

Public involvement/ participation/ engagement in research

By Maryrose Tarpey

INVOLVE advisory Group members met for a two-day symposium at the end of September and one of the many discussions we had was about the confusion language can create, for example what we mean when we use the terms 'public' 'involvement', 'engagement' and 'participation' in research and how others may have a different understanding for the same words. This was also raised in our recent webinar on public involvement in social care research. So quoting from our Briefing notes for researchers (Briefing note two – www.invo.org.uk/posttypesresource/what-is-public-involvement-in-research/) we thought we would reprint what INVOLVE means when we say:

“Public involvement in research”

We define 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’** INVOLVE 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, such as engagement and participation. When INVOLVE uses 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
- involvement in identifying research priorities
- 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.

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.