

NIHR Leicester Clinical Research Facility PPIE Strategy 2018 to 2023

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Introduction

Leicester's Hospitals NIHR Clinical Research Facility (CRF) will deliver research in partnership with patients and the public at every stage, from prioritisation, design and conduct, to conclusion and sharing of findings.

The federated model we have adopted allows for patient and public involvement/engagement (PPI/E) to remain prominent in all research clusters of our CRF. In addition it offers a trust wide operational perspective of engagement activity that integrates seamlessly into the wider field of Patient Partnership.

The enclosed is a new strategy which is open to be developed in conjunction with our PPI/E partners. As such it is to be viewed as an evolving strategy and we welcome your input. The authors would actively encourage comments to aide in the further growth of this strategy.

Comments, suggestions and enquiries may be submitted via the NIHR Leicester CRF website form <http://www.leicestercrf.nihr.ac.uk>

Background

Leicester's Hospitals already has a strong PPI/E in research pedigree. There are specific engagement groups for cardiovascular, respiratory, diabetes and lifestyle, and cardiac surgery research. These groups significantly influence study activity and are managed by a dedicated PPI/E lead within the NIHR Leicester BRC.

The Hope Research Facility of our cancer cluster has a Patient and Carer Advisory Group who link with health professionals to ensure a high standard of patient/carer satisfaction within the environment and improve research uptake in the public domain to enhance recruitment to trials and scientific discovery.

There are lay representatives on the hospital's Genomic Medicine Steering Committee and Research and Innovation Executive Board.

Within the local health environment there are various research-related public engagement groups who work closely with researchers to cultivate new ideas for future exploration.

Our BRC PPI/E manager works closely with Leicester's diverse communities at grassroots level and in partnership with stakeholders such as the East Midlands Centre for Black and Minority Ethnic Health (EMCBMEH) which has a PPI/E panel to review and support funding applications. This activity is supported by a mixed funding model including charities, NIHR Clinical Research Network East Midlands (CRN-EM) and other NIHR bodies.

Going Forward

The fundamental components of our strategy are to build on this existing work, adding value and expanding scope. We will deliver a holistic approach that encompasses all aspects of patient and public involvement. Specifically our aims for PPI/E are:

- To deliver PPI/E activity for the Leicester CRF as part of a package integrated with, and complementary to, that existing alongside other Leicester's Hospitals, University of Leicester (UoL) and NIHR funded research and infrastructure locally
- To ensure alignment with patient and public involvement activities associated with Leicester's Hospitals and UoL research groups
- To establish dedicated Leicester CRF PPI/E representation at operational management level
- To ensure all potential CRF studies have an appropriate PPI/E plan
- Involve patients and the public, to prioritise and undertake the research they want
- Involve PPI/E Groups in the design, development and review of our research
- To work with community groups and wider stakeholders such as EMCBMEH to ensure PPI/E is representative of our ethnically diverse population and develops and maintains Leicester as a national centre of excellence for PPI/E in minority and diverse population groups
- To establish a sustainable financial model to ensure effective and vibrant PPI/E activity around the Leicester CRF
- To resource our PPI/E activities so that no patient or member of the public is out of pocket for being involved
- To provide support and training for PPI/E representatives working with the CRF
- To deliver PPI/E training for researchers and support staff
- To evaluate the impact of our PPI/E activities using the Public Involvement Impact Assessment Framework (PiiAF) <http://piiaf.org.uk/>

Aims

The purpose of this evolving strategy is to define the processes by which the NIHR Leicester CRF engages with members of the public to:

- Encourage involvement in CRF activity at all levels (Board to patient experience evaluation)
- Raise awareness of research, in particular early phase trials, to ensure the CRF is doing the work the community wants
- Develop the processes within the CRF to ensure they are patient focussed
- Ensure the CRF collaborates closely with other NIHR facilities locally and other patient participant groups (such as within universities) in supporting and further developing an integrated health engagement forum for research
- Build strong relationships with diverse communities locally
- Evaluate the impact of our PPI/E activities using the Public Involvement Impact Assessment Framework (PiiAF)
- Develop training packages for public and staff on PPI/E engagement
- Public dissemination of CRF activity

