

Preventative cancer vaccinations and minority ethnic communities

Catriona Gilmour Hamilton

Since March of 2023, the PPI team at Oxford Cancer has run consultations on the subject of preventative cancer vaccination research. We have spoken to groups of people with experience of lung cancer, those with Lynch syndrome, those who consider themselves high risk because of family history, and those who are members of the public keen to support research to prevent cancer. This work highlighted the need to address the issues that prevent some groups, specifically minority ethnic communities, from equal participation and trust in research.

With this in mind, we organised a session to bring together community advocates with experience of cancer from British Muslim, Hindu, Sikh, Caribbean and African communities for a workshop. The workshop was designed and facilitated by Milly Sinclair Associates in partnership with the Oxford Cancer PPI Team and PPI representatives.

Our objectives were to:

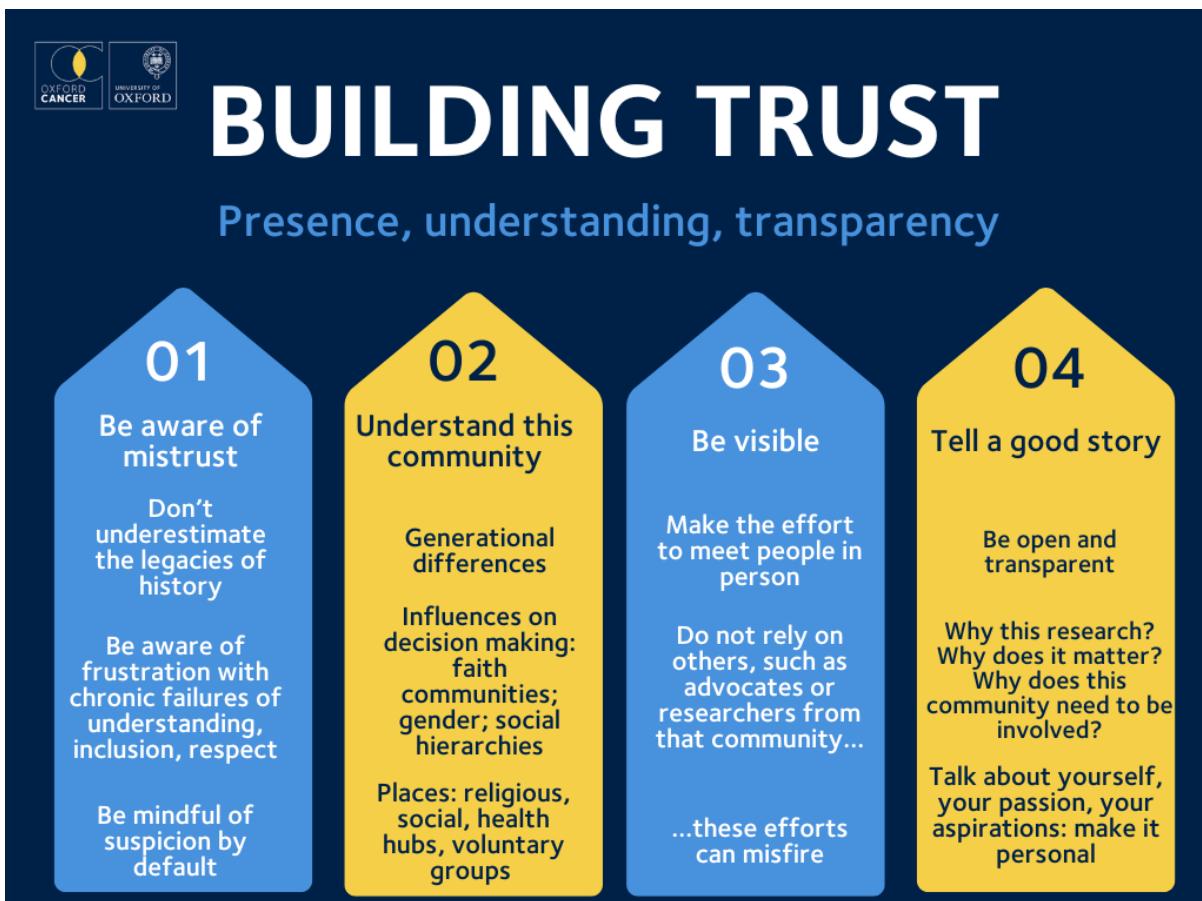
- inform further engagement work around preventative cancer vaccinations
- develop resources to support the preventative vaccines research programme
- gain insights to share with research colleagues to shape and inform future study design and patient recruitment.

We enjoyed a lively discussion over a day and lunch at St Hilda's College in Oxford, welcoming guests from Oxford, the Thames Valley, London and Birmingham. After a series of exercises and breakout group discussion, we collectively agreed the following key themes.

- Individuals asked questions and raised concerns that would apply to trials for any new drug, not specific to vaccinations: concerns about safety, side effects, implications of participation, study design and support for individual decision making.
- There was a big difference between individual confidence in research – some scepticism but generally supportive – and how people felt their communities might respond. The latter might express significantly greater degrees of suspicion and mistrust.
- Delegates described factors influencing decision making about research participation in various cultural and religious communities. These included taboos and cultural beliefs around cancer and vaccinations, and peer-to-peer influence on decision making.
- However, the **prevailing concern** was one of **lack of trust**. The issue is not trust in vaccinations research itself, but one of trust in medical research more generally. Delegates described the legacy of historical abuse and neglect, racism, and chronic failures to engage with or understand the needs and experiences of minority ethnic communities.
- Our conversations framed 'inclusivity' not as something to be strived for, but as **something to be suspicious of**. The issue is not the necessity of developing drugs that work for 'people like me', but the fear that communities are being exploited in the interests of those that have always held and exerted power. Addressing the scientific and ethical imperatives of inclusivity requires adequate understanding of this context.

When taken in their entirety, the statements of the group indicate a deep frustration with perceived failures of the medical establishment to fully understand the experiences, needs and realities of minority communities.

- To foster trust, researchers must make the effort to **ensure their visibility in the communities in question**. There must be transparency about the background to the research, the funding, why it is necessary and how it is designed. People want to hear about individual stories of participation, and individual researchers' motivations for being involved; this approach brings something to life and fosters human connections that build trust.



Next steps

We agreed that the issue of establishing trust should be addressed with senior academics from the preventative cancer research programme. At an event in central Oxford on the 10th of June 2026, academic colleagues will be invited to share their research careers and aspirations and answer questions of a panel to include the delegates from the St Hilda's workshop. It should be an enjoyable session that we hope will foster confidence and enthusiasm for researchers who will improve engagement in future.