Involving members of the public at this very early stage helps to build and strengthen the relevance, quality and the ethics of the research and can also help to improve recruitment to the research.

Public involvement in the design stage of the research can:

- demonstrate to funders and commissioners that the topic is important and relevant to the end users of research and that they have been involved in the design of the research
- identify areas that might have ethical considerations and advise on solutions
- suggest ways that people can be meaningfully involved in the various stages of the research
- ensure that your recruitment process is practical and feasible

- help you to develop a budget for public involvement in your research and ensure that the time and the support needed for public involvement is built in to the research from the beginning
- suggest ways to ensure that diversity is addressed in the research
- help you to develop written information in user friendly and plain language.

However, developing research grant applications can be a complex and lengthy process. Be clear with the people you are involving about the process and that the research may not get funded.

User involvement in the development of a research bid

The idea for the research came from a group of parents of pre-term babies. This group had been set up as a support group for parents who felt that aspects of their care had been very poor. They hoped that their involvement in research would help to improve services and make things better for future parents.

A chance meeting between the organiser of the support group and a researcher from the Royal College of Nursing Institute led to a partnership being established to develop the bid. The process involved many meetings, a literature search and consultation with an advisory group. This helped to narrow down the parents' broad interests to a clearly defined research question. A key challenge was to keep the parents' ideas central to the bid, at the same time as ensuring it would be viewed as high quality research.

Staniszweska et al 2007

Funding to support public involvement in your research grant application

It can be difficult to obtain funding to support public involvement prior to your grant application being successful. Speak to your organisation or university to see if they have any funding for public involvement.

If you are working with your local National Institute for Health Research (NIHR) Research Design Service to develop your application ask them about funding for public involvement in the grant application. Several, but not all, of the Research Design Services have processes that allow you to apply for a small grant at this stage.

It's not too late to involve people if you have already developed your research grant application. You can still involve members of the public by:

- asking people to review your proposal and give written comments on any potential difficulties in your design
- taking your proposal to a local public involvement group or panel and ask for their views – your university or NHS Trust might already have a group or panel of people who are willing to do this
- thinking about how best to involve people at other stages of the research if your application is successful.

Find out more

about public involvement in research design:

NIHR Research Design Service map and contact details
www.rds.nihr.ac.uk/

Public involvement in National Institute for Health Research (NIHR) research funding applications
www.involve.nihr.ac.uk/resource-centre/examples/

Benefits of public involvement in developing research tools and information such as questionnaires, patient information sheets and consent forms

Involving members of the public in the design and development of research tools is both practical and constructive. There are many examples of how researchers have changed their research tools as a result of public involvement. For example, changing research questions to be more relevant, adding new outcome measures and rewriting documents in user-friendly language.

You can involve people in a variety of ways such as by:

■ working with those who developed the grant application with you

■ developing or working with an existing patient/public involvement reference group or panel to look at all of the research tools and information

■ holding discussion groups

■ employing members of the public as consultants or advisors to the project.

"The birth parents involved made a big difference to all aspects of the recruitment. First we mocked up a leaflet. Everybody savaged it. They said it had way too much writing in it and looked cheap. They advised us to have it professionally designed so that people would know we were kosher and that the study was respectable. They told us to put on the minimal information – just to get people to call up – then we could give all the chapter and verse on the phone. Too much detail would put people off."

Neil 2010 page 30

"Patient members commented extensively and concluded that, as originally presented, the information was considered to be 'too simplified' and 'potentially patronising'. The causes and mechanics of Paget's disease are well understood by Paget's patients and they felt that the information leaflets, as designed by the trial team, had 'dumbed down' the science too far."

Langston et al. 2005

ICONS: Identifying Continence OptioNs after Stroke

The project has two Patient, Public and Carer (PPC) Involvement groups; one for people who have difficulty communicating (aphasia) and one for other stroke survivors and carers. The groups have improved the skills of the researchers in ensuring the research protocol takes into account the needs of patients with stroke. They helped develop materials for participants that are understandable to people with and without aphasia. We hope these materials will encourage participants to take part in the trial phase of our study and maximise the potential for trial participants to benefit from the interventions (e.g. through providing patient-friendly information leaflets).

