

Biomedical Research Centre

**at The Royal Marsden NHS Foundation Trust (RM)
and The Institute of Cancer Research (ICR), London**

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

This strategy describes how the RM/ICR BRC 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 through a co-production approach with our Patient Representatives, in consultation with patient and public groups and researchers and in collaboration with the NIHR CRF at RM/ICR to ensure consistency and enable support and cooperation across the organisation.

It is publicly available at <https://www.cancerbrc.org/public-patient-involvement/ppi-strategy>

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1 Introduction to the RM/ICR BRC

Cancer is the UK's biggest killer. For all the dramatic progress against the disease in recent decades, cancer continues to claim around 160,000 lives in the UK each year. Although survival rates have improved enormously in some types of cancer, other tumour types continue to do badly. Once the disease has spread around the body it is still often incurable. We know that cancer is an incredibly complex disease and it is this complexity that makes cancer so difficult to treat.

RM and ICR together form one of the world's top centres for cancer research and treatment, with a joint research strategy, "Making the discoveries: our strategy to defeat cancer". https://shared-d7-royalmarsden-public.s3-eu-west-1.amazonaws.com/files_trust/s3fs-public/Making-the-discoveries-Our-strategy-to-defeat-cancer.pdf focusing on improving outcomes for patients. The RM/ICR BRC is the only BRC dedicated specifically to cancer, taking leading-edge cancer research from the laboratory and rapidly making it suitable for use within a clinical setting.

Patient and Public Involvement and Engagement (PPI/E) is central to and supportive of our work at the BRC, upholding our goal to increase cure rates and improve survival with smarter, kinder treatments which significantly reduce immediate and long-term side effects and allow patients to live well with and beyond cancer.

Our vision is to fully embed PPI throughout the research cycle and across the BRC research portfolio in order to promote patient benefit. We will always place cancer patients and their families at the heart of our research, involving patients and the public at every stage of the research cycle to identify the issues most important and relevant to those directly affected by cancer and its treatments.

This strategy is designed to build on existing good practice and work undertaken in previous years, but to strive for a continuous improvement in our implementation of meaningful and rigorous PPI/E.

2 Background to This 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
- **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.

At RM/ICR, patients and their families are at the heart of what we do. We recognise that working in partnership with patients and the public when setting priorities and carrying out research is fundamental to improving the quality and relevance of our research.

There is an established tradition of PPI/E at RM, which coalesces around the Patient and Carers Research Review Panel (PCRRP). The members of this panel are all volunteers who have received training in PPI/E (PPI Colleagues). At present our PCRRP members contribute to over 60 research projects per year.

In addition, our patient-led PPI/E Steering Group provides oversight and is responsible for delivery of our overall PPI/E strategy which integrates all activities across the RM and ICR, including the NIHR CRF and the NIHR/CRUK Experimental Cancer Medicine Centre (ECMC).

This document sets out the BRC PPI/E strategy for the next five years.

3 PPI/E within the BRC

In order to build on the existing work and to enable patients and members of the public to be involved meaningfully in the BRC research, nine additional Patient Representatives were appointed in 2017. They all have direct experience of cancer, either as a patient or as a carer. Eight of these are embedded into one of the BRC Themes (Novel Cancer Therapeutics, Targeted Physical Therapies, Breast Cancer, Prostate Cancer, Gastrointestinal Cancers, Uncommon Cancers, Genotypes Phenotypes and Cancer Evolution and Digital). Each also acts as a deputy Patient Representative for another of the Themes.

The role of these Patient Representatives operates across the entire research cycle. It includes ensuring the perspective of the public is represented within the decision-making processes in our research studies, helping researchers to write clear, understandable patient literature, assisting them with research applications and engagement with the public. Strategically, our Patient Representatives will help guide, assess and drive PPI/E within the objectives and direction of the BRC.

All Patient Representatives have also formed a Patient Representative Working Group (PRWG) led by a chair Patient Representative who has previous experience of PPI/E at the RM. This group views itself as a virtual 'Theme' that 'cross cuts' across the real BRC Themes. This group meets at least quarterly aiming to provide strategic leadership in PPI/E, identify the training needs of both the Patient Representatives and the researchers and also to promote good practice in PPI/E.

The ninth Patient Representative was appointed to attend the BRC Steering Committee alongside the chair of the PRWG.

