

# INVOLVING PEOPLE AFFECTED BY CANCER IN TREATMENTS FOR CHILDREN & YOUNG PEOPLE

Dr Halsey, a translational researcher, wanted to know where and how to focus her acute childhood lymphoblastic leukaemia (ALL) research, before applying for Cancer Research UK (CRUK) grants. Patient and Public Involvement (PPI) was used to develop research ideas and questions.

## How was PPI established in the project?

Dr. Halsey approached the [Patient Involvement team](#) at CRUK to develop a PPI plan. Two parts of the project benefited from PPI:

- 1) The clinical trial work (deciding the focus of clinical trials)
- 2) The basic science work (prioritising the understanding behind new treatments and tests)

An e-consultation was sent out the [CRUK Research & Strategy Cancer Insight Panel](#) (CIP) (a panel of 15 people affected by cancer) and the CRUK Children and Young People's Advisory Panel (an online panel of 20 people affected by childhood and young adult cancers), to gather insight on the clinical work. The e-consultation questioned whether the research should test new ways to prevent or reduce brain-related side-effects of chemotherapy. The panels were given 2 weeks to feedback electronically and detailed responses were gathered.

The researcher also attended a 1.5-hour, face-to-face CIP meeting to have open, detailed and in-depth discussions, about whether to focus the research towards basic science or more clinical questions. Before the session a pre-read was sent out and a [session plan](#) produced. The CIP was [facilitated](#) with large and smaller group discussions and activities to really engage the panel.



"I was really impressed by my visit to the Cancer Insight Panel – they provided a unique perspective on my research plans and I came away buzzing with new ideas and inspiration."

Dr. Halsey

## What training and support was offered to the CIP?

- [Pre-reads](#) were given to the panel before the face-face meeting, providing context to the research and questions to think about
- [Emotional support](#) was provided to the CIP due to the sensitive nature of the topic. They were reminded that if they didn't feel comfortable providing insight they were not required to do so
- [Feedback](#) was given back to the CIP to make sure they felt valued and are confident that their contributions have been considered

"I found this really interesting, it was a good insight to see how the decisions are made and thought process behind them. It would be great to follow this trial and see how it develops." CIP member

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

### Determined research idea

The panels highlighted what areas of research would be most acceptable to patients and their families. This helped prioritise some of the underpinning scientific questions. For example, the panel preferred to reduce treatment for patients at low risk of leukaemia recurrence in the brain, over trying to neutralise the side effects of chemotherapy by using additional medicines or brain training programmes. This determined the approach of the research which will now look at trying to refine tests to accurately identify patients at low and high risk of relapse.

### Motivation & confidence

The panels urge and desire for research to be focused on basic science was surprising and reassuring. This approach was something the researcher was concerned about. Knowing that there was patient support, encouraged her to submit a grant application that focused more on basic science work packages than clinical ones. Consulting the panels provided the researcher with the confidence that the grant application accurately represented the needs of people affected by cancer.

## What challenges were faced?

1. Not knowing where PPI fitted- when the researcher approached CRUK, they were unclear as to exactly how PPI would enhance their research. However, with the help of the Patient Involvement team, they were able to see how different aspects of the project could be addressed using e-consultations and panel discussions. Together they developed a portfolio of PPI initiatives to gain maximal benefit for each area.

Having to think about the desired outcomes and potential benefit of PPI really helped shape the research trajectory.

## Advice for researchers considering PPI

1. Think about the key questions- you want to ask the panel and how to make your research lay. It really helps improve the clarity of your aims and objectives. CRUK's Patient Involvement team were a real support and helped guide me each step of the way.

2. Just do it! - meeting the panel was inspiring and I was so impressed by how quickly they mastered the brief and the depth and insight that their answers provided. I now look forward to filling in the PPI section of any funding application.

For more help, contact  
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