

Working with patients and members of the public

Our Vision

We will use transparent processes for working with patients and the public, thus ensuring that translational research in the NIHR Manchester Biomedical Research Centre (BRC) can flourish in an informed and inclusive environment.

Background

Over the past ten years, the process of empowering patients and the public to take an active part in health-related research has been highlighted as an NHS priority. The NIHR, funders of the Manchester BRC, states:

“We want patients and the public to be involved in all stages of research. This covers:

- *Setting research priorities*
- *Helping to decide what the research is setting out to achieve*
- *Choosing the methods used to carry out the research*
- *Recruiting people into research studies*
- *Understanding what the research findings mean for patients and how it can be applied in the health service*
- *Publicising the results”*

We believe that patients and the public should be involved in a variety of ways and at all stages of the BRC’s work. This ranges from information-giving activities and creative ways to stimulate thinking about translational research, to integrating public opinions into the work of the BRC and empowering patients to contribute to decision-making about research in the BRC as an organisation. Through all these approaches, we hope to stimulate an informed research environment, create an atmosphere of mutual trust and confidence between the BRC, patients and members of the public, to contribute ultimately to the highest quality translational research.

Our Objectives

In order to achieve our vision, we will deliver four strategic objectives:

1. We will consult actively, listen to and involve patients and members of the public about their views on translational research and within every research project of the BRC.
2. We will inform, educate and stimulate thinking about the work of the BRC among citizens of today and tomorrow, through methods appropriately targeted at different audiences.
3. We will ensure that patients and members of the public are embedded within BRC decision-making processes, thereby helping to guide the BRC’s future strategic directions.
4. We will place the BRC at the forefront of involving patients and public in research.

1. Engaging and consulting with the public about NIHR Manchester BRC research

To achieve this objective, the BRC will:

- I. Engage and consult a range of public and patient audiences about the work of the BRC, through:
 - a. Exhibition and arts events about BRC activities
 - b. Attitudinal research, surveys and focus groups with patients and members of the public on issues such as research directions and the translation of research into health benefits
 - c. Stimulating debate and polling public opinion through our dialogue and debate events
- II. Active involvement and consultation of patients and publics in individual research projects, by:
 - a. Planning, at the outset, public and patient input to individual research projects
 - b. Sharing good practice on patient and public involvement in research
 - c. Feeding back the results of BRC research to those who have taken part in it
 - d. Supporting patients/members of the public to 'user test' BRC information resources relating to individual research projects
- III. Enabling BRC researchers to work with patient and public audiences in their research, by:
 - a. Supporting researchers to communicate and engage with a range of audiences, and to consult with patients and the public at all stages of research projects
 - b. Providing researchers with training for patient and public engagement
 - c. Facilitating mentoring between researchers who want to learn from each other about working with patients and members of the public

2. Information, education and communication about the work of the NIHR Manchester BRC

To achieve this objective, the BRC will:

- I. Disseminate information about the work of the BRC in clear and accessible formats, by:
 - a. Support production of lay summaries of BRC research projects, for lay review on the BRC website
 - b. Creating objective and concise information leaflets and newsletters
 - c. Reaching as wide an audience as possible, through effective and accurate media coverage
- II. Support schools to learn about the work of the BRC, by:
 - a. Holding regular hands-on workshops, including laboratory-based activities, introducing school students to cutting edge BRC research
 - b. Supporting BRC researchers to engage with post-16 students
 - c. Developing curriculum and continuing professional development resources for teachers, to ensure that teaching practices reflect contemporary biomedical research
 - d. Developing positive links between the BRC and the Manchester Health Academy school in south Manchester

3. Patient partnerships in the NIHR Manchester BRC

To achieve this objective, the BRC will:

- I. Provide opportunities for patients and members of the public to influence BRC research, by:
 - a. Engaging at least one patient partner on every new BRC research project and funding application
 - b. Forming a BRC patient and public forum that could feed into decision making by reviewing lay summaries for BRC-funded pump priming awards, training fellowships etc
 - c. Ensuring public and patient input to the BRC Research Strategy Board
- II. Provide support to patients and members of the public who get involved with the BRC, through:
 - a. Bespoke training courses for patients and members of the public who act as co-investigators, members of the BRC Research Strategy Board or forum members
 - b. Mentoring by another patient, member of the public or BRC researcher
- III. Ensure adequate funding for the BRC programme of Patient and Public Involvement, by:
 - a. Including resources for a programme of working with patients and members of the public in the reapplication for BRC continuation funding to NIHR, so that patients and members of the public are properly remunerated for their contribution to the BRC

4. Placing the NIHR Manchester BRC at the forefront of involving patients and public in research

To achieve this objective, the BRC will:

- I. Contribute to networks for public engagement and patient involvement through:
 - a. Local networks, including: Manchester Beacon for Public Engagement, University of Manchester 'Widening Participation' scheme for young people and NHS Local Involvement Networks (LINKs)
 - b. Regional networks, including: North West Users Research Advisory Group (NWURAG), North West Research Design Service, Local Research Networks and the Manchester Academic Health Science Centre (MAHSC)
 - c. National networks, including: BRC Patient and Public Involvement network; INVOLVE; Clinical Research Networks, such as Medicine for Children Research Network, Gengage and The Wellcome Trust
- II. Lead, share and support best practice on meaningful patient and public involvement in research, by:
 - a. Leading collaborations in order to create an evidence base for public engagement practice
 - b. Ensuring a visible BRC presence at local, national and international patient and public engagement events and conferences

The NIHR Manchester BRC PPI strategy group consists of:

Dr Helen Middleton-Price (<i>Chair</i>)	Director, Nowgen: A Centre for Genetics in Healthcare, part of the NIHR Manchester BRC
Dr Bella Starling	Director of Public Programmes, Nowgen
Professor Jill Clayton-Smith	Genetic Medicine, Research Lead, Saint Mary's Hospital
Berenice Postlethwaite	Patient Partnership Manager, Central Manchester University Hospitals NHS Foundation Trust
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