

NIHR Manchester Biomedical Research Centre and NIHR Manchester Clinical Research Facility - Patient and Public Involvement and Engagement (PPIE) Strategy 2018-2022

This document is a full version of our PPIE strategy. An executive summary will be made available in Spring 2018 at the [NIHR Manchester Biomedical Research Centre](#) website, and the [NIHR Manchester Clinical Research Facility \(CRF\)](#) website.

1. Context and opportunities

The NIHR Manchester Biomedical Research Centre (BRC) and Clinical Research Facility (CRF) Patient and Public Involvement and Engagement (PPIE) work is led by the [Public Programmes Team](#) at Manchester University NHS Foundation Trust. The Public Programmes Team is affiliated to The University of Manchester, which has [Social Responsibility](#) as one of three strategic goals, and advised on the development of The University of Manchester's [framework for public engagement](#).

The Public Programmes Team is a specialist unit which advises on, facilitates and delivers PPIE across Greater Manchester, nationally and internationally, for a range of partners and clients. It works closely with a team of nominated staff and public contributors forming working groups for the CRF and every BRC research theme. In addition to our NIHR funding, this strategy is supported by investment from a [Wellcome Sustaining Excellence Award](#). This supports us to enhance our delivery, innovate our practice, increase our reach - especially to currently underserved audiences - build our evaluation expertise, and have greater impact nationally in PPIE.

Since April 2016, Greater Manchester has had an integrated Health and Social Care system and devolved budget, overseen by the [Greater Manchester Health and Social Care Partnership \(GMHSP\)](#). Within the Greater Manchester Research and Innovation landscape, an important stakeholder for this BRC and CRF PPIE strategy is [Health Innovation Manchester \(HinM\)](#). HinM was established to accelerate the adoption of innovation across the devolved region. This PPIE strategy is overseen by the Executive Chair of HinM through the BRC Governance Board.

Throughout the term of the NIHR BRC and CRF awards we will explore and exploit arising opportunities. These currently include:

- The devolved health and social care system (DevoManc) – working closely with [GMHSP](#) and [HinM](#) on our common aims.
- PPIE in the North – exploring opportunities to work with the [Northern Health Science Alliance](#), continuing our collaborative relationships with northern PPIE practitioners.
- [World Healthcare Congress Europe, March 2019](#) in Manchester, with a focus on P4 medicine (predictive, preventive, personalised, participatory) and arts in health.

2. Methodology and Review

This strategy has been developed over 18 months of listening, consultation and planning across Greater Manchester with people and patients, community groups, members of the public who currently input into and influence our research, researchers, clinicians, cultural partners and funders. Therefore, it builds on the existing strengths and good practice of a wealth of people and organisations supporting, contributing and delivering PPIE within experimental medicine research in Greater Manchester. As PPIE is a rapidly developing practice, it is essential that this strategy is regularly reviewed. This strategy will be formally reviewed annually with a first formal review in March 2019. Our monitoring plan is set out in section 9.

3. Our definition of PPIE

This strategy includes both Patient and Public Involvement, and Public Engagement with research. We use the following definitions:

[INVOLVE/NIHR's definition of involvement](#) is research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

[Wellcome's definition of public engagement](#) is providing the opportunity to explore, debate and shape science and health research.

We recognise that there are common approaches and challenges in both of these sectors but that both are essential to our research. **This strategy aims to innovate between PPI and PE to explore and evaluate the impact of approaches which connect or encompass both.**

4. Our vision

Effective PPIE is an essential to the work of the NIHR Manchester BRC and CRF and key to achieving our aims of delivering world-leading research and reducing health inequality.

Our vision for this strategy is to connect people and patients with our research in a meaningful and inclusive way, with positive impact both on our research and on society. Importantly we are innovating approaches to involve people and patients who are currently seldom heard, who offer different and valuable perspectives, ensuring our research recognises the needs of a wider range of the Greater Manchester population.

This strategy allows us to build a culture in our PPIE work which is collaborative, innovative, reflective and open to positive change.

