

**NIHR Exeter Biomedical Research Centre and NIHR
Exeter Clinical Research Facility
Patient and Public Involvement and Engagement
Strategy**

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Introduction

Patient and Public Involvement and Engagement (PPIE) means involving and engaging people with research. Patients and the public have perspectives based on their experiences, lives, and expertise in their own conditions which may differ from researchers'. PPIE means that people can use their lived experience to influence research, helping to make sure that it's relevant to people's lives, health, and wider concerns.

It's important for people to have a say in publicly funded research and be given the opportunity to make decisions, shape, and learn about research which might affect them; to work with research in a way that is done 'for' or 'with' them, rather than 'to' or 'about' them. Public involvement in research can make research stronger and more relevant.

The NIHR Exeter Biomedical Research Centre (BRC) and NIHR Exeter Clinical Research Facility (CRF) (see annexe for description of the two Centres) will work to involve people in ways that result in meaningful patient contributions to research design, conduct, and dissemination. Collectively, the BRC and CRF in Exeter (both funded by National Institute of Health Research, NIHR) are striving to improve healthcare by translating lab-based scientific breakthroughs into potential new treatments, diagnostics and medical technologies in clinical practice.

PPIE is already embedded in the CRF, which is an established Centre, whilst the BRC is a new Centre. This joint strategy has been developed by both Centres in collaboration with researchers and public representatives across the South West Peninsula. By working together, we believe we can build strong PPIE foundations in the BRC and strengthen and extend existing activities within the CRF.

This strategy document shows our key priorities for how we will involve patients and the public in the research of the Exeter BRC and the Exeter CRF through a programme of PPIE.

Our strategy provides a framework for the ways that the two Centres will work, separately and together, to develop PPIE activities that support our research aims. Importantly, it will be iterative and able to adapt to local and national needs as well as feedback from public collaborators and researchers, as the Centres move forward, working closely together.

We will place patients and the public at the heart of what we do, ensuring that they are embedded in all activities, and that innovations and scientific approaches are welcomed, accepted, and optimised.

Definitions

For our PPIE work, we will use the definitions provided by the NIHR¹:

Involvement - NIHR defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research.

Engagement - Where information and knowledge about research is provided and disseminated.

Participation - Where people take part in a research study.

For the purposes of this strategy, 'we' refers to the staff and researchers at the NIHR Biomedical Research Centre and Clinical Research Facility. An individual in each Centre will work as the PPIE leader who will oversee the implementation of the strategy and report on progress, but all members of the Centres will contribute to the success of the PPIE strategy. As our PPIE programme evolves, public collaborators will become a core part of the 'we' that works to deliver better patient and public involvement and engagement across both Centres.

The BRC and CRF's PPIE work will be developed in line with the NIHR Standards for Public Involvement². These are:

- Inclusive opportunities
- Working together
- Support and learning
- Governance
- Communications
- Impact

Other definitions and explanations of acronyms and initialisations used are available in the [glossary](#), at the end of this document.

¹ NIHR definitions of involvement, engagement and participation <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371#:~:text=NIHR%20defines%20public%20involvement%20in,%20or%20'for'%20them>

² NIHR Standards for Public Involvement <https://sites.google.com/nihr.ac.uk/pi-standards/home>

Goals and objectives

Six goals have been developed in recognition of the fact that the BRC and the CRF are starting this programme of work from different positions and perspectives. The newly funded BRC will need to build its PPIE programme, resources and groups. The CRF is already established and has several PPI groups and activities – the work in this strategy will sustain and improve these activities, and then bring the two together to collaborate and support each other.

Goal 1: Embed PPIE at the heart of research activities across the BRC

Patient and public involvement and engagement will improve the research conducted across the BRC. PPIE is essential to ensure that research reflects the needs of the population and will support the Centre's aims to improve translational research across South West England [see glossary for an explanation of translational research]. Some researchers will be more familiar than others with PPIE, and we will work to support and encourage them to consider public involvement in all research projects. The BRC will also include public representatives at the Board level and support their involvement.

Goal 2: Ensure the sustainability of PPIE at the CRF and optimise ways of driving it forward in collaboration with the BRC

The Clinical Research Facility has an established PPIE programme, with PPIE groups acting as an advisory board to the CRF and involved in governing access to Peninsula Research Bank resources (volunteers, data, and samples), and PPIE groups for specific conditions. We will work to ensure their sustainability and towards strengthening these activities in collaboration with the BRC as appropriate. For example, in collaborations with the BRC, the CRF will progress to expand our disease specific PPIE activities, to incorporate all themes within the BRC.