Objectives

Our objectives are our stepping stones to success in achieving our aims:

Encourage involvement in CRF activity at all levels (Board to patient Experience evaluation) through adopting a range of approaches such

- I. appointing advertised posts to the CRF board by August 2018
- II. developing the Patient Research Ambassador Role trust wide in collaboration with other NIHR services
- III. liaising with PPI/E to comment on and aide in the development of a plan for each study as appropriate

Raise awareness of research, in particular early phase trials

- I. Through developing a public facing website to be launched in April 2018
- II. Being available at public events for discussion of our activity
- III. Engage with those groups who our patient advisors represent and forge links through them with our diverse communities
- IV. Participate in trust and community wide activities
- V. Actively advertise activities through public facing channels the availability of early phase work

Develop the processes within the CRF to ensure they are patient focussed

- I. Where new projects are being proposed include engagement at the earliest phase
- II. To review proposed research projects in relation to ensuring they have had appropriate PPI/E input

Ensure the CRF collaborates closely with other NIHR facilities locally and other patient participant groups (such as within Universities) in developing an integrated health engagement forum for research

- I. The PPI/E lead will ensure close communication with other NIHR and NHS funded research bodies locally and nationally, including the NIHR Leicester BRC, NIHR Clinical Research Network East Midlands (EM CRN). The NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC), East Midlands Academic Health Science Network (AHASN) and the NIHR UK Clinical Research Facility Network (UKCRFN)

- II. The PPI/E lead will liaise with other PPI/E groups such as Leicester Academy for the Study of Ageing (LASA) at DeMontfort University and The Older Persons forum at UoL and leadership groups in order to ensure a wide representation and collaboration in relation to research activity

Build strong relationships with diverse communities locally

- I. Develop realistic collaborative approaches to engaging with hard to access communities
- II. As a specialist centre, with a large culturally and ethnically diverse community, use the expertise available to advise on drawing out and feeding into hard to reach communities where benefit can be seen to be tangible. These resources are limited and may be stretched. As such they are valuable links that may need to be used sparingly.

Evaluate the impact of our PPI/E activities

- I. Using the Public Involvement Impact Assessment Framework (PiiAF)
- II. Undertaking the NIHR UKCRFN Patient Research Awareness Survey
- III. Collaborating with NIHR CRN-EM to undertake the NIHR patient experience evaluation survey
- IV. Developing a feedback form for CRF participants which will be reviewed quarterly

Develop training packages for public and staff

- I. In conjunction with the East Midlands Research Community we will collaborate to aide in further developing a programme of cross community PPI/E training

Public Dissemination of CRF activity

- I. Through website
- II. Collaborating With NIHR Leicester BRC to produce a joint newsletter
- III. Develop media relations through the Trust's Research Communications Manager

Strategy table

Objective	Activity	Delivery	Evaluation timeframes
1. Encourage involvement in CRF activity at all levels (Board to patient Experience evaluation)	i. Appointing advertised post to the CRF board	The CRF will advertise all PPI/E positions to engage with the broadest range of candidates. We will develop the PRA role to utilise the skills of individual ambassadors. We will jointly discuss plans for individual trials during operational meetings	Appointment to have been made by August 2018
	ii. Developing the Patient Research Ambassador (PRA) Role trust wide in collaboration with other NIHR services		Annual appraisal with appointed PRAs to identify areas of achievement and further development with PPI/E lead
	iii. Liaise with PPI/E to comment on and aide in the development of a plan for each study		Develop a study evaluation form with PPI/E representatives and CRF Manager for use with new studies for the CRF to review patient involvement in development by April 2019
2. Raise awareness of research, in particular early phase trials to ensure the CRF is doing the work the community wants	i. Through developing a public facing website	A CRF website is available that will allow for members of the public to contact the CRF via a built in form.	Establish website and publish draft strategy at http://www.leicestercrf.nihr.ac.uk by end of April 2018
	ii. Being available to public events for discussion of our activity	The PPI/E lead and members of the wider CRF team will actively seek out opportunities with the wider Trust and community groups to offer talks and support discussions regarding early phase work. The CRF team will actively take up	To have attended at minimum of 2 public events annually.
	iii. Engage with those groups who our patient advisors represent and forge links through them with our diverse communities		PPI/E Lead to utilise PPI/E links to engage with community leads to discuss role of CRF to them and document actions and outcomes and further plan for engagement by April 2019

