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Public Involvement and Engagement in Public Health Research

Guidance for Researchers

Kathryn Ashton

Policy, Research and International Development Directorate

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Contents

- Introduction
- Key definitions
- Public involvement
 - Benefits of public involvement in research
 - Public involvement and grant funding
 - Why do the public want to be involved in research?
 - Steps to involving the public in public health research
- Public engagement
 - Benefits of public engagement in research
 - How to effectively engage with the public
- Tools and resources



Introduction

Members of the public play a significant role in research across Wales, and involvement is increasing across NHS, academic and other types of research.

It is important both public involvement and engagement is considered from the beginning of a research project to the end.

Emphasising the significance of public involvement and engagement should lead to the opportunity to access a wider range of research funding, improve the quality of public health research and maximise the potential impact of research outputs.

This guidance will be useful for all researchers to help understand the importance of public involvement and engagement in research, and provides information on how best to involve and engage members of the public. This will help researchers to plan, resource and support public involvement and engagement within public health research in Wales.

Key definitions

The **public** can be classified as one or more of the following:

- Patients
- Members of the public
- Potential patients
- Service users
- Carers
- Adults, children, young people
- People with current or past conditions

Public involvement can be defined as research where members of the public are actively involved in stages of the research process:

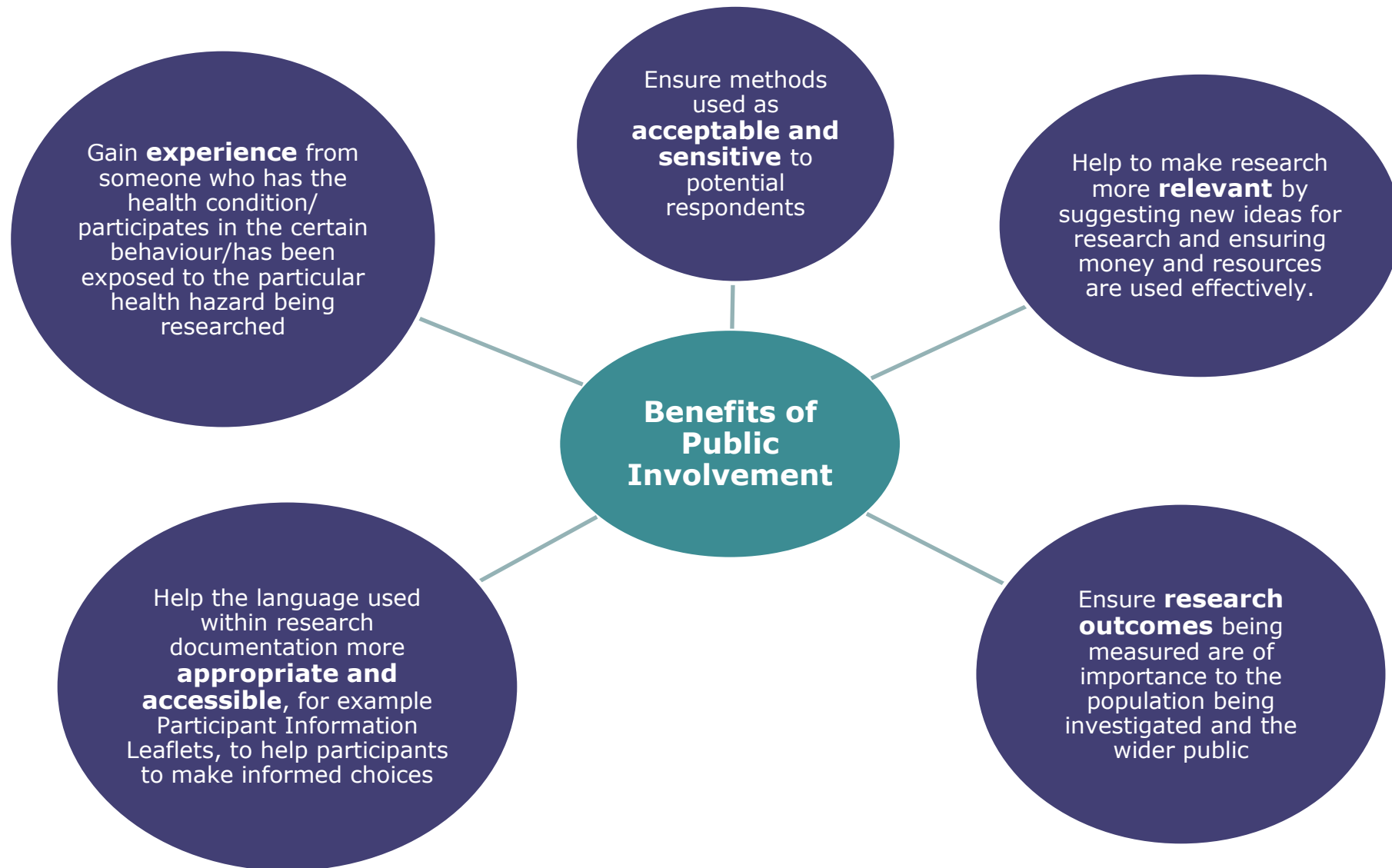
- involvement in the design of the research and research questions
- sitting on a project steering group
- inputting into the development of participant information
- peer reviewing project proposal in grant applications.

