

Patient and Public Involvement in the NIHR Southampton Clinical Research Facility and NIHR Southampton Biomedical Research Centre

Strategy document 2018-2022



Our Commitments to the Public

- We will use a variety of ways to seek the views and insights of patients and the public, and work to ensure that the diversity of people giving their views reflects the diversity of the local population.
- We will provide information that is clear, jargon free and accessible.
- We will ensure people are adequately supported in their involvement role.
- We will make sure there are no financial implications for people's involvement.
- We will involve people in a way that is open, honest and meaningful, being clear about what decisions they can and cannot influence.
- We will act on the views we have sought, and feedback to those who gave them on what we did, working in partnership with patients and the public to improve the quality and relevance of our research.

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The NIHR Southampton Biomedical Research Centre and Clinical Research Facility are part of the University Hospital Southampton Research & Development Department, delivered in partnership with the University of Southampton under the clinical academic leadership of Professors Read and Faust. This strategy relates specifically to Patient and Public Involvement (PPI) within the NIHR Southampton Clinical Research Facility and NIHR Southampton Biomedical Research Centre. It does not refer to the strategic aims, objectives or delivery of PPI within other local organisations.

Introduction

High quality and relevant research cannot happen without the support and collaboration of members of the public. The Government (via [INVOLVE](#)) has been explicit in its promotion of Patient and Public Involvement (PPI) in clinical research. The aim of PPI in research is to ensure that researchers work in partnership with the public throughout the research process, rather than using them as a 'subject' of research. Patients and the public should be involved in all stages of the research from priority setting through to project design, delivery and dissemination.

NIHR Southampton Clinical Research Facility (CRF) and NIHR Southampton Biomedical Research Centre (BRC) have made excellent progress against their previous 2011 -2016 strategic objectives. This document is a revision and refresh of the PPI strategy, building on previous successes and enabling clarity of purpose whilst ensuring effectiveness and efficiency in achieving our PPI objectives.

The BRC is formed of two major themes and three cross-cutting themes:

Major themes:	Lifecourse Nutrition, Lifestyle and Health Respiratory and Critical Care	Underpinning this is the CRF which supports early phase and experimental medicine research in Southampton.
Cross-cutting themes:	Data science Microbial science Behavioural science	

The BRC Behavioural science cross-cutting theme has established a Centre for Public Collaboration and Participation in Health Research. The Centre aims to improve health by providing programmes which will help people change unhealthy behaviours, to reduce malnutrition and obesity and to help control respiratory diseases.

Vision

Southampton strives to deliver a clinical research service that is integral to, and designed around, the needs of the research community and the needs of patients, the public and healthy volunteers participating in research (University Hospital Southampton NHS Foundation Trust [Research Strategy](#)). We need to actively engage with, and understand patient and public needs, perceptions and expectations in order to continually improve the quality of research.

Our vision for the next five years is to fully integrate PPI into the work of the BRC and CRF, from identification of research questions, through study design, delivery and dissemination, as well as actively seeking and acting on participant feedback.

In this document we have used the following terms, and for clarity have provided definitions below:

‘Patient and Public Involvement’ or ‘Involvement’ or ‘PPI’	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 is provided and shared.
NIHR	The National Institute for Health Research (NIHR) is a Government funded body, whose aims are to transform research within the NHS. It supports research personnel in ‘world-class facilities’ –such as the Clinical Research Facility to conduct ‘leading-edge research’, the needs of which are focused on patients and the public.
PPI representatives	A phrase we use to describe members of the public who are involved in our work.
Wessex Public Involvement Network (PIN)	A unique regional collaboration to share PPI resources and expertise. The Wessex PIN will focus on local issues whilst contributing to the NIHR PPI agenda. The BRC and CRF are a founding member of this network.
PPI Officer	A member of staff dedicated to PPI activities.
Patient Research Ambassador	A Patient Research Ambassador is someone who promotes health research from a patient point of view. It is a national NIHR initiative with the aim to encourage both patients and NHS researchers to recognise the importance of research in delivering health care.
PPI Strategy Group	The PPI Strategy Group is formed of PPI representatives who wish to contribute to the review and implementation of research, PPI and public engagement and participation strategy within the BRC/CRF. The group is facilitated by the PPI Officer.
Centre for Public Collaboration and Participation in Health Research	<p>A virtual centre, bringing together the capabilities, knowledge and expertise from diverse teams across the University Hospital Southampton NHS Foundation Trust, the University of Southampton and patients and the general public.</p> <p>The PPI Officer will work closely with the centre, allowing our PPI activities to benefit from the methodological expertise and its user-centred perspective.</p>

We also make reference to other organisations, centres, networks and committees. Further information about each of these can be found in Appendix 1.

