

## **Public Engagement and Public and Patient Involvement**

### **NIHR Newcastle Biomedical Research Centre and Biomedical Research Unit**

#### **Our vision**

Patients, their carers and the wider public are a fundamental and integral part of the NIHR Newcastle Biomedical Research Centre and NIHR Newcastle Biomedical Research Unit.

Our ambition is to be a world-class centre for high quality translational research on ageing and chronic disease. We want to bring research opportunities to patients and members of the public, improve our scientific understanding of ageing and chronic conditions, and investigate ways to improve the prevention, management and treatment of age-related conditions.

To achieve this aim patients, carers and the public are valued partners in what we do.

Together we want to create an energetic and stimulating research environment, with a shared commitment to the importance and value of research, the engagement and involvement of patients and the public and to the effective and timely translation of evidence into clinical practice, to make a real difference to people's lives.

A central aim is to continue to develop a range of creative approaches to share and harness patient and public insights, experience and opinions and to embed these at the forefront of Newcastle BRC and BRU activity and decision-making.

We are immensely grateful for the commitment, knowledge and enthusiasm of patients and public and for their ongoing support for NIHR Newcastle Biomedical Research Centre and NIHR Newcastle Biomedical Research Unit.

#### **Background to public engagement and patient and public involvement**

Public participation and engagement is supported and encouraged within all NIHR-funded activity (<http://nihr.ac.uk>) on the basis that this leads to better research that is more focused on the needs of patients and can accelerate the timely and effective transfer of evidence into clinical practice.

The development of knowledge about patient and public involvement and the sharing of expertise and good practice continues to be supported by INVOLVE - <http://www.invo.org.uk>.

We are keen to involve patients and members of the public in all stages of our research and we are continuously developing ways to improve the closer partnership between patients and public and researchers. Currently, patients and public are

involved in a wide range of ways. They have an especially important role in helping us to question how and why we do certain activities - for example, helping us to:

- set priorities for research;
- decide on what the research is setting out to achieve and understanding what the research findings mean to patients and members of the public;
- plan and design studies that are relevant to patients and in a way that that patients want to and are able to take part;
- recruit people to take part in research studies, particularly by helping to ensure the information we give to patients is co-developed and is clear and understandable;
- understand how the findings can be applied in practice through a strong programme of knowledge exchange and translation for maximum impact;
- communicate and share study findings and wider BRC/ BRU activity with a wide range of patients and the wider public, using a range of mechanisms such as web sites, newsletters and social media, as well as health and social care organisations and health professionals.

### **Working in Partnership**

The BRC and BRU PPI strategy is intended to facilitate close collaboration and partnership around PPI with other University and NHS organisations to effectively share best practice and expertise to reduce duplication and enhance the effectiveness of PPI.

We work particularly closely with Newcastle University's Faculty of Medical Science, the **Newcastle University Institute for Ageing** and Newcastle Upon Tyne NHS Foundation Trust.

We also work with other key NIHR organisations to support public and patient participation and engagement in research, including NIHR INVOLVE, Clinical Research Networks and other NIHR-funded organisations, including the Research Design Service, charitable organisations and business/industry.

We will strengthen and build strong relationships with patient organisations relevant to BRC and BRU research themes and those focused on public engagement, specifically Voice North – an organisation of 3000 members of the public involved in BRC and BRU supported research and wider activity.

Newcastle BRC and BRU will work in close partnership with the **NE CLAHRC**, if funded, to co-ordinate effective PPI. We will also collaborate with the Academic Health Sciences Network (AHSN) again to support the effective co-ordination of public participation and engagement in the North East and the timely translation of research evidence to maximise impact.

## Our objectives

1. **Building Capacity and Capability to develop and deliver Patient and Public Involvement (PPI) in research on ageing and chronic conditions:** We will work together with patients and public as a collective enterprise to actively share activity to facilitate greater integration and closer involvement of patients and public and to get their views on all aspects of BRC and BRU research and translation activity. We will also co-develop and deliver robust mechanisms to support researchers across the BRC and BRU to undertake PPI, including access to training and support, working closely with FMS co-ordination and Trust PPI support.
2. **Public Engagement:** we will work with a wide range of audiences, including patients and members of the public, schools and organisations working with older people to inform and stimulate thinking and debate about BRC and BRU research using a range of appropriate methods including events, meetings and workshops.
3. **Building the evidence base around PPI and Impact:** We will ensure that patients and members of the public are embedded in BRC and BRU research and related activity and that Newcastle BRC and BRU is at the forefront of involving patients and members of the public in research on ageing and chronic disease;
4. **Influencing Policy and Practice:** We will ensure that patients and members of the public have a key role in BRC and BRU decision-making processes and therefore can help shape future strategic direction of age related research and translational activity. We will have national visibility for PPI.