Public engagement includes when information and knowledge about research is provided and disseminated to members of the public. Effective public engagement is a two-way conversation, with researchers also listening to and learning from members of the public.

Section A: Public Involvement



Benefits of public involvement in research



Public involvement and grant funding

Grant funders ask applicants to demonstrate public involvement within funding applications, for which a budget can be specified to cover any anticipated costs, and it is also reviewed as part of the NHS research permissions processes and NHS Ethical approval processes.

Example : Research for Patient and Public Benefit (RfPPB)

The RfPPB is an annual funding scheme run by Health and Care Research Wales. Within the funding application, applicants are specifically asked to provide details of:

- the aims of active involvement in this project
- a description of the patients, carers or members of the public to be involved.
- a description of the methods of involvement.

More information can be found on the [Health and Care Research Wales](#) website.



Why do the public want to be involved in research?

Members of the public get involved and engage with public health research for a variety of personal and social reasons:

- Personal past and present experiences of health conditions or behaviours and health services
- Desire to influence services
- Gives individuals a voice
- Provides the opportunity to contribute to work which can improve the health of the wider population
- Increasing personal development skills and confidence levels.
- Personal interest in research topic.



<http://www.invo.org.uk/posttypepublication/why-people-get-involved-in-health-and-social-care-research/>

Public Involvement Standards Development

- Health and Care Research Wales are currently working with the National Institute for Health Research (NIHR) to develop national **Public Involvement Standards**
- <https://sites.google.com/nih.ac.uk/pi-standards/home>
- The aim of the project is to improve the quality and consistency of public involvement in research through the development and introduction of national standards.

Find out more in:

- [The project](#): The [background](#), our [work in progress](#) and [next steps](#).
- [Standards Network](#): Sign up if you would like to receive project updates and be involved in developing the standards.
- [Resources](#): A library of resources that underpin our work.
- [About us](#): Meet the Partnership members.

Steps to involving the public in public health research

It is integral to the success of the research that the public are involved as early as possible in the research design process. This will give individuals a sense of ownership in the research and provide more confidence to becoming more actively involved in the research leading to better results with more impact.

Step 1: Who to involve

Step 2: Where to find the right people

Step 3: Resources required

Step 4: Stages of the research cycle

Step 1: Who to involve

Who to involve will be dependent on the research topic. Members of the public may fall roughly into the following categories:

- Individuals who have been exposed to or affected by a health hazard
- Individuals who have an interest in a public health concern or issue because they are at direct risk or harm
- Individuals who may be unaware of public health issues, but may be able to contribute useful independent perspectives
- Those who form part of a user group for research into developing service

Be clear about what your expectations are and what skills are required.

Good practice is to have two public representatives involved in your research.

For clarity, one potential option would be to write a role description:

https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf

Step 2: Where to find the right people

There are a number of potential options for finding the right people to be involved in a research project:

- Linking with voluntary, self-help and campaign groups with public health concerns
- Existing networks such as [Involving People Network](#) which is supported by the Health and Care Research Wales Public Involvement and Engagement team
- Panel groups such as [Healthwise Wales](#)
- The [Research Design and Conduct Service](#)
- Advertising publically via a number of methods, for example local libraries, leisure centres, General Practitioner surgeries, social media, online groups and community centres.

