

Patient Experience as a research theme within the Experimental Cancer Medicine Team at The Christie NHS Foundation Trust

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Background

- Patient experience of their care, treatment and how they are supported is an integral part of high-quality care, alongside clinical effectiveness and safety¹.
- Patient involvement and engagement is important to:
 - Ensure patient centered care
 - Improve inclusion and awareness of clinical research
 - Increase staff knowledge of patient needs to continuously improve the service provided
- The Experimental Cancer Medicine Team (ECMT) at The Christie conducts early phase oncology clinical trials across all solid tumour types. To ensure a patient-centric approach, the ECMT have developed a patient experience theme as one of the core research themes.

Aims

- To give all patients recruited to a trial by ECMT personalized care, encompassing holistic needs assessments, health and wellbeing discussions and extra support needs.
- To incorporate patient involvement and engagement into all work carried out by ECMT.

Theme implementation

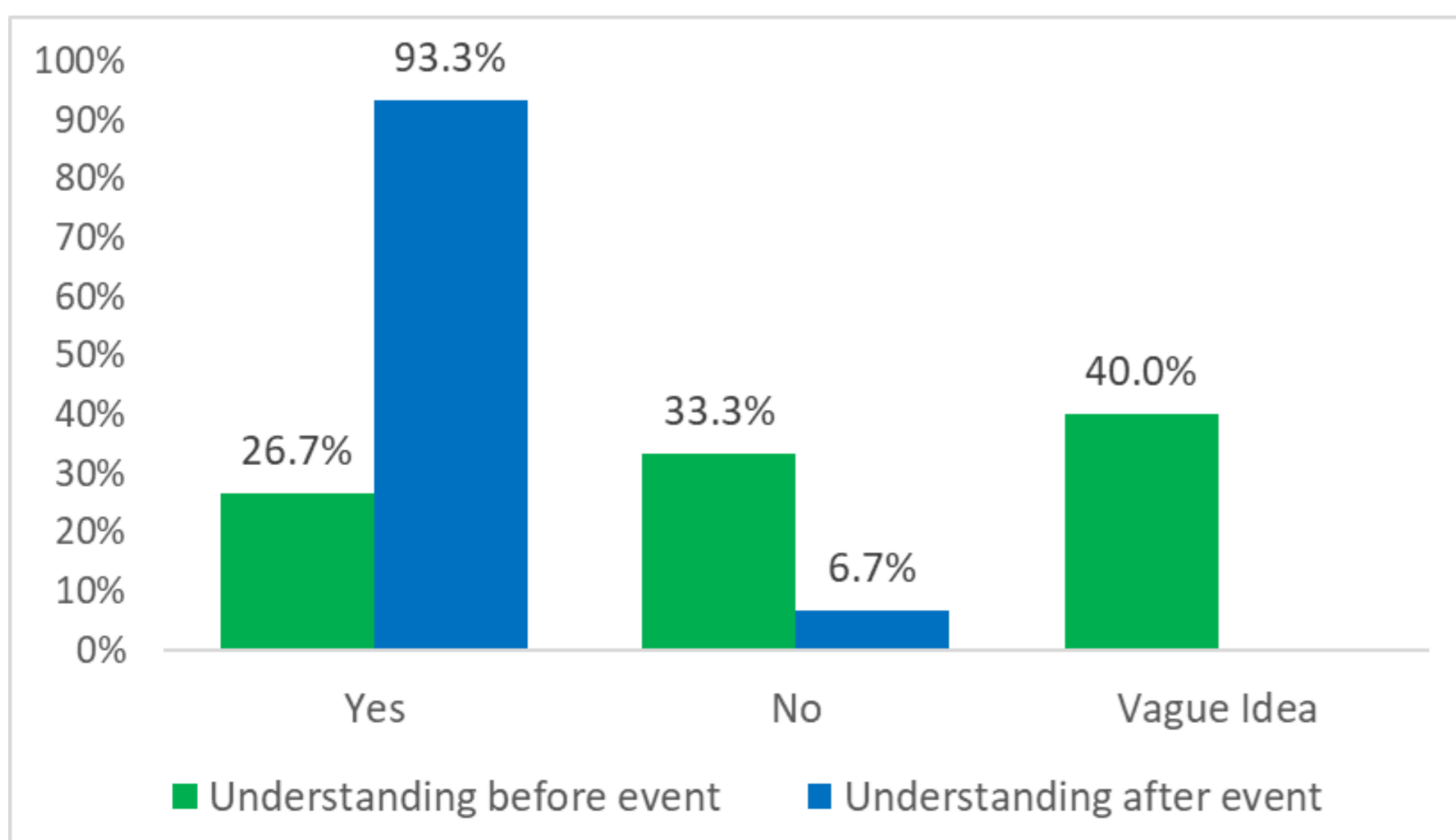
- Implemented 'patient experience' as a core clinical theme within ECMT.
- Hosted patient and public engagement events to improve understanding of early phase cancer trials.
- Developed and conducted clinical studies with a focus on obtaining information on patient views and experiences.
- Created a dedicated Experimental Cancer Medicine (ECM) Clinical Nurse Specialist (CNS) to provide holistic support to patients.
- Brought together a patient and public involvement (PPI) group to support ECM trials across The Christie.