5. Our overarching aims

Our aims work towards the [Strategic Focus Areas](#) of the Public Programmes Team. They are based both on the strengths of our existing PPIE practice, and designed to address sector-wide long-standing challenges, towards more people-centred research in Greater Manchester. We aim to:

1. Improve research and patient experience by supporting the delivery and evaluation of effective and innovative PPIE towards the strategic aims of the BRC and CRF;
2. Increase the diversity of the audiences for our work, and those involved in shaping our research, using inclusive approaches in all that we do;
3. Increase capacity and confidence for PPIE amongst researchers, staff, PPIE practitioners and people and patients involved in shaping and influencing our research;
4. Contribute to the evidence base for PPIE;
5. Increase awareness amongst people and patients of opportunities to participate in our research, especially in groups/ geographies with currently low participation rates;
6. Create a culture of engaged research, where PPIE is embedded in our work, and valued by all.

6. Our principles

- Work flexibly, inclusively and respectfully to accommodate needs, interests, concerns and aspirations of those we work with.
- Actively consult, listen to and involve people and patients in shaping all stages of experimental medicine research.
- Inform, educate and stimulate thinking about BRC and CRF research.
- Involve people and patients in decision-making processes within the BRC and CRF.
- Place the involvement of people and patients at the forefront of BRC and CRF research, establishing successful partnerships and sharing best practice with our peers.

7. Key collaborators

Our collaborators include:

People and patients – from the disengaged through to patients and the public who have been actively involved in shaping research before, working with us to steer, inform, and challenge our work. Healthwatch Manchester provides a public voice within our Governance Boards.

Community organisations - working with us to further our understanding and practice involving more diverse, marginalised or seldom heard communities within Greater Manchester in our research, e.g. Wai-Yin Chinese Society, Annana, Charter Alliance Mental Health.

Socially inclusive cultural partners - Working with us to develop innovative arts-led engagement and involvement practices with regional and national audiences, including those who are currently underserved. e.g. [Hospital Broadcasting Association](#), [Reform Radio](#), [Contact Theatre](#), [Brighter Sounds](#), amongst others.

Researchers, academics and practitioners external to the BRC and CRF who share our aims to reduce health inequality and diversify those involved and engaged with research. e.g. [Cathie Marsh Centre for Social Research at the University of Manchester](#), [Directorate of Community and Inclusion at Manchester University NHS Foundation Trust](#), [NIHR Greater Manchester Patient Safety and Translational Research Centre](#), amongst others.

PPIE practitioners within Greater Manchester including our host organisations and NIHR infrastructure e.g. [the Christie NHS Foundation Trust](#), [Salford Royal NHS Foundation Trust](#), [The University of Manchester](#), [NIHR Greater Manchester Patient Safety and Translational Research Centre](#), [NIHR Clinical Research Network](#) amongst others.