4 Development of the Strategy

This strategy has been developed through a co-production approach. Co-production was chosen as the most appropriate method of developing this strategy because it allows 'health professionals' and Patient Representatives to work in equal partnership. A working group was set up comprising four Patient Representatives

and a Clinical Research Operations Manager with PPI/E responsibilities. Careful consideration has been given to the NIHR ten year PPI/E strategy 'Going the Extra Mile' (2015), and the latest draft of the 'National Standards for Public Involvement in Research' (published for consultation November 2017), to ensure that it embodies these standards throughout.

It has been developed:

- in collaboration with the NIHR CRF at RM/ICR; and
- in consultation with BRC researchers, the PPI Colleagues, members of The Royal Marsden Cancer Charity and public/patient responders to an on-line survey developed in collaboration with the NIHR CRF at RM/ICR.

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, their 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 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 Aims of the Strategy

In order to achieve our vision, we will:

1. Ensure that patients, carers and the public have a voice in prioritising our research.
2. Involve patients, carers and the public throughout the research cycle, increasing the number of co-designed studies
3. Collaborate with internal & external PPI/E groups ensuring a cohesive & wider PPI/E function
4. Ensure the BRC Steering Committee and the PPI/E Steering Group remain updated on PPI/E activities and its impact as well as influencing the strategic direction of the BRC and Research Themes
5. Provide training for our researchers and PCRRP members and promote the benefits of patient involvement
6. Keep patients, carers and the public informed of our research through a variety of channels of communication
7. Understand and evaluate the impact of our PPI/E activities

The first five aims are more pertinent to public involvement, the sixth to public engagement and the final aim relates to the continual assessment of PPI/E to

ensure we are constantly assessing our strategy. The objectives set in order to achieve these aims are presented in section 7 'Table of Aims and Objectives' on page 8 of this document.

It is important to note that this strategy is a live document and as such will be subject to ongoing development throughout its life course

6 Delivery of the Strategy

To achieve the aims and objectives of the strategy, our delivery is separated into short, medium and longer-term actions. The reasoning behind this and their relative priorities are presented below.

6.1 Short Term – 'Organise and Develop' (1-2 years)

As described above, nine new Patient Representatives were recruited to the BRC in 2017. While all have significant PPI experience in addition to their experiences of cancer, there remains work to do to ensure that they:

- have the necessary theoretical knowledge of the work and research to understand clinical considerations and thereby present the patient perspective
- build strong relationships within their designated Themes and across the BRC
- understand the organisational structures of the BRC, RM, and ICR and extending out to other BRCs and other organisations, sharing best practice.
- identify and build the necessary 'tools of the trade' as well as the measures of progress to enable a consistent, evidence-based, high-quality PPI/E approach across the BRC used by both existing and future Patient Representatives.
- continue to contribute to and build on engagement events.

This work is a priority for the shorter term as it allows the Patient Representatives to quickly provide and demonstrate a high quality of PPI/E activity.

As we move towards the medium term we will review our plans to ensure that those plans are still relevant and reflect any key outstanding matters.

6.2 Medium Term – 'Communicate and Reach Out' (3-4 years)

During medium term we will continue to build further meaningful and rigorous PPI/E embedded for all new clinical trials submissions to the Committee for Clinical Research (CCR). We also intend to significantly strengthen our engagement activities with the public including building wider and stronger relationships, especially with 'seldom heard' elements of the public - for example, ethnic minority groups and younger adults diagnosed with cancer.

We will increase the number of 'lived-experience' co-design projects by conducting methodology teaching and raising awareness of the PPI/E opportunities to participate in such projects.

We will also start to build relationships with other BRCs to share and understand best practice for our mutual PPI/E benefit.

As we move towards the longer term we will review our plans to ensure that those plans are still relevant and reflect any key outstanding matters.

6.3 Longer Term – ‘Influence, Review and Plan’ (5 years +)

We will continue to build upon the accomplishments made in the short and medium term, but will also seek to identify and influence any remaining panels and committees within the BRC where there is no PPI/E representation.

To ensure an independent public voice, as far as practicable, the PRWG intend to develop a greater degree of self-governance (other than for funding) from the BRC.

It will be appropriate toward the end of this 5-year term to conduct a review of progress and achievements made and communicate this information to the public. Consultation with the public will also assist with the planning for the next 5-year period.

