NIHR | National Institute for Health and Care Research

Briefing notes for researchers

Public involvement in NHS, health and social care research

April 2021

Briefing note one: introduction

This guidance is for researchers new to public involvement in research and just starting to consider how best to involve members of the public in their work. It 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 it will be helpful to others interested in public involvement in research, including involvement leads. This guidance explains the different ways that members of the public are involved in research. It will help you to plan, resource and support public involvement in research.

You can find more involvement resources and guidance on Learning for Involvement.

Briefing note two: what is public involvement in research?

Definitions of involvement, engagement and participation

Researchers and others use a variety of words to describe ways of interacting with the public. The terms involvement, engagement and participation are sometimes used interchangeably but the National Institute for Health and Care Research (NIHR) ascribes specific meanings to these terms as follows:

Involvement

NIHR defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research.

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 specific communities and from organisations that represent people who use services. Also included are people with lived experience of one or more health conditions, whether they're current patients or not.

Here are examples of how members of the public might get involved in research:

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

Public involvement as defined here is also sometimes referred to as Patient and Public Involvement (PPI). More information about approaches to public involvement can be found in section seven.

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 days 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 through the National Coordinating Centre for Public Engagement.

Participation

Where people take part in a research study. Examples of participation are:

- people being recruited to a clinical trial or other research study(eg to test the efficacy of a new treatment)
- completing a questionnaire or participating in a focus group as part of a research study.

Find out more about how members of the public participate in NIHR research on Be Part of Research.

These different activities – involvement, engagement and participation – are often linked and, although they are distinct, they can complement each other.

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

Public involvement can improve the quality and relevance of research, as well as serving the broader democratic principles of citizenship, accountability and transparency. For these reasons public involvement is increasingly an expectation if not requirement of research funders. Research teams do not always clearly articulate their rationale for public involvement. A clear rationale helps researchers be more specific about who they want to involve, and in what ways.

Democratic principles

People who are affected by research have a right to have a say in it. Public involvement in research is an intrinsic part of citizenship, public accountability and transparency. It can also help empower people who use health and social care services, by providing the opportunity to influence research that is relevant to them.

Providing a different perspective

Members of the public might have personal knowledge and experience relevant to your research topic or be able to provide a more general societal perspective. They might have lived experience of one or more health conditions or of using services. Members of the public will also bring their experiences of being part of specific communities or groups.

Improving the quality of the research

Involving members of the public helps ensure that research focuses on outcomes that are important to the public. It is also a good way of tailoring your research to the needs of specific communities. For example, if you are seeking research participants from a particular community, involving members of that community in shaping the study design can help improve recruitment and retention of participants by ensuring that your ways of communicating and your research methods are sensitive to the needs, customs and circumstances of the community. .

Making the research more relevant

Public involvement can make research more relevant for example through:

- identifying a wider set of research topics than would have been generated just by academics and health or social care professionals suggesting ideas for new research
- ensuring research is focused on what matters to people - for example by prioritising symptoms that are of importance to patients with a particular condition
- helping to reshape and clarify the research.

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 clear reasons for this and be able to explain them.

For example, NIHR has a standard application form used by all research programmes. 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, including plans for evaluating impact. 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.

Ethics

The Research Ethics Service 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. They expect the involvement of the public in research, as it can help ensure that research planned is ethical, relevant and acceptable from a public perspective. Find out more about the impact of public involvement on the ethical aspects of research.

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. Some people have had difficult experiences and appreciate being able to do something positive with that experience. Others have had very good experiences, and see their involvement as an opportunity to ‘give something back’. Other people get involved to ensure the voice of their community/communities are represented in research. 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.

healthtalk.org has a series of interesting videos where various members of the public talk about their reasons for getting involved in research, including helping others and medical science and also for personal benefits.

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

UK Standards for Public Involvement

A good place to start when planning how to involve members of the public in research is the UK Standards for Public Involvement. Developed over three years by a UK-wide partnership, the Standards are a description of what good public involvement looks like. They encourage approaches and behaviours that are the hallmark of good public involvement such as flexibility, sharing and learning, and mutual respect . The Standards are for everyone doing health or social care research, and provide guidance and reassurance for practitioners working towards achieving their own best practice. The six Standards are:

1. **Inclusive opportunities** – offer public involvement opportunities that are accessible and that reach people and groups according to research needs
2. **Working together** – work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships
3. **Support and learning** – offer and promote support and learning opportunities that build confidence and skills for public involvement in research
4. **Governance** – involve the public in research management, regulation, leadership and decision making.
5. **Communication** – use plain language for well-timed and relevant communications, as part of involvement plans and activities
6. **Impact** – Seek improvement by identifying and sharing the difference that public involvement makes to research.

Below we provide more information on each Standard. The Standards were tested by over 40 individuals, groups and organisations during a year-long pilot programme, and you can find out more about these ‘test bed’ projects and how they went about implementing the UK Standards for Public Involvement in the Implementation Stories report.

