

NIHR Imperial Clinical Research Facility
Patient and Public Involvement and Engagement Strategy 2017-2022

Introduction to the NIHR Imperial Clinical Research Facility

The National Institute for Health Research (NIHR) Imperial CRF (ICRF) is a partnership between Imperial College Healthcare NHS Trust and Imperial College London. The ICRF is based at Hammersmith Hospital, and is essential in the running of many early phase clinical trials, looking at new ways of treating or preventing a wide range of conditions, such as cardiovascular disease, cancer, diabetes and malaria. We provide specialist staff and facilities for studies from a range of medical disciplines, as well as a safe environment for patients or healthy volunteers requiring day visits or overnight stays. The ICRF is most often approached once a study has been designed and is ready to begin, therefore we unfortunately are limited to what patient and public Involvement (PPI) we can conduct. Due to this barrier, we are always actively trying to form relationships with researchers so we can be involved in the earlier stages.

Background

Patients and the public are a vital part of the ICRF and there are many compelling reasons why PPI can be beneficial to biomedical research. The public can not only provide us with a first hand experience of the illness being researched, but they can offer a perspective that can improve the quality, relevance and impact of health research. As well as PPI, we have a duty to engage with the public and promote science and healthcare research. We hope to encourage the next generation to pursue careers in biomedical research and healthcare. The last component of our strategy is service evaluation; it is our responsibility to continually ensure we are providing an ever improving service.

The ICRF's 'Patient and Public Involvement Panel' is comprised of patients, carers and members of the general public. Together, we have co-produced the following 5 year strategic plan. Many of the themes in our strategy and the structure has come directly from our panel members who have been instrumental in helping us build on the ICRF's current Patient and Public Involvement and Engagement strategy .

Our Vision

The community's patients and members of the public will inspire and guide all research, development and systems in the ICRF, thus promoting an inclusive and user friendly ICRF.

Our Targets

In order to achieve our vision, we shall work to deliver 6 targets, which are comprised of involvement, engagement and service evaluation components.

1. We shall embed effective PPI in all healthcare research at the ICRF and develop consistent high level approaches to PPI.
2. We shall ensure PPI support is utilised by all researchers at the ICRF and PPI is embedded into all research studies.
3. We shall promote diversity within our Patient and Public Involvement Panel and work to ensure it is fully representative and our ICRF is fully inclusive to individuals of all needs.

4. We shall put in place a model of public engagement that stimulates and informs the whole community using methods tailored to target appropriate groups.
5. We shall drive to promote participation and dissemination of patient experience, so patients and members of the public can relate to like-minded individuals and have a support structure in place.
6. We shall ensure we maintain a high quality service which aligns with the wants and needs of patients and the public.

Involvement

Target 1. Embed effective PPI in all healthcare research at the ICRF and develop consistent high level approaches to PPI.

To achieve this target, we have the following aims

- a) We shall put patients and the public at the forefront of research:
- b) We shall continually work towards identifying good PPI practices and embedding these into processes at the ICRF:

Target 2. We shall ensure PPI support is utilised by all staff and researchers at the ICRF and PPI is embedded into all research studies.

To achieve this target, we have the following aims

- a) We shall provide support and training to staff and researchers to enable them to fully utilise PPI techniques in all aspects of their research

Target 3. We shall promote diversity within our Patient and Public Involvement Panel and work to ensure it is fully representative and our ICRF is fully inclusive to individuals of all needs.

To achieve this target, we have the following aims.

- a) We shall engage with hard to reach groups¹
- b) We shall create an evidence base for minority requirements in PPI

¹This relates to perhaps the most urgent finding of the 2018 MRC/NIHR report on public attitudes to health research.

Engagement

Target 4. We shall put in place a model of public engagement that stimulates and informs the whole community using methods tailored to target appropriate groups.

To achieve this target, we have the following aims

- a) We shall actively disseminate information about the ICRF and research studies in an understandable way.
- b) We shall promote the ICRF, research and science by informing and educating different audiences.

Target 5. We shall drive to promote participation and dissemination of patient experience, so patients and members of the public can relate to like-minded individuals and have a support structure in place.

To achieve this target, we have the following aims

- a) We shall provide patients with the opportunity to communicate with each other
- b) Ensure awareness of participation and PPI.

Service Evaluation

Target 6. We shall ensure we maintain a high quality service which aligns with the wants and needs of patients and the public.

To achieve this target, we have the following aims

- a) We shall ensure our ICRF is functioning appropriately for all users
- b) We shall continually revise service evaluations within the ICRF and collaborate with regional service evaluations within the UKCRF Network and Clinical Research Networks.
- c) We shall ensure all members of the public who visit the ICRF are well informed, at ease and welcomed openly.

Action Plan

Target 1. Embed effective PPI in all healthcare research at the ICRF and develop consistent high level approaches to PPI.