7 Table of Aims and Objectives

#	Aim	Objective	Measurement, Frequency (of measurement)	Who Responsible for Objective	Target Completion
1.	Ensure that patients, carers and the public have a voice in prioritising our research	<p>a. Establish a new digital community and use this to optimise patient and public input to the prioritisation and design of BRC research and to identify the best approach to sharing our research findings</p> <p>b. ‘Capture’ – develop multiple channels for public to provide their opinions on research priorities and research ideas (channels such as web, social media, engagement events, regular surveys as well as from Patient Representatives and PCRRP members)</p> <p>c. Identify BRC research ideas & activity at the earliest opportunity and help shape using public priorities & ideas (pro-activity rather than passivity)</p> <p>d. ‘Show strategic leadership in PPI/E activities and in theme working groups</p> <p>e. Ensure rigorous PPI/E embedded for all new submissions to CCR</p>	<p>a. Discussion taking place with digital platforms providers</p> <p>b. Review all feedback, Quarterly</p> <p>c. Report feedback activity & outcomes to each Theme Working Group and PRWG Meeting, Quarterly</p> <p>d. N/A</p> <p>f. Cross tabulation of submissions to CCR with PPI Activity logs, Quarterly</p>	<p>a. BRC Programme Manager, BRC Manager</p> <p>b. Patient Representatives supported by Theme Lead, BRC Clinical Research Operations Managers and PRWG Chair</p> <p>c. Patient Representative for Theme and Theme Lead</p> <p>d. Patient Representative for Theme</p> <p>e. Patient Representative supported by Clinical Research Operations Managers</p>	<p>a. Short Term</p> <p>b. Ongoing</p> <p>c. Ongoing</p> <p>d. Ongoing</p> <p>e. Ongoing</p>

#	Aim	Objective	Measurement, Frequency (of measurement)	Who Responsible for Action	Target Completion
2.	Involve patients, carers and the public throughout the research cycle, increasing the number of PPI/E 'co-designed' research projects ('Co-design' refers to patients, carers and the public acting as co-researchers in projects)	a. Increase the number of co-design projects by conducting methodology teaching, encouraging and raising awareness of the PPI/E opportunities to participate in such projects.	a. Number of co-designed projects submitted to CCR, Half Yearly	a. Patient Representatives/ BRC Programme Manager, Researchers	Ongoing
		b. Evaluate the PPI/E co-design experience and impact for both PPI/E colleagues and researchers and address any findings.	b. Secure feedback from PPI/E Co-researchers and Researchers, Annually	b.-d. Patient Representatives	Ongoing
		c. Sharing of Best Practice with other Themes via Patient Representatives	c. N/A		Ongoing
		d. Contributing to a 'Best Practice' Central Record	d. Minimum (TBD) number of contributions to		Ongoing

		e. Develop a 'fast-track' approach whereby PPI reviews of literature & applications can be completed at shorter notice	e. "Best practice" TBD	f. Patient Representatives, BRC Manager	Short Term
#	Aim	Objective	Measurement, Frequency (of measurement)	Who Responsible for Objective	Target Completion
3.	Collaborate with internal & external PPI/E groups ensuring a cohesive & wider PPI/E function	<p>a. Collaborate with other BRCs, and other external bodies to share best practice</p> <p>b. Attend bi-monthly PPI/E Steering Group, with members from PRWG, CRF and ICR and PCRRP meetings</p> <p>c. Help ensure meeting outcomes are clearly communicated to the Themes</p> <p>d. Collaborate with other BRCs and regionally with organisations such as the CRN London adopting/sharing best practice</p>	a. – b. No of meetings Attended, Annually	<p>a. & b. Nominated Patient Representative and PRWG Chair</p> <p>b. Patient Representatives</p> <p>c. Patient Representatives</p> <p>d. Patient Representatives</p>	Ongoing
4.	Ensure the BRC Steering Committee and PPI/E Steering Group remain updated on PPI activities and its impact as well as influencing the strategic direction of the BRC and Research Themes	<p>a. Develop mechanisms to ensure a consistent approach for reporting of activities undertaken, progress measures and evidence of impact to PRWG.</p> <p>b. Record & update PRWG Chair with activities undertaken, progress and evidence of impact in agreed format</p> <p>c. Update the PPI/E Steering Group and</p>	<p>a. N/A</p> <p>b. Written Record, Quarterly</p> <p>c. Written Record, Bi-</p>	<p>a. Nominated Patient Representatives</p> <p>b. Patient Representatives</p> <p>c. – d. PRWG Chair (and</p>	<p>a. Short term</p> <p>b. Ongoing</p> <p>c. Ongoing</p>