Our Strategic Aims

We have identified core principles which underpin our strategic aims for 2017 – 2022. These have been developed with the support of our PPI Strategy Group.

1. Promote inclusive opportunities and establish a supportive culture.

We will strive to deliver clear, meaningful and accessible opportunities for involvement regardless of age, socio-economic status, health or demographic.

2. Build capacity as identified by needs led planning

We aim to integrate PPI fully throughout the CRF and BRC, in each research program and at management level. To ensure that there is appropriate and timely access to PPI representatives who fulfill the required criteria for each individual PPI activity, we will increase capacity, diversity and accurately predict the resources required to deliver PPI locally. We will seek innovative ways to reach underrepresented audiences which are relevant to our research areas, including using innovative digital based approaches.

3. Develop evidence to support impact and value of PPI

We are committed to ensuring that the time our PPI representatives dedicate to our PPI activities has maximum value and the best possible impact on research.

4. Promote awareness and understanding of PPI within the University and Trust, and provide the skills required to practice PPI effectively.

By working with the Wessex PIN, the Southampton Academy of Research and the PPI Strategy Group and under the umbrella of the Centre for Public Collaboration and Participation in Health Research, we will educate students, academics and clinical staff to recognise the importance and value of PPI and understand how to implement it. Education will not be restricted to those directly involved in designing or delivering research, recognising that wider hospital and university staff have a role in promoting opportunities for involvement.

5. Collaboration, networking and dissemination

We will share resources and expertise locally and nationally to prevent duplication of effort and coordinate responses to the NIHR '[Going the Extra Mile](#)' issues. We recognise that collaboration, networking and sharing of best practice can enhance the work within the CRF and BRC and across the wider organisations all striving to improve health and social care.

To understand how we intend to achieve each of these aims, please see our implementation plan.

Implementation Plan

Promote inclusive opportunities and establish a supportive culture

1.1 Develop a range of methods of communication between the CRF and BRC, our existing public contributors and the general public.

- 1.1.1 Collaborate with Research and Development Communications team, the Wessex PIN and our PPI representatives to deliver clear and simple messages promoting PPI and opportunities to take part.
- 1.1.2 Continuously update and improve our existing PPI materials (leaflets, magazines, newsletters) and establish new web-based and social media pages to explain PPI and share our opportunities.

1.2 Remove barriers to involvement

- 1.2.1 Identify the individual needs of the PPI representatives before scheduling the PPI activity to ensure that we work around representatives other commitments.
- 1.2.2 Overcome restrictions related to physical condition/disease.
- 1.2.3 Ensure materials and venues for activity are accessible and suitable for the needs of the attendees.
- 1.2.4 Ensure PPI representatives are reimbursed (as per our payment policy) to ensure financial burden associated with involvement does not adversely affect those with reduced income or caring commitments.

1.3 Establish a supportive culture

- 1.3.1 Promote a culture that recognises people and their experiences as assets.
- 1.3.2 Promote mutuality and reciprocity by defining terms of reference and facilitating PPI activities to ensure all attendees are empowered to voice their opinions. Ensure the mutually agreed 'ground rules' for group activities are respected.
- 1.3.3 Feedback to PPI representatives on the impact that their involvement had, to ensure they feel valued and recognised for their contributions.
- 1.3.4 Develop peer support networks for PPI representatives.
- 1.3.5 Improve the learning and development opportunities provided and available to PPI representatives.

Milestones

Short term (1-2 years)

- Establish new website and social media pages.
- Co-produce (with PPI Strategy Group and Wessex PIN) a feedback form for PPI representatives to report on 1) how well we are meeting the needs of representatives and 2) whether the culture is facilitative.
- Define best mechanisms to feedback to representatives on their involvement (in collaboration with the PPI Strategy Group).
- Introduce a means for PPI representatives to contribute without attending in person (e.g. video conferencing, Facebook groups)

Long term (2-4 years)

- Develop a mechanism to record and report on identified barriers to involvement. Barriers will be reported to senior management, to problem solve or reallocate resources as required, with the goal to abolish the barriers.

- Produce an induction pack for patients and public who are new to PPI. This will be locally produced by the Wessex PIN 'learning and development for patients and the public' task and finish group.

Build capacity as identified by needs led planning

2.1 Increase capacity for PPI

- 2.1.1 Expand the number of public representatives in our database
- 2.1.2 Establish additional PPI groups alongside our adult, young adult, children's group and PPI strategy group, specific to our key research areas such as respiratory disease, nutrition and digital interventions.

