

# NIHR/Wellcome Trust Imperial Clinical Research Facility

## Patient and Public Involvement and Engagement Strategy

2015-2017

### 1. Introduction

The National Institute for Health Research (NIHR) Imperial Clinical Research Facility (CRF) operates from Hammersmith Hospital in North West London. It is a partnership between Imperial College Healthcare NHS Trust and Imperial College London, and provides the facilities and specialist staff required to carry out world class biomedical research.

There are several compelling reasons to **involve** lay people, namely research participants, patients and members of the public, in the research we carry out at the CRF:

- Patients and the public have knowledge of their own illness, disease or health condition that can be of benefit to researchers, who may not have first-hand experience of the illness, disease or health condition that they are researching.
- Patients and the public have the right to be involved in any publicly-funded research that may impact on their health status or the services that they receive.
- PPI has the potential to improve the quality, relevance and impact of health research, whilst also improving the transparency of the process and the accountability to the wider community of the researchers themselves.
- PPI is Department of Health and NIHR policy<sup>1</sup>.
- PPI is included in Department of Health and NIHR policy, so funding often depends on getting PPI right at the grant application stage.
- Studies have been refused/delayed funding due to lack of PPI or budget to cover PPI activities for duration of study.

As well as PPI, we also have a duty to **engage** the public in research, encouraging them to get involved in PPI, as participants or to consider careers in biomedical research, medicine and nursing.

This document sets out our vision, mission and strategy for Patient and Public Involvement and Engagement at the CRF

### 2. Context: What is Patient and Public Involvement, how is it different from Engagement, and what role does it play in clinical research?

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<sup>2</sup>.

Examples of PPI currently taking place at the CRF include:

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<sup>1</sup> Going the extra mile: Improving the nation's health and wellbeing through public involvement in research, NIHR March 2015

<sup>2</sup> <http://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research-2/>

- Having a lay representative on the Protocol Review Board
- Having a patient/participant advisory group for particular studies
- Patient experience surveys that can be used to improve our services
- Workshops where patient groups are able to set research priorities
- Reviewing materials such as participant information sheets, and leaflets to raise awareness of taking part in research.

PPI is not **participation**, where people take part in a research study, recruitment, which is finding people to take part in studies; or **outreach/ engagement**, where information and knowledge about research is provided and disseminated. However, involvement, recruitment, outreach and engagement all work together, and are integral to effective clinical research, which is why we've included engagement in this strategy.

Examples of engagement that have taken place at the CRF include:

- Open days where members of the public are invited to find out about research
- Science festivals such as the Imperial Science Festival where the public are invited to find out about research
- Freshers' fairs
- Attending community events
- Raising awareness of research through the media
- Sharing research results with participants, colleagues or members of the public.

### 3. Vision: What do we aspire to achieve at the Imperial CRF?

#### Involvement

We aim to:

- Provide clinicians and scientific colleagues carrying out experimental research with PPI support through our PPI Panel throughout the research cycle (fig 1).
- Encourage researchers to seek and involve PPI in their work, as well as take advantage of the training and educational activities open to them.
- To link to Imperial NHS Patient panels, North-west London primary care patient panels, and the public in north-west London and encourage them to raise unmet healthcare needs
- Provide training to PPI Panel members in critically evaluating clinical research and research protocols to develop a panel of expert patients and public in clinical research. We will develop training modules so patients will be accredited in providing research input. These will be shared across the NIHR infrastructure. (in partnership with other members of the Imperial PPI Forum) as well as effective support and guidance.
- Provide information about, and signpost to opportunities for, PPI involvement via our website and emails to PPI Panel members.
- As part of work to sustain and expand our PPI Panel we will ensure that it is representative of our local community.



- Develop research dissemination strategies, with the input of the PPI Panel, to improve public awareness and knowledge transfer, again in conjunction with local, regional and national strategies.
- We will continue to develop and refine materials, with the input of the PPI Panel, that illustrate the value and contribution of PPI for patients and the public, including recruitment booklets and newsletters

## Engagement

We aim to:

- Raise the overall profile of the CRF locally, regionally and nationally through positive interaction with the broader UKCRF Network.
- Undertake public events to highlight the importance of research in the NHS
- Attend public events such as science festivals and community fairs where we can reach new audiences and inform them why research is important and why they should take part.
- Encourage school students who are considering biomedical research or medicine as a career by holding regular open days at the CRF and attending external careers events.
- Increase the level of sharing of the results of clinical trials with participants and the public, where possible.
- Undertake events to increase participation in clinical trials from ethnic minorities
- Undertake Quality Improvement initiatives in the Trust to help ensure all NHS Staff aware of opportunities for research in the NHS.

### 4. Mission: How will we approach PPIE?

Wherever there is potential to improve the service we offer and improve access to participation in CRF research, we will engage with and involve patients, healthy volunteers, our Trust and College colleagues.

### 5. Strategy: What will we do to achieve our vision?

To achieve our Vision we will first recognise the following:

- **PPIE is already taking place within the CRF and our wider network:** It is important that ongoing PPIE work taking place both within the CRF as well as the Trust, College and NIHR is recognised.
- **Our PPIE effort should be in collaboration with others:** Our PPI effort should be aligned with and part of a wider effort supported by the Trust, College, local/national organisations for PPI and the NIHR infrastructure.
- **That everyone working for the CRF plays a role in effective PPIE:** Feedback from everyone is vital to measure the success of our PPI effort.
- **The PPIE Plan should be implemented realistically:** Though there is a temptation to try to do everything, this is unrealistic and there must be a focus on what activities will add value to the CRF and its service users.
- **We should measure the success of PPIE as far as we can:** PPIE should not be carried out for PPIE's sake, as it dilutes its effectiveness. Wherever possible we should determine if our activity is adding value to the CRF and/or its users. We should gather information in the most effective way to be able to demonstrate added value and we should feedback the collated feedback to those who have provided it where appropriate. Case studies will be used to qualitatively

highlight instances where PPIE has been of particular value to, or had specific impact on CRF activity.

- **PPIE Activity should add value:** Activity should be prioritised and targeted to reflect what adds the most value to both. The focus of activities will change as areas for focus are identified. Activities should not be over complicated.
- **Our PPIE effort should be in collaboration with others:** Our PPIE effort should be aligned with and part of a wider effort supported by the Trust, College, local/national organisations for PPI and the NIHR infrastructure.
- **How we carry out PPIE should be defined for all parties involved:** where we collaborate with patients or members of the public we should have clear Terms of Reference that set out the aim of the project, how long it is expected to take, and what is expected from contributors.

## 6. Objectives

We will focus on the following objectives:

1. **Increase awareness of PPI in researchers using CRF services and encourage them to make use of the resources we can offer, including the PPI Panel.**
2. **Provide a high quality experience for research participants at the CRF**  
We will collect feedback from users and participants and use this information to identify areas for improvement.
3. **Raise awareness of the work of the CRF**  
We will engage with patients, our clinical colleagues and the general public in a way best suited to their needs to educate them about the research that the CRF is doing and the impact that this research is having on progress in healthcare.