		BRC Steering Committee on PPI/E activities and impact	Annual Meetings	Deputy)	
		d. Identify and influence any remaining panels and committees within the BRC where there is no PPI representation so as to influence the strategic direction of the BRC.	d. N/A		d. Longer Term
#	Aim	Objective	Measurement, Frequency (of measurement)	Who Responsible for Objective	Target Completion
5.	Provide training for our researchers and PPI Colleagues and promote the benefits of patient involvement	<p>a. Identify gaps in PPI Colleagues knowledge or where support is required (e.g. via self-completed skills matrix)</p> <p>b. Provide training for our researchers and PPI Colleagues and promote the benefits of patient involvement</p> <p>c. Maintain & recruit further PPI Colleagues to ensure continuity of PPI activities via quality feedback incl. the impact of their inputs. Recruitment via engagement events, web & social media etc.</p> <p>d. Develop/maintain mechanisms to ensure a consistent approach for reporting of activities undertaken,</p>	<p>a. N/A</p> <p>b. No. of researchers & PPI Colleagues receiving education (Annually), Target 80% 'Very Good' or 'Good' education feedback rating, Annually</p> <p>c. Current no. of PPI Colleagues plus no. of new recruits for year (Annually)</p> <p>d. Review reporting to ensure complete and consistent</p>	<p>a. Patient Representatives/PCRRP Lead</p> <p>b. BRC Programme Manager/Patient Representatives</p> <p>c. BRC Programme Manager, PCRRP Lead Managers, Patient Representatives</p> <p>d. Patient Representatives, Clinical Research</p>	Ongoing

		progress measures and evidence of impact.	(Quarterly)	Operations Managers	
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#	Aim	Objective	Measurement, Frequency (of measurement)	Who Responsible for Objective	Target Completion
6.	Keep patients, carers and the public informed of our research through a variety of channels of communication	<p>a. Ensure we have effective multiple channels of communication – public events, /social media, webinars, newsletters, posters etc.</p> <p>b. Conduct Theme-based engagement events. Current engagement activities planned are “Advances in breast cancer research” and a “How am I beating cancer? An evening of the latest prostate cancer trials updates for patients and the public”.</p> <p>c. Utilise an extensive calendar of external events to showcase research findings and increase awareness of research (such as International Clinical Trials Day, Rare Diseases Day, World Cancer Day, Breast Cancer Awareness Month)</p> <p>d. Reach out to the wider public via</p>	No. of events, newsletters etc held, quantitative and qualitative feedback from those attending, no. of PPI Colleagues recruited, Quarterly	<p>a. Communication team, BRC Programme Manager</p> <p>b. Patient Representatives & Researchers</p> <p>c. Patient Representatives/ Clinical Research Operations Managers/Researchers/PPI Colleagues</p>	<p>a. Short and Medium Term</p> <p>b. Short and Medium Term</p> <p>c. Medium Term</p> <p>d. Medium Term</p>

#	Aim	Objective	Measurement, Frequency (of measurement)	Who Responsible for Objective	Target Completion
		community festivals, shopping centres, faith groups, schools, 'seldom heard' groups' identifying local champions in these areas as well as evaluating/using new digital initiatives such as 'Voice'		d. BRC Programme Manager, Patient Representatives	

#	Aim	Objective	Measurement, Frequency (of measurement)	Who Responsible for Objective	Target Completion
7.	Understand and evaluate the Impact of our PPI/E activities	<p>a. Having opportunities for the services users to feed back their experiences-Evaluation forms at engagement events, digital platform for service user feedback.</p> <p>b. Collaborate with the CRN and pilot their assessment tool that will be available to assess the impact of PPI/E in April 2018.</p> <p>c. Linking up with other BRC's understanding their metrics on impact</p> <p>d. Regular review of applications with PPI/E input, learning from, what worked well.-log of feedback.</p> <p>e. Acknowledging this process is continual and ensure "best</p>		Clinical Research Operations Managers/ BRC Programme Manager, Patient Representatives	Ongoing

#	Aim	Objective	Measurement, Frequency (of measurement)	Who Responsible for Objective	Target Completion
		practice" is constantly been reviewed			

7 Management and Governance

Oversight of the strategy is fully integrated into BRC governance structure. Two Patient Representatives are members of the BRC Steering Committee and report the achievements/challenges of strategy delivery twice a year.