Inclusive opportunities

Offer public involvement opportunities that are accessible and that reach people and groups according to research needs. Research is to be informed by a diversity of public experience and insight, so that it leads to treatments and services which reflect these needs. The questions below may help you reflect on and decide if you meet the Standard:

- are people affected by and interested in the research involved from the earliest stages?
- have barriers to involvement, such as payment for time or accessible locations for meetings been identified and addressed?
- how is information about opportunities shared, and does it appeal to different communities?

- are there fair and transparent processes for involving the public in research, and do they reflect equality and diversity duties?
- is there choice and flexibility in opportunities offered to the public?

The NIHR is committed to actively and openly supporting and promoting equality, diversity and inclusion, and this also applies to how we do public involvement. As such, this Standard is crucial for NIHR, and the research we fund.

The NIHR's Being Inclusive in Public Involvement in Health Research guidance provides key tips for researchers and practitioners:

- check your power - try to understand power relationships within your context and your role, and how to promote inclusion
- value the people you work with - people will bring different perspectives and opinions
- use language carefully - avoid jargon, write in plain English and be considerate
- consider inclusive locations - decide together on the best places for meetings
- listen and seek agreement
- get from A to B, perhaps via Z - be flexible
- collaborate - work with community organisations
- invest in the workplace
- commit to a relationship
- evidence, evaluate, share and reflect
- act small, think big - support people, researchers and members of the public to develop confidence, learning and skills

Find out more about EDI and accessibility:

- Being Inclusive in Public Involvement in Health Research guidance
- Different experiences: a framework for considering who might be involved in research guidance
- Government guidelines on writing about ethnicity
- The East Midlands Academic Health Science Network PPI webpages have a number of top tips leaflets for engaging with various communities
- NIHR Plain English Summaries guidance
- Strategies for diversity and inclusion in public involvement: Supplement to the briefing notes for researchers INVOLVE (2012)

Working together

Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships. Public involvement in research is better when people work together towards a common purpose, and different perspectives are respected. The questions below may help you reflect on and decide if you meet the Standard:

- has the purpose of public involvement been jointly defined and recorded?
- have the practical requirements and arrangements for working together been addressed?

- have all the potential different ways of working together been explored, and have these plans and activities been developed together?
- is there a shared understanding of roles, responsibilities and expectations of public involvement?
- have individuals' influence, ideas and contributions been recognised and addressed?

Support and learning

We offer and promote support and learning that builds confidence and skills for public involvement in research. We seek to remove practical and social barriers that stop members of the public and research professionals from making the most of public involvement in research. The questions below may help you reflect on and decide if you meet the Standard:

- is there a range of support to address identified needs?
- have specific resources been designated to support learning and development opportunities for both the public, researchers, and staff?
- do the public know where to go for information and support about public involvement?
- is there a culture of learning- by- doing, building on and sharing that learning for researchers, staff and the public?

Different types of training might be:

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

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
- IT support for remote working
- informal or formal mechanisms of peer support.

Find out more about guidance, training and support on Learning for Involvement.

Governance

Involve the public in research management, regulation, leadership and decision making. Public involvement in research governance can help research be more transparent and gain public trust. The questions below may help you reflect on and decide if you meet the Standard:

- are public voices heard, valued and respected in decision making?
- are public involvement plans in place that are regularly monitored, reviewed and reported on?
- is there visible and accountable responsibility for public involvement throughout the organisation?
- are realistic resources (including money, staff, time) allocated for public involvement?
- is the privacy of personal information protected by collecting and using it in a suitable way?

Communications

Use plain language for well-timed and relevant communications, as part of involvement plans and activities. Communicate with a wider audience about public involvement and research, using a broad range of approaches that are accessible and appealing. The questions below may help you reflect on and decide if you meet the Standard:

- has a communications plan been developed for involvement activities?
- are the needs of different people being met through inclusive and flexible communication methods?
- are processes in place to offer, gather, act on and share feedback with the public?
- are you sharing your public involvement learning and achievements, good and bad?

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, and agree the aims of the research. It can be helpful to develop a role description and/or terms of reference so people know what is expected of them, and what they can expect from you.

Impact

Seek improvement by identifying and sharing the difference that public involvement makes to research. Understand the changes, benefits and learning gained from the insights and experiences of patients, carers and the public. The questions below may help you reflect on and decide if you meet the Standard:

- are the public involved in deciding what the assessment of impact should focus on, and the approach to take?
- is it clear what information you will collect to help assess impact, including who has been involved and how?
- are there processes in place to help reflect on public involvement?
- is there a commitment to learn from the public involvement experience and, where possible, to act on this learning?

Resource public involvement in research

To achieve good quality public involvement, as set out by the UK Public Involvement Standards, it is crucial to consider how to 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 NIHR, will actively encourage and expect public involvement to be adequately costed in research proposals. It can be challenging 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. You can find in-depth information on budgeting for involvement in the NIHR's Payment Guidance for researchers and professionals.

Do I need ethical approval for public involvement?

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. For more information, the following resources are recommended: Qualitative research and patient and public involvement in health and social care research: What are the key differences? and Patient and public involvement in research and research ethics committee review .

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 (HR). 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 HR may raise about the proposed arrangements. If there are any concerns raised by these departments you will have time to address them early on.