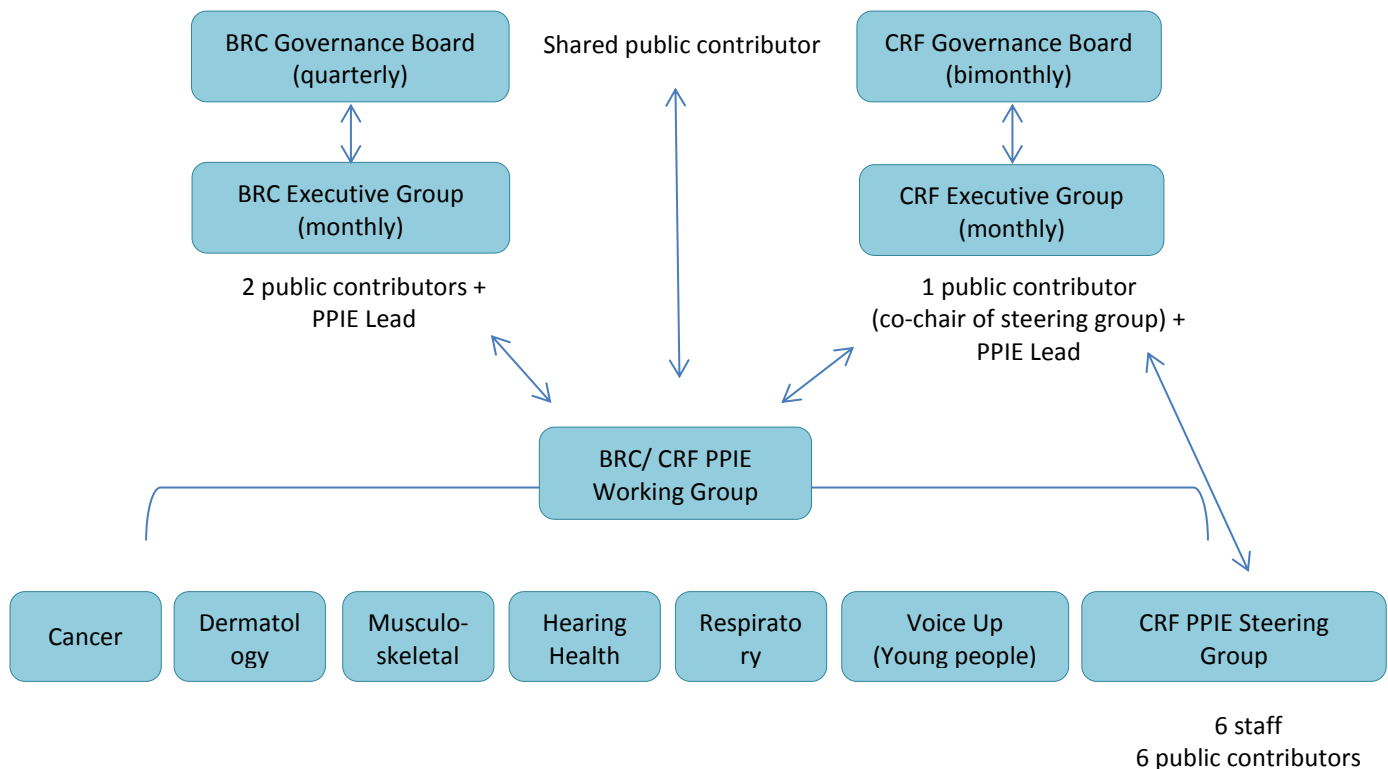
PPIE practitioners across the North, and nationally - We will continue to build relationships, share learning and collaborate on delivery with colleagues across the North, and UK wide.

8. Work programmes and infrastructure

Our delivery plan at a glance:

	Y2 2018-19	Y3 2019-2020	Y4 2020-2021	Y5 2021-2022
PPI	PPI in Governance and Executive Boards and Working Group PPIE Steering Group for CRF Established patient panels including face to face, online and response mode opportunities (cancer, hearing health, musculoskeletal, respiratory, young people) Bespoke support for Dermatology Project based PPI Community-led PPIE			
PE	Ongoing programme of work delivered by BRC and CRF staff Community-led PPIE			
	Data sharing (multi-stakeholder) Dermatology (BRC only) Cancer (BRC and CRF)	Hearing Health (BRC only) Cancer (BRC and CRF) 1 x Fixers project	Musculoskeletal (BRC only) Cancer (BRC and CRF) 1 x Fixers project	
Capacity Building and Talent Development	Supporting contributors (at least 1 annual event) All staff seminars (1 per year) Training by theme (as needed) CRF and BRC induction sessions Establish volunteer network (2019) MRes module/ AHP taster sessions - annual delivery			
Monitoring, Evaluation and Research	Establishing demographic datasets Annual survey and interviews	Formative data capture, monitoring and research. At least 4 peer-reviewed publications Annual surveys and interviews		Ongoing and summative evaluation Annual surveys and interviews
Celebrating our Community	Summer event x 4 Ongoing communications PPIE staff champion x 4			

Our infrastructure:



