# INVOLVING PEOPLE AFFECTED BY CANCER TO IMPROVE BREAST CANCER RADIOTHERAPY

The Auto-outLininG in Breast Radiotherapy (ALGeBRA) research project aims to evaluate the use of auto-outlining software in clinical practice. Currently, breast cancer specialists perform manual outlining of treatment areas and normal tissues they wish to avoid during radiotherapy on computerised tomography (CT) scans. This is time-consuming, requires specialist skills and causes delays. Auto-outlining could improve quality and efficiency in breast radiotherapy. Patient and Public Involvement was used when developing a research application and disseminating and implementing the results.

### How was Patient and Public Involvement (PPI) established in the project?

The team presented their initial research project to the Imperial Cancer Research UK Patient and Public Involvement (PPI) Group. Those from the <u>focus group</u> who were interested in the topic were asked to join a <u>steering group</u>.

The steering group was set up to ensure that patients and service users perspectives were considered and applied to any issues faced during the research. The group meet once or twice a year and consists of two patients, one member of the public and three service users.

#### They have helped to:

- Determine the level of support that there was for the research project
- Prepare a plain English summary of the research for the grant application
- Discuss the best ways of disseminating the research findings

"The overwhelming support from the PPI group for my research was re-assuring and their validation of the project added to my confidence as a new researcher" Ms Welgemoed, Researcher



## What training and support was offered to the steering group members?

- <u>Training day</u>- the patient representatives attended a training day to brief them on the research project.
- The group were given <u>reading materials</u> and questions were welcomed. A free lunch was provided.
- They thought it would be useful to see a demonstration of the treatment machines and the application of auto-outlining software in designing treatment volumes and organs. They were the first group to see the new linear accelerator before being used clinically.

This day was used for the team to get to know each other. The individual skillsets of everyone were explored.



### What was the impact of involving people affected by cancer?



The steering group were overwhelmingly supportive of the research and agreed that it could improve the outcomes of patients and service users. As a new researcher this was very encouraging to hear.

Greatly improved the quality of the research There were some initial concerns, that due to the technical nature of the project, the steering group may not have been able to provide thorough insight. However, the group surprised with their <u>experience</u> in physics, science and healthcare, and discussed radiation safety issues, treatment techniques and patient pathways. PPI has improved the quality of the research by identifying issues which would not have been considered otherwise.

Supported research communications & public engagement The steering group have become great advocates of the project, helping to make it more accessible to a lay audience and other researchers. For example, although journals and conferences are effective dissemination methods, the group felt it important to identify other platforms and suggested the Science Café's at Imperial. One member even initiated a fundraising project to help cover meeting expenses.

### What challenges were faced?

1. Unsure of how to start PPI – not being clear on how to involve patients in such a technical project was slightly daunting. However, by <u>recruiting experienced PPI representatives</u>, who understood their <u>role</u>, meant this was not an issue. They used their initiative and guided the researcher through the PPI process. They contributed and suggested things without the researchers input.

Advice for researchers considering PPI

Start PPI early – you will be surprised at how much knowledge experienced PPI members have and how much insight they can offer. Share and discuss your research idea with them. They will raise logistical things that as a researcher you never considered.

For more help, contact <a href="mailto:lnvolvement@cancer.org.uk">lnvolvement@cancer.org.uk</a>

