

Introduction to Public Involvement in Healthcare Research

Health and social care research is carried out in the UK and worldwide, taking many different shapes. The main aim of health research is to ultimately improve human health, by finding out more about health issues such as causes of ill health or the effects of new treatments. Social care research focuses on the social care needs for disabled people, vulnerable children, and older people, by providing everyday support, finding ways to improve people's lives and help them live well.

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



There are many ways members of the public (including patients, potential patients, carers and health advocates) can get involved in health and social care research. **Public Involvement** is an active partnership between patients, carers and members of the public with researchers that influences and shapes research. Examples of public involvement include 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 the Patient and Public Involvement videos on Healthtalk.org.

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

- help select and prioritise 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 help shape research 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 public involvement in healthcare research.

- 1) The Starting Out Guide has been written to help and advise members of the public who are interested in getting involved or have recently become involved in research. The guide outlines key information and principles about getting involved in research, whatever your experience or prior knowledge. www.nihr.ac.uk/documents/starting-out-guide-why-and-how-to-get-involved-in-research/30145
- 2) The **Public Information Pack (PIP)** was developed for patients, carers and members of the public who are interested in getting involved in health or social care research. It aims to answer the questions that people frequently ask when they first get involved in research.

 www.nihr.ac.uk/documents/public-information-pack
- 3) The NIHR UK Standards for Public Involvement are a set of standards designed to improve the quality and consistency of public involvement and health and care research. They provide guidance and reassurance for users working towards achieving their own best practice. sites.google.com/nihr.ac.uk/pi-standards/standards
- 4) The **NIHR Learning for Involvement** website offers both researchers and members of the public who are interested in getting involved in research a range of resources, including a welfare benefits jobcentre letter if you are in receipt of welfare benefits and are considering paid involvement. It also provides an interactive course for new and experienced reviewers of health and social care research. www.learningforinvolvement.org.uk/
- 5) **People in Research** is a website that helps to match people with research opportunities. This may include 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. www.peopleinresearch.org/
- 6) **The Barts Health Trust Research Engagement team** works 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 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 members of our community to become involved. We strive to ensure our research includes people from all the diverse backgrounds within our community. We want to work in partnership with the community to make our research more inclusive and representative. 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.net** or alternatively, for more information visit **www.bartshealth.nhs.uk/takepart**







