IN Volving PeoPle Affected by Cancer in Precision-Panc

The Precision Panc study aims to improve the effectiveness of current pancreatic cancer treatments by better understanding the biology of different types of pancreatic cancer. It hopes to accelerate the development of new drugs and get them to patients faster with smarter clinical trials. The programme comprises of clinical, pre-clinical and translational research. Patient and Public Involvement (PPI) has been used when carrying out research.

How was PPI established in the project?

The team developed a patient involvement plan with Cancer Research UK (CRUK), Pancreatic Cancer UK (PCUK) and the Precision Panc PPI working group. This identified key areas where PPI could add value to the research and specific tasks required from the Patient Advisory Group (PPAG).

A PPAG role profile was created which set out:

- time commitments
- payments
- a brief description of the study
- the skills and experiences needed
- the requirements of the role
- support offered by the team

The role was advertised through PCUK and CRUK’s involvement networks. Candidates who expressed interest were shortlisted, and interviews held. Unsuccessful candidates were given feedback. Seven panel members were recruited.

The panel have reviewed the content, language and format of a brochure and patient information sheets. They also helped to improve the Precision Panc website and a video explaining what the study is about.

“The PPAG has been invaluable to the research programme.” Precision Panc Researcher

“Being a member of the PPAG has allowed me to turn the difficult experience of being a wife of someone with stage 4 pancreatic cancer into something positive.” PPAG member

What training and support was offered to the PPAG?

- Training materials explaining precision medicine and the Precision Panc programme.
- Training advisors to support and pass on any queries to the Precision Panc PPI leads.
- Feedback is consistently given to make sure they feel valued and are confident that their contributions have been considered and actioned.
- A consultation document, detailing what is required from the PPAG and with all the information they need before commenting on a consultation.

Together we will beat cancer
What was the impact of involving people affected by cancer?

- Improved the quality of the research

The PPAG reviewed documents for patients and the acceptability of proposed treatments, ensuring the research is relevant, acceptable and feasible for patients. The team is now confident that the proposed research is acceptable and meaningful to patients with pancreatic cancer.

- Created clear information for lay audience

The panel ensured information about providing tissue samples and taking part in eventual stratified clinical trials is clear for future patients. For example, they highlighted overwhelming language and pointed out that questions had not been addressed in the brochure. This has made the research accessible to a lay audience.

- Aided the dissemination of results

Some PPAG members have spoken at PPI events across the country and ensured that the Precision Panc video was sensitive for patients. For example, they stressed that the video shouldn’t concentrate on lifestyle issues or include a surgeon taking a pancreatic cancer biopsy. Instead they preferred a surgeon’s narrative on how Precision Panc may benefit future treatments. This has ensured that the outcomes of the study will have an impact on how pancreatic cancer is understood amongst patients.

What challenges were faced?

1. **Recruitment** — the nature of pancreatic cancer made recruiting patients hard. Most panel members are relatives, but they provide consistent support and have insight on what it is like to experience a diagnosis and treatment of pancreatic cancer.

2. **Overloading** — being conscious not to overload the panel with too many consultations in quick succession. By recruiting 7 members, tasks can be divided across the group if needed.

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

Advice for researchers considering PPI

1. **Notify charity PPI partners at the earliest opportunity**—to develop your PPI plan effectively and with the greatest amount of advice and support.

2. **Thoughtful communication**—ensure the patients you work with feel well supported, with access to clinical backup for any queries.

3. **Consultation template document**—researchers complete a template when they wish to consult the panel and include set questions to be answered. This has saved time when trying to make consultations clear to the panel.