National Institute for Health Research

South Manchester Respiratory and Allergy

Clinical Research Facility

Patient and Public Involvement and Engagement Strategy

2014 – 2016

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Overview

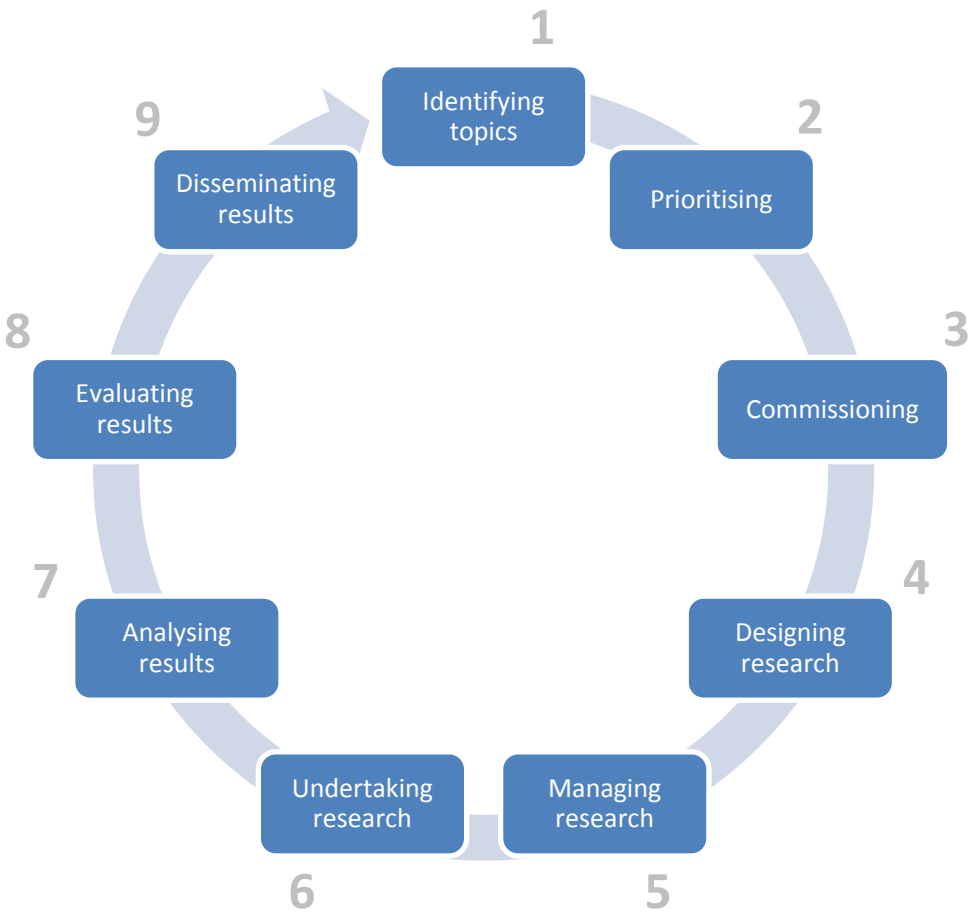
This document describes the rationale and approach for developing patient and public involvement (PPI) and engagement opportunities in the NIHR South Manchester Respiratory and Allergy Clinical Research Facility (RACRF) and should be read alongside the overarching strategy for the RACRF.

Background

Defining patient and public involvement and engagement in research

Patient and public involvement (PPI) is defined as an active partnership between researchers and the public in 9 stages of the research process (figure 1), rather than as subjects of research.

Figure 1: The research process (adapted from Hayes et al, 2012)



PPI is founded on the core principle that people who are affected by research have a right to have a say in what and how research is undertaken and is considered a key component of a quality research culture (Department of Health, 2005).

Research funders and sponsors increasingly require PPI to be demonstrated in different stages of the research process. The rationale for this is that involvement can lead to research studies which are more relevant, better designed, more likely to recruit (thus completing to time and target), and whose results are more useful and better disseminated (Brett *et al*., 2010; Goodare and Smith, 1995; Staley, 2009).

Public engagement (PE) is defined by the National Coordinating Centre for Public Engagement (NCCPE) as the myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is therefore a two-way process, involving interaction and listening.

The RACRF have committed to:

> *Providing opportunities for patients and the public to learn more about research activities, share their experiences and have a say in respiratory research*

Terminology

No common agreed terminology exists to describe the people who access health and social care services. Indeed, several terms are used in the literature including 'user', 'patient', 'consumer', 'customer' and 'lay person'. INVOLVE (established by the Department of Health as a national advisory group to support active patient and public involvement in the NHS, public health, and social care research) use the terms "the public" or "people who use services".

Patients and the public will be the term used throughout this document.

Current levels of involvement and engagement in RACRF

Researchers working within the core themes of the RACRF have demonstrated pockets of good practice with respect to involvement and engagement of patients and the public in research. As a facility, however, the RACRF has lacked a coherent strategic plan for involvement which sets out key objectives and realistic goals. Establishing key performance indicators (KPI's) for these goals will ensure that activity is measurable, and that reporting shows progress towards achieving the objectives of the PPI/E strategy.

