INVOLVEMENT TYPES

Identifying and prioritising

Research teams work collaboratively with patients, service users, carers and/or health and care practitioners to ensure research priorities are aligned with those people who have a personal or professional interest in the subject, and agree on research questions together.

Example: While working on a project with a group of women who had experienced domestic abuse, researchers discussed a number of ideas about what to research next. The women said research on how GPs could better identify and support children affected by domestic violence was a high priority for them. This influenced the researchers' decision about which project to work on next.

Commissioning

This is where members of the public are involved 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. 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

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 participants in the study. 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. Here are a couple of examples.

Example: Researchers are working on the design of an App that will enable intuitive reporting of pain. The involvement of people with arthritis or long-term musculoskeletal conditions will help researchers by talking about their pain and how they deal with it.

Example: Researchers are developing a tool to identify the concerns people have after a stroke. The involvement of people who have had a stroke or are carers of someone with a stroke, will help researchers with the design of the tool

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.

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

Example: A researcher assessing the accommodation needs of Gypsy and Irish Traveller people worked with members of the community to design and carry out the research. She recruited members of the community to interview people about their needs. The Irish Traveller people who were involved advised her that it would be unacceptable for a male interviewer to interview a woman. The researcher therefore made sure that she paired up female interviewers with women in the study, to avoid causing any offence or upset.

Undertaking

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

Example: In a project assessing the problem of drug use in prisons, the researchers invited an ex-offender to work on their team. He helped to recruit prison inmates to take part in focus groups. He helped run the groups and to make sense of the findings. He identified issues that the researchers might otherwise have missed.

Disseminating

Dissemination involves communicating the findings of a research project to a wide range of people who might find it useful. This can be done through producing reports, publishing articles in journals or newsletters, issuing press releases or giving talks at conferences.

Example: A patient who was involved in a research project about secondary breast cancer helped to present the results at a conference. Having the patient speak seemed to 'electrify the audience'. It can be extremely powerful to hear directly from the people who will be affected by

the research. They have a perspective that researchers don't always hear, and they can give a realistic view on whether the results are genuinely useful.

Implementing

This is where members of the public can help implement research findings, putting them into practice. For example, members of the public might be able to establish influential relationships with key agencies and policy makers.

Example: A group of older people, who worked with researchers on a project about how to prevent falls amongst older people, presented the results to senior managers from their local authority. A couple of the older people were then asked to join a working group within the local authority, to look at how to apply the findings to make practical changes in local care homes and day centres.

Evaluating impact

This is where members of the public can help evaluate the impact of the research project and its findings, from the public perspective.
Example: Researchers developed a trial which suggested new treatment for newly diagnosed lung cancer. Public contributors were recruited to examine the results of the trial and to help the researchers evaluate the impact of the trial and therefore, of the suggested new treatment.

Reviewing

If members of the public are required to study and examine documents connected with a research study and then provide feedback then the involvement type should be described as 'reviewing'. Here are some examples of actions where the involvement type should be described as 'reviewing':

- reading a research proposal and giving feedback
- examining patient information on patients included in a trial and feeding back comments
- reading study materials and providing feedback to the researcher
- examining the language of a questionnaire and feeding back to the author as instructed