



**National Institute for
Health Research**

**Patient and Public Involvement,
Engagement and Participation Strategy
2017-2022**

NIHR Newcastle Clinical Research Facility

Context

The NIHR Newcastle Clinical Research Facility (CRF) delivers high quality, cutting-edge experimental medical research across three sites in the city of Newcastle Upon Tyne:

- Newcastle CRF in the Leazes Wing of the Royal Victoria Infirmary
- Clinical Ageing Research Unit (CARU) on the Campus for Ageing and Vitality (CAV)
- Newcastle Dental CRF within the Newcastle Dental Hospital and School of Dental Sciences.

This document outlines NIHR Newcastle CRF's strategic aims and objectives for Patient and Public Involvement, Engagement and Participation (PPI/E).

In delivery of its objectives, the NIHR Newcastle CRF supports the research priorities of the Newcastle NIHR Biomedical Research Centre (BRC) and our PPI/E strategy maps closely to that of the NIHR Newcastle BRC. This ensures that there is coordination of planning and activities as well as helping to maximise available resources.

We also work closely with the PPIE Team of our host organisation, Newcastle-upon-Tyne Hospitals NHS Foundation Trust (NuTH) which is one of the largest NHS trusts in the UK. This includes engagement with a highly successful Patient Research Ambassador scheme, which places the patient voice at a very senior level within the partner organisations. The Trust successfully appointed its first Non Executive Director Research Champion in April 2016 and through the Joint Research Office and Clinical Research Network North East and North Cumbria, it supports a network of over 100 lay representatives from a variety of patient groups and voluntary organisations.

On a national level our PPI/E strategy implementation and planning will be informed by the recently published National Standards for Public Involvement in Research (https://www.nihr.ac.uk/news-and-events/documents/Public_Involvement_Standards_March%202018_WEB.pdf) and as part of our annual PPI/E planning cycle we plan to use the to assess our progress and inform future activity.

Our Vision

Our vision for PPI/E is based on valuing and maximising the involvement, engagement and participation of patients and the public, who are central to our delivery of patient-focused translational research.



We use NIHR INVOLVE definitions of patient and public Involvement, Engagement and Participation; that is research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.

Involvement – where members of the public are actively involved in research projects and in research organisations

Participation – where people take part in a research study.

Engagement – where information and knowledge about research is provided and disseminated.

We recognise that all three elements are complementary, and essential to maximising the relevance, quality and impact of our research. Our aim is to make our research visible and accessible to patients and the public, with clear routes for getting involved and participating in research.

We are committed to actively involving patients and members of the public in all stages of our research and are continuously developing ways to improve the partnership between patients, public and researchers and the organisations who work with them.

Strategic Objectives

In order to achieve our vision we have identified four key objectives that will guide our PPIE strategy.

1. Patient, Carers and Public Involvement - Increase opportunities for patients, carers and the public to get involved.

- Develop and explore opportunities to register patients interested in research such as <http://www.sjogrensregistry.org/index.php> and <https://www.contactme-ibs.co.uk/>.
- Engage with the existing Patient Focus Research Groups across speciality areas and/or patients research council.
- Continue to promote and participate annually in the NIHR “I am Research” and International Clinical Trials Day.
- Pro-actively identify opportunities to attend and participate in external events and seminars.
- Provide up to date information and sign post to opportunities for PPI involvement through our website.
- Engage with members of the public and patients through our close involvement with the NIHR Bioresource.
- Utilise and engage with the NuTH Patient Research Ambassador scheme.

- Promote the involvement of patient and carers with Industry funded studies through their participation in SIVs.

2. Engagement and development - To create an involvement culture within research

- Develop a specific PPIE section of our staff Induction process to embed a culture where PPIE is the norm.
- Increase the visibility of available PPIE funding and opportunities through standing items in staff meetings.
- Support staff development activities around PPIE through our dedicated NIHR PPIE funding and partner organisations such as the BRC and LCRN.
- Collect case studies that illustrate the impact of CRF activities and disseminate through NIHR, our website and wider networks.

3. Patient experience and feedback - Develop resources to capture the patient's experience of research

- We will continue to actively promote our participation in the NHS Friends and Family Test in order to capture feedback from patients as to whether they are happy with the service provided in the CRF and to identify where improvements are needed.
- We will also seek opportunities to capture patient feedback such as through the NIHR's patient experience survey and Young Person's Advisory Group North England through our links to the Great North Children's Hospital <http://www.ncl.ac.uk/gnch/>.

4. Partnership working - Work in collaboration with stakeholders locally, regionally and nationally.

- Build on and expand our existing links with charities to reach specific patient groups and hard to reach groups which are under-represented in research.
- Contribute to national policy through UKCRF network engagement.
- Build further links between our Paediatric Team and the Great North Children's Hospital -
- We will proactively engage with commercial sponsors at the Site initiation stage to ask, "what have you done for PPI/E?" and offer to deliver PPI/E activities for them.



Collaboration

We will continue to work closely with the NIHR Newcastle BRC, which acts as a catalyst for a joint strategic approach to PPI/E across our entire NIHR infrastructure, incorporating the Academic Health Science Network for the North East and North Cumbria. This is in line with recommendations in the NIHR 'Going the Extra Mile' report. We will continue to maximise efficiency through the recently configured 'One NIHR North East' initiative and through this engage with the Northern Health Science Alliance.

VOICE Digital Platform

VOICE North is an established organisation to harness the immense insights and ideas of the public on research and innovation on ageing. We have recently scaled our activity and reach through the launch of the VOICE digital platform, which provides scores of opportunities for the public to get involved in research. This includes events, blogs, research summaries, discussion groups, polls and online courses; effectively building a national community of 'Research Active Citizens'.

The VOICE digital platform is the NIHR Newcastle BRC's mechanism to enable the public and patients to have opportunities to be involved, engaged and participate in research and we are seeking to develop with link for the CRF.

Leadership and reporting

We will continue to monitor PPIE progress through our Monthly CRF Management Meetings and will engage with our partner organisations to share experiences and good practice. Our regular monitoring and review activities will include capturing examples of impact.

Resources

The NuTH Research & Development PPI Manager Tracy Scott works closely with the PPI/E link nurses (one each at CARU and the Dental CRF, and two at the RVI CRF site) and external PPI/E leads to ensure that the delivery of strategy locally, regionally and nationally is consistently implemented. Our Overall CRF PPIE Lead is Research Sister Dorothy Carmen.