Goal 3: Improve PPIE through collaboration with other local NIHR Centres and infrastructure. NIHR Centres and infrastructure across the UK, and the NHS

Collaboration is essential to success. By working with other NIHR-funded Centres and infrastructure across the South West we can avoid duplication of effort and maximise resource use in key priority areas. This will support us in meeting our aims and provide more people

across the region with PPIE opportunities. Learning from each other to constantly improve the quality and delivery of PPIE will improve the practice and quality of research conducted across the network. This includes working closely with PenARC, who have done excellent work in developing strategies and good practice in involving people in research in the region. We will also work with national BRC and CRF working groups to share best practice, collaborate and learn from others working in PPIE, and learn from good practice within our own Centres (e.g. the engagement team in the BRC mycology theme). We will attend relevant external meetings/ conferences (e.g. UKCRF annual conference) so that we can also share our knowledge and learn from PPIE colleagues in other centres / institutions.

Goal 4: Develop an environment where researchers, from junior to senior, feel able to confidently conduct PPIE within their own research, and utilise engagement as an outreach tool, including beyond the life of the BRC and CRF

By providing researchers with the support and tools to conduct PPI and engage the public with their own research, we will provide sustainability and a continuation of PPIE practice beyond the life of the BRC and CRF. Increasing the skills of researchers to work with patients and the public will support our aim to embed PPIE within research at the BRC and CRF and deliver more projects utilising PPIE.

Goal 5: Involve groups under-represented in PPIE and under-served by research from across the South West – including those from ethnic minorities, older people, those living in rural and coastal communities, and those with multiple health conditions.

So that health research can benefit everyone we need to give a wide range of people the opportunity to influence research through involvement. Additionally, there are challenges and barriers to involvement that are specific to the South West region. For example, many people live rurally/ coastally with poor transport links, making travel to a central site difficult. We aim to identify and engage with people who are under-represented in PPIE and in research and develop methods that enable their involvement and participation. This programme will work alongside the BRC's and CRF's joint Equality, Diversity and Inclusion strategy to strengthen these ambitions.

Goal 6: Bring the work of the Centres to the public through a range of outreach and engagement activities and events

Engaging people with research is an essential part of a research programme that works with and for the community it is embedded in. By sharing our research projects and activities with public audiences, we not only inform them of research being undertaken, but also start conversations about research and the possibility of involvement. This should also include engagement and communication of the outcomes of research, and the outcomes of involvement within research, in understandable language and accessible places (i.e. beyond scientific publications). The CRF has established outreach activities, and the BRC and CRF will work together to build on this to reach more members of the public.

How we will achieve our goals: Programme of projects and activities

To achieve our goals and respond to the needs of researchers, projects, and patients and the public, we will work flexibly and responsively. For each goal, there are some key objectives against which to measure progress, including planned activities in years one and two.

