

How do people decide to take a genetic test?

Framing the trajectories of decision-making in the context of predictive and prenatal genetic and genomic tests

What is this study about?

Most genetic tests are carried out to confirm a diagnosis.

But some people are offered genetic tests for reasons that are only partly medical and where the patient's personal views and preferences are as important (if not more important) than any medical reasons.

The purpose of this research is to understand how patients make these decisions.

How will this study help?

Understanding more about how patients decide will help us to develop the counselling that genetic services provide to patients, and to consider whether patients would benefit from support while they are thinking through their decision.

Who is included in this study?

Patients who are over the age of 18 and are offered a genetic test to help them plan or prepare for the future.

Who is excluded?

Patients under the age of 18; people who might be distressed by participating; who are not in a position to help; or who lack the competence to consent to participating

Which clinics are included?

- i. Predictive genetics clinics
 - Patients at risk of a neurodegenerative condition
 - Patients who have a family history of a condition that might need to be treated in the future
- II. Prenatal genetics clinics
 - Patients who have had an ultrasound scan that indicates the baby has a genetic condition
 - Patients with a family history of a genetic condition who seek counselling on whether to test to see if their baby is likely to be affected

How is this study being carried out?

Researchers are trying to gather as much information as possible on what is influencing patients as they make their decisions.

This means (1) observing and recording clinics where consultants and counsellors explain tests to patients; (2) involving patients in the project as co-researchers by asking them to record their own thoughts in whatever format suits them. Then (3) some weeks after any decisions, tests, results etc., a researcher will interview the patient to talk about their experience.

How can I finding out more?

If you would like to know more, please ask a member of staff

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A senior doctor in the research team may approach you if we feel you may be suitable for the study

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If you would like to become involved, you can always email the research team on ConsideringGenetics@cardiff.ac.uk