Examples of issues you might need to consider are:

- payment and expenses policies
- methods for paying people (including tax and national insurance deductions)
- confidentiality agreements –(where these apply, all members of the research group should be asked to sign , not just the members of the public
- health and safety
- honorary contracts
- 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, and ideally has relevant experience and skills in public involvement
- 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 support
- if asking your own patients or their carers to work with you on a study consider if this is appropriate and how this might affect your relationship with them
- where appropriate, discuss in advance what will happen should people become ill for periods of the research
- discuss in advance with the people you have involved whether and in what ways they might want to stay involved after the project. For example they might be interested in supporting dissemination of the research, getting involved in further research, developing a longer-term relationship with the relevant research institution, connecting

with other groups and organisations, or other means whereby they can continue to contribute and to use the skills they have developed.

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 perspectives 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.

Key points to consider when deciding who might be involved in research, are set out in the guidance note: Different Experiences: A framework for considering who might be involved in research guidance and include the following:

- be clear about the purpose of involving people in research and what experiences and knowledge they can provide
- include a diversity of relevant views and perspectives
- take a common sense approach to who you involve
- people can wear several hats, and their contributions may be broader because of this range of experiences
- the type of lived experience required will vary depending on the focus of the research.

For most studies it is not appropriate for people involved in the research also to 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.

Involve more than one person

Involving more than one person allows you to include different people at different stages of the research, and provides them more choices in how they are 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
- make the overall public presence more resilient to individual absences resulting from illness or clashing commitments Include a diversity of relevant views and perspectives.

Consider the broad and different views and experiences you will need to include in your research. 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.

You can read the Being Inclusive in Public Involvement in Health Research guidance for further information, and refer to the 'inclusive opportunities' Standard for public involvement.

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. Rather than inviting people in to talk to you, go out and engage with communities or groups where they already meet, whether that be in physical spaces or online forums.

Others have contacted people by:

- for specific communities, getting in touch with relevant community groups, community and faith leaders, or other individuals who can help you engage with specific groups of people
- 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 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.

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. 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:

- Watch this Youtube video from Caroline Barker, from the University Hospital Southampton NHS Foundation Trust, on Reaching new public members in a virtual world
- People in Research is a national platform to help members of the public find opportunities to get involved in research and for research organisations and researchers to advertise involvement opportunities
- Vocal creates opportunities for people to find out about, and have a voice in, health research in Greater Manchester
- North West People in Research Forum – supporting patient and public involvement and patient engagement in health research in the North West
- Patient has a comprehensive list of national and local support groups and organisations

Briefing note seven: approaches to public involvement in research

We use the terms consultation, collaboration, co-production and user controlled describe different broad approaches to involving people in research, associated with progressively increasing levels of power and influence for members of the publicIn practice, research projects can include a combination of these four and boundaries between them are not clear cut. Moreover, each approach encompasses a range of specific methods for involving people.

For example, you might work with one or two service users or carers as collaborators throughout a research project, as well as consulting with a wider group of service users on a specific aspect of the study, while some 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. Be clear about these aims with the people you involve. 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 .

If you decide to consult 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.

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
- as the consultation is framed by your own concerns and questions, you might not get the level of insight from consultees that could emerge in a more two-way process
- 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.

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.

Co-production

Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge. The assumption is that those for whom the research is most relevant are best placed to design and deliver it in partnership with the professionals, and have skills, knowledge and experience of equal importance. There is an overlap with the collaboration approach but what defines co-production is the values and principles that underpin it, rather than any specific tools or techniques. Indeed, there is no single formula or method for co-production and such an approach would be counter to the innovation and flexibility that is implicit in co-produced research. Rather, co-production requires that relationships are valued and nurtured, that efforts are made to redress power differentials, and that people are supported and enabled to realise their potential in carrying out their roles and responsibilities in the project.

Co-producing research can include partnerships between academia and organisations representing the public as well as individual public members working with organisations, for example universities, which undertake research.

The NIHR's Guidance on co-producing a research project describes key principles and features of co-production. These are summarised below:

Key principles:

- Sharing of power – the research is jointly owned and people work together to achieve a joint understanding.
- Including all perspectives and skills – making sure the research team includes all those who can make a contribution.
- Respecting and valuing the knowledge of all those working together on the research – everyone is of equal importance.
- Reciprocity – everybody benefits from working together.

- Building and maintaining relationships – an emphasis on relationships is key to sharing power. There needs to be joint understanding, consensus and clarity over roles and responsibilities. It is also important to value people and understand opportunities for their development.

Key features:

- Establishing ground rules
- Continuing dialogue
- Joint ownership of key decisions
- A commitment to relationship building
- Opportunities for personal growth and development
- Flexibility
- Continuous reflection
- Valuing and evaluating the impact of co-producing research.

The NIHR's Guidance on co-producing a research project also presents some challenges that need to be addressed to enable more opportunities for co-producing research. These challenges touch on the topics of power (and power sharing), flexibility in research approaches and practices, the need for more guidance on co-production, and how to assess and evaluate co-produced research.