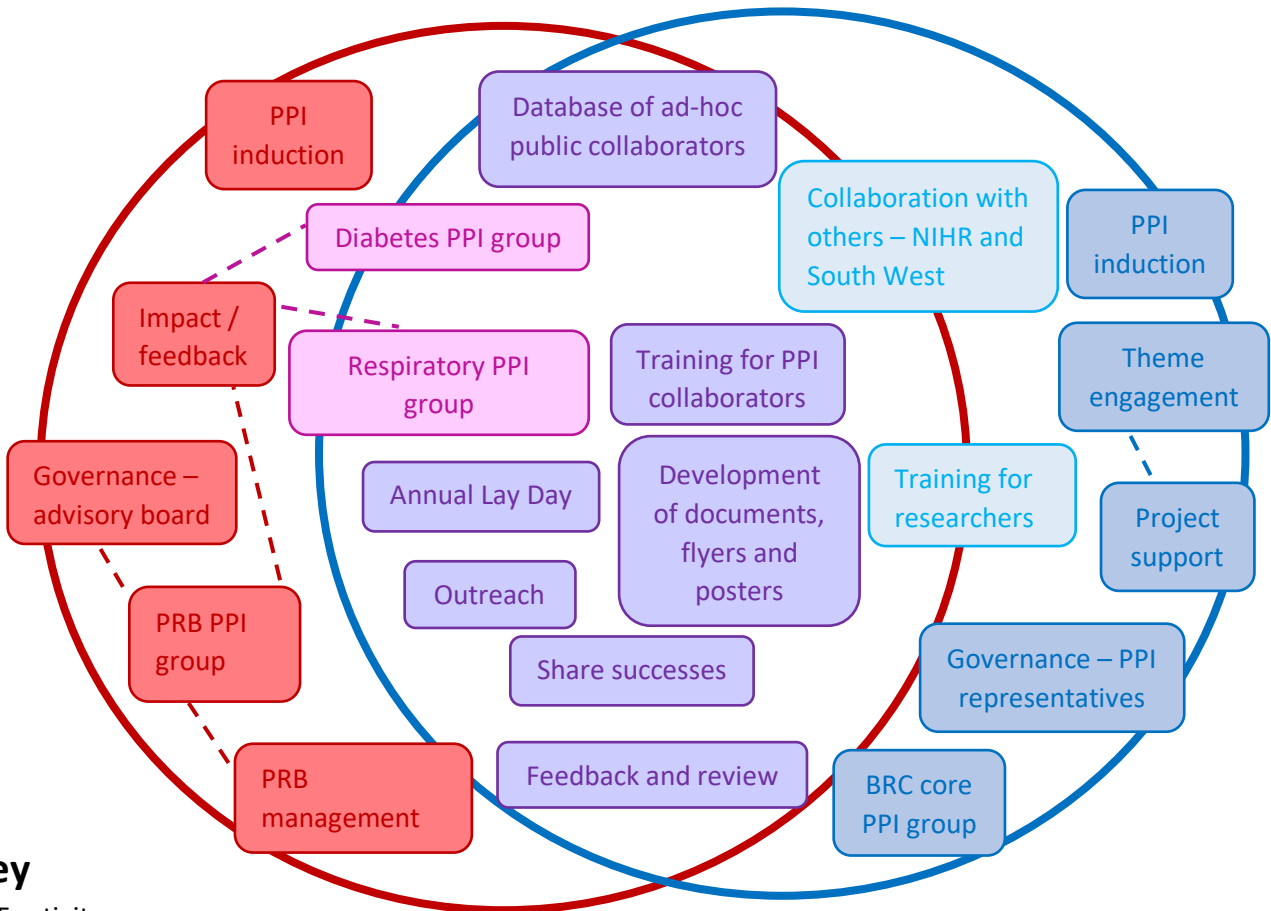
These activities are not exhaustive, and we will work with our public collaborators and researchers to further develop activities and areas of work based on need. We will report on all key activities undertaken as part of the programme.

This strategy will be iterative and will include a review with patients and the public in 2024 to update goals and objectives in line with challenges, progress and ambitions.

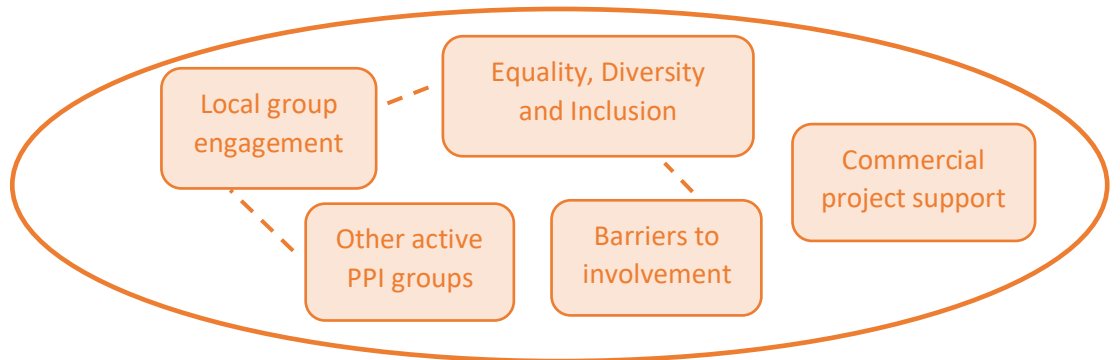
The diagram on the next page captures some of the core activities that underpin these goals, outlining who will lead on the work and how the BRC and the CRF will work together.

