

Have Your Say on the Future of Early Detection Research

Join a friendly group to share your views and opinions about how the public and researchers should work together to improve early detection research.

You'll receive £37.50 for your time and input and £5 to contribute towards internet connection costs.

When? 6.30-8PM on Monday 23rd June 2025

Where? Online – Group Zoom call

What's the session about?

University of Manchester researchers are helping to define the risk of a subsequent cancer once an individual with a known gene alteration that may increase their lifetime risk of developing a cancer, including patients with an altered RB1 gene that increases their risk of developing retinoblastoma, has received a first cancer diagnosis. Defining this risk will help to identify who may benefit from prevention and early detection strategies.

One such early detection strategy that the research team are aiming to develop is a blood-based test to try and identify cancers early (for example, Stage I-II) in adolescents and young adults with a gene alteration that may potentially be associated with an increased cancer risk.

This is dependent on using patient data held by the NHS for research purposes and participants donating blood samples for a research study.

We want to make sure that patients and their families are at the centre of the planning for our research projects.

Who are we looking for?

We are looking for guardians / parents to a child who received a hereditary retinoblastoma diagnosis or young adults (between the ages of 16 to 24) previously diagnosed with a hereditary retinoblastoma to co-develop a research proposal.

You do not need to have any previous research experience or taken part in previous patient feedback sessions in order to take part. We are keen to hear a range of opinions and viewpoints.

Your participation is entirely voluntary and if you decide not to take part, this will not affect your clinical care in any way.

Why do we need your help?

We'd like to hear your views and opinions on:

- What's important to patients and caregivers when considering sharing their medical data or giving samples (like blood, tissue biopsies or organs) for research?
- What factors might encourage or put people off giving a sample for research?
- What information and support should be available to people thinking about giving a sample for research?

Will I be paid?

You'll be paid £37.50 as a thank you for your time and contributions and £5 to contribute towards internet connection costs.

Payment will be by an online bank transfer after the session. Please note this can take up to 6 weeks. Payment via a voucher can also be arranged if preferable.

Voucher choice is between the four options below:

1. Love 2 Shop UK (which covers a wide group of high street retailers)
2. Love 2 Shop International
3. Amazon
4. Blackwell's/National Book tokens

How do I take part?

If you'd like to take part in the session, or have any questions, please contact Steph via email on stephanie.ng@manchester.ac.uk to receive the schedule for the session and details for how to join the Zoom call.

On the day, please come with an openness to share your thoughts and a willingness to listen to others. There's nothing you need to prepare in advanced.

The session will only be recorded if all attendees give consent. The recording would be used for accurate transcription purposes and will not be shared outside of the research team.

The topics being discussed can be emotive and sensitive. Your wellbeing is our priority, and we want to make sure that everyone feels comfortable and supported. A designated staff member will be present to provide wellbeing support on the day. If there's anything that we can do to help you to take part, please let us know.

Looking forward to hearing from you soon!

Thank you for giving your time to support health research at The University of Manchester!