

Related articles



[1]

Getting involved: for patients and the public [1]

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[2]

Our patient and public engagement events [2]

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[3]

What is patient and public involvement and engagement at the BRC? [3]

BRC patient representatives: our experiences



BRC patient representative Margaret Perkins

Representing the patient voice at the BRC

In 2017, the BRC appointed a patient representative to each of the eight **Research Themes** ^[4], all of whom have direct experience of cancer either as a patient or as a carer.

The patient representatives meet quarterly to provide strategic leadership in PPI/E, identify the training needs of both patient representatives and researchers and also to promote good practice in PPI/E. The Chair and the Deputy Chair of the group, both patient representatives, also provide patient voice at the governance level of BRC.

Patient representatives: our experiences

The BRC patient representatives are involved in a wide range of activities, across all stages of the research cycle to ensure the perspective of patients and the public are embedded within the decision-making processes in our research studies. They also help researchers to write clear and easy to understand patient literature, and assist with and/or co-design research applications. They also engage with other patients, carers and public to promote the research being carried out and the progress made.

An uncommon cancer diagnosis: understanding the lived experience

Patient representatives for our **Uncommon Cancers research theme** ^[5], Alison Allam and Margaret Perkins, were instrumental in planning and delivering a pilot project to understand the lived experiences of patients with uncommon cancers.

Read more about how Alison and Margaret shaped this research and the impact it will have for patients. ^[6]

PROFILES: monitoring patient wellbeing

Della Dolapo Ogunleye, the patient representative for our **Digital research theme** ^[7], played a key role in helping to promote a new online tool to enable patients to record information on their quality of life.

Read more about why Della got involved in this project and the impact this new tool will have for patients. ^[8]

Improving bowel cancer treatment: unlocking the power of a single cell

Pete Wheatstone, our **Gastrointestinal Cancers Theme** ^[9] patient representative has lent his perspectives and expertise to a wide range of projects for the BRC, including an on-going study investigating new techniques to improve the treatment of bowel cancer.

Find out how Pete is helping to shape this ground-breaking research. ^[10]

Organising the UK Interdisciplinary Breast Cancer Symposium 2020

Mairead McKenzie, patient representative for our Breast Cancer Theme, served on the organising committee for the UK Interdisciplinary Breast Cancer Symposium 2020 (UKIBCS). She played an instrumental role in ensuring that the patient voice was represented at the Symposium and organised a successful patient-led session on diet and exercise.

Find out more about how Mairead was involved in UKIBCS 2020. ^[11]

Training and support for PPI/E ^[12]

We offer training and support to patients and the public who are involved in research, and to researchers to help them involve patients in their work.

Source URL: <https://www.cancerbrc.org/patient-and-public-involvement-and-engagement/brc-patient-representatives-our-experiences>

Links

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[3] <https://www.cancerbrc.org/patient-and-public-involvement-and-engagement/what-patient-and-public-involvement-and-engagement-brc>

[4] <http://www.cancerbrc.org/our-research>

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