CRF

BRC



- Key**
- CRF activity
 - CRF-led joint activities
 - Joint activities
 - BRC-led joint activities
 - BRC activity
 - Areas requiring scoping to plan



Tables of proposed activities to achieve each goal:

Goal 1: Embed PPIE at the heart of research activities across the BRC

Responsible for activity	Years 1-2	Years 3-5
<p>BRC</p> <p>The PPIE leader will initiate this and researchers will support through participation.</p>	<p>Academics across the BRC themes and the PPIE team will meet to learn about one another's work, build a joint understanding of the PPIE support needs within the BRC and meet those needs through training and other support.</p> <ul style="list-style-type: none"> - Develop a training programme suitable for researchers at different stages of understanding and use of PPIE (include researchers from the CRF in this). - Through discussions with researchers, identify any specific PPIE methods that researchers could benefit from training and support in implementing. 	<p>Maintain and adapt the training programme for researchers based on the strategy review.</p>
<p>BRC</p> <p>The board will have this on their meeting agenda and the PPIE leader will present.</p>	<p>The BRC management will work with the PPIE team to identify priority projects within the work themes to</p>	

Decisions will be made jointly at the board.	support with PPIE team resources.	
BRC	The PPIE team will embed PPIE into internal BRC funding rounds, ensuring PPIE is integral to funding decisions and is considered by applicants from the earliest stages.	Review internal funding availability, and embed PPIE within those processes based on learnings from earlier rounds.

Goal 2: Ensure the sustainability of PPIE at the CRF and optimise ways of driving it forward in collaboration with the BRC

Responsible for activity	Years 1-2	Years 3-5
CRF	The CRF will continue to involve the lay members of the Peninsula Research Bank Steering Committee as an advisory group to the CRF Management Board and Senior Management Team contributing to governance decisions across the CRF. This group will meet monthly, with the flexibility of additional meetings as needed.	
CRF/BRC PPIE leaders	(1) Support existing CRF PPIE groups and activities (CRF led), (2) collaborating on projects and resourcing to build on these and develop new resources where appropriate (Joint CRF and BRC).	
CRF	To explore ways that we can extend our approach for capturing 'impact' from researchers, PPIE representatives and students.	To review these approaches and adapt accordingly.

BRC/CRF commercial leads with PPIE leaders	Explore ways to work with commercial organisations to utilise BRC and CRF PPIE groups and public members, and find the best ways of working with companies to enhance their research with PPIE.	
BRC/CRF	In 2024, the PPIE teams across the BRC and CRF will review this strategy with the input of Centre management and PPIE groups, updating goals and activities as necessary.	Plan for future reviews of the revised strategy to maintain a responsive PPIE programme.
BRC/CRF staff to feed in to PPIE leaders who will incorporate into training and capacity building resources.	Share success stories on the use of PPIE internally across both the BRC and the CRF so that researchers can better understand the value that it can bring to their work, fostering a culture of sharing and learning around the use of PPIE in research.	
BRC/CRF PPIE leaders and teams	Support early and continuing involvement in research and projects, encouraging researchers to include PPIE in research design and grant applications, involve people at all appropriate stages of their projects (including dissemination of results) and developing public and/or participant-facing documents.	
BRC/CRF PPIE leaders and teams	In partnership with existing members, develop a structured induction process for public collaborators for the BRC and CRF. This will be tailored to each Centre/ involvement group and will include information and training.	Review the induction processes for each centre/group.

BRC/CRF PPIE leaders and teams	<p>Deliver training to public collaborators that enables them to feel confident in their involvement, and provides information on topics and research areas of interest.</p> <p>We will:</p> <p>(1) maintain the existing CRF PPIE training programme</p> <p>(2) expand and support delivery to include BRC members and additional resources.</p>	

Goal 3: Improve PPIE through collaboration with other local NIHR Centres and infrastructure, NIHR Centres and infrastructure across the UK, and the NHS

Responsible for activity	Years 1-2	Years 3-5
Led by BRC PPIE leader with CRF involvement	Build relationships with other PPIE teams across the South West and other BRCs and CRFs.	
Led by BRC PPIE leader with CRF involvement	Identify opportunities for shared working with local NIHR Centres and infrastructure to increase the reach and scope of PPIE activities and promote PPIE across the region.	
Led by BRC PPIE leader with CRF involvement	Work with the PPIE team from PenARC (including their PPI group, PenPEG) to identify collaborative ways of working. This will include regular team meetings, sharing of resources, and sharing examples of good practice.	

BRC/CRF PPIE leaders	Collaborate with other NIHR Centres and infrastructure across the South West, and other BRCs and CRFs across the country, to share best practice examples and work together on projects where appropriate. Including, for example, attending NIHR UKCRF PPIE working group meetings and presentations at national URKCRF conference. This will include sharing case studies to improve PPIE across the Centres, and ultimately PPIE in health research.
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Goal 4: Develop an environment where researchers, from junior to senior, feel able to confidently conduct PPIE within their own research, and utilise engagement as an outreach tool, including beyond the life of the BRC and CRF

Responsible for activity	Years 1-2	Years 3-5
BRC/CRF PPIE leaders	Identify training needs and opportunities for researchers with varying levels of PPIE experience, advertising opportunities and supporting researchers to attend. This links to Goal 1 activities.	Maintain and adapt the training programme for researchers based on the strategy review.
BRC/CRF PPIE teams	Build on the training programme already provided by the CRF to its PPIE representatives to widen participation and support the delivery of relevant training for public collaborators. This will include presentations from	Review and adapt the training programme as needed.