2.2 Reach underrepresented audiences

- 2.2.1 Capture and report on the demographics of our PPI representatives to identify areas of under-representation.
- 2.2.2 With the Centre for Public Collaboration and Participation in Health Research, investigate new methods of engaging underrepresented populations in PPI and develop a program of outreach activities, including online methods to reach those unable or unwilling to attend in person.

2.3 Accurately predict resources for local PPI delivery

- 2.3.1 Record and report on active and potential PPI activities to ensure current and future workforce and capacity planning, providing regular updates to Management Teams.
- 2.3.2 Complete accurate costings (as per payment policy) prior to facilitating PPI activities and ensure that, where PPI activities are delivered on behalf of a researcher, that researcher is invoiced for all associated costs. The costs will be returned to the CRF/BRC PPI finances.

2.4 Fully integrate PPI throughout all levels of the CRF and BRC organisations

- 2.4.1 Involve the PPI Strategy Group in the ongoing review and implementation of our research and PPI strategies.
- 2.4.2 Invite PPI Strategy Group members to meet with the CRF & BRC Managers and provide layperson insight and opinion on the topic being discussed.

Milestones

Short term (1-2 years)

- Continue to take part in Trust Open days and relevant University public engagement events, promoting our public involvement opportunities to the attendee of these events.
- Be involved in a Wessex-wide diversity audit, which is being carried out by the Wessex PIN 'inclusivity and diversity' task and finish group, of which we are a member.
- Identify key local community groups, organisations, online media and events to reach underrepresented audiences. This will be done in collaboration with the Centre for Public Collaboration and Participation in Health Research and the Wessex PIN 'growing capacity' task and finish group, which our PPI Officer is leading on.
- Implement formal agreement process with researchers around cost of activities and the process of reimbursement, to ensure funds are always recovered into PPI finances.

Long term (2-4 years)

- A public representative will be appointed to each BRC Theme and will attend theme-specific management and operations meetings.
- Develop an accurate template for calculating resources required for each PPI activity, based on data

captured relating to time spent on individual tasks over previous 2 years, to allow accurate resource planning.

- Carry out regular community outreach and digital media activities to target new audiences.
- PPI representatives from the PPI Strategy Group will be given the opportunity to have oversight and input into all levels of the CRF and BRC organisations.

Develop evidence to support impact and value of PPI

3.1 Ensure maximum value to our PPI activities

- 3.1.1 Set specific, measurable, achievable, realistic and timely objectives for each PPI activity, and share these with PPI representatives in advance.
- 3.1.2 Collect feedback from PPI representatives on how well they understood the objectives of an activity, and whether they felt these objectives were met.
- 3.1.3 Monitor how effectively we are delivering PPI activities and identify training needs or areas of improvement, using data collected from the 'PPI feedback form for researchers' and from PPI representatives.
- 3.1.4 When appropriate, develop a job description for PPI representatives working on a specific project or study and have tailored terms of reference.

3.2 Monitor the impact of our PPI activities

- 3.2.2 Researchers to complete the 'PPI feedback form for researchers' following each activity they undertake, capturing information on how the PPI activities have influenced the project.
- 3.2.3 Keep up-to-date records of the objectives of each PPI activity, whether these objectives were met and how the PPI activity influenced the project.
- 3.2.4 Work closely with the BRC Centre for Public Collaboration and Participation in Health Research and Wessex PIN to evaluate the impact and value of PPI, benefiting from the methodological expertise of the Centre and Wessex PIN members.

Milestones

Short term (1-2 years)

- Formalise mechanism for researchers/staff to record the objectives for a PPI activity and share the objectives with the PPI representatives involved.
- Refine feedback form for researchers, following pilot of existing form.
- Define means to collect feedback from PPI representatives on 1) their understanding of the objectives and 2) whether they were achieved (and if not, why not). This will be done in collaboration with the PPI Strategy group.
- Host a workshop exploring PPI impact, bringing together experts from the field. This will be held in collaboration with the 'exploring impact' task and finish group of the Wessex PIN, which our PPI Officer is leading on.
- Funding bid to obtain resource to evaluate PPI impact, in collaboration with the BRC Centre for Public Collaboration and Participation in Health Research and Wessex PIN.

Long term (2-4 years)

- Programme of research to explore the impact of public involvement in health research. The major outcome of this research will be the development of a training resource for CRF/BRC staff to optimise conduct of PPI and facilitate evaluation of impact.

