Guide for researchers involved in NHS research especially those applying or thinking of applying for NHS research funding. Also, for others involved or interested in the process, including research managers, public contributors and the wider public. The guide is split into two sections.

Section one: **Points to think about.**
Section two: **Additional explanatory notes.**
Highlighted text boxes: **Tasks/topics public/academic teams may want**

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Contents

Section one: Points to think about

Preliminary stage: preparing for public contributor involvement in research

Initial things to think about:

1. **finding public contributors** to inform the development of an area of research and making sure that the public contributors chosen are as close as possible in situation and condition to the people the research is about. Whilst we use the term 'public contributor' throughout, we mean this to include actual patients, service users, carers, potential users of services and the wider public. For example, consider involving members of communities or groups that you are interested in such as those from a particular ethnic group or geographic location

2. **finding information on paying public contributors**; levels, effect on tax and benefits, how to pay

3. **considering skills and experiences you need your public contributors** to have and what skills you can build on once part of the team to support their involvement in research

4. **considering what will happen to public contributors at the end of the project**, e.g. other research projects to become involved in, belonging to a public contributors' group.

Writing a simple person specification and role description can help the team to consider any specific health or life experiences, attributes or knowledge that a project may need a public contributor to have, also the key research areas they may contribute to.

Consider equality and diversity, health inequalities when thinking about any requirements and who you're targeting, this will help you plan how best to reach potential public contributors and things that may be useful to put in place to support them to take part.

Stage one: Identifying and prioritising research topics

Involving public contributors at this stage will help to:

1. identify topics for research of concern/importance to patients, service users, carers and relatives

2. balance professional views in topic selection

3. ensure topics are clearly focused on the needs of patients and service users

4. encourage research that is relevant to practice and more likely to be implemented

5. foster best use of available research monies

6. identify more critical topics amongst other important topics.

> **Be clear about what elements public contributors can contribute to and to what extent they can influence. In multi-stakeholder meetings, discussing and ranking priorities can help identify the different perspectives/challenges for all members and highlight areas for further discussion. It also gives everyone the same role in the meeting, whether professional or public member. Think about sharing responsibility, could public contributors take the role of co-chair or co-minute taker?**

Stage two: Commissioning

Involving public contributors at this stage will help to:

1. inform programmes and calls for research

2. ensure funding is allocated to topics of concern to patients, service users, carers and relatives

3. comment on the quality of public involvement in research grant applications.

> **Research teams may wish to involve a public co-applicant on research applications. Public contributor Co-applicants should be involved from an early stage and have the opportunity to substantially contribute to discussions and planning of the research.**

Stage three: Design

Involving public contributors at this stage will help to:

1. ensure the right questions are asked in the right way to get meaningful answers.
2. ensure methodologies are deemed appropriate by public contributors e.g. fit for purpose, ethically sound
3. ensure sampling and recruitment approaches for participants are realistic/workable
4. encourage selection of methods that will be received well by participants
5. inform design, content and format of tools to make them user friendly e.g. questionnaire structure, interview guides, info sheets
6. avoid assumptions about the population being researched e.g. older people don't have sex, drug users don't want help
7. build in opportunities for public contributor input in analysis plans e.g. means of analysis, validation of emerging findings
8. identify meaningful opportunities for public contributors to be involved in research roles e.g. advisors, reference group, co-researchers
9. ensure mechanisms to support, reward and recognise public contributors are appropriate and in-built.

> **Once a public contributor is in place, you can revise the role description together to incorporate the public contributors specific experience, interests and skills. Working through the research plan together, it may highlight opportunities for their involvement at stages you hadn't thought about.**

Stage four: Management of research projects

Involving public contributors at this stage will help to:

1. build in mechanisms to ensure the user voice is present and heard e.g. sufficient numbers of public contributors, effective meeting Chair
2. anticipate and identify strategies to mitigate power imbalances when public contributors join research teams for advisory/steering meetings and other elements of study management
3. consider what training might be relevant and needed for public contributors
4. ensure structures and processes are inbuilt for appropriate involvement e.g. advisory groups, reference groups
5. challenge and question any aspect of the research conduct e.g. finances, ethical conduct
6. inform project decisions e.g. recruitment of researchers
7. ensure build in effective support mechanisms e.g. venues, payment for carers, communication methods.

> **Work with your public contributor to map out the information flow within and governance of a project. This should help identify information that the public contributor may need access to and tasks which they could play an active role in.**

Stage five: Ethics

Involving public contributors at this stage will help to:

1. comply with research governance and ethics approvals requirements e.g. Integrated Research Application System (IRAS)
2. ensure study information is user friendly and informative
3. bring a broader perspective about what is ethically acceptable.

Stage six: Undertaking research

How public contributors can be involved in this stage:

1. to explore potential roles for public contributors in the undertaking of research e.g. co-researchers, advisors, critical friend, critical readers
2. to carry out substantive roles e.g. user-led and user-controlled research
3. to explore intermittent or ongoing involvement opportunities e.g. design only, all stages, step-on step-off
4. to identify training needs for both public contributors and professional researchers.