	<p>researchers on specific topics of interest identified by public collaborators thus providing another opportunity for researchers and public collaborators to start meaningful conversations.</p>	
BRC/CRF PPIE teams and theme leads	<p>Support researchers to develop programmes of work with PPIE included from an early stage.</p> <p>This can include hosting ‘PPIE cafes’ where researchers can discuss their projects with public participants and the PPIE team and receive advice and support.</p>	
BRC/CRF research leaders and PPIE teams	<p>Encourage the resourcing of PPIE within grant bids, and support the development of funding applications through regular communications with relevant researchers, and offering support to help them to do so.</p>	
CRF/BRC PPIE teams and researchers	<p>Encourage the engagement of student (undergraduate and postgraduate) involvement and experience with PPIE activities within the CRF, including at an annual Lay Day and other outreach events.</p>	

Goal 5: Involve groups under-represented in PPIE and under-served by research from across the South West – including those from BAME communities, older people, those living in rural communities, and those with multiple health conditions

Responsible for activity	Years 1-2	Years 3-5
BRC PPIE team	<p>Our population in the South West is older than average.</p> <p>To support research that</p>	

	<p>aims to address older peoples' needs, build a 'core group' for involvement in the BRC with older people, including those affected by neurodegenerative conditions, to complement the existing groups at the CRF to support the work of BRC themes.</p> <p>This group will meet at least six times per year.</p>	
BRC PPIE leader	<p>Identify demographic and geographic barriers to involvement across the region, through conversations with local community groups and those working in PPIE across the South West. Develop plans to build relationships with groups and communities to overcome these barriers.</p>	
BRC/CRF PPIE teams and leaders	<p>Work in tandem with the BRC's Equality, Diversity and Inclusion Manager to identify under-served and under-represented groups, and develop an outreach plan. This will involve research on demographics within the South West, and seeking out under-</p>	<p>To maintain and adapt these outreach activities /plans as needed.</p>

	represented communities through local groups and networks.	
BRC/CRF PPIE teams and researchers	Gather information on existing relationships that researchers across the Centres have with patient and public groups, learning from previous activities.	
BRC PPIE team	Utilise a range of involvement techniques and methods to remove barriers to participation (e.g. travelling for workshops, reliance on strong internet connection for video calls), working with people to find the methods that suit them. This will stem from work to build relationships with under-represented communities and local groups to understand barriers to participation.	
BRC/CRF PPIE teams with the EDI Manager	Along with the BRC EDI Manager, conduct annual reviews of the demographics of public collaborators (where possible) involved in research projects, and collaborators in our active networks, to monitor and develop plans for improvement.	

Goal 6: Bring the work of the Centre to the public through a range of outreach and engagement activities and events

Responsible for activity	Years 1-2	Years 3-5
BRC PPIE leader	Develop materials and activities with public collaborators relevant to BRC research, suitable for events and sharing information relating to PPIE.	

	This will include flyers and posters for outreach events, and activities that share information about research projects and their outcomes.	
BRC PPIE team	Learn from existing good engagement practice within the BRC themes (e.g. mycology engagement team) to support the development of activities relating to research across the BRC, which can be used in outreach communities across the region.	
BRC/CRF theme leads and PPIE teams/leaders	To continue outreach activities (e.g. country shows) and programmes of work developed by the CRF to reach audiences relevant for both the BRC and CRF. We will use these to share information about the Centres and encourage people to sign up as public collaborators for opportunities across the Centres and our networks.	
BRC/CRF PPIE leaders	Identify new opportunities such as festivals and fayres across the South West to	

	attend and promote the BRC and CRF's work.	
BRC/CRF PPIE leaders and teams, with researchers	Linked to the goals above, we will attend a minimum of four events with an outreach activity per year. Use these opportunities to speak with members of the public about research, about the work of the CRF and BRC, and as an opportunity for people to become involved. We will involve public collaborators in these opportunities where possible.	
Led by BRC PPIE leader and team	Participate in the British Science Festival 2023, introducing members of the public to research in the South West and the ways they could become involved.	
BRC PPIE team	Work with researchers within the BRC research themes to support engagement activities specific to their research. Support the development of materials, training for researchers to deliver engagement events, and promotion of events.	
BRC/CRF PPIE leaders and teams	Work closely with our communications teams to share successes and news, and develop engaging, helpful web pages for those interested in becoming involved with BRC and CRF research. Include public collaborators in the dissemination of success stories and outcomes where possible.	
BRC/CRF researchers and PPIE teams and leaders	Develop plans with researchers to share their research at important points, as engagement opportunities can be used to inform people about involvement and participation opportunities. This includes the dissemination of research outcomes.	