Find out more about co-production:

- NIHR Guidance on co-producing a research project
- NIHR Co-Production in Action (Number One)
- NIHR Co-Production in Action (Number Two)
- NIHR Co-Production in Action (Number Three)
- BMJ: 'Co-production of knowledge: the future' Collection of articles (2021)
- The NIHR Research Design Service South East have produced a podcast series on co-production
- The Co-Production Collective is a community of patients, carers, researchers, practitioners, students and anyone else who is interested in co-production (in the health context or more generally).

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, written up and disseminatedThe 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.

The Faulkner (2010) report 'Changing our worlds: examples of user-controlled research in action' highlighted several key reasons why user controlled research is important for service users:

- 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 the research
- a user controlled organisation might commission you to carry out research under their direction.

Find out more about user controlled research in this report: User Controlled Research: its meanings and potential (Turner and Beresford 2005)

Organising and hosting meetings

Regardless of the approach you take, involving members of the public is likely to entail organising and hosting meetings. How you do this 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.

If you do choose meetings, you need to consider whether face-to-face, online, or a combination of the two work best for your research project, and your public contributors.

Planning for meetings: face-to-face

- 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)
- 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
- consider developing terms of reference and/or ground rules for the meeting so that those attending know why the meeting is being held and the responsibilities of those attending

Planning for meetings: online

The NIHR School for Primary Care Research (SPCR) has developed useful guidance on how to hold a PPI meeting using virtual tools, which details these key tips and tricks:

- keep it simple - use easy software and tools
- send documents in advance
- don’t chair and make minutes simultaneously
- choose appropriate software - SPCR provide specific tips for Microsoft Teams and Zoom
- promote the opportunity widely - virtual meetings give you the opportunity to involve people not usually involved in research
- adjust the agenda accordingly - take into consideration more frequent breaks
- have a backup plan if technology fails
- provide support before and during the meeting

There is a wide range of guidance on good practice for online meetings for involvement. Here are some of the ones we think might be most useful:

- here is an overview of the best video conferencing apps for accessibility
- National Coordinating Centre for Public Engagement Online Engagement: a guide for creating and running virtual meetings and events
- a blog by University College London on Engagement in a time of social distancing, which also includes further resources and reading

- NIHR Research Design Service South Central Top tips for carrying out PPI activities during COVID-19
- Engaging at a distance guidance from Being Human, which has a useful online event checklist
- Holding Accessible and Inclusive Virtual Meetings guidance from the International Foundation for Electoral Systems (IFES)
- there are particular considerations to keep in mind when hosting online meetings which will be accessed by disabled people. Find out more about how to make your virtual meetings and events accessible to the disability community and how to run accessible online meetings for disabled people working and studying from home

Conducting the meetings (face-to-face and online)

- brief the Chair and other committee members to ensure that the members of the public are welcomed and included during the meeting. You can find out more about chairing a meeting by reading the TwoCan Associates guidance for chairs
- offer a pre-meeting or telephone discussion for members of the public to discuss the agenda and papers
- for face-to-face meetings, provide name badges in a large clear text font
- 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
- 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 as people might need to take medication or find sitting for long periods difficult
- for face-to-face meetings, see if it is possible to have a spare room to allocate 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 (breakout rooms online) 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

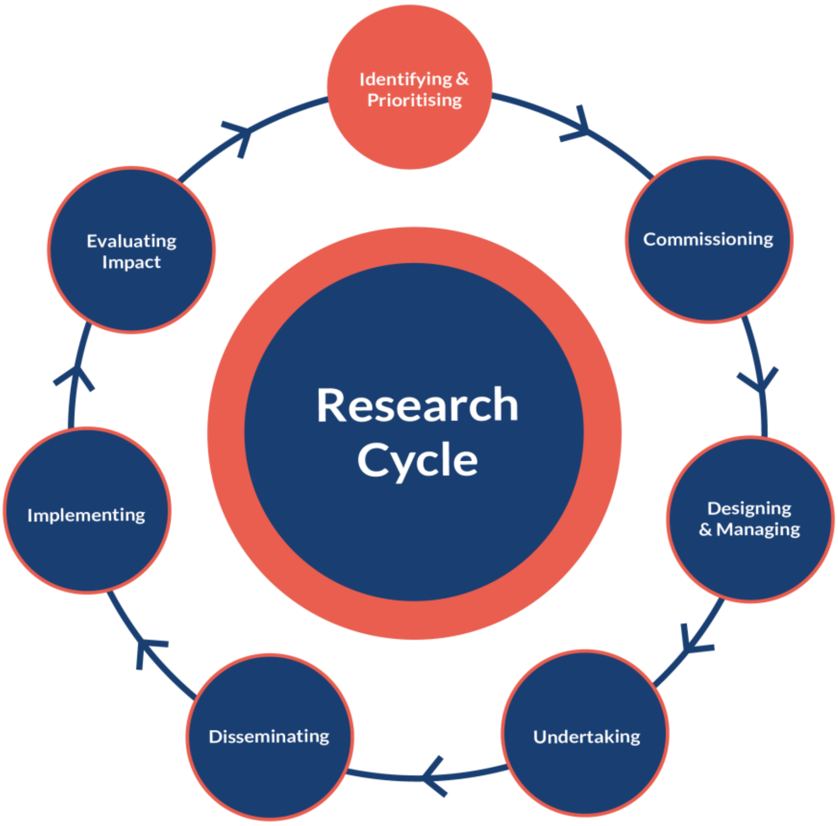
After the meeting (face-to-face and online)

- share a write up of the event, including any recommendations or outcomes
- 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

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 section considers the different ways members of the public can get involved in the stages of the research cycle. When reading through this section, keep in mind the six UK Standards for Public Involvement: inclusive opportunities; working together; support and learning; governance; communications; impact.