Our work streams:

A. RESEARCH-LED PPIE - Involvement and engagement which arises from the needs of research

Scaling-up successful methods and infrastructure, and introducing new ways of working to diversify approaches and audiences. Work streams include:

i) Patient and Public Involvement (PPI)

- Continue public representation on BRC/CRF Governance Boards, Executive Groups and Working Groups.
- Continue CRF Involvement and Engagement Steering Group .
- Continue and enhance public research advisory panels serving research in Cancer, Respiratory, Musculoskeletal, and Hearing Health. Research advisory panel infrastructure includes a schedule of face-to-face meetings, digital involvement and response-mode opportunities for involvement.
- Establish (April 2018) and maintain effective processes to support PPI in Dermatology using the principles applied to other themes.
- Continue and enhance *Voice Up* – a research advisory group working across all our strategic aims, made up of young people and patients of Greater Manchester.

ii) Public Engagement (PE)

- Continue support to staff and researchers to generate ideas, deliver innovative and impactful engagement projects, evaluate effectively, and attract further funding for PE.

- Wherever possible, work in alignment with national NIHR priorities e.g. I am Research, International Clinical Trials Day to raise awareness of opportunities to participate in research.
- Work collaboratively with patients, researchers, and cultural partners to deliver up to 7 innovative arts-led public engagement projects co-produced with patients. Reaching regional and national audiences through events, audio broadcast and social media. Creating legacy, and encouraging progression routes into research involvement for contributors.

B. DEMAND-LED PPIE - Involvement and Engagement which arises from the needs of people and patients

Continuing a new programme of work to foster and support PPIE which is conceptualised, driven and co-delivered by people and patients. Work streams include:

- i) Developing effective partnerships to tackle health inequality in experimental medicine research**
 - Continue work to identify and collaborate with key stakeholders - academic, health, community partners and organisations - who are working towards greater understanding and improved practice in diversity and inclusion of PPIE, and research participation, e.g. Cathie Marsh Institute.
- ii) Relationship building with communities who are seldom heard in research**
 - Continue to work with established community groups and influencers to build mutually beneficial relationships and co-deliver PPIE projects. Signpost progression and research participation opportunities.
- iii) Youth voice**
 - Support two young people's personal campaigns relating to PPIE or health research.
- iv) Community-led/social innovation of PPIE**
 - Establish work to support and facilitate an on-going programme of community-led innovation in PPIE practice. Where possible, work with contributors/leaders as co-researchers in PPIE, contributing to PPIE evidence base.

C. CAPACITY BUILDING AND TALENT DEVELOPMENT

Continuing to build knowledge, skills and confidence in PPIE in research amongst people and patients, staff and PPIE practitioners, embedded within the BRC and CRF training programmes. Work streams include:

- i) Supporting public contributors**
 - Continue training and support for public contributors. Deliver at least 4 training sessions for public contributors by 2022. Identify and signpost opportunities for public contributors to progress. E.g. more experienced contributors co-

designing and delivering training to those new to involvement roles, movement between engagement projects and involvement roles.

- Support mentoring approaches amongst public contributors.

ii) All staff seminars

- Deliver at least 4 further all staff interactive training sessions in PPIE, informed by needs assessment and evaluation, working with public contributors to co-design and deliver as part of the BRC seminar series.

iii) Training by theme

- Deliver bespoke interactive training sessions for each BRC theme and the CRF as needed (see implementation plans) working with public contributors to co-design and deliver.

iv) PPIE sessions for staff induction and academic courses

- Bespoke sessions for MRes in Experimental Medicine/Clinical Oncology, BRC and CRF staff induction programmes, academic taster sessions for AHPs, amongst others.

v) Mentorship and advice

- Support staff with a response-mode offer providing bespoke support for PPIE projects or problems. Support PPIE professional development through practice including advice on grant ideas and preparing funding applications.

vi) Volunteering network

- Establish and train a network of up to 10 early-career researchers and/or public contributors who are interested in developing PPIE skills by March 2019.