CRF/BRC PPIE teams and researchers	Expand the CRF annual 'lay day' into a joint event, bringing researchers, students and public collaborators together to update on research projects and present their research.

Annexe

What is the Exeter Biomedical Research Centre (BRC)?

NIHR Biomedical Research Centres (BRCs) are collaborations between world-leading universities and NHS organisations that bring together academics and clinicians to translate lab-based scientific breakthroughs into potential new treatments, diagnostics and medical technologies.

The Exeter BRC will cover the South West region of the UK, comprising Cornwall, Devon and Somerset. It will be the gateway for research, carrying out high-quality science into the health areas that are most important to our communities, always putting patients at the forefront of what we do. Our partnership brings together world-class medical research leaders from across the region, including clinical and laboratory scientists, doctors, nurses, and data experts. Their technical knowledge will be partnered with expertise from patients, carers, and families to identify and drive forward important new research. Our team will focus on five major, complementary research themes that all aim to improve how we diagnose, treat, and care for people. This will transform lives, improve the NHS and ensure patients receive the treatment and care that is best for them. These themes represent our greatest strengths. They are:

- Neurodegeneration: We will find and test new, better drugs that prevent and treat major brain conditions in older adults such as dementia and Parkinson's disease.
- Rehabilitation: We will use exciting new approaches to help older people to recover from illness or manage their long-term conditions like dementia and arthritis. This will include using technology to improve movement, maintain brain health and prevent falls.
- Diabetes: We will improve the way diabetes is diagnosed and treated, and we will explore how to help those most at risk of developing the disease.
- Genetics: We will unlock the power of genetics, using it to improve diagnosis of rare illnesses in children and rare cancers, and to create treatments for common diseases that can be tailored to different people based on their unique genetic profile.
- Clinical Mycology: We will seek better treatments to prevent and manage fungal infections that are common in the UK and understand better how fungi become resistant to drug treatments.

As a BRC we will carry our approach through to:

- address the challenges of PPIE in experimental medicine and translational research
- evidence our strong commitment to diversify our PPIE base

- implement all NIHR Standards for Public Involvement, and continuously improve and innovate with our offering
- integrate our regional resources and work with other BRCs to learn how to diversify participation and share excellence
- deliver an approach that is inclusive, responsive, and informative and develops respectful, trusting and sustainable relationships.

What is the Exeter Clinical Research Facility (CRF)?

The NIHR Exeter Clinical Research Facility (NIHR Exeter CRF) and NIHR Exeter BioResource Centre is a partnership between the Royal Devon University Healthcare NHS Foundation Trust and the University of Exeter.

The NIHR Exeter CRF supports and conducts clinical research studies and is based in a purpose-built unit within the Research Innovation Learning & Development (RILD) Building at the Royal Devon University Healthcare NHS Foundation Trust.

The NIHR Exeter CRF aims to improve patient care by increasing understanding of the causes of disease and improving diagnosis and treatment. Its collaborative and centralised approach maximises efficiency, minimises bureaucracy and ensures the patient voice is central in clinical research.

Key objectives of the CRF

To improve and increase the use of the available excellent infra-structure that supports patient-orientated research.

To support new and established investigators in Exeter, both within in the NHS Trust and University, in developing and running clinical research.

To increase external studies by active engagement with other CRFs, external investigators and industry.

The Exeter Clinical Research Facility was established in 2009. It has embedded PPIE activity into its operations. The Clinical Research Facility use an integrated approach which ensures PPIE at all stages of our research, for example, CRF PPIE Representatives:

- Govern access to Peninsula Research Bank resources;
- Act as an advisory board to the CRF;
- Help shape research questions, grant applications and participant facing documents;

- Advise on the feasibility of studies;
- Participate in CRF outreach events;
- Involved in co-producing PPIE related resources and conference presentations;
- Aid dissemination of results

Resources to support this programme of work

Staff

BRC: To deliver this strategy, there is a PPIE team based within the Biomedical Research Centre, comprising a PPIE Manager, Jess Smith (1 full time equivalent (FTE) role), and a PPIE Administrator, Emma Wood (0.5 FTE). This team is supported and supervised by the PPI Lead, Dr Kristin Liabo (0.05 FTE) who works across a broad range of PPIE projects and groups. Future plans enable the recruitment of a further PPIE Officer (0.8 FTE) to support with the delivery of PPIE within projects. Subject to funding via specific projects, additional team members to deliver PPIE within projects may be recruited and supported during the lifetime of the Biomedical Research Centre.