Identifying and prioritising research



Involving the public in helping to identify and prioritise research questions is a powerful way of ensuring that your research priorities are aligned with those of people who have a personal stake in the subject, for example if they have the condition you are researching or 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.

People with lived experience - and the organisations that represent - researchers and health and care practitioners will all have distinct, though often overlapping research priorities. By working together you can develop a shared agenda. 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 questions were developed and the different influences on the questions 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 support organisations 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 living with their condition/s, or using treatments or services, before discussing how these might be turned into research questions.

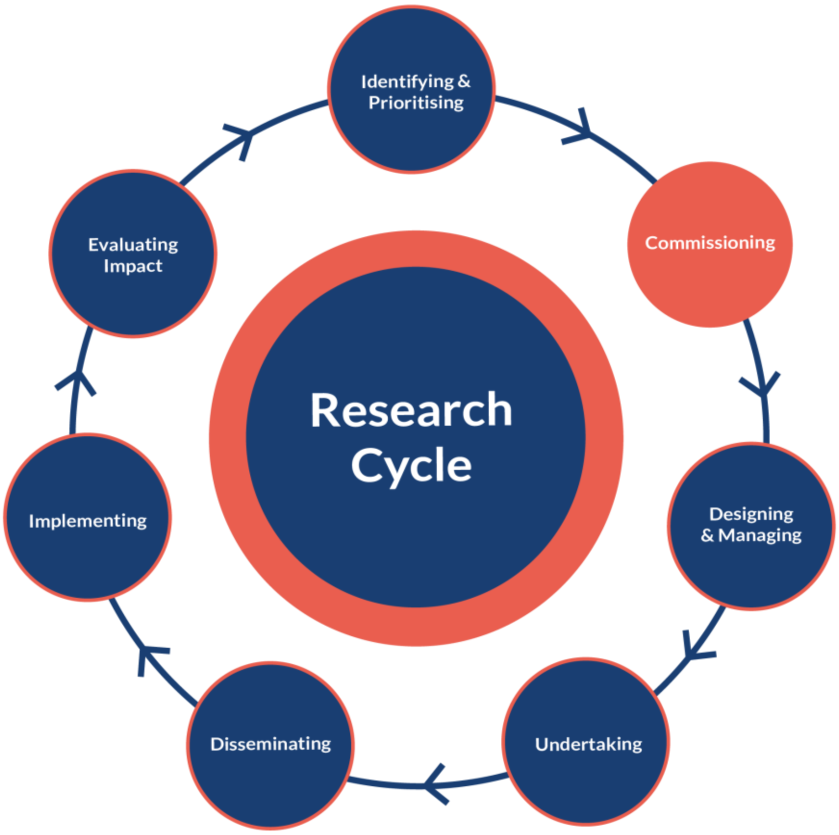
Find out if others have worked with members of the public to identify research topics

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 NIHR, facilitates Priority Setting Partnerships. These partnerships bring patients, carers and health and care practitioners together to identify and prioritise the care and treatment uncertainties which they agree are the most important for research.

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.