D. CELEBRATING OUR COMMUNITY THAT DRIVES RESEARCH

Valuing the contribution of our research community, including all of our collaborators, partners, staff and researchers. Work streams include:

i) Celebration event

- Deliver 4 annual events co-designed and delivered with patients and the public to celebrate collective success and say thank you.

ii) Patient Research Ambassadors

- Encourage sign up and work with Patient Research Ambassadors.

iii) Celebrating staff champions

- Develop an annual award to recognise our PPIE Champion. Encourage and nominate staff for local and national awards in PPIE.

9. Measuring success

Linked to our aims, our overarching success criteria are shown below.

Definitions and descriptions:

- Our governance structures described here (Working Groups, Executive Groups and Governance Boards) all have active public involvement.
- Relevant BRC projects will be defined by the BRC Operational Management team for each BRC theme. These are termed here as prioritised projects.
- BRC staff are staff which work on the BRC projects as defined above. CRF staff includes all staff working routinely within the Manchester CRF.
- Effective PPIE is involvement or engagement works which meets its aims and objectives, and contributes positively to research by informing a future action or opinion.

Aim	Success criteria	Measured by	Monitored by
<p>1 – PPIE supporting the strategic aims of the BRC and CRF</p> <p>PPIE has had a positive impact on our research</p>	<p>BRC has effective PPIE within 50% of prioritised projects by 2020 and 95% of prioritised projects by 2022.</p> <p>Support could include: PPIE training, Advice/mentorship on PPIE planning, Utilising PPI panels and processes, Facilitation or delivery of bespoke PPIE meeting research needs.</p> <p>All research progressing through BRC and CRF infrastructure is supported with PPIE throughout. Support could include: PPIE training, Advice/mentorship on PPIE planning, Utilising PPI panels and processes, Delivery of bespoke PPIE meeting research needs.</p> <p>At least 7 publications published or submitted by 2022, by the BRC or CRF have public contributors as named authors.</p> <p>Publications could include peer-reviewed research papers, editorial/commentary pieces or other channels reaching</p>	<p>Monitoring data on all BRC research projects and PPIE work</p> <p>Monitoring data on BRC/ CRF academic sponsored projects and PPIE work</p> <p>Number of publications from work beginning in April 2017</p>	<p>BRC and CRF PPIE Working Group (quarterly)</p> <p>BRC and CRF Executive Groups (annually in October)</p>

	<p>research and health professional audiences.</p> <p>Ongoing monitoring of involvement work shows a maintenance or increase in reported changes actioned as a result of patient input, which the contributors ratify as meaningful impact.</p>	<p>PPIE monitoring data from involvement work – especially feedback forms from involvement opportunities</p>	<p>Public contributors ratify actions.</p> <p>BRC and CRF PPIE Working Group (quarterly)</p> <p>BRC and CRF Executive Groups (annually in October)</p>
<p>2 – Improve diversity of our audiences, contributors, and inclusivity of our approaches</p>	<p>Increased interest and confidence of researchers to work with more diverse populations and socially disadvantaged communities.</p> <p>Effective processes to gather and maintain demographic data on PPIE are in place by October 2018.</p> <p>Increase number of diverse community organisations and support groups that are regularly contacted by Public Programmes Team year on year.</p> <p>Maintain or increase diversity (by all protected characteristics) of patient contributors across all PPIE work streams to achieve demographics in line with University/ NHS Trust workforce demographics by 2022.</p>	<p>Tailored questions within BRC and CRF annual staff survey and follow up interviews</p> <p>Monitoring requests/ advice provided to staff about underserved audiences</p> <p>Public Programmes CRM system</p> <p>Monitoring data from all PPIE work including Public Programmes communications reach and outputs, organisations will have an equal opportunities/ diversity and inclusion policy</p> <p>Monitoring data across all PPIE work</p>	<p>BRC and CRF PPIE Working Group (quarterly)</p> <p>BRC and CRF Executive Groups (annually in October)</p> <p>BRC and CRF PPIE Working Group (quarterly)</p> <p>BRC and CRF PPIE Working Group (quarterly)</p> <p>BRC and CRF PPIE Working Group (quarterly)</p> <p>BRC and CRF Executive Groups (annually in October)</p>

