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## Getting started with involving the public in public health research: An information sheet for researchers.

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### Why this information sheet?

How public health topics are identified and researched, may affect a very wide range of stakeholders. However, the public, the 'end users' of public health research, have a key interest, and may have important things to say about the prioritisation, planning, managing, undertaking, analysing and dissemination of research. Their perspectives may be new to the researcher, because they arise from outside the research 'community'. Involving the public sometimes means that research will take longer, but it is more likely the research will be relevant to the public once it is complete.

The reasons for involving the public in NHS, public health and social care research are now well established. The INVOLVE publication '**Involving the public in NHS, public health and social care research: Briefing notes for researchers**' Hanley et al (2004) INVOLVE, sets out many of the principles and practicalities of involving the public in research. This paper focuses on some issues that are particularly relevant to public health research

There are numerous voluntary, self-help, and campaign groups with public health concerns, covering a very wide range of public health issues. These might be the researchers first port of call for involvement, bearing in mind that in turn these groups will have their own links and networks in the area of interest. What researchers should think about is the need to get a range of public perspectives, rather than relying on the involvement of one group alone.

However, sometimes it is not clear exactly who to involve and how. The reason for this may be that the research might be very generic, or that the research is targeted in an area of study where there is not necessarily an obvious 'user group'.

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### Who should I involve?

People who might get involved in public health research might roughly come into four categories:

- People who have been affected by a health hazard.
- People who have particular concerns about an issue or believe they are at risk or harm.
- People who have a potential interest or concern because the research is of relevance to them.
- People who may initially be unaware of public health issues, but who, given sufficient information, might contribute helpful perspectives as members of the public.

Which category of people researchers might involve depends upon the subject being researched. In some cases it might be all four.

Public health research is often focussed on issues where some members of the public have experience and therefore expertise. For example, in research on the effects of pesticides, there are members of the public who have specific experience, and/or concerns. The Pesticide Action Network is an example of a group one might approach. This group has access to people who believe they have experienced a health effect as a result of pesticide use or believe they are at risk.

Some people may not know that they could have an active interest in a topic being researched because they do not have enough information. For example, young people, given enough information presented accessibly and in interesting ways, may begin to take an interest in some proposed research into sexual health, and develop views as to what research should be done and how it might be conducted.

Other research may affect a very broad population of people, for example, research into climate change or air quality. With other issues, members of the public may be unfamiliar with the relevance of topics concerning the researcher, perhaps because the issues are not reported in the media. The effects of crime on health might be an example. Given sufficient information, members of the public may well feel they have useful views about what, and how such research might be conducted.

Some members of the public may want to be involved in research as a matter of citizenship. They may be motivated because of altruism, a concern about how public money is spent, or because they are beneficiaries of public health work in general. They may also simply be interested in learning more.

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### **Where do I find the right people?**

There are a number of potential routes and methods. For example via:

- advertising in local libraries, community, sports, and health centres etc.
- advertising in papers and newsletters
- networking through voluntary, religious, or educational networks in the community
- networking through online health networks
- local authority and civic networks
- promotional events i.e. an open evening, or at a farmers market.

It is important to be inclusive in your approach. Think about social diversity. Consider age, ethnic and social background, gender, sexuality, disability, geography etc. Who might you be leaving out?

Information pathways are critical if members of the public are to get involved in public health research. The connection between the daily life of an individual and how public health research generates evidence that in turn influences public health policy, that in turn impacts on daily life, is not common knowledge. Researchers need to be ready to provide clear understandable information about the issue being researched, why the research is taking place, how the research could affect public health policy and practice, and what the potential impacts on the public and on public health are.