Thomas et al 2010

It's not too late to involve people even if you have already written your materials. Ask them to review and comment on:

■ whether the information is clear and easy to understand

■ whether the information is accessible to the audience it is aimed at – for example, young people will have different requirements to older people, or to people with communication difficulties.

Managing research

One of the main ways that members of the public get involved in managing research is through membership of a study steering group or management committee.

Increasingly members of the public are taking a more active role in research as co-collaborators or in some cases as the principal investigators in studies. In these circumstances they will often be employed as a member of the research team.

Involving members of the public in managing research can help to ensure that:

■ a public perspective is maintained throughout an individual project or a programme of work

■ public involvement in the project is properly budgeted and funded

■ effective support is developed for members of the public involved in the study

■ advice is available on improving the recruitment of participants to the study

■ there is involvement in the selection process of staff and researchers for the study – particularly helpful if they are going to be working with research participants.

Find out more

about public involvement in managing research:

Exploring the impact: examples of public involvement in research
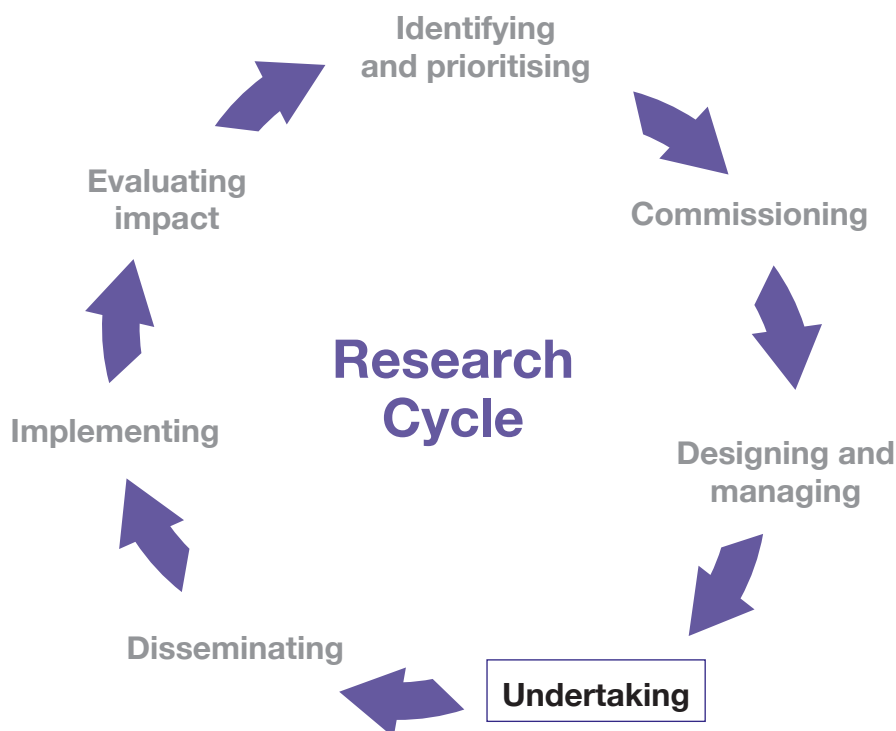www.involve.nihr.ac.uk/resource-centre/examples/

Public involvement in clinical trials: Supplement to the briefing notes for researchers (INVOLVE 2012)
www.involve.nihr.ac.uk/resource-centre/resource-for-researchers

INVOLVE online resource for researchers
www.involve.nihr.ac.uk/resource-centre/resource-for-researchers

Undertaking the research

Research Cycle

Identifying and prioritising → Commissioning → Designing and managing → **Undertaking** → Disseminating → Implementing → Evaluating impact → Identifying and prioritising

Members of the public can get involved in a variety of roles in carrying out the research such as:

- gathering and reviewing documentary evidence
- undertaking library-based research
- carrying out interviews
- running focus groups
- developing research tools and information
- analysing and interpreting the results of research.

Gathering and reviewing documentary evidence and undertaking library-based research

Members of the public can help in looking at different types of evidence and in interpreting the literature from a public perspective.

Public involvement in a systematic review

A systematic review of research into sexual health promotion involved representatives from organisations providing services and campaigning on behalf of men who have sex with men in reviewing the literature. They were involved in recommending priority areas for study and in deciding which sexual health outcomes were to be prioritised in the review.