It is important that the researcher considers diversity and how to not socially exclude potential participants when recruiting members of the public.



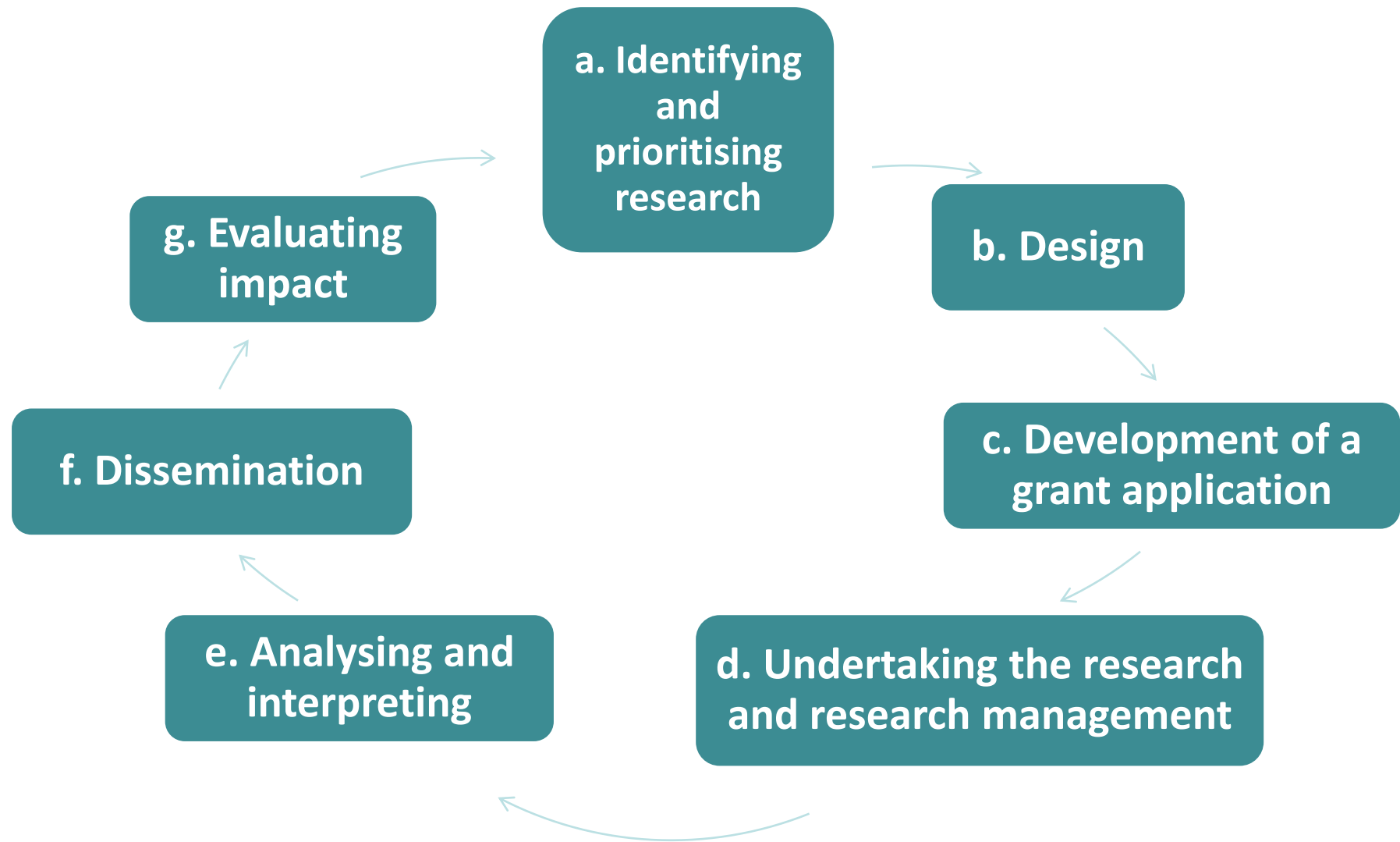
Step 3: Resources required



- Public involvement and engagement needs to be adequately costed into the research proposal. If not funders may question why not,
- This can include travel and subsistence costs, additional time to run whatever public involvement is being planned and administrative costs.
- The majority of funders will include public involvement and engagement costs within funding bids. This needs to be planned at the onset as can be difficult to achieve retrospectively.

