

Introduction to Public Involvement in Healthcare Research

There are many different kinds of health and social care research taking place in the UK and worldwide. Broadly, health research aims to find out more about health issues such as causes of ill health or the effects of new treatments. Social care research is about social care needs such as everyday support for disabled people, vulnerable children and older people.

Health and social care research can help to:

- find out what people think about services
- identify health and social inequalities
- evaluate how effective services are
- improve treatments and services
- improve the environment, health and wellbeing of a local population
- identify people at risk of getting ill and help to prevent illness
- identify the best use of resources
- test treatments to make sure they are safe and effective
- ensure services and treatments are relevant to the public

Members of the public (including patients, potential patients, carers and health advocates) are getting involved and fulfilling crucial roles throughout the whole research process. **Public involvement** in research is 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, undertaking interviews with research participants.

You can find out more about people's personal stories and experiences of being involved in research by viewing a series of [videos](#) on Healthtalk.org

INVOLVE has also created a two-minute animation, [This is my story](#), based on the true story of a young man, Tom, who was diagnosed with an illness and through this became involved in research.

Some of the things that patients and members of the public might be asked to do are:

- help **select** research that is important and relevant
- help researchers **design** their projects
- help develop understandable **information sheets** for people taking part in research
- join a research **management or advisory** group
- train to **carry out** some of the research (for example interviews)
- help **interpret** the results of the research
- help make sure the research is reported in **understandable** ways
- help make sure good research is **heard about**.

Some of the ways that members of the public make a difference to health and social care research are by:

- making sure that researchers ask the **right questions** and in a way that the public understand
- keeping the research **on track** so that it stays relevant
- making sure the **people being researched** are approached in the right way
- improving the **quality** of the research by adding another point of view to the design and conduct.

For more information about public involvement, including how you can get involved in Barts Health NHS Trust research, please visit www.bartshealth.nhs.uk/takepart

Below are some resources that you may find useful, if you would like to find out more about healthcare research and how you can get involved.

- 1) The **National Institute for Health Research** (NIHR) has worked with key partners involved in the different elements of NHS research to transform research in the NHS. It has increased the volume of applied health research for the benefit of patients and the public, driven faster translation of basic science discoveries into tangible benefits for patients and the economy and developed and supported the people who conduct and contribute to applied health research. See the link below for more information on how you can get involved: <https://www.nihr.ac.uk/patients-and-public/>
- 2) **INVOLVE** is a national advisory group that supports greater public involvement in NHS, public health and social care research. INVOLVE shares knowledge and learning on public involvement in research: www.invo.org.uk/
- 3) **People in Research** is a website that helps to match people with research opportunities. 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. The term '**public**' includes 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. www.peopleinresearch.org/
- 4) **HealthTalkOnline.org** and **YouthHealthTalk.org** were developed to give patients a forum to share their stories of living with a disease. It aims to provide reassurance that there are other people out there going through the same experiences as you and shares stories from patients who have been involved in research. www.healthtalkonline.org/peoples-experiences/medical-research
- 5) **The UK Clinical Trials Gateway** provides information about clinical research trials running in the UK, and gives you access to a large range of information about these trials. It is designed to enable you to locate and contact trials of interest to you. www.ukctg.nihr.ac.uk/default.aspx
- 6) **The Centre for Public Engagement** team at Queen Mary University of London exists to support QMUL researchers and students to engage individuals and communities outside of academia with their research and teaching, from creating to disseminating knowledge. They offer a suite of support including funding for projects, training, networking opportunities and providing advice and connections. More details about public engagement at QMUL can be found: www.qmul.ac.uk/publicengagement/cpe/index.html
- 7) **The Barts Health Trust Research Engagement and Diffusion team** work with researchers, patients and the public to build stronger partnerships in research development and delivery and encourage greater levels of *engagement*, *participation* and *involvement* in our research amongst patients and local residents. The team provide a wide range of services from advising researchers and supporting the development of grant applications through to running events to raise awareness about the wide range of research conducted within our hospitals.

The team are a central point of contact at for patients and local residents who are interested in participating or getting involved in Barts Health research and regularly send news and information about research events and opportunities for local residents to become involved. All members of the public are welcome to join our mailing list and be kept informed of future events and opportunities to get involved in research, please email patientsinresearch@bartshealth.nhs.uk or alternatively, for more information visit www.bartshealth.nhs.uk/takepart