Rees and Oliver 2007

Find out more

about public involvement in systematic reviews:

Public involvement in systematic reviews: Supplement to the briefing notes for researchers (INVOLVE 2012)

www.involve.nihr.ac.uk/resource-centre/resource-for-researchers

Interviewing and running focus groups

If you are going to involve members of the public as peer interviewers (people who have direct experience of the topic being researched and who carry out interviews with other members of the public) or in running focus groups, we suggest you consider:

■ who the 'peers' are for your research project, for example their gender, age, ethnicity or experience of using a particular service

■ training and support required to carry out the role.

Peer interviewing has been reported to strengthen the collection of qualitative data and increase its relevance and reliability. However, there are also reports of negative consequences of involving peer interviewers which could have been addressed by providing appropriate support and training (Staley 2009).

"For the interviewers, it proved crucial that we provided lots of training and support. Most importantly we provided the training that the peer interviewers said they wanted. We knew we had to provide training on issues such as confidentiality and child protection for ethical reasons – but there were other things they asked for that I wouldn't have thought of, such as dealing with awkward people and how to probe for more information."

Greenfields 2010 page 11

An evaluation of a teenage pregnancy prevention strategy

Jennie worked on a project funded by Leicester City Council to evaluate the local teenage pregnancy prevention strategy. Young people were involved in the project as peer researchers. They designed the information collection methods, carried out interviews with other young people in local youth clubs and schools and helped with the analysis and presentation of the findings.

"I don't think that there's any way, that without their involvement, we could have got the sort of data that they got – even if we had an advisory group and used their questions and advice. Without a doubt they had it".

Fleming 2010 page 25

Find out more

about training and support for peer interviewing:

INVOLVE online resource on training and development
www.invo.org.uk/resource-centre/training-resource

See also designing research page 31

Analysing and interpreting the results of research

Involving members of the public in analysing and interpreting research findings can:

- help to identify themes that researchers might miss
- help in checking the validity of the conclusions from a public perspective
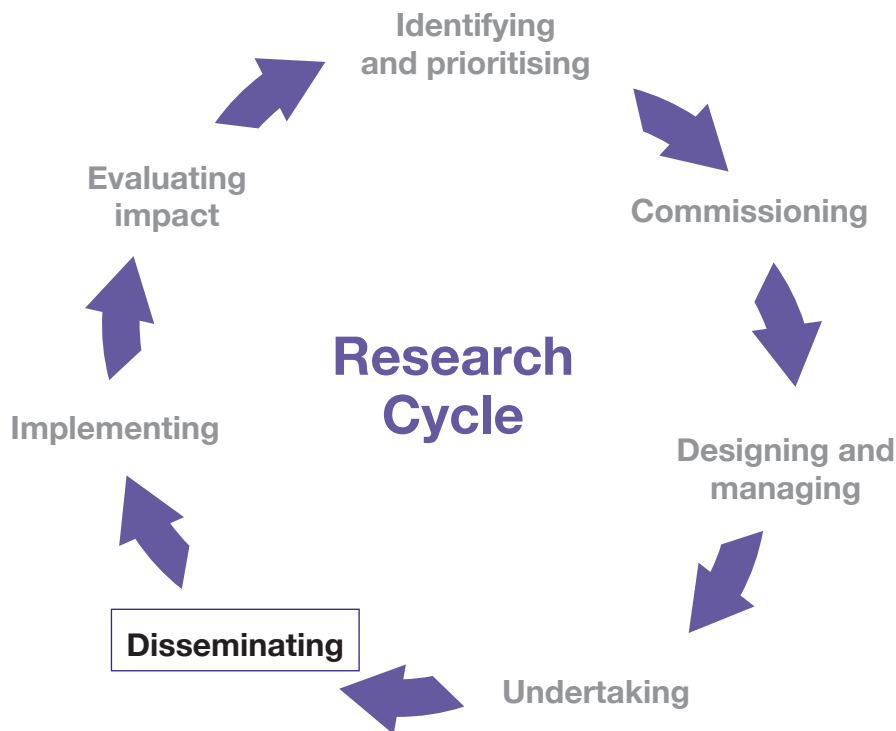- highlight findings that are more relevant to the public.