INVOLVE online cost calculator: <http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>

Step 4: Stages of the research cycle



a. Identifying and prioritising research

The public can be involved by:

- Helping to inform research priorities
- Used for consultation on potential topics
- Help to develop research priorities.

This can be achieved by:

- Discussions with existing public groups through the [Involving People network](#).
- Holding a specific event or focus group to discuss initial ideas or priorities
- Surveys and interviews with members of the public.

You can find out whether discussions on your research area have previously been held by others by contacting the [Public Health Wales Research and Development Office](#) or the [Involving People network](#).

Public involvement which needs to be resourced before a funding application has been submitted could potentially be funded by the [Public Health Wales Research and Development Office](#).

b. Design

The public can inform the design of the research by helping to ensure what the researcher is planning is relevant.

This can be achieved via the following methods:

- Helping to clarify the research questions
- Ensuring methods selected are appropriate for the desired participants
- Reviewing any participant facing documentation for clarity and checking whether it is accessible for the target audience
- Assist in the development of the recruitment strategy.

c. Development of a grant application

Public involvement can help to build the relevance of the research and also strengthen the quality and ethics.

The public can help to:

- Demonstrate the importance of the topic to funders and commissioners
- Review the application before submission and suggest potential areas for change
- Consider from their perspective whether the application would encourage potential respondents to participate in the research
- Advise on areas where there may be particular ethical considerations
- Advise on appropriateness of the lay summary within the application
- Ensure that the recruitment process would be feasible from their perspective.

Members of the public could also potentially be included as co-applicants on the grant application.

d. Undertaking the research and management of the research

After funding for your research has been obtained, it is important that the public involvement in your research isn't dropped and is maintained throughout the duration of the project.

Members of the public can be involved in the management of the research through involvement in the steering group to both manage and monitor the research.

They can also be involved in undertaking the research by assisting in the running of focus groups, interviews or administering surveys , reviewing documentary evidence, or being Citizen Scientists, depending on your research design.

e. Analysing and interpreting

The public may be able to assist the research team when developing themes for analysing data and may be able to explore the data and provide their perspective as a lay public member of the research team. This will be dependent on the previous experience on the members of public involved.



f. Dissemination

Previous experience has found that involving the public solely at the dissemination stage of the research process is less successful than if they had been included at earlier stages in the process.

The public could be involved in the following ways:

- Contributing to discussions on the different avenues for dissemination of the research findings
- Jointly presenting the findings to different audiences
- Write outputs and lay summaries of the research outputs for members of the public
- Help to disseminate the results of the research, particularly to hard-to-reach groups who may be reluctant to engage.

g. Evaluating impact

Members of the public can be involved in both evaluating the impact of the research, but also evaluating the impact of the public involvement in the research.

Elements to consider when evaluating public involvement in research are as follows:

- Assess whether the aims and objectives of the public involvement have been achieved
- Understand what contribution the public involvement has made
- Share the learning from the evaluation
- Celebrate success
- Generate evidence to improve planning for future public involvement.

Useful links for evaluating impact

- Barber, R., Beresford, P., Cooper, C., and Faulkner, A. (2011). Evaluating the impact of service user involvement on research: a prospective study. *International Journal of Consumer Studies*, 35 (6), 609-615.
- Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C. and Suleman, R. (2012). Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations*, 17 (5), 637-650.
- Morrow, E., Ross, F., Grocott, P. and Bennett, J. (2010). A model and measure for quality service user involvement in health research. *International Journal of Consumer Studies*, 34 (5), 532-539.
- Wright, D., Foster, C., Amir, Z., Elliott, J., and Wilson, R. (2010). Critical appraisal guidelines for assessing the quality and impact of user involvement in research. *Health Expectations*, 13 (4), 359-68.

