

# INVOLVING PEOPLE AFFECTED BY CANCER TO UNDERSTAND BOWEL SCREENING UPTAKE

Dr Katie Robb's research focused on why the uptake of bowel screening lags behind the uptake of breast and cervical screening, aiming to understand public perceptions of cancer. Patient and Public Involvement (PPI) was used when developing the research question, developing the research application and carrying out research.

## How was PPI established in the project?

Two very experienced [patient representatives](#), that the team had met at a conference and worked with previously, were [recruited](#) to advise on issues throughout the research project.

They were involved in:

- The initial [discussions about the research idea](#)
- Giving feedback on the grant proposal
- [Steering group meetings](#)
- Providing feedback on the [participant information sheets](#) and invitation letters that were created

Steering group meetings occurred once or twice a year, lasting no more than 2 hours.

"It's a pleasure working with Katie and her team. They immediately make you feel welcome and treat you as an equal partner. Our views and opinions are taken on board throughout the research projects. During these partnerships, of PPI and researchers, you find that it is the person that is being treated and not just the illness " Tom Haswell, Patient Representative



## What training and support was offered to the patient representatives?

- [Meeting briefs](#) – the team would email or call the patient representatives ahead of meetings to inform them about what was going to be discussed. Calls were offered after the meetings to ensure any queries or concerns were answered.
- Different ways to provide feedback - hard copies of documents were sent to those who wanted them, with a free-post envelope, rather than via email. They were also offered the option of commenting on the documents over the phone.

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

Highlighting new research questions & changing the direction of research

The patient representatives highlighted new research questions and ideas to the team. For example, they emphasised that the team were not doing enough to address people's fear of cancer in the initial research questions. This has helped the researchers take a step back and see the research from the patient's perspective and the potential impact on real people. This changed the direction and quality of the research, ensuring that the questions posed would not be frightening or overwhelming to patients.

Created clear information for lay audience

The patient representatives improved the language used in the patient facing documents. For example, they shortened the documents and made the language more direct, yet less formal. This has helped make the research more accessible to a lay audience and increase the transparency of the research.

## What challenges were faced?

1. Remembering certain requirements – realising and being considerate that some patient representatives have certain access requirements, is often hard to remember.

Making minor changes to how you interact and work with them can make their experience much more enjoyable and productive. For example, try to hold meetings in an accessible, neutral location, or book taxis to and from the station for them.

For more help, contact  
[Involvement@cancer.org.uk](mailto:Involvement@cancer.org.uk)

## Advice for researchers considering PPI

1. Identify PPI methods throughout the research – keep re-evaluating the research project at relevant points to see if PPI can be added.

2. Start as early as possible – involve people affected by cancer from the earliest point possible; this will help shape the research for it to have the most impact.

"Involving people affected by cancer in my research over the years has motivated me by keeping the end goal of improving cancer outcomes more clearly in mind" Dr. Katie Robb