Aims	Objectives	Outcome Measures	Target
We shall put patients and the public at the forefront of research	a) To develop an appropriate human and financial resources plan, with annual review.	Have a clear plan of what PPI/E can be delivered and what resources we have to use.	By April 2018, have a plan in place.
	b) To provide all new members of our PPIP with a basic understanding of the ICRF and PPI. Provide them with a welcome pack, detailing ground rules, glossary of research terms, expense forms etc.	Ensure all PPI contributors are aware of what we expect them to do and how our ICRF functions. Create a more streamlined PPI process. Less uncertainty for PPIP members. Reflect this in post activity evaluation forms.	By June 2018, produce the training pack and distribute to all new PPI members.
	c) To establish different groups within our PPI panel; virtual group, core group, those interested in different parts of the research cycle and engagement advisory group.	PPIP members are involved in activities that they find rewarding and are interested in. PPI surveys can show if PPI contributors are happy with their activities.	By July 2018 establish different groups. By Aug 2018 ensure PPIP members are put into groups they will find rewarding.
	d) To support our PPIP in co-producing all general ICRF documents together with the PPI panel	Fully integrate PPI into practice at the ICRF.	Ongoing.
We shall continually work towards identifying good PPI practices and embedding these into processes at the ICRF	a) To review all PPI activities at the monthly ICRF management meetings and feedback to PPI Panel.	Fully integrated PPI. Appropriate changes can be discussed and implemented based on panel input.	Ongoing
	b) To create an evidence based approach to PPI by routinely evaluating all PPI techniques used.	Evaluate which PPI activities work and how we can improve.	Ongoing

Target 2. We shall ensure PPI support is utilised by all staff and researchers at the ICRF and PPI is embedded into all research studies.

Aims	Objectives	Outcome Measures	Target
We shall provide support and training to staff and researchers to enable them to fully utilise PPI techniques in all aspects of their research	a) To provide all new staff and researchers with a basic understanding of PPI by embedding a mandatory PPI training session into all inductions at the ICRF and update new PPI practices at the ICRF training day	Increase the number of staff and researchers considering PPI.	By May 2018 all inductions will include PPI.

	b) To facilitate an in depth PPI training program to all staff and researchers so they can develop further PPI knowledge.	Accurate training available to all ICRF users to ensure appropriate resources are in place to conduct PPI and to complete PPI activities.	By July 2018, have developed the training material. By Aug 2018, ensure training sessions are ready to be booked by all ICRF users. By July 2018 develop PPI guidelines and guidance on developing lay summaries.
	c) To facilitate a PPI discussion during the approval process of all trials run at the ICRF, to inform researchers about PPI possibilities	Incorporate PPI in more studies run at the ICRF.	By July 2018 begin delivering discussions.
	d) To develop links with researchers, to ensure they are fully supported in incorporating PPI in the early stages of study design.	Increase the number of studies incorporating PPI during early stages of study design. Coordinating with researchers to ensure they are aware of what PPI could be done on their projects before they submit to the ICRF for approval.	By Dec 2018, have approached 4 research groups about PPI in the design stages of a clinical trial. By March 2019 have at least 2 studies which have had PPI input in the design stages.
	e) To develop a PPI researcher's support group, where researchers are able to share ideas and provide advice to each other.	Provide a discussion to support learning and ideas.	By May 2019 have an established support group with researchers actively conducting PPI

Target 3. We shall promote diversity within our Patient and Public Involvement Panel and work to ensure it is fully representative and our ICRF is fully inclusive to individuals of all needs.

Aims	Objectives	Outcome Measures	Target
We shall engage with hard to reach groups¹	a) To encourage young people to be actively involved in PPI activities – Open days etc	Increase in diversity and age range in our PPI panel.	Ongoing.
	b) To target minority groups in the community and develop a network of contacts with leads in these groups		By March 2019, have links with 5 community groups.

	c) To encourage members to take part in specialist group discussion opportunities.	Provide an outlet and give the community an opportunity to discuss topics with clinical staff members.	By Dec 2019, set up a focus group with our panel members, to ascertain what they would like to discuss and with whom.
We shall create an evidence base for minority requirements in PPI	a) To hold focus groups with individuals with different access requirements (such as sensory, carer and mobility requirements), to understand how we can adapt our ICRF to be more inclusive	Ensure the ICRF is less restrictive to individuals with access requirements. An increase of interest in our PPIP by individuals with access requirements, Evaluation and feedback forms should measure this.	By Jan 2019, facilitate 2 focus groups.

Target 4. We shall put in place a model of public engagement that stimulates and informs the whole community using methods tailored to target appropriate groups.