Section B: Public Engagement



Benefits of public engagement in research

Public engagement in research has the following benefits:

- Opens up the opportunity for the public to get involved in research.
- Helps to enhance the research through new collaborations and partnerships.
- Raises aspirations in research by stimulating individuals to be curious about the world of research and inspiring the next generation of researchers.
- Helps to improve the quality and impact of research.
- Helps to build trust and also help researchers think about the social and ethical implications of their research.

Examples of public engagement are as follows:

- Opens discussions and debates on research
- Open days at research centres
- Raising awareness of research via tv, radio, social media and websites
- Dissemination to research participants on the findings of the study.

How to effectively engage with the public

- As a starting point the [The Engaging Researcher](#) provides a very useful introduction to engaging the public with your research.
- [The National Co-ordinating Centre for Public Engagement](#) website contains a wealth of information including a practical ‘How to do it’ toolkit.
- Be clear about why you are engaging with the public:
 - Are you inspiring individuals to take an interest in your research topic?
 - Are you disseminating the results of your research to a wide range of individuals?
 - Are you consulting with the public on your research topic?
 - Are you encouraging people to help you to do your research?
- Think about your desired audience – it is important to think about different groups, build a profile of your target group and consider barriers and learning styles.

How to effectively engage with the public

Similar to public involvement:

- Allow enough time to plan public engagement thoroughly.
- Remember to build evaluation in at the start of the public engagement and share learning with others.
- Ensure enough resource is allocated to public engagement when you develop the funding application.
- Measure the impact of the public engagement work.

Section C: Tools and Resources



Tools and resources

- **Involving People Network** – supported by the Health and Care Research Wales Public Involvement and Engagement team, the network brings together members of the public from across Wales who are interested in working with researchers to improve treatments and care and provides training:
<https://www.healthandcareresearch.gov.wales/involving-the-public-in-your-research/>
- **Healthwise Wales** – unique opportunity for members of the public to be part of shaping the health and well-being of future generations in Wales, and help the NHS in Wales to plan for the future :
<https://www.healthwisewales.gov.wales/homepage/>
- **Research Design and Conduct Service (RDCS)** - aim to support staff working in social care and NHS in developing research projects for public benefit as well as improving the health and well-being of the people of Wales:
<https://www.healthandcareresearch.gov.wales/research-design-and-conduct-service/>

Tools and resources

- **National Centre for Population and Public Health Research:**
<http://ncphwr.publichealthnetwork.cymru/en/news/ncphwr-public-engagement-officer-recruited/>
- **National Institute for Health Research (NIHR) INVOLVE** – supports active involvement in NHS, public health and social care research:
<http://www.invo.org.uk/>
- **East Midlands Academic Health Science Network (EMAHSN)** - produced a series of how to guides for public involvement:
<http://emahsn.org.uk/useful-document-and-links/how-to-guidance>
- **People in Research** is a website hosted by INVOLVE and connects the public to researchers:
<https://www.peopleinresearch.org/>

Tools and resources

- **Research Design Services' PPI Handbook for Researchers:**
<http://www.rds.nihr.ac.uk/wp-content/uploads/RDS-PPI-Handbook-2014-v8-FINAL.pdf>
- **The Wellcome Trust** provides information, activities, training/support and case studies on engagement with research:
<http://www.wellcome.ac.uk/Funding/Public-engagement/Engagement-with-your-research/index.htm>
- **InvoDIRECT** – an online directory of networks, groups and organisations that support active involvement in NHS, public health and social care research:
<http://www.invo.org.uk/communities/invodirect/>

Tools and resources – video links

Public Involvement in Research. This film, aimed at researchers, highlights some of the many benefits of involving the public in research. It describes ways in which you can involve the public in the research cycle and effectively signposts researchers to the support, guidance and resources available in Wales:

<https://www.youtube.com/watch?v=0irTNhHYZRc&t=1s>

Why get involved in Research? This film, aimed at members of the public, highlights why research is important. It provides several options of how you can use your voice to make a difference to health and social care research. Finally, it provides contact information on how members of the public can get involved in research in Wales: <https://www.youtube.com/watch?v=iTlxuGYhInc>

These films were produced by Cardiff University School of Medicine (<http://www.cardiff.ac.uk/medicine>) supported by an award from the Wellcome Trust ISSF Fund.