8 Monitoring delivery and measuring success

The PRWG chair will be responsible for regularly assessing progress made against the Aims and Objectives Table. Quarterly summary progress reports will be made by the PRWG chair to the Clinical Research Operations Managers and the BRC Programme Manager. Bi-annual reports will be presented to the BRC Steering Committee. Outside of this formal reporting structure, there will be very regular contact between the Patient Representatives, the PRWG chair, the BRC Programme Manager and the Clinical Research Operations Managers.

We see the key measures of success as described below:

Aim	Aim Description	Measure	Measurement Frequency
1.	Ensure that patients, carers and the public have a voice in prioritising our research	a) Review feedback from digital platforms and evaluation forms b) Report activity & outcomes to each Theme Working Group and PRWG Meeting c) N/A d) Cross tabulation of submissions to CCR with PI Activity logs	Quarterly Quarterly N/A Quarterly
2.	Involve patients, carers and the public throughout the research cycle, increasing the number of co-designed studies	a) N/A b) Recording number of PPI co-design projects & publications c) Recording number of PPI collaborations & co-researchers d) Ongoing e) Minimum (TBD) number of contributions to 'Best Practice' Central Record	N/A Annually Annually N/A Annually
3.	Collaborating with internal & external PPI/E groups ensuring a cohesive & wider PPI/E function	a)– b) Number of meetings Attended c) N/A d) N/A	Annually

Aim	Aim Description	Measure	Measurement Frequency
4.	Ensuring the BRC Steering Committee and PPI/E Steering Group remain updated on PPI activities and impact and influencing the strategic direction of the BRC and Research Themes	<ul style="list-style-type: none"> a) N/A b) Written Record c) Written Record, Bi-Annual Meetings d) N/A 	Annually Quarterly Bi-Annually N/A
5.	Provide training for our researchers and PPI Colleagues and promote the benefits of patient involvement	<ul style="list-style-type: none"> a) N/A b) Number of researchers & PPI Colleagues receiving education, Target 80% 'Very Good' or 'Good' education feedback rating c) Current number of PPI Colleagues plus number of new recruits for year d) Review reporting to ensure complete and consistent e) N/A 	N/A Annually Annually Quarterly N/A
6.	Keep patients, carers and the public informed of our research through a variety of channels of communication	<ul style="list-style-type: none"> A) Number of events, newsletters etc held, quantitative and qualitative feedback from those attending, number of PPI Colleagues recruited, B) Collaborate with local PPI groups such as the CRF and nationally with the CRN 	Quarterly
7	Understand and evaluate Impact of PPI/E	<ul style="list-style-type: none"> A) Collaboration and piloting the impact tool with the CRN B) Use of evaluation forms to capture the voice of the service user. C) Bigger roll out of digital platform, to capture wider audience. 	Annually

9 Resources

Our BRC Programme Manager, three Clinical Research Operational Managers (who have PPI responsibilities within their remit) and our group of ten Patient Representatives (the PRWG Chair, deputy and 8 Theme-linked Patient Representatives) are all working together to execute this strategy.

Travel and childcare expenses are reimbursed for meeting attendances and training. Additionally, Patient Representatives are remunerated on an activity basis, based on the INVOLVE guidance. In order to maximise resources wherever possible, events and training will be held in collaboration with the NIHR CRF at RM/ICR.

10 Training and Support

As described above, initial and ongoing training as well as support is provided as based on the needs of the individual Patient Representatives and PPI Colleagues. We have described on page 12 how we will develop suitable educational material to support training of researchers on PPI.

11 Glossary

BRC - Biomedical Research Centre

CCR – Committee for Clinical Research

CRF - Clinical Research Facility

ICR – The Institute of Cancer Research

NIHR - National Institute of Health Research

PCRRP - Patient and Carer Research Review Panel

PPI/E – Patient and Public Involvement/Engagement

PRWG - Public Representatives Working Group

RM – The Royal Marsden NHS Foundation Trust