

Incidental findings found through genetic testing

I am looking for people join a new patient & public involvement (PPI) group to help me design a research project on incidental findings found through genetic testing.

An incidental finding is something found during a medical test that is unrelated to the original reason the test was requested. Incidental findings can happen in many areas of medicine, for example, a chest x-ray may suggest something unrelated to a patient's symptoms that then needs further investigation.

My focus is on genetic testing. We now often look at large chunks of the genetic code routinely. Someone's genetic code may suggest future health risks, for example, the likelihood of developing cancer or heart disease. These risks are often not well understood by doctors, so it can be unclear what further tests or follow-up care should be offered. People may also differ in whether they would want to know about an incidental finding.

I want to look at what medical professionals and patients think about these issues. The PPI group would ensure my research addresses questions of importance to patients and the public.

The group would meet on a minimum of two occasions (online) to help shape the design and methodology of my research proposal. Interested participants may be invited to review parts of the proposal and/or contribute to the research longer term following a successful funding outcome.

I am interested in hearing from a range of individuals:

1. People who have had genetic testing for medical reasons (or have a family member who has).
2. People who have received an incidental finding (or have a family member who has). This could have been through genetic testing or another medical test such as a scan or blood test.
3. People with no prior experience of genetic testing (for medical reasons) or incidental findings

No prior experience of being part of a PPI group is necessary.

If you would like to take part, please send a few sentences by email (helena.carley@well.ox.ac.uk) explaining your interest and which of the above categories best describes you. A short (5-10 minute) telephone or video call may be arranged to discuss your interest further.