Commissioning research

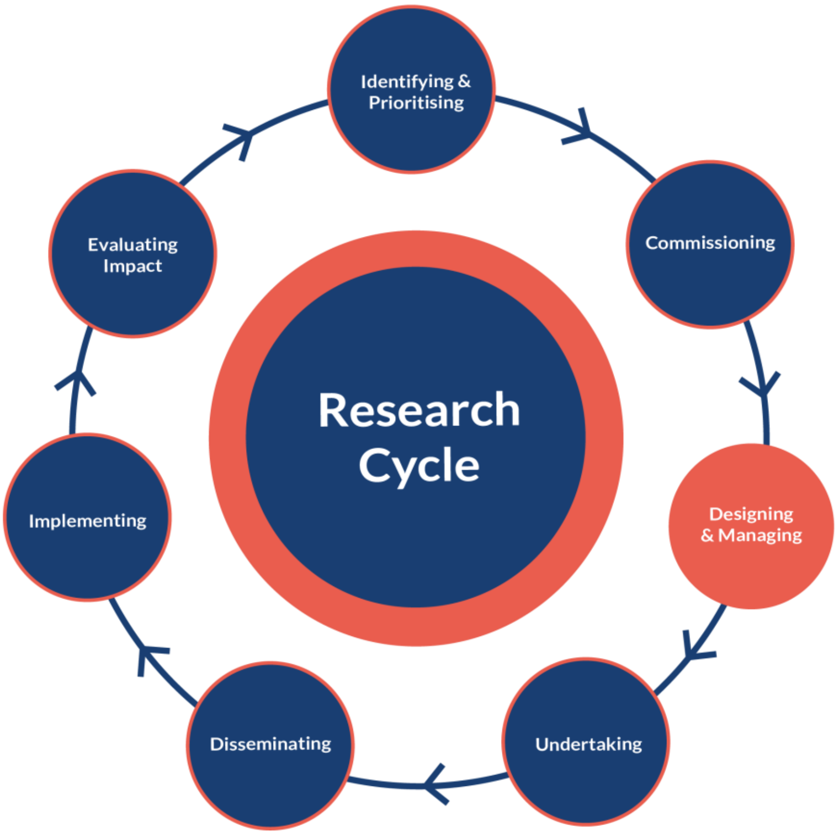


Many funding organisations now involve members of the public in commissioning research. For example the NIHR recruits and supports patients, carers and members of the public to give feedback on health and social care research funding applications. This gives a broader perspective to the review process, by considering the issues that are important from a public and patient perspective.

Involvement in commissioning can be done 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.

Designing and managing research



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 that the research questions and outcomes are clear. It strengthens the ethical basis of the research, and can help improve the recruitment and retention of volunteer participants in the study. 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 aspects of the research that raise ethical considerations and provide a broader set of perspectives on solutions
- suggest ways that people can be meaningfully involved in the various stages of the research
- suggest ways to ensure that diversity and inclusion are addressed in the research, for example in ensuring that volunteers can be recruited from certain ethnic communities
- 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
- help develop written information in user friendly and plain language, which is appropriately targeted at specific communities

Be clear with the people you are involving about the fact that the funding process can be lengthy and that the research may not get funded.

Funding to support public involvement in your research grant application

It can be challenging 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 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 local 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.

Managing research

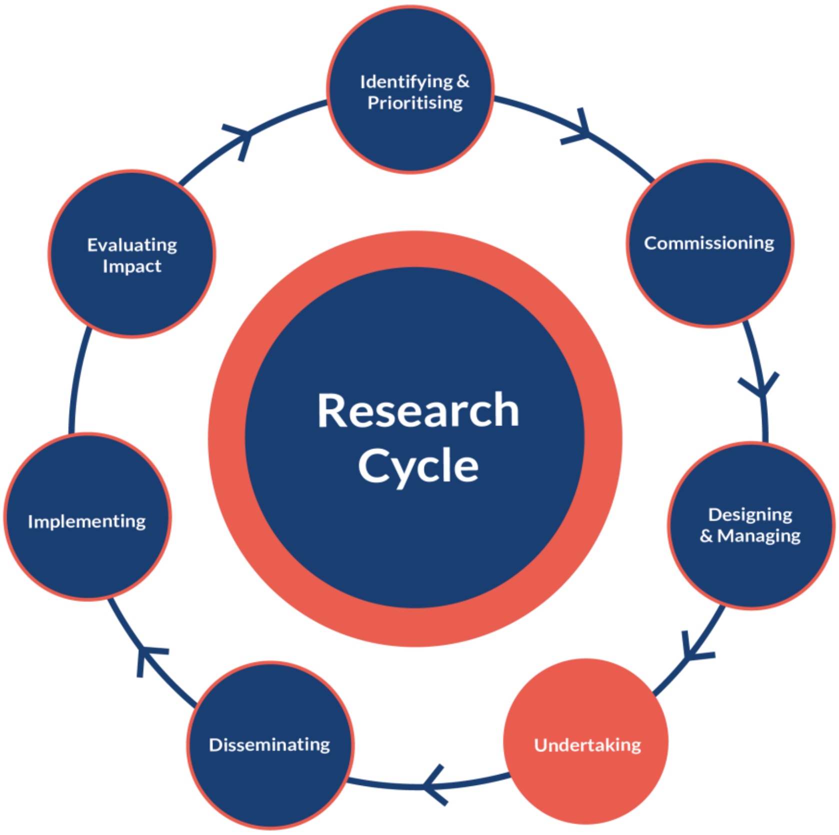
One of the main ways that members of the public get involved in managing research is through membership of a study steering group or management committee. Increasingly members of the public are taking a more active role in research as collaborators or in some cases as the principal investigators in studies. 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 and societal 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 your research on the NIHR website. There is also specific guidance on public involvement in clinical trials.

Undertaking the research



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
- analysing and interpreting the results of research.

Gathering and reviewing documentary evidence and undertaking library-based research

Members of the public can help look at different types of evidence and interpret the literature from a public perspective. Find out more about public involvement in systematic reviews.

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, K. (2009) Exploring Impact: public involvement in NHS, public health and social care research).