You might involve the members of the public who have been working with you on the research project to analyse and interpret the research findings. Alternatively you could hold a small event to find out the views of a wider audience on the findings.

"We had massive amounts of data and we thought it would be impossible to ask them to advise us on all of it. So we thought about where their input would be most helpful and focused on that. We thought about doing a presentation or handout or slides, but then remembered what everyone had said about literacy. So we decided to present the material by audio on a CD. We selected 10 minute excerpts from some of the key interviews and made sure these reflected the issues we were trying to tackle in the analysis. The birth parents gave us their views on what they thought about the interviews.

A lot of what they said agreed with what we thought, but some of it was really different and that was particularly valuable."

Neil 2010 page 33

Disseminating research

Research Cycle

Identifying and prioritising

Commissioning

Designing and managing

Undertaking

Disseminating

Implementing

Evaluating impact

Members of the public involved in your research will want to ensure that the findings are widely disseminated so they can influence and change practice for the better. It has been found that involving people just at the dissemination stage is less successful if they have not been involved at earlier stages of the research as they do not have either the ownership or knowledge of the context of the research. However if they have been involved at other stages in the research they will be more likely to disseminate the results to their networks. They will be able to help summarise the research findings in clear user-friendly language and ensure that the information is accessible to a public audience.

To encourage and support public involvement in dissemination:

■ develop progress reports or newsletters to keep people informed throughout the project, reporting both negative and positive results

■ feedback results to all those you consulted and collaborated with as well as participants

■ work with members of the public to develop your dissemination plans – they will often have access to groups and forums that researchers are not aware of

■ involve people in presenting at conferences, speaking to patients, support groups and service providers

■ ask members of the public involved in your research to be co-authors in journal and newsletter articles

■ acknowledge the contribution members of the public made to the research when writing journal articles and reports.

Remember to include in your grant application, funding for public involvement in disseminating the findings and consider if you will need to allocate funding for developing and printing summaries and for postage.
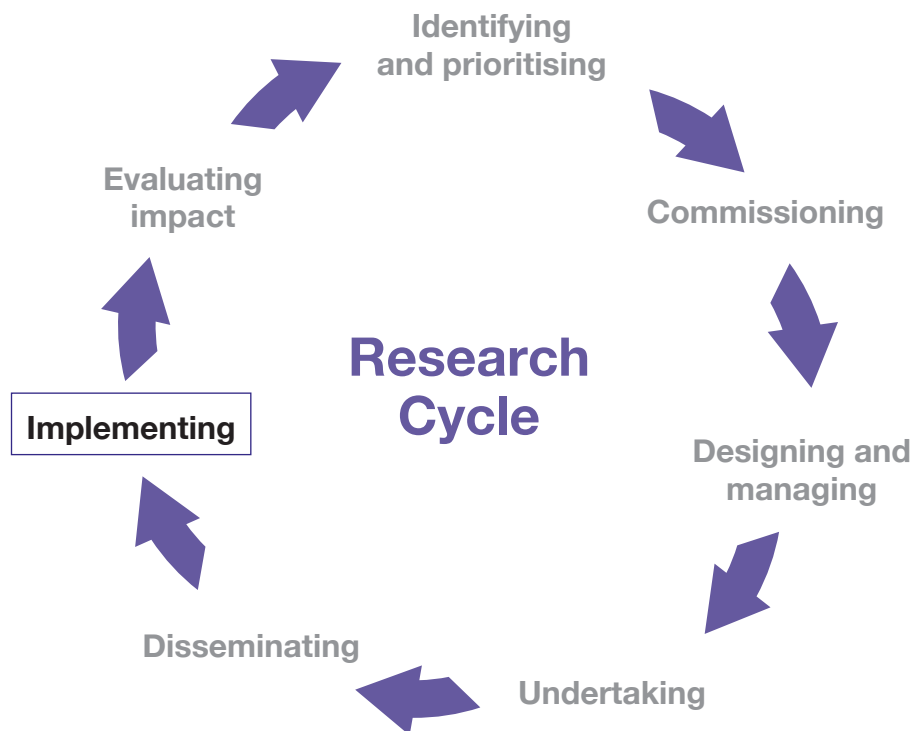
"Without doubt the participation of young people in presentations of the results to professionals brought home some of the findings and recommendations more powerfully than if they had been presented by the researcher alone."