	<p>iv. Participate in Trust and community wide activities</p>	<p>invitations to visit and present to groups and forums with a view to engaging with the harder to reach communities.</p>	<p>To have attended Leicester's Hospitals open forum events such as the Trust Annual Public meeting and health fair to demonstrate the activities of the CRF</p>
	<p>v. Actively advertise activities through public facing channels the availability of early phase work</p>		<p>The CRF Team and PPI/E representatives will take the opportunity in conjunction with the wider research community at Leicester's Hospitals to engage with various forms of media with the advice and assistance of the Research Communications Manager.</p>
<p>3. Develop the processes and facilities within the CRF to ensure they are patient focussed</p>	<p>i. Where new projects are being proposed include engagement at the earliest phase</p>	<p>Liaise with PPI/E representatives at operational management level.</p>	<p>New projects to be taken to operational group for PPI/E comment at feasibility stage. Actions to be documented.</p>
	<p>ii. To review proposed research projects in relation to ensuring they have had appropriate PPI/E input</p>		
<p>4. Ensure the NIHR Leicester CRF collaborates closely with other NIHR facilities locally , other patient participant groups (such as within</p>	<p>i. The PPI/E lead will ensure close communication with other NIHR bodies locally and nationally. Including the Leicester BRC, EM CRN, CLAHRC, AHASN and the UKCRFn</p>	<p>The PPI/E lead and members of the CRF board and Operational group to liaise closely with local NIHR funded research groups to ensure a collaborative approach to PPI/E activity including training and development of both representatives and staff. The CRF Manager and staff will actively engage with health</p>	<p>PPI lead to attend and collaborate with the NIHR CRN-EM PPI group and their activities.</p>
	<p>ii. The PPI/E lead will liaise with other PPI/E groups (Such as LASA @ DMU and The Older Persons forum at UoL) and</p>		<p>To run joint International Clinical Trials Day events annually with other NIHR facilities.</p>

Universities) in developing an integrated health engagement forum for research	leadership groups in order to ensure a wide representation and collaboration in relation to research activity	research groups that are not part of the NIHR network.	To have engaged with and supported in the training and development activities for PPI/E of the East Midlands NIHR research groups.
			To actively engage in and publicise the NIHR “I am Research” campaign. https://www.nihr.ac.uk/news-and-events/support-our-campaigns/i-am-research throughout 2018/19
			To join in the celebrations for NHS70: Celebrating 70 years of the NHS https://www.england.nhs.uk/nhs70
			To conduct NIHR UKCRFN Patient/Staff Research Awareness survey evaluation and share outcomes via CRF Website July 2018 http://www.leicestercrf.nihr.ac.uk
			To Conduct NIHR UKCRN Participant Research Awareness Survey in collaboration with NIHR CRN-EM and share outcomes via CRF website December 2018 http://www.leicestercrf.nihr.ac.uk
5. Build strong relationships with diverse communities	i. Develop realistic collaborative approaches to engaging with hard to access communities	To engage with CLAHRC Research Engaging Patients and Public (REPP) Forum To utilise the experience	PPI/E lead to join REPP group and establish a working relationship by August 2018

