

NIHR Southampton Biomedical Research Centre and Clinical Research Facility joint public engagement and participation strategy 2017-2022

Summary

This strategy outlines our aims, ways of working and plan for engaging with the public about our clinical research, and encouraging their participation in that research, over 2017-2022.

To ensure joined up working, it is aligned with the 2017-2022 public engagement and participation strategy of our host organisation, University Hospital Southampton NHS Foundation Trust (UHS).

In 2012 Southampton was the first NHS Trust site to establish a dedicated communications and engagement resource for all onsite clinical research and development (R&D). The consistent, joined-up engagement and participation activities delivered by this team for local National Institute for Health Research (NIHR) facilities, including the NIHR Southampton Biomedical Research Unit (BRC) and NIHR Southampton Clinical Research Facility (CRF), provide the platform for this strategy, which has three aims:

1. To raise public awareness of, and engagement with, our clinical research, its benefits and what it means for them (engagement)
2. To support discussion between the public, healthcare professionals and BRC and CRF researchers to inform research practice and the growth of new research activity in Southampton (engagement into involvement)
3. To raise awareness of, and increase access to, opportunities to participate in clinical research amongst the public and staff (participation)

These aims will be delivered through a range of activities onsite, offsite and online, with evaluation to inform and improve our approach.

As part of this work we will identify and engage with audiences and communities who have shared interests, and partner with people and organisations at local, regional and national level, with the strategy evolving to best support audience needs and our intentions.

Our work will be closely linked with the BRC-CRF joint patient and public involvement (PPI) activity, to use engagement and participation as entry points for public and staff involvement.

Introduction

This strategy outlines our aims, ways of working and plan for engaging with the public about our research, and encouraging their participation in that research over 2017-2022, and the context for this.

In 2012, Southampton became the first NHS Trust site to establish a dedicated university-hospital R&D communications and engagement resource – joining up engagement and communication activity for all local NIHR facilities and wider research in one place.

The engagement and participation activities that have been delivered over the last five years through this work form the basis for this strategy.

The context: Southampton's view of public involvement, engagement and participation

Southampton makes a clear distinction between public involvement on one hand, and public engagement, communications and promotional activities on the other.

These areas of activity cross-over and support each other but the purpose and expectations of people involved differs. Put simply, it is the difference between committing to doing research in partnership with someone and acting on their input (involvement), versus sharing the nature of research with someone (engagement) or inviting someone to be part of a study (participation). See appendix one.

We think being clear on this is critical to success, and it is why we have separate PPI and PPE-P strategies, delivered by specialist teams.

The context: summary of local activity to date

Our 2012 communications strategy provided a plan for building joined-up communications and engagement activities across Southampton's NIHR facilities and wider research.

We developed a range of activities that were piloted and delivered through that strategy, including a single online presence (with microsites for each NIHR facility), social media, e-newsletters, print and digital publications, onsite and offsite events, and support for NIHR campaigns.

Reach has been extensive, including approximately 100,000 web visitors per year, 3-5,000 members of the public engaged through the annual UHS open day event, and around £400-600,000 of advertising-equivalent value (the cost of space taken by our stories if paid through advertising) of research press and media coverage per month.

The context: regional insight

The aims, ways of working and plan described here also take into account recommendations from an insight project that took place in 2014. This project looked at views of clinical research, participation influences and barriers to taking part amongst public and healthcare professionals across the Wessex region.

Overall, the results from this centred on a move from broad awareness campaigns, towards supporting clinician-public engagement, focussing in on individual or group personal motivations around research and improving access to trial information and opportunities.

What we want to see by 2022 – our vision and aims

Our vision

We want the people of our region to have easy access to our clinical research participation information and opportunities that are relevant to their needs or interests. We want them to be freely able to learn more about, debate and become directly involved in the development of that research.

Strategic aims

Based on the above, our strategic aims are:

1. To raise public awareness of, and engagement with, our clinical research, its benefits and what it means for them (engagement)
2. To support discussion between the public, healthcare professionals and BRC and CRF researchers to inform research practice and the growth of new research activity in Southampton (engagement into involvement)
3. To raise awareness of, and increase access to, opportunities to participate in clinical research amongst the public and staff (participation)

Approach and resources

In delivering these aims, we will:

- Develop and grow what we do based on existing activities, outputs and platforms, and continuously evaluate to inform and improve our approach.
- Identify and engage with audiences and communities who have shared interests, for example disease-specific interest groups and sports clubs.
- Work with others, both inside and outside our organisation, sharing our learning across the NHS and NIHR.
- Make this work part of what we, as an organisation, do routinely and make it sustainable in the long-term.

The UHS R&D communications and engagement resource will deliver this strategy with, and for, the BRC and CRF. They will continue to work with colleagues at the University of Southampton (including the Public Engagement with Research Unit) and Southampton Cancer Research UK Centre, CRN Wessex and NIHR, to ensure joined-up delivery of activities.

Key areas of work

Activities, outputs and platforms will include:

Onsite engagement, outputs and events

We will develop new onsite engagement activities and events using existing opportunities, including the annual UHS annual open day event, UHS membership events and local facility open-door events.

Offsite and community and partner engagement, outputs and events

Through our engagement with specific audiences and communities, we will develop new formats, using our and others' existing events as starting points.

Capacity building, evaluation and resource development

We will use evaluation frameworks established by the National Coordinating Centre for Public Engagement (engagement) and UK Government (participation, communications and promotion) to assess the reach, efficacy and quality of our work.