## To achieve these objectives we will:

- Engage, consult and involve a wide range of patients and members of the public about the work of the BRC and BRU through a range of methods including questionnaires, surveys, focus groups, events and workshops;
- Establish a patient and public forum to support active involvement in BRC and BRU research, including early involvement in grant applications, contributing to lay summary's etc., to inform how research is conducted and embed active public and patient involvement in BRC and BRU research;
- Co-develop training and support for patients and members of the public to have an active role in the BRC and BRU, working closely with INVOLVE guidance;
- Develop training and support for BRC and BRU researchers to sign post advice and guidance to actively undertake public engagement and patient and public involvement and embed in their research;
- Develop leadership amongst patients and public to promote research literacy and stimulate debate with patients and members of the public on research evidence, interpretation and translation;

- Develop a range of resources to support involvement, including concise information leaflets, newsletters, web pages and videos to promote involvement and disseminate and share BRC and BRU activity through regular feedback, and to facilitate involvement in specific projects;
- Work in partnership with the Faculty of Medical Sciences, **Newcastle University Institute for Ageing** and Newcastle Upon Tyne NHS Foundation Trust to engage with a wide range of audiences, where appropriate through joint initiatives, to support the development of relevant research and timely and effective translation into practice;
- Actively evaluate the impact of public engagement and participation in BRC and BRU activity;
- Ensure the public engagement and patient and public involvement programme is effectively resourced to support robust delivery;
- Ensure a visible BRC and BRU presence at local, national and international events and conferences.

## BRC and BRU PPI Action Plan

Objective	Task	Date	Status
<b>Building Capacity and Capability to develop and deliver patient and public involvement in research on ageing and chronic conditions: co-ordination and capture</b>	Establish a patient and public advisory group to support PPI in research across BRC and BRU.  Meetings held quarterly.  40 research ambassadors to be appointed	April 2015	Complete  Ongoing  Complete
	Create a series of toolkits to support best practice in patient and public engagement using INVOLVE guidance, working in collaboration with FMS coordinator.	September 2015	Ongoing
	Collect monthly case studies to capture public and patient involvement and engagement activity, working closely with FMS coordinator.		Ongoing
	Training and Support for patients and members of the public	June 2013	Complete
	Web based advice and guidance for researchers.	September 2015	Ongoing
	Developing resources – web based, information leaflets about getting involved	April 2013	Complete. Updates Ongoing

<b>Public Engagement:</b>	<p>To deliver a series of public engagement events across all themes of BRC and BRU related research – “Frontiers of Science: Research Matters” series to involve 300 individuals:</p> <ul style="list-style-type: none"> <li>• Frontiers of Prevention:</li> <li>• Arthritis Matters</li> <li>• Keeping Active Matters</li> <li>• Mitochondrial Disease Matters</li> <li>• PPI Matters: Creating Connections: Better Together</li> <li>• Genetics Matters</li> <li>• Launch of the Doctoral Training Centre</li> <li>• Fatigue Matters</li> <li>• Arthritis Matters</li> <li>• Parkinson’s Disease Matters</li> <li>• Diagnosis Matters</li> <li>• Genetics Matters</li>   <li>• Dementia Matters</li> </ul>	<p>October 2013 June 2014 July 2014 July 2014</p> <p>November 2014 February 2015 September 2015</p> <p>October 2015 October 2015 November 2015 November 2015</p> <p>February 2016</p> <p>June 2016</p>	<p>Complete Complete Complete Complete</p> <p>Complete Complete Complete</p> <p>Complete Complete Complete</p> <p>Complete</p> <p>Planning</p>
<b>Building the evidence base around PPI and Impact:</b>	<p>Evaluation of impact of PPI on BRC and BRU research and activity, working closely with NE CLAHRC.</p>	<p>May 2016</p>	<p>Planning</p>
<b>Influencing Policy and Practice Visible profile of BRC and BRU PPI nationally</b>	<p>LC representation on BRC and BRU on the cross NIHR PPI working group facilitated by INVOLVE</p>	<p>June 2013</p>	<p>Complete</p>

	INVOLVE 2013 programme on early involvement of patients in research studies <a href="#">Representation at CRFUK PPI conference</a>	May 2013 <a href="#">July 2013</a>	Complete
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**Useful links:**

- [INVOLVE](#) - Supporting public and patient involvement in NHS research
- [People in Research](#) - Opportunities for the public to get involved in clinical research
- [Research Design Services North East](#) - advice for researchers
- [Newcastle Biomedicine](#) Local activities
- [FMS Engagement](#)
- [Newcastle Initiative for Changing Age](#)

**Lynne Corner, BRC/BRU, revised April 2016**