locally	ii. As a specialist centre, with a large culturally and ethnically diverse community, use the expertise available to advise on drawing out and feeding into hard to reach communities where benefit can be seen to be tangible. These resources are limited and may be stretched as such they are valuable links that may need to be used sparingly.	established specialist teams, such as the NIHR Leicester BRC to inform and liaise with regard access to hard to reach communities. Invite communication directly with open access social media such as an e-mail address and web page forms utilising the experience of the Trust's Research Communications manager.	PPI/E lead to liaise with local research groups such as the NIHR Leicester BRC and NIHR CRN-EM for the CRF to gain access to established gateways to engage with Leicestershire's culturally diverse communities.
6. Evaluate the impact of our PPI/E activities using the Public Involvement Impact Assessment Framework (PiiAF)	i. Using the Public Involvement Impact Assessment Framework (PiiAF) ii. Using the NIHR UKCRFN Patient Research Awareness Survey iii. Collaborating with NIHR CRN-EM to undertake the NIHR patient experience evaluation survey	CRF PPI/E lead to develop a strategy to utilise the PiiAF. Undertake the UKCRFN Patient Staff	CRF PPI/E lead to investigate use of PiiAF and liaise with PPI/E representatives on the format assessment by October 2018 Undertake and publish annually, by October each year, results of outcomes of the NIHR UKCRFN Patient Research Awareness Survey and the NIHR patient experience evaluation survey
7. Develop training packages for public and staff.	i. In conjunction with the East Midlands Research Community we will collaborate to aide in further developing a programme of cross community PPI/E training	Collaborate with NIHR partners in the development and delivery of an East Midlands PPI/E training programme.	CRF PPI/E lead to engage with local NIHR community to offer support in the established training programme PPI/E representatives by December 2018

8. Public Dissemination of CRF activity	i. Through our website and Twitter channel	Via http://www.leicestercrf.nihr.ac.uk Provide evidence to research partners such as charitable groups and organisations for their wider dissemination.	To promptly publish outcomes of survey activity following review by the operational group.
	ii. Collaborate closely with our the local Health Research partners		Review the dissemination process for study outcomes by research teams utilising the CRF resources as part of the PPI/E evaluation process.
			Maintain links to published papers on the CRF website for public review updated quarterly

Oversight and Governance

The CRF PPI/E Lead will report directly to the CRF Manager and be a member of CRF Operations group.

The Operations group is formed of the CRF Clinical Director, CRF Manager, Assistant Director of Research & Innovation, NIHR Leicester BRC Representatives, two public representatives (to be appointed), Research Communications Manager, Senior Research Nurse and the CRF Data Administrator.

Additional activities of the CRF PPI/E representatives are yet to be further defined as part of this ongoing developing strategy, however it is anticipated that they will be engaged not only in advising with regards to the structure and future development of the federated model but they will also be actively involved in supporting the activities that assess the public impact of CRF activities.

The CRF PPI/E lead is actively engaging with the UKCRF Network PPI/E Working Group, the NIHR Leicester Biomedical Research Centre PPI/E Group and the NIHR UKCRN East Midlands PPI/E structures.

The PPI/E lead role is undertaken by a Senior Research Nurse who is engaged to undertake other clinical activities. The anticipated funding for all direct PPI/E activity is anticipated to be no more than £500 annually.

Impact measurement

Impact measurement will relate to CRF activity and will be conducted based on the methods outlined in the the Public Involvement Impact Assessment Framework (Piaf) <http://piaf.org.uk> . In addition the PPI/E lead in collaboration with the PPI/E representatives will undertake to formulate a schedule to review the National Standards for Public Involvement in Research <https://www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/nihr-central-commissioning-facility/Documents/Draft-PI-Standards-June17.pdf>

As a working dynamic document this draft strategy is open to amendment. During the first annual cycle it will actively be updated quarterly.

Further information

For further information about the NIHR Leicester CRF you can contact us via our web form at <http://www.leicestercrf.nhr.ac.uk>

Telephone 0116 2585973

E-mail the CRF PPI/E Lead Aidan Dunphy at aidan.dunphy@uhl-tr.nhs.uk