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Listening to public opinion

The involvement of patients and the public in the design of cancer research is a priority for The Royal Marsden and the ICR. We highlight three BRC-funded studies in which their views have been vital



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Patient and public involvement ^[6] (PPI) is a central function of the BRC at The Royal Marsden and the ICR, as it ensures that our research reflects the issues considered important and relevant to those potentially affected by it.

The Royal Marsden's patient and carer research review panel gives patients and the public an active role in shaping future research projects at the BRC. The panel of around 35 laypeople meets four times a year to discuss and prioritise research ideas presented by investigators, as well as to ensure that the information given to patients is easy to understand.

PPI is about empowering individuals and communities so they can play a greater role in shaping health and social care research



Dr Natalie Pattison, PPI Lead at The Royal Marsden, said "the contributions of patients can be extremely valuable, providing alternative views to those of the research team. Patients are able to make judgements based on their understanding of their condition and may have different thoughts about health outcomes that academics and researchers may not have considered."

CASE STUDY

Understanding patients' priorities

In a pilot study conducted over a four-week period, The Royal Marsden asked 780 patients to complete the PACER survey in order to discover which areas they thought should be priorities for cancer research. The top priorities given were detection and prevention of cancer, scientific understanding, curative treatment and personalised treatment.

The results were published online in the *ecancermedicalscience* journal. The Royal Marsden's Dr Sing Yu Moorcraft, Clinical Research Fellow for the study, says: "The top priorities identified were remarkably consistent across age, gender and a variety of tumour types. We believe that the views of patients should be considered alongside the views of cancer researchers and clinicians, in order to ensure that research strategies and proposals

are appropriately balanced and patient-focused.?

The patient's perspective

Martin Lee was treated at The Royal Marsden for head and neck cancer in 2009 and continues to be monitored by the hospital, while his father-in-law and stepfather are also patients. He now plays a part in shaping future research as a member of the patient and carer research review panel.

"PPI is essential as it provides invaluable real-time experience for the academics, enabling researchers to understand the impact on patients," says Martin. "It's very important to get patients and the public involved throughout all stages of NIHR and BRC-funded studies, from the initial idea to the release of results."

"For PPI to really work, it needs to have support from the top of the Trust. It's obvious to me that everybody at The Royal Marsden sees PPI as very important and takes it incredibly seriously – it's not just a box-ticking exercise."

CASE STUDY

"Patient mentors can share their experience, provide advice and reassure new patients who are about to start the trial. We have consulted patient groups at all stages of the trial, including the design of the ProSpare device."

Professor David Dearnaley, Professor of Uro-Oncology at the ICR and Consultant at The Royal Marsden

Using 'invisible' ink for breast radiotherapy references

Royal Marsden clinicians found that using dark ink tattoos as external reference marks during breast radiotherapy was unpopular with patients, as the marks continue to be visible after treatment. As a result, researchers – with input from patients and the public – designed the BRITER pilot study to evaluate the use of fluorescent ink tattoos, which are only visible in ultraviolet light.

Steven Landeg, Operational Superintendent and lead author of the study, says: "Dark ink tattoos can negatively impact the patient's long-term cosmetic outcome and serve as a reminder of their diagnosis and treatment. Fluorescent ink tattoos offer an innovative alternative."

"The results of the study suggest that women who had fluorescent tattoos felt better about their bodies one month following treatment, compared with those women who received black ink tattoos. PPI was important in this study as it confirmed the wider need for a less conspicuous marking method for this patient group," says Steven. "A patient forum also

helped us with the design of the study.?

CASE STUDY

Reducing side effects in prostate radiotherapy

Patient mentors are being used for the first time in The Royal Marsden and the ICR's Phase II POPS trial, which is funded by the BRC and Sussex Development Services LLP. The study aims to improve the accuracy in radiotherapy delivery for prostate cancer patients in order to minimise the radiation dose delivered to healthy tissue and reduce side effects.

It is recruiting 245 post-prostatectomy patients across 18 sites and involves the use of ProSpare, a device that is inserted by the patient into the rectum at each radiotherapy treatment.

Read more

- [Find out more about PPI](#) [7]
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