

NIHR Newcastle BRC Strategy for Patient and Public Involvement, Engagement and Participation

Our vision

The NIHR Newcastle BRC aims to build on and harness experimental medicine in individual long-term conditions, to advance the diagnosis, treatment and prevention of ageing syndromes such as sarcopenia, frailty and multi-morbidity.

Our strategy is based on valuing and maximising the involvement, engagement and participation of patients and the public, who are central to our partnership in delivering patient-focused translational research.

We use NIHR INVOLVE definitions of patient and public **Involvement, Engagement and Participation**. 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.

We have set five objectives to help us to achieve our aims:

Our Objectives

1. **Meaningfully engage the public in debate and dialogue about our research**

We will expand our thriving and successful Research and Innovation Matters public engagement programme. Each year over fifteen events are held, focusing on and promoting NIHR Newcastle BRC research, directly involving over 1000 people. These events are aligned to national events (such as Brain Awareness week) and help strengthen strategic links with external partners, including patient groups and charities, health and social care, voluntary and community sector organisations. The programme for each event is co-designed with patients and the public to ensure the content is relevant, accessible and informative.

We will hold “Matters” events specifically related to each of our key themes (**Dementia, Liver, Skin, Musculoskeletal, Neuromuscular and Skin and Oral Disease**). A further aim of the series is to connect the themes together, furthering public involvement and the shared understanding of key cross cutting science related to research on long-term conditions to advance the diagnosis, treatment and prevention of **ageing syndromes**. We will therefore hold “Matters” events on **sarcopenia, frailty and multi-morbidity**. We will also hold discussions to cover key issues such as **Ethics, Consent and Patient Data** working in partnership with relevant stakeholders.

2. **Illustrate the impact of research and explain how it is making a difference for patients**

We have established a James Lind Alliance Priority Setting Partnership on **multiple conditions**

in later life. This partnership, involving patients, academics, clinicians, charities and service providers, highlights patients' priorities for research around living with multiple

conditions in later life. The process will produce a set of research questions, linked to and informed by BRC research, and will inform the direction of our research themes. This will also identify gaps in innovation for products and services required to support an ageing population, and we will work closely with the **National Innovation Centre for Ageing, NIHR Innovation Observatory** and the **Academic Health Science Network North East and North Cumbria** to address these.

3. Ensure our research is informed by patient and public priorities

Newcastle has pioneered the CRESTA clinics, which are an innovative service model to address the health and social care needs of older people living with multiple conditions. We will work closely with patients and public attending the CRESTA clinics to capture patient views and perspectives, inform and develop priorities for research on our themes, and identify unmet needs and gaps in provision to help ensure meaningful public involvement in the research and management of long-term conditions and multimorbidity.

4. Provide opportunities for patients and public to influence the strategy and projects of the BRC.

We have well developed mechanisms to embed and support public involvement, resourced and supported by our BRC that we will continue to build on. The **VOICE North Research Support group** (which comprises of 20 research ambassadors) meets monthly and advises on all aspects of PPI/E in the BRC, as well as navigating and signposting researchers to specific groups for tailored PPI advice and guidance. The group is represented on the BRC Executive Committee, has a key advisory role and contributes to the peer review process for internal competitions. Members also work with the NIHR BRC research trainees to help embed PPI/E in their career pathways.

We will continue to expand our patient-led '**Peer to Peer support forum**' to enable patients to share their experiences of involvement in research as part of our focus on continual improvement, shared learning and development on what works well. We will embed specific PPI/E I in all our Research Themes and associated projects. Our PPI/E leads deliver a programme of training, guidance and support on all aspects of PPI/E, including development of toolkits and policies on, for example, payment, learning and development and linked to NIHR INVOLVE resources.

5. Collaborate with key partners

We have developed effective relationships with individuals and patient/public groups, and have an active programme of engagement and involvement, which we will continue to build on. The NIHR Newcastle BRC is 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 also actively engage with the Northern Health Science Alliance. This will enable a culture of empowerment and support for locally driven PPI/E,

while remaining strategically consistent with NIHR goals.

We will achieve this by:

- Providing a PPI/E Forum as a platform for those working in PPI/E across our NIHR infrastructure and research programmes to regularly connect and develop a shared and consistent approach;
- Developing and strengthening mutual partnerships and opportunities for collaboration and ensuring effective communication between partners;
- Identifying cross-cutting activity and developing joint delivery plans, with shared resourcing ensuring that evidence of ‘what works well’ is shared and accessible to ensure the best use of available information;
- Improving support available to researchers and patients and the public locally and regionally by maximising awareness and efficient use of local and national resources and mechanisms for PPE/I (including the NIHR Research Design Service, the NIHR Clinical Research network, and the NIHR UK Clinical Trials Gateway);
- Strengthening our programme on the evaluation and impact of PPI/E, including hosting a series of national workshops on evaluation;
- Ensuring a focus on inclusion, equality and diversity, and widening participation, working closely with patient and community groups in the region.