Results

Patient engagement events

- In February 2019, The Christie hosted a face-to-face event attended by 55 patients & public. The day included educational presentations, tours of the NIHR Clinical Research Facility (CRF) and interactive stalls. Feedback suggested a 93% understanding of early phase trials following the event compared to 27% before (figure 1).
- A follow up virtual event in April 2021 was attended by 115 patients, members of the public and non-research staff.

Figure 1: Responses to event feedback question asking about attendee understanding early phase trials before and after the event



Results (continued)

Figure 1: Photographs from engagement event in February 2019



Patient-centric clinical studies

- ECMT and digital ECMT have designed and conducted clinical studies with primary outcomes that focus on patient wellbeing.
- Patient involvement has been integral to the design and conduct of these studies.

Table 1: A summary of the patient centered clinical studies designed and conducted by ECMT

Project	Description
EPIC study	An Evaluation of the Psychological Impact of Early Phase Clinical Trials using validated tools
Financial toxicity and burden in early phase trials	Understanding the financial issues patients experience when participating in trials and what we can do to alleviate these pressures.
Assessments of activity and exercise levels in trials	Understanding how active patients are and whether they think this is important in their clinical management.
Patient reported experience measure tool	Validated tool for patients and carers on their experience of experimental cancer medicine trials.
Patient Reported Opinions About Clinical Tolerability tool (called PROACT)	A digital tool developed by digital ECMT which allows patient experiences on early phase trials to be collected to inform the drug development process.
Continuous monitoring of vital signs of patients with COVID-19 (COSMIC-19 study)	During the COVID-19 pandemic, funding from Innovate UK was re-purposed to contribute to a study to continuously monitor vital signs in patients using wearable sensors.
NOTION in-home sampling Of cyTokines in Immunotherapy patieNts	Proof of concept study investigating the collection and measurement of in-home dried blood spot samples of cytokines in patients with specific disease type receiving first-line combination immunotherapy.
Encouraging inclusivity in technology clinical trials workshops	A project bringing together diverse patient groups and research teams through online workshops to create inclusivity guidance for technology clinical trials

Patient experience centred roles

- The CNS role has been created to fill a current care gap, aiming to ensure patients are well supported for wider holistic needs whilst on an ECM trial, to liaise with wider MDT services and teams and ensure continuity of care post trial with a view of improving patient experience.
- Closer links have been formed with the trust physico-oncology team providing better access to support roles for ECM patients.
- Feedback will be sought from both patients and clinical teams to review this new service.

Dedicated patient & public involvement group

- The Manchester PPI group have helped revise several trial documents, particularly facing materials to ensure they are clear and understandable.
- The group has been instrumental when making decisions on how to develop and manage the patient centered studies listed in table 1.

Next steps

- Follow on studies from EPIC and PROACT.
- Patient reported experience measure tool to be utilized across the ECMT network to assess patient experience and identify areas for improvement.
- PROACT tool to be validated and be made available nationally.
- Continuation of CNS role in ECMT.
- Additional PPIE events to be hosted.

Conclusion

Patient experience should be a core consideration for any clinical research team to facilitate excellent patient care, and ultimately improve awareness and inclusion in trials. The ECMT has demonstrated that this can be an integral theme within the research setting.

For more information contact Emma Darlington (e.darlington@nhs.net)

Acknowledgements:

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References:

1. NHS England. 'Cancer Experience of Care' <https://www.england.nhs.uk/cancer/ipe/> 2022