Meet to map public contributor skills to help identify what skills they'd like to develop and where the team may need to provide training. It can be useful to map training needs of other team members too in terms of public involvement.

Stage seven: Analysing and interpreting

Involving public contributors at this stage will help to:

1. add rigour and insight to analysis
2. validate emerging and final findings
3. identify gaps in the data and questions to fill these
4. inform study recommendations so that they are realistic and meaningful
5. identify topics for future research.

Stage eight: Dissemination

Involving public contributors at this stage will help to:

1. ensure the findings are communicated to all appropriate audiences using appropriate means including presentations to local communities, newsletters, popular press, blogs etc. as well as peer reviewed journals, conferences
2. ensure accessibility of outputs e.g. written reports, lay summaries, presentations
3. explore opportunities for involvement in dissemination e.g. presenters, co-presenters, co-authors.

> **Public contributors may be well placed to advise on the most suitable communication methods and routes to reach certain groups. Involve public contributors in planning communications and dissemination.**

Stage nine: Implementation of research findings

Involving public contributors at this stage will help to:

1. increase the likelihood of uptake of research findings
2. add to the validity and resonance of findings
3. may identify networks/contacts for implementation opportunities.

Stage 10: Monitoring and evaluation of the research

Involving public contributors at this stage will help to:

1. ensure the research stays focused e.g. keeping to original objectives.
2. monitor use of resources
3. anticipate and troubleshoot problems that arise
4. inform evaluation of the public involvement and build evaluation into the study
5. inform actions based on evaluation findings to strengthen study.

Section two: Explanatory notes

Preliminary Stage

Identifying public contributors for involvement

This might take time. Consider why and how you would like to involve people in your research. Seek one or two public contributors who you can access easily that have insight into the topic e.g. a patient, relative or neighbour of yours. Locate and approach existing groups e.g. Stroke Association, local stroke groups, Speakeasy and seek their help. Be aware some may charge for access to members for research. Work with a contact e.g. a practitioner who has access to the population you are interested in. Work with public contributors to locate others, especially if difficult to locate, e.g. by adverts in places that will reach your intended audience, word of mouth and association. Provide information for public contributors on the opportunities for involvement and what skills and experience you are looking for. Use plain language in all communications.

> **Recruiting two public contributors to a role can offer peer support in contributing to tasks and meetings. There's less pressure on a single individual and any time 'off' can be covered with little disruption. Pairing a more and less experienced public contributors together helps capacity building. It also gives the team a 'fresh' view alongside a post holder more familiar with the research process. Two contributors of course also bring twice the experience and expertise.**

Payment

The minimum wage rate applies to recognition payments for public contributors. Organisational processes will need to be followed when making payments, which may mean paying monthly and in arrears. Payments received may also be liable for tax. Making and receiving payments can be a complex issue especially when people are in receipt of welfare benefits or tax credits. In these cases, the person should notify the Jobcentre Plus their intention to take up involvement activities and seek advice on how any payments, whether for their time or reimbursement of expenses, may affect their benefits.

There is information on payment on the NIHR website. The NIHR has produced guidance on rates of payment and reimbursement for involvement activities.

Additionally, the NIHR has produced guidance for members of the public.

> **Public contributors should be informed what payment is available for each piece of work at the point the opportunity is offered to them. The contributor can then choose whether to accept the opportunity with all the information about the role and payment.**
>
> **It can take time to set public contributors up on the local payment systems so check the process early. Once an activity has taken place and payments are submitted, ensure the public contributor knows when to expect payment and has a contact to follow up with in case of delays.**

Ending the project

Be aware at the outset of the need to seek/create opportunities for public contributors to go on to other activities beyond the lifetime of the project, which may or may not be research, should they wish. Especially after a long project, strong relationships and friendships may have formed, public contributors have invested time and energy and so a staged and/or supported withdrawal needs planning. Consider a final event, celebration or debriefing and also ask public contributors about this issue. Seek local and national opportunities for further involvement in research e.g. locally through your own department/centre/research contacts; regionally via NIHR RDS and nationally at '[People in Research](#)'.

> **Involve public contributors in discussing their motivations for being involved and planning what support they'd like from the team. This is a two-way relationship and they may like to build their skills, CV, networks or knowledge. Work alongside public contributors to achieve their aims throughout, which can form part of any 'exit plan' to support them at project close.**

Evaluating involvement

Plan ways of evaluating the user involvement within your project, does it work, in what circumstances, how do you know? Find ways to share your learning e.g. presentations, a section in your final report, share with organisations such as NIHR Centre for Engagement and Dissemination who have an interest in developing the evidence base for public involvement.