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 will be our mechanism to enable the public and patients to have opportunities to be involved, engaged and participate in BRC research and it will help us to achieve our objectives.

The NIHR Newcastle BRC Strategy for Patient and Public Involvement, Engagement and Participation and associated delivery plan is intended to ensure we create a flourishing and supportive environment, where patients and the public are integral partners in world-class research, as we together build on and harness experimental medicine in individual long-term conditions, to advance the diagnosis, treatment and prevention of ageing syndromes such as sarcopenia, frailty and multi-morbidity.

	<ul style="list-style-type: none"> • Consent • Patient Data <p>Plan a programme of engagement, involvement and participation opportunities for the national “I am Research Campaign”.</p>		May 2018	
	Create a series of infographics that clearly illustrate the definitions of involvement, engagement and participation and upload on to the BRC website.	Engagement	October 2017	In progress
Illustrate the impact of research and explain how it is making a difference for patients	Produce a series of videos involving patients, which highlight the complexities and challenges of living with multiple conditions in later life and the importance of BRC research in addressing these. The content will then be uploaded on to the NIHR BRC website.	Involvement	May 2018	
	Work with a resident artist and patients/public to organise an art exhibition that will complement the videos, which illustrates the complexities of multiple conditions in later life. It will be a mechanism to engage with new audiences on the BRC research taking place.	Involvement	July 2018	
	Ensure that the final report of the “Living with Multiple Conditions in later life” NIHR James Lind Alliance Priority Setting Partnership is accessible for public and patients through the BRC website.	Engagement	April 2018	
	Collect case studies that illustrate the impact of BRC research and disseminate through the VOICE digital platform.	Engagement		In progress

	Evaluate the impact of PPI on BRC research by working with the Senior Research Associate who is leading a project on Evaluation of PPI.			
	Host a series of national workshops on evaluation	Engagement & Involvement		
Ensure our research is informed by patient and public priorities	Organise a series of focus groups with patients and public who attend the CRESTA clinics to capture their views and perspectives on the BRC research themes and ageing syndromes.	Involvement		
Provide opportunities for patients and public to influence the strategy and projects of the BRC.	<p>Expand our patient-led 'Peer to Peer support forum' to enable patients to share their experiences of involvement in research.</p> <p>Provide training and support to patients and public to enable them to contribute.</p> <p>Provide opportunities for patients and the public to influence BRC projects through the Voice North Research Support Group.</p> <p>Provide a comprehensive training and support programme for BRC researchers to help them embed PPI/E in their research through the following mechanisms:</p> <ul style="list-style-type: none"> • Monthly PPI/E & Impact advice and guidance drop in sessions 	<p>Involvement</p> <p>Involvement</p> <p>Involvement</p>	October 2017	<p>In progress</p> <p>Ongoing</p> <p>Ongoing</p>

	<ul style="list-style-type: none"> • Training Matters: PPI/E – a programme of training on topics such as “Introduction to PPI” and “Science Communication” • Engagement Forum – bi monthly meetings open to all BRC researchers to share case studies and best practice on all aspects of PPIE. <p>Provide opportunities for BRC researchers to contribute to national public engagement events, such as Pint of Science 2018 and Soapbox Science 2018.</p>	Engagement		Ongoing
	Create a series of toolkits to ensure BRC researchers are equipped with the latest knowledge on PPI from NIHR INVOLVE.	Engagement		Ongoing
Collaborate with key partners	<p>Represent the BRC through attendance at National Meetings and Conferences.</p> <p>Represent the BRC through the PPI/E regional forum: Creating Connections: Better Together.</p> <p>Provide opportunities for public and patients to participate in research by linking to other NIHR digital platforms e.g. UK Clinical Trials Gateway</p> <p>Through VOICE, and working with the NIHR Innovation Observatory, collaborate with other BRCs and NIHR infrastructure, including the Northern Health Science</p>	<p>September 2017 INVOLVE – November 2017 ENGAGE –December 2017</p> <p>Participation</p>		

	Alliance, to significantly widen the reach of local PPI/E activity and support coordination of opportunities to maximise involvement, engagement and participation in research via the VOICE platform.			
Expand our reach of PPI/E through the VOICE digital platform	Recruit new members through our voice platform by working with local patient and community groups in the region. Ensure that there is a focus on increasing diversity.	Engagement and Involvement		Ongoing

Useful links

[INVOLVE](#) – Supporting public and patient involvement in NHS research

[VOICE](#) – VOICE Digital platform

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