

NIHR Norfolk Clinical Research Facility (CRF) Patient and Public Involvement and Engagement (PPIE) Strategy

Our strategy sets out the way we involve and engage with patients and members of the public to shape our research, building on past successes and learnings.

PPIE facilitates information exchange, discussion, debate, and decision making. It involves interaction and listening, with the goals of generating outcomes of mutual benefit; building trust; increasing understanding and collaboration; and increasing the impact of our research outputs on society. PPIE activities range from information-giving to consultation, public-led events and everything in between.

Central to our approach is the provision of accessible opportunities for participation to research for the population in the region we serve and also for NHS staff to be involved. This is expressed in our Equality, Diversity and Inclusion (EDI) policy which is particularly relevant in rural and coastal North Norfolk where there are healthcare needs, but low research activity 'under-served' communities. North Norfolk is recognised as having one of the UK's oldest populations and our aim is to bring research closer to the local community at Cromer Hospital which is part of Norfolk and Norwich University Hospitals but without direct transport links.

Our principles are:

- To offer the highest quality experience for our research participants.
- For our research to address patients' needs.
- To use innovative approaches to widen participation in research.
- Make sure research participants and those involved in PPI feel valued and meaningfully involved.
- To deliver Goal 3 of [NNUH Research Strategy 2020-2025](#) 'Develop sustainable strategic partnerships critical to the region and wider NHS, aimed at addressing the imbalance between high level of healthcare need and low research'.

Our PPIE Action Plan is given below. It focuses on getting it right in Our Workplace, and on collaborating in Our Region and Our Partners and has goals for the short term (Years 1-2), medium term (Years 2-3) and long term (Years 4-5).

We will use different approaches, reflecting the degree to which those involved can influence the outcomes and long-term impact of the projects, ranging from providing information to consultation so new research studies are well-designed and research participants are routinely informed of the study findings. We will provide accessible information and diverse ways to recruit participants to research.

NIHR Norfolk CRF PPIE action plan

Theme: Working in In Our workplace			
Action	Key outcome	Time frame	Success criteria
<p>Embed the Participant in Research Experience Survey (PRES) and act upon feedback where appropriate</p> <p>Lead: PPIE Lead</p>	PRES reports monitored and feedback actioned	1-2 years	Patients report a high-quality experience when using our CRF
<p>Appoint a dedicated PPIE Lead to make effective links with other local PPIE groups and to ensure the PPIE Working Group is properly constituted</p> <p>Lead: CRF Directors</p>	An effective point of contact and lead for PPIE activities	1-2 years	PPIE Lead appointed; PPIE Working Group meets regularly and Terms of Reference ratified
<p>Invite patients and public involvement to the PPIE Working Group; co-create an induction and support plan for public and patient contributors; ensure an equal footing and, as appropriate, that decision-making in the Norfolk CRF is challenged</p> <p>Lead: PPIE Lead</p>	An induction and training plan for public contributors has been implemented	2-3 years	2-3 public members PPIE trained, contributing to the PPIE Working Group and the strategic development of the CRF
<p>For our researchers, bring together a suite of high quality PPIE training materials</p> <p>Lead: CRF Operations Manager</p>	Researchers are regularly engaged in PPIE activities	2-3 years	Online materials signposted e.g., NIHR Academy
<p>Implement a system to capture and report PPIE activity and monitor its effectiveness</p> <p>Lead: CRF Directors / PPIE Working Group</p>	PPIE activities are recorded	2-3 years	PPIE action plan is regularly reviewed by the PPIE Working Group
<p>Use patient forums, creating new ones if necessary, so recruitment to studies is accessible to diverse communities and new research studies are well designed</p> <p>Lead: Investigators; delivery team leads</p>	PPIE enhances efficient research delivery	4-5 years	Measurable widening of research participation; grant applications receive positive feedback
<p>Feedback is given to participants at the end of a study summarising the findings, thanking participants and that their involvement is highly valued</p> <p>Lead: Chief Investigators</p>	Participants feel valued and aware of the importance of their involvement	4-5 years	Participants receive an end of study letter
<p>Gather evidence that PPIE improved research delivery and participation; disseminate information, share learning</p> <p>Lead: PPIE Lead</p>	Increased numbers of PRES respondents, Public Research Champions, public contributors, study participants	4-5 years	Start and end points are understood; there has been change over time; learning is shared including exemplar cases