Promote awareness and understanding of PPI within the University and Trust, and provide the skills required to practice PPI effectively

4.1 Improve available guidance for researchers wishing to carry out PPI

- 4.1.1 Make our existing guidance documents readily accessible and provide additional resources based on researcher feedback.
- 4.1.2 Host monthly drop-in sessions where staff can talk informally to the PPI Officer about PPI ideas or to ask for support.

4.2 Increase awareness and understanding of PPI within the Research and Development department

- 4.2.1 Deliver an outreach educational program to promote PPI to staff within the BRC by presenting on PPI at laboratory team meetings or other relevant scientific meetings.
- 4.2.2 Strengthen delivery of PPI training to new Research and Development staff as part of their local induction program, and introduce an annual update on PPI for CRF staff by presenting at nurse forums or education days.

4.3 Provide researchers with the skills required to carry out effective, meaningful PPI activities

- 4.3.1 Work with BRC training leads and the Southampton Academy of Research to identify skills deficits and education and training needs relating to PPI.
- 4.3.2 Integrate quarterly PPI training into researcher's professional development, with educational lecture series and workshops.

4.4 Promote the importance of PPI in research to wider staff within University and Trust

- 4.4.1 Strengthen the delivery of undergraduate teaching on PPI to medical students, with an aim to extend into courses for the non-medical professions, such as nursing and allied health professionals.
- 4.4.2 Strengthen representation at the Trust Patient Experience and Engagement Steering Committee and the University of Southampton's Engaged University Strategy Committee.

Milestones

Short term (1-2 years)

- Establish PPI pages for researchers on the CRF and BRC websites, where researchers can readily access guidance documents.
- Co-produce new guidance documents for researchers, including designing a job description template for PPI representatives and writing case studies and examples of different approaches and methods.
- Develop and deliver PPI training targeted at investigators and trainees aligned with BRC research areas and cross cutting themes. This training will be co-designed with the PPI Strategy Group, Centre for Public Collaboration and Participation in Health Research and BRC training leads.

Long term (2-4 years)

- Extend undergraduate PPI training to additional related professions.
- Implement annual updates into CRF staff training.
- Define and deliver quarterly PPI training as part of BRC researchers' professional development.

Collaboration, networking and dissemination

5.1 Collaboration on a local level

- 5.1.1 Play an active role in the Wessex PIN, for which we are a founding member.
- 5.1.2 Maintain our positive relationships with PPI leads, delivering joint projects when appropriate. This includes the NIHR Research Design Service South Central, Southampton CRUK-NIHR Experimental Cancer Medicine Centre, MRC Lifecourse Epidemiology Unit and the University of Southampton.

5.2 Sharing of best practice

- 5.2.1 Continue involvement with the NHS Research and Development Forum, UK Clinical Research Facility Network PPI/E work stream and BRC PPI/E leads group.
- 5.2.2 Attend and present at relevant regional and national PPI/E meetings and conferences.
- 5.2.3 Make examples of success publically available, through formal publication or through our CRF and BRC websites.

Milestones

Short term (1-2 years)

- Lead on delivery of the 'building capacity' and 'exploring impact' task and finish groups of the Wessex PIN, which match the priorities of the CRF and BRC.

Long term (2-4 years)

- Make successes publically available.
- Continue to collaborate with the MRC Lifecourse Epidemiology Unit, co-leading on PPI for a large 5 year study programme with their PPI lead.

Public Engagement

The BRC and CRF have separate public engagement and participation strategies, aligned to University Hospital Southampton NHS Foundation Trust's R&D Public Engagement and Participation Strategy. This is led by the Research and Development Communications team. This engagement and participation strategy strives to:

- Stimulate public interest in, and engagement with, our clinical research;
- Raise participation rates;
- Enable exchange of ideas, views and knowledge between the public and BRC/CRF staff;
- Support people's progression from engagement to involvement.

Underpinning our PPI strategic aims is the need to engage with patients, public and staff. Each of our core principles will require engagement in order to be delivered, and our PPI Officer will collaborate closely with Research and Development Communications team at all stages. To support engagement activities, our PPI Officer will continue to grow and develop the NIHR Patient Research Ambassador initiative. These ambassadors will ensure relevant and appropriate promotion of PPI and clinical research awareness and participation, across the Trust and community settings.

Resources

The CRF and BRC have a full time member of staff dedicated to PPI activities (the PPI Officer) who will lead on implementation of this strategy. We will use internship schemes to increase the workforce of the PPI team.

