

University Hospital Southampton NHS Foundation Trust

public engagement and participation strategy

Executive summary

This strategy outlines the aims, approaches and plan for public engagement and participation activities in support of the 2017-2022 University Hospital Southampton NHS Foundation Trust (UHS) R&D strategy.

UHS was the first NHS Trust to establish a dedicated R&D communications and engagement function and over the last five years, that function has grown through and informed the thinking and activities underpinning the 2017-2022 R&D strategy.

This positions UHS well to deliver engagement and participation activity against strategy aims, articulated through three engagement and participation aims:

1. To develop peoples' awareness of, and engagement with, the nature of our clinical research, its benefits and implications (engagement)
2. To foster discussion between the public, healthcare professionals and researchers to inform research-as-care thinking, research practice and growth of new research activity (engagement into involvement)
3. To ensure maximum awareness of, and access to, opportunities to take part in clinical research amongst the public and healthcare staff (participation)

These aims will be delivered through a broad programme of activities onsite, offsite and online, with robust evaluation informing a continuous improvement model of working.

Existing and new partnerships with key local and national stakeholders and their relevant functions will support delivery and strategic development of these programmes of work, with the strategy evolving to best support the vision and intent.

Introduction

This strategy outlines our aims, approach and plan for public engagement and participation activity in support of the 2017-2022 UHS R&D strategy.

The importance of effective public engagement and participation activity to support the promotion and facilitation of clinical research is an established fact. National drivers from the National Institute for Health Research (NIHR) and other major funders, coupled with ground-up demand for professional and effective services have led to investment in dedicated posts and functions across the NHS.

Southampton was the first NHS Trust to establish a dedicated, university-hospital partnership communications manager and function.

The structures and outputs developed through this function have grown and informed the thinking and activities leading to the emergence of the 2017-2022 R&D strategy. This developmental path means that UHS is well placed to use these platforms and activities for the effective delivery of the R&D strategy from 2017-2022.

Southampton's view of public involvement, engagement and participation in clinical research

Southampton makes a clear distinction between public involvement on the one hand, and public engagement (plus communications supporting participation) on the other. This is dissonant with the wider interpretation within the NIHR infrastructure and NHS, which typically incorporates all three activities into one strategy and function.

Our approach reflects the importance we place on clarity of purpose, and draws on the following established definitions of public engagement and public involvement.

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.”

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

The context: summary of local activity to date

The 2012 Southampton Centre for Biomedical Research Communications strategy provided a cohesive framework for effective communications and engagement across Southampton’s NIHR and other clinical research infrastructure, and wider clinical research activities.

Under that strategy, a single online presence (with microsites for each NIHR entity), social media, e-newsletters, print and digital publications for public and patients, live events onsite and offsite, and support for NIHR campaigns were piloted and delivered. This establishment of coherent, effective platforms for communicating and engaging about clinical research has progressed in step with development of content, interventions and tactical approaches tied to research delivery and strategic development needs.

Reach has been extensive and includes ~100,000 web visitors per year, 5,000 visitors engaged through the UHS annual open day event, and ~£400-600,000 of advertising-equivalent volumes of press and media coverage per month.

Variable capacity within the UHS R&D communications function has seen variable exploitation of this infrastructure and reach. However it represents a solid base to serve strategic development of communications, public engagement and participation activity.

The context: 2014 Wessex clinical research perceptions study

In 2014 R&D communications commissioned a major insight project looking at public and healthcare professionals’ perceptions of clinical research, barriers to participation and influences around this. With a representative sample of the Wessex region, and insight into both sides of the clinical conversation, it represents a unique learning resource in NHS R&D.

Summarised in the reports, available at www.uhs.nhs.uk/communications, the main findings were:

- Confirmation of highly positive public views of clinical research per se
- Confirmation of perceptions of risk, and time commitments being the primary barriers
- The above contributing to a participation funnel that went from ~90% positive views, through 10% having been spoken to about research opportunities, to <1% participating.
- Identification of personal, or loved ones’, health as the key motivator
- Identification of healthcare professionals as trusted voices in explaining research
- Key barriers for clinicians lying in time pressures, access to information and self-identification as either research or practitioner

Recommendations made in the report centred on a movement away from broad awareness campaigns, towards fostering effective clinical conversations about research, supported by clinician access to information and empowerment of the public, and closing in on individuals’ or groups’ personal motivations.