Theme: Working in Our Region			
Action	Key outcome	Time frame	Success criteria
Engage with wide audiences through our Research Champions and a rolling programme of outreach activities: <ul style="list-style-type: none"> • local 'pop-up' events e.g., NNUH's Annual General Meeting, Annual Research Fair • Research Promotion Stands at Cromer Hospital • The Royal Norfolk Show • Norwich Science Festival week • International Clinical Trials Day Lead: CRF Operations Manager / Biorepository Manager	Promote research, raise awareness of the NIHR Norfolk CRF and early phase and translational research	1-2 years	A regular programme of outreach and activities is supported and feedback used to inform our research services
Maintain and strengthen relationships with other local PPIE groups and identify opportunities to collaborate Lead: NIHR Norfolk CRF Joint Strategic Management Committee	Create list of current relationships and seek new ones	2-3 years	Productive relationships and regular contact; best practice is shared
Enhance communications about research through: Trust-wide Daily Staff Bulletin, 'Stars of Research', annual research awards; local news; social media, webpages, and Easy-Read Materials Lead: NNUH Communications Lead	Promote research, raise awareness of the NIHR Norfolk CRF early phase research and facilitate recruitment	2-3 years	Increased awareness of research success among staff and public

Theme: Working with Our Partners			
Action	Key outcome	Time frame	Success criteria
Work together with other PPIE groups on the Norwich Research Park - for example NNUH's Patient Engagement & Experience Team, University of East Anglia's Citizen's Academy Lead: PPIE Lead	Raise awareness, promotion new studies and increased engagement with the communities we serve	2-3 years	Best practices and resources are shared
Engage with previous NICU and paediatric research participants who may be willing to contribute to PPIE activities, considering their ideas and opinions Lead: NICU Research Nurse		2-3 years	Norfolk CRF is a safe, child and family friendly environment, providing a high-quality experience
Our neonatal / young child research, often involves working with families and carers at the most vulnerable times, further develop our established project specific PPI groups and involve the specialist clinical care team to facilitate participation in research. Lead: NICU Research Nurse		4-5 years	The needs of the young families are understood and reflected in our research

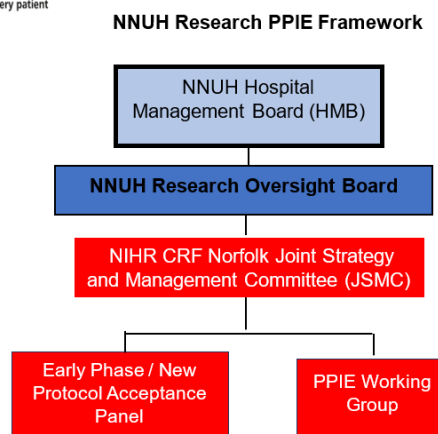
Equality, Diversity and Inclusion

People from different backgrounds and with different experiences provide us with fresh ideas, broader perspectives, and insights into potential challenges. Everyone should be able to contribute and have a voice. This may mean making reasonable adjustments to facilitate PPIE participation. We will seek out a diverse range of voices and perspectives and strive to ensure that anyone who engages with us finds it easy to do so.

Leadership and Lines of Reporting

The Directors of the NIHR Norfolk CRF provide overall leadership supported by a number of dedicated committees and by NNUH's Research Oversight Board. The committee reporting structure is shown to the right (and see below).

Delivery of our PPIE Strategy will be principally driven through the PPIE Working Group together with the NIHR Norfolk CRF Joint Strategy and Management Committee* (currently Chaired by the CRF Operations Manager). The remit will be to develop and support initiatives to promote and increase patient and public involvement and provide a platform that allows our community a say in the research we do. Our action plan is focused on 'getting it right' in our workplace.



About our Research Committees

Research Oversight Board - provides assurance to the Trust Board of Directors that appropriate measures are in place and research at NNUH has solid foundations and is well managed and governed.

***NIHR CRF Norfolk Joint Strategy and Management Committee (JSMC)** - oversees the NIHR Norfolk CRF; includes representatives from NNUH, Quadram Institute Bioscience and University of East Anglia and the PPIE Designated Lead and Chair of PPIE Working Group.

Early Phase / New Protocol Acceptance Panel – a working group providing due diligence and oversight on new early phase and translational studies to be delivered in the CRF.

PPIE Working Group – responsible for overseeing the implementation of the PPIE strategy. This group is Chaired by the Designated PPIE Lead and involves patients, members of the public and NNUH researchers; it links with other local PPIE groups such as: UEA Citizen Academy, QIB PPIE group, CRF Public Research Champions, NNUH Patient experience team, NNUH's Neonatal Intensive Care Unit patient group. A Report from PPIE Working Group is always an agenda item for JSMC.

Partners and collaborators

We work closely with East of England NIHR Clinical Research Network, UKCRF Network and organisations on the Norwich Research Park. We aim to establish new links with other networks and community groups using innovative approaches to identify and remove barriers to research participation, particularly 'underserved' communities e.g., locations or patient groups for which there are low level of research activity.