Where engagement activities have occurred, measurable impact has not previously been considered, although excellent feedback from attendees has been received. Ensuring PE activities are congruent with the RACRF PE strategy going forward will be essential in order to measure impact of such activities and meet annual reporting requirements.

The facility has lacked *formal* support for researchers on 1) how to involve patients and the public in the research process, and 2) how to manage the expectations of involvement from the patient and public perspective. Establishing and/or signposting researchers to PPI/E guidance documents or training opportunities will be vital in order to ensure the importance and value of PPI is fully appreciated and subsequently embraced by RACRF researchers.

The RACRF strategy should therefore aim to encompass commitment, awareness, training and tools to measure its success.

Proposed Patient and Public Involvement Strategy

The facility has employed a Public Involvement and Engagement Manager 0.4FTE to drive its commitment to PPI and PE activities within its core themes. The PPI and PE strategies thus reflect the time and resource allocated to PPI/E to complete the objectives.

Objective 1: Increase awareness of PPI to both RACRF researchers and patients and the public	
Goal	**KPI – Metric**
1.1) Publish a statement of the RACRF commitment to public involvement (e.g. patient pledge) which researchers sign up to	▪ Number of researchers signed up to pledge
1.2) Develop a guidance document for patients and the public on the purpose of PPI reviewed by patients and the public	▪ Number of patients/public involved ▪ % positive feedback
1.3) Meet patients, the public and representative organisations (where applicable) to promote the RACRF and opportunities for involvement	▪ Frequency of interactions
1.4) Create a register/advisory group of patients, the public and representative organisations (where applicable) who are willing to get involved in the research process	▪ Number of members on register/advisory groups

Objective 2: Ensure high standards in PPI through education and training	
Goal	**KPI – Metric**
2.1) Source or develop a guidance document for researchers on the purpose of PPI and benefit of involving patients and the public (incl. a PPI knowledge quiz)	▪ % knowledge quiz scores
2.2) Develop an online information resource (to include 2.1) for researchers on PPI activities (e.g. briefing notes for researchers, INVOLVE payment guide)	▪ Number of downloads of each resource item
2.3) Provision of advice for researchers to ensure they are aware of and understand the principles and benefits of PPI and maximise impact.	▪ Individual feedback from researchers receiving advice ▪ PPI training in the induction of new staff (n=)
2.4) Collaborate with other CRFs (Christie and Central Manchester) to provide formal training for researchers on how to involve patients and the public in the research process and manage their expectations	▪ Number of staff receiving training
2.5) Collaborate with other CRFs (Christie and Central Manchester) to provide formal training for patients and the public (where requested) on how to get involved in the research process	▪ Number of patients and the public seeking support
2.6) Assess the confidence and skills of researchers who have involved patients and the public in their work	▪ Individual feedback from researchers receiving training ▪ Case studies (n=)
2.7) Assess the confidence and skills of patients and the public who have been involved in the research process	▪ Individual feedback from patients receiving training ▪ Case studies or digital stories (n=)

Objective 3: Measure PPI inclusion at stage 1 of the research process	
Goal	**KPI – Metric**
3.1) Assess whether researchers have considered PPI during the RACRF adoption process	▪ % that complete PPI question ▪ % that understand PPI question
3.2) Assess whether researchers have considered PPI when designing studies and writing grant applications (academic research)	▪ % that include PPI? ▪ Reasons for non-inclusion of PPI?
3.3) Ensure PPI is appropriately costed in commercially sponsored studies where RACRF has oversight	▪ % of studies where PPI is costed ▪ Amount of PPI funds raised

Objective 4: Measure the effectiveness of PPI on core metrics of RACRF activity	
Goal	**KPI – Metric**
4.1) Increase recruitment rates into RACRF studies	▪ Average duration of recruitment (e.g. 1 month per 10 subjects)
4.2) Reduce dropout rate in RACRF studies	▪ % dropout rate
4.3) Studies to be completed to time and target	▪ % of time taken to complete the study

Proposed Patient and Public Engagement Strategy

Objective 1: Maximise the visibility of the RACRF on a local level	
Goal	**KPI – Metric**
1.1) Scoping exercise to understand patient and public awareness of RACRF within host institution (UHSM)	▪ % awareness
1.2) Participation in NIHR Ok to Ask campaign / International Clinical Trials Day	▪ Number of engaged individuals ▪ Number of leaflets distributed
1.3) Produce patient-friendly leaflets and/or booklets for local distribution (e.g. UHSM open day, clinics, GP offices)	▪ Volume distributed
1.4) Hold a RACRF open day for patients and the public	▪ Number of events/attendees
1.5) Develop a new RACRF website created with the assistance of patients and the public with regards to content	▪ TBC

Objective 2: Provide resources to facilitate engagement/information exchange for patients and the public	
Goal	**KPI – Metric**
2.1) Produce RACRF research newsletters	▪ Editions/volume ▪ Open rate on emailed content
2.2) Support public engagement events	▪ Number of events/attendees
2.3) Patients register to receive information about future studies	▪ Volume
2.4) Increase participation in research studies	▪ Volume

References

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