Aims	Objectives	Outcome Measures	Target
We shall actively disseminate information about the ICRF and research studies in an understandable way	a) To promote a wider reach by facilitating production of public-facing documents in different formats tailored to the audience (e.g. minority languages, video summaries, audio clips, posters etc.)	Promote reach to wider audiences.	Have 2 documents per year using a new tailored format. Evaluate format and review.
	b) To promote dissemination of information in partnership with PPIP.	Increase PPIP presence at engagement events and conferences/meetings and patient/carers podcasting.	Ongoing. Co-present with one PPIP member in each presentation/conference attended.
We shall promote the ICRF, research and science by informing and educating different audiences	a) To raise awareness of the importance of the ICRF services and staff roles.	Increased understanding of the role of the ICRF in health research and job opportunities within research	Ongoing. Increase open days to at least 2 open days per year.
	b) To expose students to new science skills or life skills via an enrichment scheme.	Upon discussion at our open day, children said they would like to learn more life skills outside of school. Provide a safe environment where students are able to learn extra-curricular skills.	By Jan 2019, put together a series of enrichment class. By March 2019, enrol 15 students into a series of classes. Evaluate series.

	c) To promote STEM subjects	Increase the number of staff members acting as STEM Ambassadors and increase interest in stem subjects,	Ongoing. Attend or facilitate 3 STEM clubs per year. Get 2 extra staff stem ambassadors, by Jan 2019.
	d) To link with the wider community and facilitate conversations about science and research.	Provide an opportunity for an open discussion in an inclusive environment, allowing individuals to come together and discuss new healthcare ideas. Partnership with charity groups to raise awareness and promote PPI/E.	Ongoing. Attend one community coffee morning, every 2 months. Establish a journal club for our PPI panel and those with an interest in science. Hold 1 journal club every 3 months. Hold an event for the International Clinical Trials day in May 2018. Create 2 new charity links by Jun 2019.
	e) To encourage students to pursue science careers.	Expose students to the different health research and science roles that they can pursue.	By Dec 2018 develop a one week work experience program. By Jan 2019 enrol 2 students into the programme. Evaluate whether it was valuable.

Target 5. We shall drive to promote participation and dissemination of patient experience, so patients and members of the public can relate to like-minded individuals and have a support structure in place.

Aims	Objectives	Outcome Measures	Target
We shall provide patients with the opportunity to communicate with each other	a) To facilitate and encourage patients sharing their experiences with each other.	Coordinate with patients and our PPIP to create a patient buddy scheme, where patients can be paired with individuals considering participation.	By June 2019 have developed the patient buddy scheme. By Sep 2019 have 2 patients enrolled in the scheme. We plan to put this into place where

			possible for appropriate studies.
Ensure awareness of participation and PPI.	a) To publicise participation opportunities through our social media outlets and website.	Using a social media for targeted recruitment. Increase recruitment numbers.	Ongoing.
	a) To showcase public involvement and patient experience through our website.	Increase the number of volunteers expressing an interest in participating in a research study or PPI.	By July 2019, have collected feedback from 20 patients and 10 volunteers. By Sept 2019 make this information available online. Collect evaluation forms for those using the platform.
	b) To showcase the steps involved in a clinical trial on our website – to allow individuals to process what’s involved in recruitment and participation.	Less uncertainty for those considering participating in a research study.	By Dec 2018, have produced the video. After final review from our panel, by Feb 2019 make the video available on the website.

Target 6. We shall ensure we maintain a high quality service which aligns with the wants and needs of patients and the public.

Aims	Objectives	Outcome Measures	Target
We shall ensure our ICRF is functioning appropriately and to the best standard for all users	a) To facilitate a fully inclusive website. For example incorporate audio clips and videos into our website, targeted at those who would prefer listening rather than reading information.	Tailor the website to individuals with different access needs. Reach a wider audience.	By Sept 2019 have an audio clip available for each page on our website.
	b) To revise service evaluations within the ICRF and collaborate with regional service evaluations within the UKCRF Network and Clinical Research Networks.	Appropriate changes will be made based on feedback from the evaluations to ensure the ICRF aligns with the needs of the public.	Ongoing.
We shall ensure all members	a) To consult with the PPIP on suitability of ICRF	Feedback on evaluation surveys.	Ongoing

of the public who visit the ICRF are well informed, at ease and welcomed openly.	information sheets.		
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Resources: We are an active CRF, within the UKCRFN working group and have a dedicated PPI/E Manager, Aman Nathan, who oversees all PPI/E activities within the ICRF

We have an established Patient and Public Involvement Panel, who work alongside us on a variety of different involvement and engagement activities and in co-producing all of our ICRF documents. We currently offer PPI training co-delivered by the Biomedical Research Centre and Imperial Clinical Trials Unit. Soon we hope to work alongside the BRC and ICTU in delivering the training.

Partners and collaborators: We work closely with the UKCRF Network, the Imperial Biomedical Research Centre and the Clinical Research Network and will be working to establish and strength our links with various charity and community groups.

Self-Assessment and Impact: We shall conduct pre and post evaluation surveys for all ICRF involvement and engagement activities. By doing so we shall assess the activity and its impact. Using our self-assessment tools we will review and refine our strategy yearly.