Petrie et al 2006 page 44

It's not too late – if you have reached the stage of disseminating your research, there are still options open to you for involving people. (See **briefing note five** for things you need to consider):

■ discuss your research findings with members of the public and listen to their views

■ ask for their ideas on how best to report your findings to others such as networks, newsletters and different media and formats

■ involve people in working with you to ensure that the information is clear and easy to understand for different audiences

■ reflect on and plan how you will involve people earlier in your next project.

Implementing research

Research Cycle

- Identifying and prioritising
- Commissioning
- Designing and managing
- Undertaking
- Disseminating
- Implementing
- Evaluating impact

Public involvement in your research can influence, support and add strength to the way your research is taken into practice.
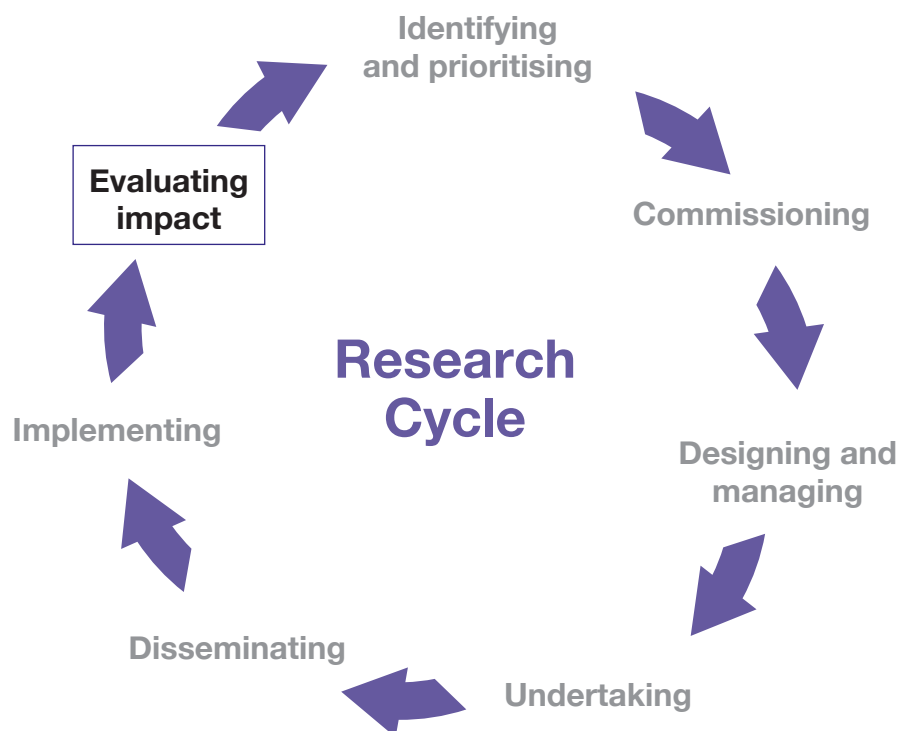
Public involvement in research often provides a route to effecting change and improvement in issues which concern people most and so can lead to new improved services and changes in practice. Members of the public involved in research are often passionate to ensure that action happens as a result of the research and are able to establish relationships with key agencies and policy makers.

Staff training package

A multi-disciplinary research team (which included three service user researchers) carried out an action-research project focusing on the lived experience of detained patients in a psychiatric hospital. In-depth qualitative interviews were undertaken and a staff training package on therapeutic interventions was formulated using data from these interviews. The training was then implemented and evaluated, with positive results. As a result, this training in therapeutic interventions is now being given to a number of staff teams in a mental health trust, co-delivered by the nursing researcher and one of the service user researchers.

St George's, University of London 2011

Evaluating impact

Identifying and prioritising

Commissioning

Designing and managing

Undertaking

Disseminating

Implementing

Evaluating impact

Research Cycle

From the beginning of your project think how you are going to monitor and evaluate public involvement and its impact throughout the project. Working with the people you involve, document and write up an evaluation of the public involvement in your research recording short and long term impacts. This will help you for future projects and provide valuable knowledge for other researchers looking to involve members of the public in their work.

