

INVOLVING PEOPLE AFFECTED BY CANCER IN BREAST CANCER SURGERY METHODS

The research develops imaging systems to be used in Breast Conserving Surgery, whereby the tumour is removed whilst preserving the healthy breast tissue. It aims to help surgeons identify and more efficiently remove breast tumours. This could decrease re-operation rates, improve patient's treatment and post-operational recovery, as well as save the health service millions of pounds annually. Patient and Public Involvement (PPI) was used when developing the research idea, developing the research application and disseminating results.

How was PPI established in the project?

People affected by cancer (PaC) were accessed through the Imperial Cancer Research UK PPI group. The [focus group](#) were consulted virtually, at several stages of the research project, and in person when discussing [important updates, findings and results](#).

The group have:

- Helped develop and inform the research's direction in the planning stages
- Advised on clinical trial risks/risk management strategies, inclusion and exclusion criteria for participants of the study and wording for the research application
- Identified preferable ways to disseminate the study results

Open ended questions are used to really engage the members and [facilitate discussion](#). At times, the group were asked to decide between two options and specify why they had chosen that option.

Continuous feedback from the group was established through e-mails, on-online platforms, [science cafes](#) and public showcase presentations.



"Our conversations gave me will power and extra motivation to do the best I can as a researcher to improve patient experience" Maria Leloglou, Researcher

What training and support was offered to the focus group?

- [Training materials](#) – the group were given a [study summary](#) to make the project clear to them, before consulting and offering recommendations.
- [Pre-reads](#) – were sent out before face to face meetings, explaining what would be discussed. This helped the meetings run more smoothly
- [Time to feedback](#) – when reviewing the patient facing documents, it was ensured that the group had sufficient time to process the tasks and feedback
- Key contacts – the group could contact the researcher at any point with any queries

What was the impact of involving people affected by cancer?

Shaped the research idea & questions

The group raised issues and challenges that breast cancer patients face. For example, in some patients, cancer cells overexpress receptors on their surface. Adjuvant therapies target those receptors to decrease their activity, but they do not always work and can cause unpleasant side effects. The PPI group helped the researcher understand how difficult this is. They thought it more important to investigate fluorescent contrast agents, which could show if cancer cells express specific receptors and predict whether adjuvant therapies would work. This could help patients avoid unnecessary side effects. By shaping the research idea, the group focussed the project on the needs of patients and motivated the researcher.

Helped make the research more accessible

PPI helped communicate the research in lay terms to those being recruited on to clinical trials. For example, they changed the wording and way the patient's risks were being presented in patient facing documents. They also recommended ways to minimise certain risks such as to run a pre-test to check if the patient is allergic to a contrast agent or pre-medicate patients for likely anaphylactic shocks. Such changes should facilitate recruitment to the clinical trials.

Identified the best ways to disseminate results

The group helped identify preferable ways to disseminate clinical trial results. For example, they stressed they would prefer researchers to come to science café talks, then share published summaries.

What challenges were faced?

1. [Finding PaC to work with](#) – accessing patients was hard as the researcher was unaware of local PPI groups.
2. Time and distance – organising and attending PPI meetings can be time consuming and often requires travel. CRUK can support in the delivery of sessions to make the process easier.

For more help, contact
Involvement@cancer.org.uk

Advice for researchers considering PPI

1. Involve PaC from the start and throughout the entire research project- they will be well informed about the work that has been done and will be able to give more informed suggestions and feedback