

**National Institute of Health Research (NIHR) Clinical Research Facility (CRF) at The Royal Marsden
NHS Foundation Trust and Institute of Cancer Research, London.**

Patient and Public Involvement and Engagement (PPI/E) Strategy 2017-22

This strategy describes how The Royal Marsden CRF will involve patients as partners in our research and engage with the public to raise awareness of the clinical research we undertake.

It has been developed in consultation with patient and public groups (to ensure patient focus), researchers (to determine requirements and resource) and in collaboration with other NIHR infrastructure to ensure consistency and enable support and cooperation across the organisation.

It is publicly available on our web pages:

<https://www.royalmarsden.nhs.uk/our-research/our-research-facilities/nihr-imaging-clinical-research-facility>

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1.0 Introduction to The Royal Marsden CRF

The NIHR Royal Marsden (RM) Clinical Research Facility (CRF) provides infrastructure support for medical imaging research at RM and The Institute of Cancer Research (ICR). Medical imaging visualises structure and function of the body's internal organs and is an essential part of cancer care and research. It is used to diagnose cancer, to assess how a patient is responding to treatment, and to plan surgery and other treatment options.

Our facility has five MRI (Magnetic Resonance Imaging) and three PET/CT (Positron Emission Tomography and Computed Tomography) scanners and a multidisciplinary team of specialist clinical research and support staff. Together, this enables the development of specialised imaging techniques that can help evaluate new cancer treatments and improve early diagnosis.

The objectives of our CRF are to:

- Develop the best imaging methods to evaluate response to each of the new treatments RM and ICR researchers are developing.
- Enhance scanning techniques to improve tumour detection and characterisation to select the most appropriate treatment and to change treatment if it isn't working.
- Develop new technologies to provide better, more accurate image-guided surgery and radiotherapy.

These imaging techniques will guide improved treatments aimed at increasing survival from cancer with reduced side effects, thereby allowing patients to live well with and beyond cancer.

2.0 Background to the Strategy

The NIHR has a clear vision to create a health research system which is “focused on the needs of patients and the public”. This is because research that reflects the needs and views of the public is more likely to produce results that can be used to improve health and social care.

Creation of a research active population requires: **public involvement** - research that is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them; **public engagement** - raising awareness of research, sharing knowledge and creating a dialogue with patients and the public and **participation** - when patients and members of the public are recruited to take part in a study. Establishing successful partnerships between public and researchers requires addressing all three of these elements.

In the last five years, PPI/E has become imbedded into the research culture of our CRF with many benefits for both patients and researchers. As we move into our next five year funding term we aim to build on this successful foundation of partnership working. Our PPI/E strategy sets out how we will do this.

3.0 Aims of the Strategy

This strategy has been developed to align with and support the objectives of the Royal Marsden CRF. It sets out our commitment and approach to involving and engaging with patients and the public to improve the quality, value and relevance of our research.

While continuing to encourage and support consumer involvement across all stages of the research process, as a clinical research facility predominantly involved in delivering research, we will ensure that patient experience is central to the development and delivery of imaging techniques for cancer detection, characterisation and assessment of treatment response.

We will continue to:

- Raise public awareness of our research work
- Promote and support public involvement in our research work
- Ensure our research is delivered in an informed and inclusive environment

4.0 Development of the Strategy

Our previous PPI/E strategy (2012-2017) has provided the successful foundation from which this strategy (2017-2022) has been progressed.

It has been **aligned** with the NIHR ten year (2015-25) PPI/E strategy 'Going the Extra Mile' and the INVOLVE National Standards for Public Involvement in Research, which provide a framework for improving the quality and consistency of public involvement in research.

It has been developed:

- in **collaboration** with the NIHR PPI/E leads, the UKCRF Network and The Royal Marsden and Institute of Cancer Research NIHR Biomedical Research Centre(BRC), and
- in **consultation** with CRF researchers, CRF Patient representatives, the Royal Marsden Patient and Carer Research Review Panel, members of The Royal Marsden Cancer Charity and public/patient responders to an on-line survey.

The on-line survey consisted of a few short questions designed to determine how patients and the public would like to be involved in our research, the preferred way to learn about involvement opportunities, what support they would need and how they would like their input recognised.