Help to build the evidence base and let others know about what worked well and what didn't and the impact of public involvement in your research by:

- including the information in your research reports
- publishing information on the impact in journal articles
- contacting INVOLVE to put an article in our newsletter
- add details to the research project database on the INVOLVE website

www.involve.nihr.ac.uk/resource-centre/research-project-database

Find out more

about reporting evaluating impact of public involvement in your study:

INVOLVE Evidence Library - a collection of references that consider the impact of public involvement in research
www.involve.nihr.ac.uk/resource-centre/evidence-library/

Exploring impact: examples of public involvement in research
www.involve.nihr.ac.uk/resource-centre/examples/

PiiAF – The Public Involvement Impact Assessment Framework and Guidance (Popay, Collins et al 2013)
http://piiaf.org.uk/

Economic and Social Research Council impact record:
www.esrc.ac.uk/impacts-and-findings

Exploring Impact study: public involvement in NHS, public health and social care research (Staley 2009)
www.involve.nihr.ac.uk/resource-centre/publications-by-involve

What does it mean to involve consumers successfully in NHS research? A consensus study (Telford et al 2004)

Public involvement in research applications to the National Research Ethics Service (Tarpey 2011)
www.involve.nihr.ac.uk/resource-centre/publications-by-involve

Briefing note nine:
What to do when things go wrong

In these briefing notes we have provided information to help you think through how best to involve people in your research. However, there will occasionally be times when things go wrong.

Problems can often be sorted out by informal discussions but if you think that things are going wrong it is best to act quickly. If left unresolved, problems can affect other members of a team or organisation. Depending on what the issue is we suggest you consider some of the following:

■ acknowledge that there is a problem

■ listen to any concerns and openly discuss them with those concerned along with any concerns that you might have

■ allow space and time for all involved to reflect. Public involvement in research is a learning process

■ refer back to any relevant documents that you have developed such as ground rules for meetings, complaints policy, confidentiality agreements

■ set a timescale for agreed change to happen

■ let people know about any actions/changes/decisions

■ ensure support is available if necessary

■ consider using a skilled external facilitator to help with the reflection process.

If you are unable to resolve issues using some of the above strategies or if either you or the member of the public feel a more independent review of the situation is required then a more formal approach should be considered. It is helpful to outline in your planning and preparation the procedure for complaints and resolving differences so that the information is clearly available from the beginning.
(See briefing note five)

More formal procedures might be:

■ Patient Advice and Liaison Service (PALS) Officers www.nhs.uk/Service-Search/

■ University complaints procedures

■ Local authority complaints procedures.

If you are working with people representing a non-statutory organisation that organisation might have its own process.

Find out more

about examples of complaints policies:

INVOLVE complaints procedure
www.involve.nihr.ac.uk/about-involve/keep-in-touch/complaints

Association of Medical Research Charities complaints procedure
www.amrc.org.uk/about-us_complaints-procedure

Further examples are available in the INVOLVE online resource for researchers
www.involve.nihr.ac.uk/resource-centre/resource-for-researchers

Where to go for further information

INVOLVE resources

All of our publications and resources are freely available to view or download from the INVOLVE website.

INVOLVE online resource for researchers

Ten briefing notes on how to involve members of the public in research.

Supplements on:
- Strategies for diversity and inclusion in public involvement
- Public involvement in clinical trials
- Public involvement in systematic reviews

Case studies highlighting examples of public involvement in research.

Templates with examples of useful documents such as job descriptions and terms of reference.

www.involve.nihr.ac.uk/resource-centre/
resource-for-researchers

INVOLVE Putting it into practice database

A database of references for reports and publications on:
- guidance on good practice
- reports of the lessons learnt from direct experience of involvement
- descriptions of involvement in research projects
  www.involve.nihr.ac.uk/resource-centre/
  putting-it-into-practice-database

INVOLVE Evidence Library

A database of references on the impact, nature and extent of and reflections on public involvement in research
www.involve.nihr.ac.uk/resource-centre/
evidence-library

