

# WHAT DOES INVOLVEMENT MEAN?



Involving patients, carers, and advocates in research is about doing research **with** the public rather than **to** or **about** the public. It is a way of allowing lay representatives to influence the research agenda. If research reflects the needs and views of the end user, it is more likely to produce results that can be used to improve practice in health and social care. Public involvement means not only monitoring *what* is done during the life of the research project, but the way in which it is done.

Involvement can be:

**CONSULTATIVE:** This is where researchers consult members of the public to find out their views and then try to incorporate these views into the research.

**COLLABORATIVE:** This involves active, on-going partnerships between researchers and members of the public e.g. through collaboration in an advisory group, or on a steering committee.

**USER CONTROLLED:** Here, members of the public take the lead in directing the research and driving it forward, making key decisions about the project in the process.

An advisory group can have different levels of involvement in a project, depending on the nature of the research project, and the level of commitment group members want to make in terms of time. For example, it is possible that members could help to co-facilitate focus groups as part of the research, or help to recruit people to the project through their own networks.

Ultimately, involvement is about meaningful communication and information exchange between researchers and the advisory group. It is about building up lasting relationships for the duration of the research project and giving people the opportunity to contribute and to have those contributions valued and incorporated into the research study.

"I would like to see any skills that people have in the group being used more. You know, if people have got skills sitting in front of the computer inputting data, I know you'd have to sign forms and so on, but I for one would be quite happy to do that. Or setting up spread sheets or filming stuff you know. Because at one time we were professional people and we had important jobs some of us (or jobs we like to think were important!) and we can bring all that."

**Jacqui Gath**, member of the advisory group