INVOLVING PEOPLE AFFECTED BY CANCER IN EARLY PHASE CANCER TRIALS

Mekala Gunaratnam (Centre Manager, UCL ECMC) and her team aimed to understand what patients consider when thinking about taking part in early phase cancer trials, as well as patients' views towards the collection, use and security of their data. Patient and Public Involvement (PPI) happened when developing a research question, carrying out research and disseminating and implementing results.

How was PPI established in the project?

After securing a University College London Hospital (UCLH) Biomedical Research Centre Starter Grant, the team recruited a Cancer Patient Panel. Various patient leads at UCLH helped with the recruitment process. The panel was made up of individuals who had experienced early phase trials or had a member of their family recruited to an early phase study.

At a face-to-face meeting, the panel were introduced to the project and its objectives. They decided that the best way to address the aims of the research, was to develop a survey.

Two methods of PPI were used:

1) Fully involving people affected by cancer (PaC) in the development, design and dissemination of a survey

2) Surveying patients who were recruited to early phase trials at the NIHR UCLH Clinical Research Facility, on their experiences, to improve future patients' experiences accordingly

> "Patients positively influenced the project at every point. It was eye-opening to compare our own views against those of the patients!" Mekala Gunaratnam, Researcher

What training and support was offered to the Cancer Patient Panel?

- Training materials - a detailed presentation on early phase cancer trials and how genomic data is generated, stored and accessed, was presented to them
- Background reading – although most of the patients had experience of serving on other PPI groups, they were given materials to read with context to the specific research project
- Diverse communication – discussions with the patient panel took place via email, with occasional face to face meetings, to cater for all needs

What was the impact of involving people affected by cancer?

New ways of interpreting and understanding results

The panel interpreted the results from a completely different perspective. For example, 70% of the patients joining trials found the consent forms easy to read. The researchers understood this negatively, interpreting that 30% of patients did not understand what they read. The patient panel understood that 100% of the patients understood the consent forms- 30% of people did not find them *easy* to understand. This was eye-opening, and it meant no changes needed to be made to the forms, as they were accessible.

Extremely high response rates

The survey had an extremely high response rate (80%). The researchers put this down to the PPI and the panel understanding the sorts of questions patients would want to answer in a hospital setting. For example, PPI helped narrow down the questions per section, from 6 or 7, to 3 or 4. The panel changed the layout of the questionnaire, to no more than 3 A5 pages, insisting the survey should not be too long. Ensuring the survey was not too taxing helped recruitment.

Validating current processes

Results from the survey revealed that patients had positive attitudes towards the collection and use of their data. This was contrary to the team's expectations. PPI has provided the team with reassurance that the level of information being given to patients is correct and that the standard should be maintained.

What challenges were faced?

1. Face to face attendance —some of the panel members were unable to attend all the face to face meetings due to the nature of their disease.

Allowing them to feedback via email resolved this issue.

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

Advice for researchers thinking about doing PPI

1. Reasonable timelines- PaC have other commitments! Give time to feedback. Plan for this when planning projects.

2. Thoughtful communication—offer different communication channels to ensure everyone is included (i.e. via teleconference, emails and face to face)

3. Convenience payments—panel members should not be out of pocket while helping you