INVOLVE online resource on training and development

www.involve.nihr.ac.uk/resource-centre/
training-resource

invoDIRECT

An online directory of networks, groups and organisations that support active public involvement in NHS, public health and social care research
www.involve.nihr.ac.uk/find-out-more/
invodirect/

Budgeting for public involvement

Practical advice on how to budget for public involvement and an online cost calculator
www.involve.nihr.ac.uk/resource-centre/
involvement-cost-calculator/

People in Research

A resource to help members of the public find opportunities to get involved in research and for research organisations / researchers to advertise involvement opportunities
www.peopleinresearch.org

Examples of other sources of information

Visit our online resource for researchers for a full list
www.involve.nihr.ac.uk/resource-centre/resource-for-researchers

NIHR Research Design Service (RDS)

www.rds.nihr.ac.uk/

NIHR Research Design Service (RDS) supports researchers to develop research proposals for submission to the NIHR and other national, peer-reviewed funding competitions for applied health or social care research. This includes giving advice on patient and public involvement in the development of proposals.

There are ten NIHR Research Design Services:

East of England
www.rds-eoe.nihr.ac.uk

East Midlands
www.rds-eastmidlands.nihr.ac.uk

London
www.rdslondon.co.uk

North East
www.rds-ne.nihr.ac.uk

North West
www.rds-nw.nihr.ac.uk

South Central
www.rds-sc.nihr.ac.uk

South East
www.rds-se.nihr.ac.uk

South West
www.rds-sw.nihr.ac.uk

West Midlands
www.rds-wm.nihr.ac.uk

Yorkshire and the Humber
www.rds-yh.nihr.ac.uk

NIHR Clinical Research Network

The Clinical Research Network website provides an overview of their work and information on the research networks and public involvement and engagement.
www.crn.nihr.ac.uk/can-help/patients-carers-public/

National Institute for Health Research (NIHR)

Information for researchers on public involvement in NIHR funded research and how members of the public are involved in the NIHR
www.nihr.ac.uk

Involving London

– a website providing a range of information and opportunites for patient and public involvement in London
www.involvinglondon.co.uk

North West People in Research Forum

– an organisation supporting patient and public involvement and engagement in the North West
www.northwestpeopleinresearchforum.org/

User involvement in research: a route map TwoCan Associates

– for organisations who commission or fund research and want to involve service users in their work (2010)
www.twocanassociates.co.uk/routemap

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INVOLVE publications can be downloaded from the Resources section of our website www.involve.nihr.ac.uk/resource-centre

Appendix

Workshop to inform content of a new INVOLVE resource for researchers
Thursday 30th September 2010
King's Fund, Cavendish Square, London W1M 0AN
Delegate details

Name	Organisation
Stephanie Armstrong	The Stroke Association
Sophie Auckland	NIHR Guy's and St Thomas'/King's College London, Biomedical Research Centre
Sarah Buckland	INVOLVE Coordinating Centre
Jean Cooper Moran	NIHR Central Commissioning Facility
Jean Craig	Research Design Service – East of England
Barbara Dawkins	INVOLVE Coordinating Centre
Alison Ford	NIHR Evaluation, Trials and Studies Coordinating Centre
Bec Hanley	TwoCan Associates
Gill Hastings	NIHR School of Social Care Research
Helen Hayes	INVOLVE Coordinating Centre
Sarah Howlett	INVOLVE Coordinating Centre
Anne-Maree Keenan	NIHR Leeds Musculoskeletal Biomedical Research Unit
Martin Lodemore	NIHR Diabetes Research Network
Jo Moriarty	Social Care Workforce Research Unit
Sandra Paget	
Sue Pavitt	Clinical Trials Research Unit (CTRU), University of Leeds
Wendy Rickard	Folk.us
Lesley Roberts	
Andrew Robinson	Research Design Service – North East
Lucy Simons	INVOLVE Coordinating Centre
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Doreen Tembo	Research Design Service – East of England
Monique Tomiczek	Medical Research Council – Clinical Trials Unit
Jenny Trite	
Christine Vial	INVOLVE Group member
Derek Ward	Research Design Service – South Central
Tracey Williamson	University of Salford, INVOLVE Group member

Notes:

Notes:

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INVOLVE is a national advisory group funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research.

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