Conversations about cancer vaccines: recent PPI activity from Oxford Cancer

Sustained and creative patient and public involvement and engagement (PPIE) is critical to the success of cancer vaccine trials and research.

The programme will rely on a wide range of engagement activities, with and for a variety of groups of people, to create opportunities for conversations and consultations on this fascinating and possibly game changing area of cancer research.

First steps: testing the water and preventative vaccinations

Consultations with patient groups began in the Spring and Summer of 2024. In partnership with Oxford's Oncology Clinical Trials Office (OCTO), and with the help of professional facilitators, Oxford Cancer organised a pair of meetings to hear from people on the subject of cancer vaccinations.

The first meetings focussed on people with experience of lung cancer. These sessions were in support of the LungVax study.

For the second meeting, we invited people who considered themselves to be at risk of cancer, either because of family history, a known genetic mutation or a chronic condition that increases the risk of cancer. Carers and close family members of people with cancer were included.

The purpose of these sessions was to

- Establish what people think when they hear the term 'cancer vaccine'
- Explore potential obstacles to participation in clinical trials of cancer vaccines.

The sessions were designed in partnership with PPI reps from the LungVax study, and were held online on Zoom. Although it is difficult to replicate the energy of all being in a room together, the online environment makes it much easier for people from across the country to take part and is more inclusive for people with mobility or health issues that make it harder to travel to meetings. Participants were offered payment for their attendance.

Participants were recruited from local and national networks and through clinical colleagues working with high-risk groups.

Each meeting welcomed 20 people, diverse in age, geographical location and ethnicity. Using the in-meeting polling platform, Mentimeter, participants were presented with a series of questions about vaccinations. What are the words that spring to mind when you hear the word 'vaccine'? Do you think cancer vaccines might be a good idea? What would worry you if you were asked to take part in a trial for a vaccine? It's surprising how many ideas and thoughts a relatively small number of people can come up with and the conversation this can generate.

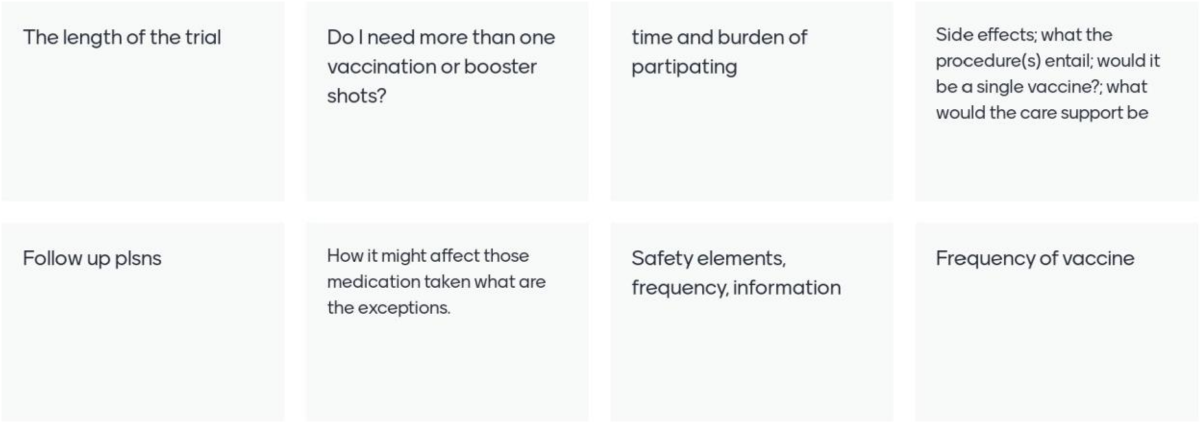
The meeting then split up for small group discussion in break out rooms. With the support of facilitators, each person in the group was invited to speak for a limited period of time about their answers to the earlier questions, and how they felt that 'cancer vaccines' might be perceived in the wider community. These breakout rooms were a great chance to share views and have a conversation, and each room had a note taker, feverishly scribbling away to capture what was being said.

At the conclusion of the meeting, Professor Sarah Blagden, Professor of Experimental Oncology, Director of the Oncology Clinical Trials Office, and the lead for the preventative vaccines programme, joined to introduce the group to the science behind vaccinations.

Putting Sarah at the end of the meeting was intentional. We wanted people to talk freely and to hear their gut reactions about cancer vaccines without feeling that an expert scientist or doctor was present. Hearing the science first might have meant they felt reluctant to raise question or concerns in case they sounded 'silly'. Many of those who attended the meetings joined a subsequent session during which Sarah talked in greater detail about how cancer cells hide from the immune system and how preventative vaccines are being designed.

In addition to Sarah's presence, the meetings were supported by trial management staff from the Oncology Clinical Trials Office who volunteered to help with facilitation and note taking. One of the unforeseen bonuses of running the meetings in this way was the opportunity for colleagues working on trial

design to meet and talk to people with experience of cancer in person, which has provided insights and brought things to life for those who got involved. Hearing people's concerns and questions helps us to consider the research questions which are of most interest, how our trials can be designed to encourage participation, and the ways in which information will be provided to trial participants.



The length of the trial

Do I need more than one vaccination or booster shots?

time and burden of partipating

Side effects; what the procedure(s) entail; would it be a single vaccine?; what would the care support be

Follow up plsns

How it might affect those medication taken what are the exceptions.

Safety elements, frequency, information

Frequency of vaccine

It is perhaps reasonable to suggest that, ahead of these meetings, our research colleagues were fearful of what people might have to say. In the wake of the pandemic, with anxieties and misinformation about vaccination, a vocal anti-vax movement, and understandable degrees of vaccine hesitancy or scepticism, many researchers were concerned about the public appetite for cancer vaccination. But we were able to offer some reassurance for our colleagues: although there were some who expressed significant reservations, most people are enthusiastic about the research and excited by a potential future when many might be spared the distress of cancer or the loss of loved ones. Those who live with high-risk conditions – especially those conditions that can be passed on to future generations – are particularly keen on interventions that might offer them greater hope for future health and longevity. And participants were all absolutely fascinated by the science and its potential.

Of course, this is just an opening gambit in a long process of conversation and consultation. Clearly those who have already had the experience of cancer, or those who have cared for others, are going to be biased in favour of something that might prevent this happening to people in future. People who have never considered cancer, and who believe themselves to be at low risk of getting it, are likely to have different views of the technology and its place in their own lives and choices about their health. Which is why we look forward to future consultations, in partnership with community groups and artists and social sciences professionals, film makers and animators, and writers and story tellers. The journey is just beginning.

A preventative vaccine would be "The pinnacle. Then we've made it. A gamechanger. Lifechanging."