Patient Representative

Role description

Background
The National Institute for Health Research (NIHR) Biomedical Research Centres (BRCs), formed through partnerships between England’s leading NHS organisations and universities, are leaders in translating lab-based discoveries into new cutting edge treatments, technologies, diagnostics and other interventions in clinical settings. The BRC at the Royal Marsden NHS Foundation Trust (RM) and the Institute of Cancer Research (ICR) was first designated as the UK’s only specialist BRC for Cancer in 2007. In 2011 and 2016 the BRC status was successfully renewed.

Our BRC allows us to rapidly translate scientific research about the genetic and molecular basis of cancer into improved therapies in the clinic, and transform the lives of cancer patients. Our research falls under six Research Themes: Novel Cancer Therapeutics, Targeted Physical Therapies, Breast Cancer, Prostate Cancer, Gastrointestinal Cancers, Uncommon Cancers and two Cross-cutting Themes.

Patients and their families are at the heart of what we do, we aim to involve patients and the public at every stage of the research cycle to allow us to identify the issues most important and relevant to those potentially affected. Working in partnership with patients, their carers, and family members is fundamental to achieving this and ultimately improve the quality and relevance of our research. Our cohort of PPI colleagues - patients, carers and members of public who contribute to all aspects of research that we undertake - work with researchers and clinical teams to develop research ideas, review and conduct research. PPI colleagues contribute to our research through a variety of activities, for example, taking part in discussion groups about our research priorities or as members of a clinical trial team inputting into trial design.

Further information can be found at https://www.cancerbrc.org/.

About the role
PPI representatives form a key part of our BRC’s governance structure; they are members of the BRC Steering Committee and/or BRC Theme Working Groups and are directly involved in strategy discussions, determining allocation of BRC funding. They are responsible for ensuring that the views of patients their families and carers, and members of the public are represented in all our research and are also members of the PPI Steering Group.

BRC Steering Committee
The BRC Steering Committee oversees the strategic direction of the RM/ICR BRC and ensures delivery of BRC's objectives. The Committee is also responsible for the BRC strategies to ensure active and meaningful patient and public involvement and capacity building and training. It is chaired by the Director of Clinical Research in his role as BRC Director, comprises Research and Cross-cutting Theme Leads, other key clinical academics, allied health professionals, patient representatives and senior management from both Institutions. The BRC Steering Committee meets quarterly.
BRC Theme Working Groups
Theme Working Groups are responsible for ensuring implementation of the Theme’s strategy, monitoring overall performance and activity within the theme, prioritising and allocating resources, and maximising BRC funding through leveraging of other sources of income. The Working Groups meet quarterly and report to the Steering Committee.

PPI/E Steering Group
The PPI/E Steering Group supports the development and coordination of patient and public involvement and engagement (PPI/E) in research across RM and ICR. 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 both institutions. It meets on bi-monthly basis.

Main responsibilities
PPI representatives are responsible for ensuring that the views of patients their families and carers, and members of the public are represented in all our research.

- Attend and participate in meetings that develop BRC research strategy and the allocation of funding - Theme Working Group meetings and/or BRC Steering Committee – providing patient and public perspective and raising any issues for clarification
- Support the implementation of PPI/E Strategy through contribution to PPI/E Steering Group meetings and support the BRC team with the development of the strategy.
- Attend other ad hoc meetings and events, lead training events for researchers and PPI colleagues, and act as mentors for new PPI colleagues, representing their views at the PPI/E Steering Group, Theme Working Groups and BRC Steering Committee.
- Act as an advocate for PPI/E in research across the RM and ICR.
- Assist researchers with grant applications, review and comment on research ideas, research portfolios and research funding applications
- Represent the RM/ICR BRC in nominated external meetings and engagements

Person specification
You will need to be an enthusiastic, confident person who is able to fully and actively contribute to the variety of the high-level meetings described above. You would need to provide a patient perspective on all kinds of research deliberations.

Essential experience/attributes:
- Experience of cancer services
- Keen interest in cancer research and a basic understanding of what cancer research entails
- Ability to present an independent, lay perspective at a senior level and offer constructive challenge
- Ability to confidently voice your opinions in a meeting of mixed professionals
- Ability to listen to others, respect viewpoints and expertise and express own views in in a polite but effective manner
- Ability to understand and evaluate a range of information and evidence and provide constructive feedback
- Ability to represent the views of other people and able to give a balanced viewpoint, including an understanding of a range of different perspectives
- Maintain confidentiality where required
- Ability to consider wider PPI across the organisation and liaise with the Trust Lead for PPI
• Ability to travel to attend meetings, and to carry out other activities, such as reviewing documents

Desirable experience/attributes:
• Experience of serving on user panels/patient and public involvement/committee work
• Understanding of current PPI issues
• Good communication and team-work skills, and a potential willingness to speak in public
• Willing to discuss and represent PPI issues within the BRC to other members of the RM/ICR

Time commitment
PPI Representatives positions are normally a three year fixed term position (with the possibility of renewal for a further two years). During this term, we would expect attendance at every meeting (up to 14 per year), wherever possible. Meetings last between 1.5 to 2.5 hours. PPI Representatives are expected to dedicate sufficient time to read the relevant paper work before the meeting. Including preparation for meetings and travelling time, PPI representatives usually commit around one - two days per month.

Occasionally, there may be associated tasks that Patient Representatives will be encouraged to assist with such as PPI training for researchers and PPI colleagues, mentoring PPI colleagues, helping researchers with writing grant applications.

Support
The BRC Office and Trust Lead for PPI will support you in your role and help you to identify any training needs as appropriate. All PPI representatives will be provided with relevant training to support them to undertake their role, there is also the opportunity to access training support via our induction programme and the RM Patient and Carer Research Review Panel.

Payment
All travel, and childcare expenses are reimbursed for meeting attendances and training. Additionally PPI representatives are remunerated on an activity basis, based on the INVOLVE guidance (INVOLVE, 2016).

These fees are ‘honorarium’ payments, a form of reward and recognition offered for the voluntary contribution that PPI Representatives make to the BRC. Payments most often relate to involvement in the activities of the BRC Steering Committee, BRC Theme Working Groups, BRC PPI training events and external meetings where the BRC Office has asked the PPI Representatives to represent the BRC. Currently, the standard daily fee for a committee meeting is £150 (this includes time taken to prepare, attend and follow up) or £75 for involvement in ad hoc requests or activities which equate to approximately half a day's activity.

Conflicts of interest
PPI representatives are required to disclose any involvement with individuals, government bodies, commercial interests or third parties which could lead to a conflict of interest with the work of the BRC Steering Committee and the Theme Working Groups. A conflict of interest doesn’t stop someone from being a patient/public member.

Raising concerns
We want to encourage an open and friendly environment. Please feel free to raise any concerns you may have with either the Trust Lead for PPI or the BRC Manager.