Through this, and through working with BRC and CRF staff, we will build our own knowledge base of what works, and share this resource with colleagues across the NHS and NIHR. We will also work with the Southampton Academy for Research (SoAR) to explore formal training.

Implementation plan

Aim 1: To raise public awareness of, and engagement with, our clinical research, its benefits and what it means for them (engagement)

Milestones and objectives:

1. Evaluate of a minimum of two onsite and two offsite engagement activities (2018-2019)
 - a. Audience-led development and delivery of one event per quarter
 - b. Produce a summary of learning and recommendations for 2019 onwards
2. Use learning under (1) to plan and deliver an annual programme of engagement activities (2019-2022)
 - a. Plan annual programme of activities based on recommendations under (1)
 - b. Deliver 2019-2022 programme and continually evaluate to inform and approve our approach
3. Produce recommendations for future development of engagement and communications beyond 2022 (2021-2022)
 - a. Collate learning into evaluation report
 - b. Consult with audiences, internal and external stakeholders on findings
 - c. Deliver recommendations beyond 2022

Aim 2: To support discussion between the public, healthcare professionals and BRC and CRF researchers to inform research practice and the growth of new research activity in Southampton (engagement into involvement)

Milestones and objectives

1. Deliver and evaluate a minimum of two pilot disease or interest-specific, discussion activities (2018-2019)
 - a. Audience-led development and delivery of activities
 - b. Produce a summary of learning and recommendations for 2019 onwards
2. Use learning under (1) to define and deliver an annual programme of two priority-area discussion activities (2019-2020)
 - a. Plan annual programme of activities based on recommendations under (1)
 - b. Deliver 2019-2020 programmes and continually evaluate to inform and approve approach
3. Use learning under (2) to develop a minimum of two engagement into involvement activities annually (2020-2021)

- a. Follow up engagement with those involved in activities under (2) to deliver events with PPI function that builds on discussion of key issues/areas to facilitate new PPI partnerships with BRC and CRF researchers
- 4. Produce recommendations for future engagement-into involvement work beyond 2022 (2021-2022)
 - a. Collate learning into evaluation report
 - b. Consult with audiences, internal and external stakeholders on findings
 - c. Deliver recommendations beyond 2022

Aim 3: To raise awareness of, and increase access to, opportunities to participate in clinical research amongst the public and staff (participation)

Milestones and objectives

1. Develop online listing of BRC and CRF participation opportunities via a 'UHS trial finder' search function on the Clinical Research in Southampton website and/or equivalent provision on UHS patients' My Health Record portal (2018-2019)
 - a. Inform the development of working processes to enable online listings and enquiries
 - b. Deliver the communications aspects of process to develop trial finder function
2. Establish a mechanism to record staff participation rates in BRC and CRF research studies, including baseline data (2018-2019)
 - a. Work with UHS R&D and HR teams, and external colleagues, to explore existing mechanisms
 - b. Implement mechanism and reporting cycles
3. Evaluate a minimum of two study-specific awareness-raising campaigns developed at study setup stage with study teams and target demographic (2018-2020)
 - a. Work with BRC and CRF colleagues to identify possible studies and develop campaign plans
 - d. Deliver campaigns and continually evaluate to inform and approve approach
5. Use learning under (3) to develop off-the-shelf participation communication/promotional packages, with costings for commercial studies, as part of the study setup process for BRC and CRF studies (2019-2020)
 - a. Design and develop packages and template materials
 - b. Work with UHS R&D team research support team to ensure packages become part of the standard offer/practice in the study setup process
4. Implement and evaluate a pilot staff research participation and/or referrals reward scheme (2019-2020)
 - a. Explore options for reward scheme with onsite contractors/external colleagues and existing similar schemes
 - b. Deliver reward scheme pilot and evaluation report to inform approach going forward
5. Evaluate metrics on staff awareness of, and referral to, BRC and CRF research activities and report on these metrics
 - a. Develop and deliver annual survey and focus group activities to gather insights
 - b. Based on learning from (5a) develop annual reporting methods
 - c. Use learning under the above and continually evaluate to inform and approve approaches
6. Produce recommendations for future participation communications and promotional work beyond 2022 (2021-2022)
 - a. Collate learning into evaluation report
 - b. Consult with audiences, internal and external stakeholders on findings

c. Deliver recommendations beyond 2022

Appendix one

Public engagement and public involvement defined

Public engagement defined

"Public engagement describes the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit."

The National Centre for Coordinating Public Engagement (NCCPE)

The NCCPE created this definition through the 2006-2011 Beacons for Public Engagement initiative. This project gave five UK universities five years' money and support in developing organisation-wide public engagement activity, producing the largest and most robust body of learning, guidance and resources on the subject.

Public involvement defined

"INVOLVE defines public involvement in research as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants."

INVOLVE

Part of NIHR, INVOLVE is the national advisory group for collating and facilitating best practice in public and patient involvement in clinical research. They clearly distinguish between involvement, engagement and participation activities, with engagement defined per the NCCPE statement and participation defined as "where people take part in a research study."

In Southampton, involvement, or PPI, is delivered by the PPI function against a specific BRC-CRF PPI strategy. Whilst engagement/participation (PPE-P) is delivered by UHS R&D communications against this BRF-CRF PPE-P strategy which is aligned to the wider UHS PPE-P strategy. There is significant cross-talk and collaboration between these functions, to progress public interactions from engagement and/or participation towards involvement.

To ensure clarity of purpose and expectations for all, it is important Southampton makes the same distinction as INVOLVE, based on these established definitions.