Researchers within the BRC will also be responsible for the delivery of PPIE activities within this strategy, working towards their aim of having patients at the heart of the Centre.

CRF: The Clinical Research Facility has a PPIE lead (Dr Kim Gooding (0.2 FTE)), with limited admin support.

Activities will also be supported by collaborators in other research centres, and by the BRC and CRF's core teams.

Training

We will seek to identify relevant training opportunities for researchers and public collaborators as appropriate. Where none are available, or more tailored training is required, we may commission trainers or develop our own training, with the support of the BRC's Training Manager.

The CRF have an established training programme for their public collaborators, and the BRC will work to integrate, support and expand these opportunities.

Partners and collaborators

The PPIE programme will be one that builds relationships and collaborates widely with researchers, research centres, PPIE teams, and community groups, creating a 'we are all part of one team working together to drive research forward' spirit. These relationships are absolutely essential, and their number will continue to grow through the delivery of this strategy.

The partnership between the BRC and the CRF is the key one underpinning the programme. By sharing ideas, resources and infrastructure, we will provide a wider range of opportunities for involvement and increase the level of support for researchers to include PPIE in their work.

We will partner with a wide range of groups, centres, and people throughout the course of the Centre. These include, but are not limited to:

- Other NIHR Centres. This includes PenARC, other NIHR Centres across the South West, and other BRCs and CRFs across the country.
- Other PPIE groups and support networks within the University and NHS Trusts.
- Community groups working with members of the public across the region, specifically those working with under-represented and under-served members of the public.
- Colleagues within the university and NHS Trusts, including the core BRC team.
- Patients and members of the public, through formal groups such as our core involvement team (existing and new groups/collaborations to be established), public representatives in our reporting structures, and a wide range of the public that we reach through outreach activities and groups.

How did we develop this strategy?

A strategy, developed in collaboration with stakeholders, is key to establishing our underpinning aims and ambitions for PPIE at the Exeter BRC and Exeter CRF. It enables us to clearly state what our priorities are, the areas of focus for our work, and importantly allows us to be held accountable in delivering against these goals.

In the development of its plans, the BRC has run several workshops with patients and the public, covering different themes and geographical areas of the Centre. Three meetings were theme specific (neurodegeneration and mycology), and two were place-based (one in Cornwall, one in Somerset).

They raised important and thoughtful points on ways to improve involvement, increase our reach to involve members of the public from underrepresented groups, and ways that we can support our patient and public collaborators to become involved and stay engaged with the process.

An existing PPIE group from the NIHR PenARC – called PenPEG – have also contributed via discussions and suggestions based on experience. Our PPI representatives for the BRC, who sit on our board, also provided feedback and advice regarding the strategy.

The CRF PPIE representatives have been consulted during the development of this strategy document, and their feedback has been invaluable, changing the way that the information has been presented. CRF PPIE groups will be consulted from the earliest stages in the review for this strategy at its next iteration.

The academics involved with the Biomedical Research Centre and the Directors of the CRF have also been consulted to ensure that as well as developing a strategy that puts patients and the public at the heart of the research of the BRC and CRF, it meets the needs of researchers and academics and supports them in the skill development required to enable the strategy's delivery.

Monitoring, review and reporting

BRC: The BRC will have a core team delivering the functions of the BRC and supporting academics and others involved in research. This team includes the Chief Operations Officer, the Equality, Diversity and Inclusion Manager, Training Manager, Communications Officer, and PPIE Manager. This group are responsible for overall monitoring of progress on a day-to-day basis.

The Management Board for the BRC will meet monthly, and includes academic leads for each of the BRC themes and representatives from NHS Trusts in addition to the core team. This Board will monitor progress against aims, and set priorities for individual teams. Importantly, we have two public representatives who sit on the Board and attend meetings to hold us accountable for the delivery of strategies and plans across the breadth of the Centre. One of these representatives is from Exeter, and the other from North Devon. We will seek to appoint a third member, from Cornwall or Somerset.