Vision, strategic intent and strategic aims

We want to see universal access to the right research opportunities for the people in our region. Our intent is to ensure that Southampton is a place where people are aware of, and can easily access, research opportunities relevant to them, and are freely able to learn more about, debate and become directly involved in the development of that research.

Based on this, our strategic aims are:

1. To develop peoples' awareness of, and engagement with, the nature of our clinical research, its benefits and implications (engagement)
2. To foster discussion between the public, healthcare professionals and researchers to inform research-as-care thinking, research practice and growth of new research activity (engagement into involvement)
3. To ensure maximum awareness of, and access to, opportunities to take part in clinical research amongst the public and healthcare staff (participation)

Approach

In delivering against these aims, we will:

- Build engagement activities through continuous improvement and learning, using robust evaluation measures for all activities – including frameworks established by NCCPE and UK Government
- Work on an audience-focussed basis, centred on communities of interest and social networks
- Work collaboratively internally and externally, disseminating learning across NHS/NIHR colleagues
- Work towards sustainability through capacity building, resource development and income generation

The R&D communications function will continue to work with partner organisations, including University of Southampton and Cancer Research UK, CRN Wessex and NIHR, to ensure cohesion and effective delivery of engagement and participation activities.

Within UHS, we'll work with R&D colleagues, information services and clinical leadership, via the associate medical director for research, which will underpin efforts to develop the research culture, and awareness of research and research referrals.

Key areas of work

Key strands of work and outputs will include:

Onsite engagement, outputs and events

We will build on and refine previous activities to engage patients and public on the UHS site. Previous examples include the annual UHS annual open day event (~5,000 reach), UHS membership events (reach 100-200 bi-monthly) and open-door events within NIHR infrastructure.

Offsite community and partner engagement, outputs and events

Through our work with communities of interest we will develop new formats and refine our previously delivered activities, including the Discovery Talk pay events (reach of ~200), public spaces engagement (e.g. world COPD day activities in Southampton city centre), where appropriate.

Capacity building, evaluation and resource development

We will work in partnership with Southampton BRC and CRF staff to deliver engagement, participation and communication outputs, sharing learning through doing and developing resources of lasting value for wider use and sharing.

Alongside this we will use evaluation frameworks established by NCCPE and UK Government to implement tailored, purpose-led evaluation of individual activities and programmes of work.

Implementation plan

Aim 1: To develop peoples' awareness of, and engagement with, the nature of our clinical research, its benefits and implications (engagement)

Milestones and objectives

1. Evaluation of a minimum of four onsite, four offsite engagement activities/event formats (2018-2019)
2. Definition and delivery of an annual programme of public engagement activities/events based on above (2019-2020)
3. Exploration and expansion of engagement activity with key communities and audiences to progress minimum three major engagement into involvement activities (2020-2021)
4. Consolidation of key partnerships and community relationships in standing programmes of engagement (2021-2022)

Aim 2: To foster discussion between the public, healthcare professionals and researchers to inform research thinking, practice and growth of new research activity (engagement into involvement)

Milestones and objectives

1. Evaluation of a minimum of two pilot disease-specific discussion and dialogue event formats (2018-2019)
2. Definition and delivery of annual programme of four priority-area discussion and dialogue events based on the above (2019-2020)
3. Exploration and expansion of dialogue follow-on activity to progress minimum two engagement into involvement activities annually(2019-2020)
4. Consolidation of dialogue and discussion activities into standing programmes and partnerships centred on communities of interest (2021-2022)

Aim 3: To ensure maximum awareness of, and access to, opportunities to take part in clinical research amongst the public and healthcare staff (participation)

Milestones and objectives

1. Establishment of a mechanism to record staff participation rates in research studies (2018-2019)
2. Implementation of a refined 'trial finder' function on the UHS and Clinical Research In Southampton websites and/or equivalent provision on My Health Record portal (2018-2019)

3. Evaluation of pilot staff research participation and/or referrals reward, enablement and awareness interventions (2019-2020)
4. Implement, and integrate into R&D processes, standard communications packages for studies in setup, with costings for commercial studies (2020-2021)
5. Evaluate a minimum three trial-specific campaigns developed at study setup stage with study team and target demographic (2020-2021)
6. Establish evaluation/metrics on staff awareness of, and referral to, research activities (2021-2022)