The responses obtained have been used to develop a PPI/E involvement and engagement programme that is tailored to the needs of our patient/public group and ensures appropriate support and resource to enable productive interactions with researchers.

5.0 Delivery of the Strategy

We support patient and public involvement throughout the research cycle ensuring our research reflects issues relevant to those potentially affected by it. This programme of activities will be delivered in partnership with patient contributors and is appropriate to our resource.

5.1 Raising awareness of our research work

Planned Activities	Aims	Outcome Measures	Target
News bulletins, information leaflets, and study publicity on CRF research boards	To raise awareness of our research work with staff and patients within the Trust.	Increased understanding of the role of imaging in cancer research. Publicity of research participation opportunities. Publicity of research involvement opportunities.	1. Produce two newsletters a year 2. Update information leaflet Q2/Q3 2018 3. Highlight one study each quarter.
Information on CRF web pages	To raise awareness of our research work with both internal and external audiences.	Increased reach to a wider and more diverse patient and public group. Facilitated access for other NIHR infrastructure.	Update web content six monthly.
Further develop and maintain links with cancer charities	To use charity groups to publicise our research news, involvement, engagement and participation opportunities.	Dissemination of information to relevant target patient groups. Increased attendance at engagement events and interest in study recruitment.	1. Newsletters (2/year) 2. Engagement event May 2018 3. Make links with one additional charity
Research studies entered on public databases	To regularly update and maintain publicly available study details and lay summaries.	Accurate research study information available to the public and research community. Increased study awareness. Route provided for patients to enquire about study participation.	Update all study information in an ongoing manner – six monthly reviews.
Public engagement events 1. Within the Royal Marsden Hospital 2. Within the wider community	To link with the wider patient/carer community to stimulate interest in research and promote its value in NHS patient care.	Provide a forum for open discussion about imaging techniques, perceived impressions and concerns and the role of cancer imaging research. Engagement with a wider public audience Increased involvement in research	Hold an engagement event for International Clinical Trials day – May 2018

Measures of success:

Monitor

- distribution of research information
- enquiries to CRF (dedicated email address)
- attendance at engagement events
- responses to research awareness surveys run in collaboration with the UKCRF Network

5.2 Promoting and supporting involvement in our research work

Planned Activities	Aims	Outcome Measures	Target
Engagement with and involvement of patient/public groups	To consult with The Royal Marsden Patient and Carer Research Review Panel on suitability of imaging research study documentation	Appropriate changes will be made based on panel input. These will be recorded to assess impact and reported back to the panel to acknowledge their contribution to the research.	All new CRF-led research studies
	To publicise involvement opportunities in particular research projects/activities through our PPI colleague database	Coordinating and liaising between patient colleagues and researchers. Formation of topic-specific discussion groups, establishing patient co-investigators and representatives for steering groups.	Ongoing, as new study opportunities arise
Supporting patient involvement in all stages of our research	To support two patient representatives, as members of the Management Strategy Group, in the governance and management of the CRF	Fully integrated PPI/E that is aligned with the objectives and practice of the CRF. Patient relevant research.	Ongoing.
	To support the Patient Research Ambassador (PRA) initiative	Promoting health research from a patient point of view. Encouraging others to become involved in research. Support network with other PRAs. Supporting CRF Network PPI working group objectives and sharing best practice.	Establish one PRA Q3/4 2017
	To facilitate and encourage patient co-	Partnership working between patients and	All applicable new studies

	investigators on research studies and funding applications	researchers. Appropriate patient insight. Patient acceptability of research proposals. Better quality research applications with favourable outcomes.	
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Measures of success

Monitor:

- Percentage of CRF studies receiving patient panel input
- Changes made as result of patient input
- Number of researcher requests for patient input
- Number of patient responders to research requests
- Managed budget for PPI with appropriate reimbursement
- Registered PRA with publicised case study
- Number of patient co-investigators on studies
- Number of patient co-applicants on grants and funding outcomes

