INVOLVING PEOPLE AFFECTED BY CANCER BASIC RESEARCH

This basic research project hopes to build a deeper understanding of DNA damage—what causes it and how it leads to cancer. By collecting samples from 5,000 pancreatic, kidney, oesophageal and bowel cancer patients, from countries with different levels of these cancers, they aim to figure out what causes roughly 25 cancer-associated mutational fingerprints and identify which are due to environmental exposures and lifestyle behaviours. Patient and Public Involvement (PPI) has been used when disseminating and implementing results.

How was PPI established in the project?

Two patient representatives, who had existing relationships with the institute leading the project, were recruited to the team.

The project has a PPI coordinator employed by the lead institution. The coordinator connects the patient representatives with the research team and project leads to organise and facilitate involvement and engagement projects.

The advocates have been on two fieldtrips; to Kenya and the Czech Republic. The advocates use their personal experiences of cancer to shape conversations with nurses, doctors, policymakers, patients and family members in each location, to gain vital cultural and societal insights. These will inform how the results from the research are disseminated across different countries in the future.

They have also fed into the design the team’s website, to make the research accessible and clear for lay audiences.

“The patient advocates bring new insights and alternative points of view to the project from both their personal experience and from what they’ve learned on the field trips—they are a great asset to the project.”
Research team member

What training and support was offered to the patient representatives?

- **Briefing prior to meetings**—the patient representatives are invited to come to meetings, which can be science heavy. The project leads and PPI coordinator provide briefing notes and regular teleconferences for them to ensure they are comfortable with their role in the meeting. They run through the meetings and help frame questions.

- **Communication**—the project leads and PPI coordinator help secure dedicated time at steering group and scientific project meetings for the patient representatives to talk, raise issues and ask questions.

- **Costs covered**—costs for attending meetings/travel are covered by the team.
What was the impact of involving people affected by cancer?

The fieldtrips have highlighted societal and cultural opinions of cancer and cancer prevention. For example, the advocates learnt that in Kenya, they do not necessarily welcome Western medicine, but rather trust the advice of community elders. In the Czech Republic, there is little charity culture and charities are not trusted sources of information like they are in the UK, but people are also often resistant to perceived ‘interference’ from the government. These findings will influence how the research results are disseminated to patients, policymakers and healthcare professionals across different countries. PPI will help ensure that the results will be disseminated in ways that will have maximum impact. This could not have been done by the scientists/PPI coordinators alone.

What challenges were faced?

1. Lack of PPI experience – many of the researchers in the team are geographically dispersed and their institutions have no PPI culture. This has made the logistics of PPI hard. The project leads and experienced patient representatives have helped make sure the value and impact of PPI is seen and understood.

2. Balancing time – having to be mindful of how to balance the patient representatives' time when attending 2-3 day long scientific meetings.

“It's been a very interesting experience being a patient advocate for this project. While it can sometimes be hard to grapple with the complex science, we feel that our voices and opinions are being heard by the researchers and that we are part of a team that will make a real difference for cancer patients and their families in the future” Patient advocate

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

Advice for researchers considering PPI

1. Calculate your PPI budget - do this carefully and ensure you can cover the costs of honorariums, travel and food for patient representatives. Think about budgeting time for a specialist PPI coordinator if you are running a large, multicentre project. You do not want your PPI to have less impact because it could not be implemented appropriately.

2. Effective communication—keep your patient representatives updated throughout the research process. If there are no updates, inform them of this, so they know what is happening and when next to expect information.

3. Start PPI early— for people affected by cancer to really shape and improve the quality of the research e.g. at the grant application stage. If your project involves patients (e.g. as sample providers) then think of involving them in the drafting of Patient Consent forms and Patient Information Leaflets. This will also help when considering budgets and what matters to patients.