The BRC's progress against stated aims and ambitions is further monitored and overseen by a Joint Strategic Partnership Board. The public representatives will also sit on this Board.

CRF: The CRF's governance structure comprises a management board, including the CRF Directors, Senior Research representatives from the Royal Devon University Hospital and the University of Exeter, CRF PPIEP lead and a CRF Senior Nurse. This group meets twice a year.

As part of the CRF's Peninsula Research Bank (PRB), individuals participating in research studies, particularly the Exeter 10,000 study, are given the option to gift samples to the PRB. The PRB Steering Committee, which approves access to these samples comprises predominantly of lay members, most of whom are donors of the samples. This model, referred to as "Dynamic Consent by Proxy", allows broad consent to be obtained for the storage of samples from thousands of participants, but also for approval for use of the samples to be granted by 10s-100s of public representatives. This strategy allows members of the public to choose the level of engagement and involvement that they have with the process, whilst ensuring robust governance oversight of samples.

The BRC and the CRF will provide separate progress reports annually to the NIHR, including progress against goals and aims in this strategy and specific activities. The BRC and CRF PPIE teams will meet regularly to discuss activities, collaborative ways of working and ways that we can share successes and learnings, reviewing our activities and updating with the support of PPIE groups where needed.

Glossary of terms

BRC – Biomedical Research Centre – these types of Centres support translational research, which 'translates' scientific research into research that can benefit patients. BRCs are funded

by the NIHR. You can find out more about BRCs here: <https://www.nihr.ac.uk/explore-nihr/support/experimental-medicine.htm#one>

CRF – Clinical Research Facility for Experimental Medicine are dedicated NIHR funded facilities, where specialist clinical research and support staff from universities and NHS Trusts work together on patient-orientated commercial and non-commercial experimental medicine studies. You can find out more about CRFs here: <https://www.ukcrfnetwork.co.uk/>

Engagement – [NIHR definition] - Where information and knowledge about research is provided and disseminated.

Involvement – [NIHR definition] - NIHR defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research.

NIHR – the National Institute for Health and Care Research. They are the funder of the BRC and the CRF, and many other types of research centres, supporting research that will benefit patients. You can find out more about the NIHR here: <https://www.nihr.ac.uk/>

Participation – [NIHR definition] - Where people take part in a research study.

PenARC – this is the NIHR Peninsula Applied Research Collaboration, known as PenARC. PenARC conducts a type of research called 'applied research', also across the South West Peninsula. PenARC and its PPIE team are based at Exeter and bring a wealth of PPIE experience that we can build on and collaborate with. You can find out more about PenARC here: <https://arc-swp.nihr.ac.uk/>

PenPEG – this is the Public Engagement Group for PenARC. This is a core involvement and engagement group for PenARC, providing support and advice to the PenARC PPIE team, members of whom are regularly involved in projects across PenARC. They have been incredibly supportive of the BRC and the development of this strategy and other activities.

PPIE – this stands for 'Patient and Public Involvement and Engagement'.

PRB – Peninsula Research Bank

Translational research – Translational research is research that builds on excellent lab-based science, and works to make it relevant to patients, ready for clinical studies or use in care. Some people describe this approach as 'from bench to bedside' research, representing the movement from lab-based to people-based research. Because of the difference in the way that

lab-based and people-based research is done, this step is needed to 'translate' research from one type to the other.

Document history			
Version	Creation date	Author	Reason/ amends made
1	30/01/2023	Jess Smith	First BRC draft for consultation – sent to BRC PPIE Lead, PenPEG members, BRC PPI representatives.
2	20/02/2023	Jess Smith	Updates on discussions and amendments from BRC PPIE Lead, PenPEG members, BRC PPI representatives. Update to combine BRC and CRF goals, to create a joint strategy.
3	17/03/2023	Jess Smith/ Kim Gooding	Joint BRC and CRF goals and objectives.
4	22/03/2023	Jess Smith/Kim Gooding	Updates based on discussions. Version to go to the BRC Management Board and CRF PPIE groups.
5	24/04/2023	Jess Smith/Kim Gooding	Updates based on feedback from BRC Management Board and CRF PPIE group members.
6	12/05/2023	Jess Smith/Kim Gooding	Updates based on further discussions between BRC/CRF PPIE teams. Sent for review with CRF PPIE group members, BRC Communications Officer, BRC PPIE representatives, CRF Management.
7	30/05/2023	Jess Smith/Kim Gooding	Final version based on feedback. Version submitted to NIHR.