5.3 Ensuring our research is delivered in an informed and inclusive environment

Planned Activities	Aims	Outcome Measures	Target
Providing information about our research in a range of formats	To ensure research awareness and opportunities for involvement and participation are made as widely available as possible.	An increase in the range and diversity of our patient/public involvement. An increase in research awareness among patients and staff.	Paper copies in facility waiting areas, electronically on web pages, emails to patient colleagues, personal interactions and discussions. Information to be updated six monthly.
Take part in user experience initiatives such as OK to Ask and Research Awareness surveys	To ensure our research is delivered and communicated in the best way for our patients and staff.	Identify areas for improvement and inform communication strategy.	May 2018
Providing clear, audience appropriate information	To develop patient information in partnership with patient representatives.	Clear and easily understandable information for patient population. Good research awareness, compliance	Ongoing

		and participation.	
Patient input into study design	To involve and consult with patients, carers and the public in research study development.	Patient-centred protocols that improve research experience for participants and facilitate participation.	Ongoing
Fully integrate patient representation into the management and governance of the CRF	To ensure patients, carers and the public have a voice in the planning and delivery of our research.	An environment of partnership working between researchers and patients that allows open discussion and suggestion.	Ongoing

Measures of success

Monitor:

- Levels of research awareness among patients and staff (research awareness survey)
- Reach of research information to target populations (review of responders)
- Communication strategy aligned with needs of target patient groups (consumer survey)
- Patient experience feedback
- Study participation
- Mutually beneficial partnership working between patient representatives and researchers

6.0 Partners and Collaborators

We will work closely with the BRC at The Royal Marsden and Institute of Cancer Research, London so that PPI/E delivery within the Clinical Research Facility is consistent and cooperative across the joint organisation. A strong collaborative working relationship is already well established and this will continue to maximise shared resource.

- Open day activities and other public engagement events will be jointly planned and delivered.
- Our CRF has already contributed to the establishment of a PPI colleague database of patients, carers and public who would be interested in working with researchers. We will continue to work with the BRC on promoting this resource to patients, to increase the number and diversity of our colleagues, and to researchers to access relevant and targeted input into their research.
- CRF patient representatives will attend induction training and education events, where relevant, that are developed by the BRC. Joint meetings will be held for all patient representatives across the BRC and CRF to enable support and collaboration.

Through the UKCRF Network PPI Work Stream we will support and deliver a collaborative programme of work aligned to and contributing to National public involvement strategy and standards. We will:

- Share best practice case studies
- Participate in patient experience initiatives, such as Ok to Ask and Research Awareness surveys
- Explore and develop the role of Patient Research Ambassadors (PRAs)
- Access training and support for PPI Leads
- Report, monitor and review impact

Our PPI/E activities will be fully aligned with INVOLVE and will make full use of available resources through the London Research Design Service, People in Research and The Royal Marsden Cancer Charity.

7.0 Management and Governance

As PPI Lead for the CRF, member of the UKCRF Network PPI Working Group and the RM BRC PPI Steering Group, our CRF Manager is well placed to deliver a strategy for public involvement that aligns with both local, RM and ICR, and National, UKCRFN and NIHR/INVOLVE policy - Breaking Boundaries Report (2015) and National PPI Standards (2017).

Oversight of the strategy is fully integrated into our governance structure; two patient representatives are members of the CRF Management Strategy Group and PPI/E is a set agenda item at the monthly meetings. This ensures that PPI/E is aligned with the objectives and practice of the CRF. One of our patient representatives is also involved in an NIHR work stream focussing on PPI in early phase research and the Genomics England PPI working group. This allows regular feedback and input on external PPI issues and best practice that can be incorporated into our strategy. It is guided by patient and researcher consultation to ensure it is appropriate and relevant to the needs of both and proportionate to the resource of the CRF. It is an evolving process, subject to regular review and delivery assessment.

There is support at the highest level for this strategy, through the CRF Manager and Director, implemented in collaboration with the BRC PPI Steering Committee, and reported to The Clinical Research Executive at The Royal Marsden and Institute of Cancer Research. Despite funding cuts, we have maintained a protected budget for PPI/E.

8.0 Monitoring Delivery

We will continue to raise the profile and standard of PPI/E within the CRF by developing an approach of “Ask”, “Act” and “Assess”. Each activity will be planned around ‘asking’ what it wants to achieve, and its success will be ‘assessed’ by evaluating what difference it made. The details of research projects seeking PPI/E input through the CRF will be recorded by the PPI Lead to inform reporting and feed into the overall trust PPI data. Impact will be established by assessing what changes were made as a direct response to patient input. Researcher registration and feedback forms are being developed to facilitate this process. Where appropriate, particular examples will be prepared as case studies to publicise how patient and public involvement has helped shape research supported by our

CRF. These will feature in newsletters, on the Patient Research Ambassador web site, in reports to the NIHR and be made available to the UKCRF Network to allow the sharing of best practice.