	<p>Patient contributors feel included within the pPIE work that we do. Arising issues around inclusion are acted upon within one month.</p> <p>Audiences of large-scale engagement projects are at least 40% from localities that are currently blue (or lowest) on our heat map.</p>	<p>Evaluation of inclusive practice within every involvement event. Annual survey and follow up interviews with public contributors</p> <p>Project by project evaluation</p>	<p>BRC and CRF PPIE Working Group (quarterly)</p> <p>BRC and CRF PPIE Working Group (quarterly)</p>
3 – Increase capacity and confidence in PPIE	<p>At least 40% of BRC and CRF staff have received support on PPIE by 2020, 60% by 2022. This could be via seminars, inductions, volunteering or delivery of PPIE activity.</p> <p>Increase or maintain number of staff reporting increase in PPIE knowledge, skills and confidence year on year.</p> <p>20% of contributors have taken on an additional role or responsibility by 2020, 40% by 2022 due to their involvement in PPIE. This could be a role within research, personal life or in the workplace e.g. becoming a co-author on a publication or taking on the role of disability awareness officer at work.</p>	<p>Monitor data on training, advice/mentorship, volunteering, inductions, taster sessions, delivery of PPIE activity</p> <p>Survey and interview at induction for new starters Annual survey and follow up interviews of BRC and CRF staff Follow up interviews with random sample of staff</p> <p>Annual survey and follow up interviews with public contributors. Follow up to 10 public contributors in depth – six monthly reviews</p>	<p>BRC and CRF PPIE Working Group (quarterly)</p> <p>BRC and CRF Executive Groups</p> <p>Training Lead (BRC and CRF) annually</p>

<p>4 - Increase evidence base</p>	<p>Annual dissemination at national conferences, monthly blog posts and at least 10 social media posts per month.</p> <p>Public Programmes Team and/ or BRC and CRF staff submit or publish 4 peer-reviewed publications about PPIE work by 2022, and/or nationally/regionally relevant impactful publications (e.g. INVOLVE guidance).</p>	<p>Monitoring data about dissemination – conference presentations</p> <p>Monitoring data on publications to include grey literature, blogs, and other communications. Monitor impact and reach of social media</p>	<p>BRC and CRF PPIE Working Group (quarterly) BRC and CRF Executive Groups (annually)</p>
<p>5 – Increase awareness of opportunities to participate in research</p>	<p>Clear objectives agreed and implemented to signpost research opportunities for each engagement events (face to face and online opportunities).</p> <p>At least five new Patient Research Ambassadors are signed up each year from April 2018, and share their story with the Greater Manchester community.</p> <p>At least 40% of audiences from face to face events report a maintenance or increased awareness of research.</p>	<p>Project objectives signed off by PPIE Lead and relevant BRC/ CRF lead</p> <p>Monitoring data on Patient Research Ambassadors</p> <p>Evaluation of engagement events on a project by project basis</p>	<p>BRC and CRF PPIE Working Group (quarterly) BRC and CRF Executive Groups (annually)</p>
<p>6 – Create culture of engaged research</p>	<p>This is a subjective measure. Indicators include all of those specified above.</p>		

10. Communications

Our PPIE strategy is supported by the Research and Innovation Communications Team at Manchester University NHS Foundation Trust.

Our PPIE work will make best use of appropriate communications to promote our work, celebrate our individual and collective achievements, and disseminate our findings, to our colleagues, partners, stakeholders and funders.

11. Acknowledgements

We wish to thank all of the people who have given their time and expertise to support the development and implementation of this strategy. We have received over 100 responses to our consultation, and each has been valued. Particular thanks extend to all of our active public contributors and partner organisations – your insight, enthusiasm and support is hugely appreciated.