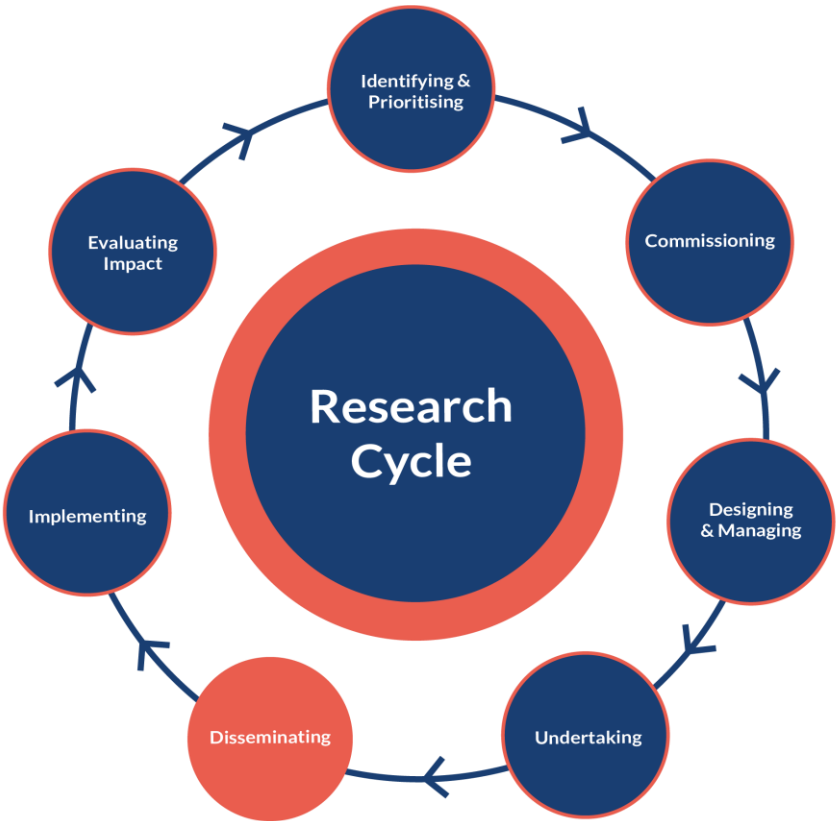
Analysing and interpreting the results of research

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

- help to identify themes that researchers might miss
- help check 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.

Disseminating research



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 at the dissemination stage is more successful if they have also been involved at the earlier stages of the research as they then benefit from a sense of ownership of the research and an understanding of the context and background. This means they will be more likely to disseminate the results to their networks, 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:

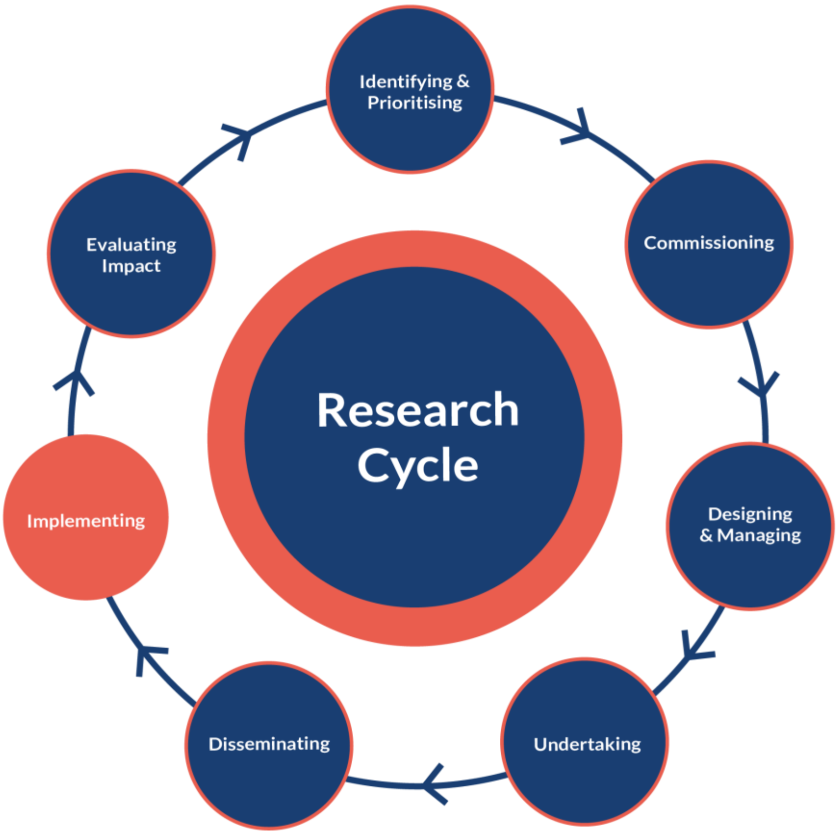
- develop progress reports or newsletters to keep people informed throughout the project, reporting both negative and positive results
- feedback results to all those you consulted and collaborated with as well as participants
- work with members of the public to develop your dissemination plans – they 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 funding for public involvement in disseminating the findings in your grant application, and consider if you will need to allocate funding for developing and printing summaries and for postage.