Our strategy will be reviewed annually to assess progress and maintain alignment with the UKCRFN PPI Working Group objectives. We were one of six CRF's who took part in the 2017 Research Awareness Survey, the results of which will help inform how we raise awareness of research through the CRF and can act as a benchmark to monitor our progress in delivering on this objective.

Through collecting age and gender data from public/patient responders to the on-line survey that helped shape this strategy we can ensure that we are delivering a strategy that reflects the views and opinions of our patient demographic.

Our CRF will contribute to PPI monitoring and recording across the NIHR infrastructure and the development of the NIHR Impact Report.

Strategy review will be a dynamic process of lay and professional contributions that will ensure appropriate support and enhancement of the CRF.

9.0 Resources

In recognition of the importance of PPI/E to the working of our CRF we have a named PPI lead who oversees the development, instigation and co-ordination of patient and public involvement and engagement activities within the facility. Due to the small size and limited resource of our CRF, this role is undertaken by the CRF Manager, Katherine May. It includes membership of the UKCRFN Working Group, through which Network resources are accessed.

We have two Patient Representatives who are members of the CRF Management Strategy Group and work with us on various involvement and engagement activities. In addition, we also work with a number of other patients and carers on particular projects and events. We have a dedicated PPI budget from which travel and other associated expenses are reimbursed for meeting attendances and training. Additionally, patient representatives are remunerated on an activity basis, based on INVOLVE guidance, and funding is made available for the organisation of engagement activities. To maximise our resources, where possible, these are held in collaboration with the BRC at The Royal Marsden and Institute of Cancer Research.

Resources for delivering our PPI/E strategy will be subject to ongoing review with adjustment, where possible, with consideration of alternative funding options.

Our PPI budget for 2017-22 is approximately £6000.

9.1 Training

Patients and public: Support is provided to all patients and members of the public who join the colleague database, become Patient Research Ambassadors or take up Patient Representative positions. Administered through the BRC, induction packs are sent to all new patient colleagues and Training Needs Analyses completed from which appropriate training is coordinated. An induction meeting is planned for new Patient Representatives, both BRC and CRF, to provide an overview of

research processes and the different opportunities available for working with us. This will provide a forum for the representatives to meet and enable them to develop their support networks. Quarterly joint meetings will facilitate this ongoing interaction. Mentoring will be available to people new to working with us by more experienced representatives.

Researchers: PPI/E is well established within the CRF team and is a standing agenda item on our monthly CRF Management Strategy Group meetings, which our two patient representatives attend. This provides a forum for easy researcher-patient interaction and for opportunities and issues to be discussed.

We have previously developed and held our own patient-led PPI training sessions for researchers and also facilitate researcher participation in BRC training opportunities and those of external organisations such as the Research Design Service. New CRF staff are provided with the NIHR UKCRF Induction Framework, which includes briefing sheets on patient and public involvement in research. All staff are aware of the routes to access user involvement in their research, which is coordinated through the CRF PPI Lead.

10. More information

This five year strategy has been developed to support and enhance the work of the Royal Marsden Clinical Research Facility.

If you would like more information about The Royal Marsden Clinical Research Facility or are interested in working with us, you can contact the Clinical Research Facility by email:

imagingCRF@rmh.nhs.uk

or telephone:

0208 915 6624

Or contact Katherine May, the CRF Patient and Public Involvement Lead:

Email: Katherine.may@rmh.nhs.uk

Telephone: 0208 642 6011 Ext.4109

Information sources:

1. Royal Marsden CRF, <https://www.royalmarsden.nhs.uk/our-research/our-research-facilities/nihr-imaging-clinical-research-facility>
2. NIHR, <https://www.nihr.ac.uk>
3. INVOLVE, www.invo.org.uk
4. Royal Marsden BRC, <https://www.cancerbrc.org>
5. London RDS, www.rds-london.nihr.ac.uk
6. People in Research, <https://www.peopleinresearch.org>