> **Involve public contributors throughout in evaluating their experience of being involved in the research.**

Stage one: Identifying and prioritising research topics

Invite public contributors and other stakeholders e.g. carers, professionals (PCT managers, practitioners, social care managers etc.) to a forum to compare and agree priorities for research. Public contributors may have very different ideas of priorities from researchers whilst funders may also take a different view. Make venues and arrangements suitable for the audience. Consider time of day, duration, access, diet/refreshments, breaks, expenses, carer's needs, seating, acoustics, audio-visual, toilets, parking etc. Plan support mechanisms e.g. buddy system, mentoring, large print documents at least a week prior, some means of follow up/feedback after the event etc. Be aware that people will be from different backgrounds and have varying levels of confidence, understanding, and experience of working in groups in this way etc. Involvement at this stage may be about agreeing what is the most relevant research question. Be aware that whilst a question may be important it may not be the most critical issue for public contributors hence the need for discussion. Consider and be clear about how the decision-making process will work.

Stage two: Commissioning

[Public involvement guidance](#) has been developed by NIHR.

This includes practical guidance for researchers, research commissioners and members of the public on public involvement in research grant applications, peer review of research proposals and on commissioning boards. Guidelines are also available for researchers on public involvement in research grant applications.

Stage three: Design

Informally engage with one or two people with insight or lived experience for initial ideas. Decide what degree of involvement you are looking for according to what activities you expecting public contributors to be involved in. Try to maximise opportunities for involvement within confines presented by ethics committee requirements, funding and time available. Design your systems for gaining that involvement more formally e.g. exploratory discussion or event, advisory group, reference group, research methods training etc. Employ approaches that help public contributors to express their ideas and enable them to be listened to. Identify public contributors' training and support needs and respond to these fully as individuals or groups. Don't underestimate the challenge of these activities and build in time and funding for them in your bid. Seek advice or input from others experienced at training public contributors to be involved in research. Plan where to access public contributors, see 'Explanatory Notes 'Preliminary Stage: Identifying public contributors for involvement, and establish what is required for recognition payments and expenses, including mechanisms for these permitted by your organisation. Aim for a minimum of two public contributors on an advisory group or similar and consider more for peer support, in case public contributors leave and for variety of views.

Stage four: Management of research projects

Ensure public contributor views are gained and listened to. For example, agree ways of working with the public contributor and wider team to ensure it is democratic, inclusive e.g. how to ask a question/raise a point at a meeting, how to feed back on a document. Establish means of building a rapport and good working relationship with public contributors. Identify a Public Involvement lead in the research team who will coordinate this element of the study and/or appoint co or sole public contributor lead. A buddy to prepare public contributors prior to meetings may help. Identify and address any training needs to help public contributors to make a contribution to project management.

Stage five: Ethics

Involve public contributors in development of study tools e.g. participant information sheets and consent procedures. Involve public contributors in the ethics application processes. See guidelines for [Integrated Research Application System](#) (IRAS).

As well as IRAS, approvals are required from Research & Development departments and there are other regulatory requirements especially for trials of medicines and medical devices.

Approval is only required when people are to have direct contact with the research participants. If access is only to anonymised data NHS ethical approval will not be required.

Stage six: Undertaking research

Establish public contributors' previous work roles, life experiences etc from which they may have transferable skills and knowledge. Public contributors may want to develop new skills rather than use existing ones. Discuss what opportunities are available and discuss levels and types of possible involvement. Train and support public contributors for roles and activities they are to undertake. Appreciate that public contributors may not know at the outset what kind of involvement they would like. Also, that public contributors may not want to be involved in all available stages of the research process and may want to contribute fully or in part to certain activities e.g. analysis of data. Prepare the study environment for such involvement including preparing the research team for public contributor involvement.

Stage seven: Analysing and interpreting

Some public contributors may wish an active hands-on approach to analysis and interpretation. If they can be suitably trained and supported to do so and if ethical bodies have approved their involvement e.g. access to data. Steps to make data more accessible may need to be taken e.g. asking their views on poignant or problematic chunks of data or inviting them to verify emerging findings identified by the research team. When verifying

findings or identifying gaps or new perspectives in analyses, workshop type events often work well or individual work at home to be later shared as a group. Discuss and agree study recommendations with public contributors and areas for further research.

Stage eight: Dissemination

Plan early for publicity and dissemination of project activities and findings. Build costing for public contributors to be involved in dissemination into your research proposal. Identify public contributors' preferences for involvement in dissemination and train and support accordingly e.g. presentation skills, poster development. Find out where public contributors would like findings to be disseminated and the best means e.g. informal presentations at community groups. Value their suggestions as much as dissemination in professional journals especially after project end when researchers' commitment may shift to their next study. Take on board user views on what constitutes a plain language report and don't limit their input to summary reports only. Remember that plain language makes your report more accessible to professionals outside your specialism too.

Stage nine: Implementation of research findings

Appreciate that public contributors may have an influence on those that can act upon findings, as their involvement can strengthen the perceived value of a study. Be aware of the added value of public contributor voices in study reports and presentations etc and build these in e.g. quotes, video clips, co-presenting.

Stage 10: Monitoring and evaluation of the research

Public contributors can often ask the awkward questions and challenge study direction and progress and should be supported to do so by e.g. the study public involvement lead, a research buddy, or project champion. Public contributors can be involved in planning for any evaluation, of their involvement, to make plans more meaningful and workable. They can suggest actions to be taken in the light of evaluation feedback to further strengthen the public involvement approach being

taken.