There is a dedicated PPI budget to support the following:

- Staffing costs for the PPI Officer and any additional staff costs associated with each PPI activity. This includes covering costs of an additional staff member for out-of-hours work (to meet requirements of UHS lone working policy) or paediatric nursing support for PPI activities with children.
- Expenses and time reimbursement for PPI representatives contributing to BRC and CRF wide activities, such as those attending the PPI Strategy Group or being involved online.
- Consumables (including writing materials, printing resources, digital resources)
- Conference attendance and training course costs and travel expenses relating to PPI/E activity.
- Travel and refreshments expenses for Patient Research Ambassadors (as per UHS volunteering policy).

Principal investigators are expected to fund PPI representatives' expenses for study-specific PPI meetings. For pre-funding activities researchers can apply for funding support from the Research Design Services to cover PPI costs.

Reporting

The PPI Officer reports on the current workload to CRF management on a fortnightly basis. In addition, PPI is a standing item on management team meetings agendas for the CRF (weekly) and BRC (six weekly). A metrics database is used to document all PPI activities, including advisory services. Our PPI feedback form for researchers allows us to continuously monitor outcomes from our PPI activities, enhancing our reporting and ability to measure impact. PPI activities will be reported externally in CRF and BRC NIHR annual reports.

Monitoring and review

PPI representatives will be involved in the ongoing monitoring and review of the strategy and associated work plan through PPI Strategy Group meetings. The strategy will be reviewed annually and the work plan will be under constant review, with formal review of the PPI Officer's progress against deliverables integrated into the post holders' UHS annual appraisal.

Date last reviewed by PPI Strategy Group: February 2018.

Associated documents

[UHS Research Strategy](#), UHS volunteering policy, UHS lone working policy, Terms of Reference for PPI Strategy Group, [UHS Patient Experience Strategy](#), PPI in the NIHR Southampton CRF/BRC payment policy, University Hospital Southampton NHS Foundation Trust Research and Development Public Engagement and Participation Strategy, NIHR Southampton Biomedical Research Centre and Clinical Research Facility Joint Public Engagement and Participation Strategy, NIHR [Going the Extra Mile](#) report, University of Southampton [Faculty of Medicine](#) and [Faculty of Health Sciences](#) research strategies, Wessex PIN Action Plans, Wessex PIN Task and Finish group documentation.

Appendix 1

The following table briefly describes other organisations, centres, networks and committees which are mentioned in this strategy.

INVOLVE	INVOLVE is a national advisory group that supports and provides guidance relating to public involvement in the NHS, public health and social care research - funded by and part of the NIHR.
Research and Development Communications team	The Trust Research and Development Communications team works to engage public, clinical, industry and policy audiences with our work regionally and nationally.
UK Clinical Research Facility Network PPI/E work stream	The UK Clinical Research Facility Network supports and shares best practice in clinical research across the UK and Ireland. The PPI/E work stream provides: leadership and support to CRF PPI leads; an open forum for delivering a collaborative program of work; a process for reporting, reviewing and monitoring impact.
Trust Patient Experience and Engagement Steering Committee	The Patient Experience and Engagement Steering Group is a sub-group of the Trust's Quality Governance Steering Group and is established to set, steer and monitor the delivery of the trust's patient experience strategy and public involvement strategy.
Engaged University Steering Group	This group oversees and provides strategic leadership for the University of Southampton's public engagement activity.
Southampton CRUK-NIHR Experimental Cancer Medicine Centre	The Experimental Cancer Medicine Centre provides the specialist laboratory, administrative and clinical delivery support needed to deliver early phase cancer studies quickly and fully.
MRC Lifecourse Epidemiology Unit	The Medical Research Council (MRC) Lifecourse Epidemiology Unit 's mission is to promote human health using lifecourse epidemiological methods.
NHS Research and Development Forum	A UK-wide community of practice and professional network for the health and care research management, support and leadership workforce.
NIHR Research Design Service South Central	The Research Design Service provides support to health and social care researchers across England on all aspects of developing a grant application, including involving the patients and the public.
Southampton Academy of Research	The Academy works to ensure the education, training and career development of Southampton's research workforce. They will inform the development, and support delivery, of education and training to enable junior investigators to manage PPI and engagement activities in their research projects and programmes.
University Hospital Southampton Research and Development Department	The Research and Development Department is the department in which the NIHR CRF and NIHR BRC sits.
BRC training leads	Each of the 5 themes of the BRC has a nominated training lead. The leads work closely with the Director of the Southampton Academy of Research to support and train BRC-associated staff and students.