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:

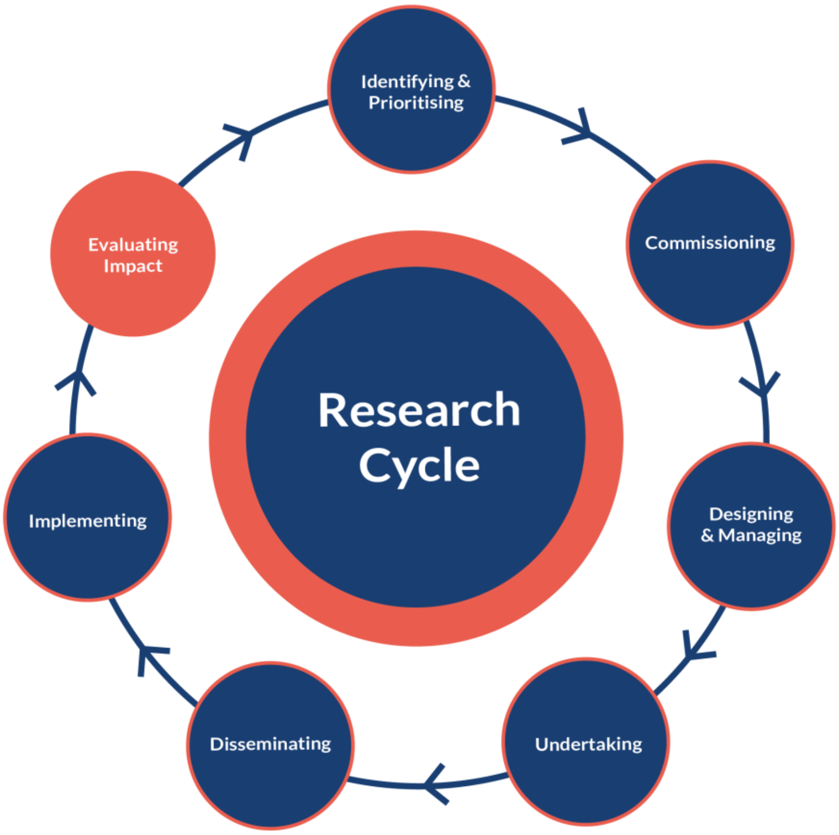
- discuss your research findings with members of the public and listen to their views
- ask for their ideas on how best to report your findings to others through networks, newsletters and different media and formats
- involve people in working with you to ensure that the information is clear and easy to understand for different audiences
- reflect on and plan how you will involve people earlier in your next project.

Implementing research



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 aspects of health and care practice that are of particular concern to people. Members of the public involved in research are often passionate to ensure that action happens as a result of the research and might be able to establish influential relationships with key agencies and policy makers.

Evaluating impact



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 the NIHR to put an article in our newsletter: ced@nihr.ac.uk

Find out more about reporting evaluating impact of public involvement in your study:

- PiiAF – The Public Involvement Impact Assessment Framework and Guidance (Popay, Collins et al 2013)
- Exploring impact: examples of public involvement in research (INVOLVE 2013)
- Exploring Impact study: public involvement in NHS, public health and social care research (Staley 2009)
- What does it mean to involve consumers successfully in NHS research? A consensus study (Telford et al 2004)
- PIRICOM study: a systematic review (Brett et al 2010)

- Public involvement in research applications to the National Research Ethics Service (Tarpey 2011)
- Service user involvement in nursing, midwifery and health visiting research: A review of evidence and practice (Smith et al 2008)

Briefing note nine: what to do when things go wrong

In this guidance 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 get worse and affect a growing number of 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 involved 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.

More formal procedures might be:

- Patient Advice and Liaison Service (PALS) Officers
- university complaints procedures
- local authority complaints procedures.

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

Briefing note ten: where to go for further information

NIHR information

Learning for Involvement allows you access training and guidance on public involvement

People in Research reports live opportunities for public involvement in NHS, public health and social care research, and allows you to submit your own

Read the NIHR Payment Guidance for researchers and professionals

NIHR Research Design Service (RDS) - The RDS provides support to health and social care researchers across England on all aspects of developing and writing a funding application, including research design, research methods, identifying funding sources and involving patients and the public. There are ten RDS centres across England. Each RDS has a patient and public involvement manager.

NIHR Clinical Research Network (CRN) - The NIHR Clinical Research Network (CRN) supports patients, the public and health and care organisations across England to participate in high-quality research, thereby advancing knowledge and improving care. The CRN comprises 15 Local Clinical Research Networks (LCRN) and 30 Specialties which coordinate and support the delivery of high-quality research both by geography and therapy area. National leadership and coordination is provided through the CRN Coordinating Centre. Contact your LCRN.

Acknowledgements

This resource was reviewed by NIHR in March 2021 for accuracy and currency. The NIHR endorses this resource.

This guidance is due for review in March 2023.

The previous version was referenced as: INVOLVE (2012) Briefing notes for researchers: involving the public in NHS, public health and social care research. INVOLVE, Eastleigh.
The authors of the 2012 version of the Briefing Notes for Researchers were Helen Hayes, Sarah Buckland and Maryrose Tarpey, who used to work for the INVOLVE Coordinating Centre. Additional contributors to thank for their involvement in the development of the 2012 version are: Ann Louise Caress, Alison Ford, Lesley Roberts, Carer, Kati Turner, Derek Ward, Tracey Williamson, Sarah Howlett, Lucy Simons, Philippa Yeeles, Gill Wren, Paula Davis, Sandra Paget, Doreen Tembo, Christine Vial.