Integrating patient, carer and public involvement in cancer research: an unified approach

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Background:

Patient, carer and public involvement (PPI) incorporates and integrates patients’ or users’ perspectives into research, throughout different stages of research so that cancer research reflects issues that are important and relevant to those whom the research potentially affects.

Objectives:

To map and describe the development of an integrated approach to establishing and developing Patient, carer and Public Involvement (PPI) in research in the UK’s only Biomedical Research Centre (BRC) for Cancer and the RM/ICR NIHR Clinical Research Facility (CRF).

Method:

A process mapping exercise to analyse how PPI is integrated into all types of research was undertaken. It aimed to demonstrate progress with the development of an integrated approach to involving patients and the public in research within the RM/ICR NIHR BRC and CRF.

All PPI activity and processes were reviewed within the BRC and was undertaken in conjunction with, and reviewed by, members from the Patient and Carer Research Review Panel. This exercise was then used to develop the BRC PPI strategy, which aims to enhance the amount and type of patient and public involvement to help develop a research portfolio that is truly in the patient/public interest.

Figure 1. Continuum of PPI


The BRC PPI strategy currently meets this level of involvement with development of user-led research in certain areas (e.g. health services research).

Findings

From computer modelling to bench to bedside and beyond....

The mapping exercise has allowed us to understand how several strands of PPI are interwoven to create and develop a culture of patient and public involvement in cancer research. At present the BRC and CRF are at the Creative end of the PPI continuum, representing collaboration and co-production of research, where research is shaped by PPI and PPI partner input and insight has made a difference to planned research design. However, there is a shift along the continuum with two user-led studies in the process of being developed.

PPI has extended across the research spectrum and included imaging, translational research, drug development and health services research. Over seventy studies have been reviewed by the Patient and Carer Research Review Panel with a tangible impact in terms of changing the study design, beyond tokenistic reviews. The strands to embed PPI across the BRC and CRF can be seen in Figure 2 and include: the panel; development of open web-resources to engage and involve patients and the public; priority-setting processes that rank patient and public suggestions for what kind of cancer research should be undertaken, training and increasing awareness of how patients and the public can get involved in ground-breaking cancer research.

Figure 2. Mapping of PPI Strands

Conclusion:

Involving patients and the public in cancer research requires a culture shift across organisations, but the imperative for PPI is compelling and results in research with clinically important and meaningful patient outcomes. Research into experiences of the public into PPI is currently underway.