

What are incidental findings?

Incidental findings are results from genomic testing that are not relevant to the reason why the patient underwent testing. Incidental findings can have important consequences for patients and their relatives. The possibility of incidental findings should be discussed with patients before genomic testing is arranged.



Bedside resource: GeNotes



Watch the webinar



Read Sarah & Molly's story



Possible Incidental findings from a genomic test:



Clinically relevant finding not related to referral reason



Reveals that a couple are biologically related to each other



Result not consistent with biological parentage



Carrier of a recessive genetic condition

Dealing with Incidental findings



- 1** Meet the patient/family **before** arranging the test
Delivering difficult results is easier if you already know the family context.
- 2** Explain the **possibility** of an incidental finding before arranging the test
Specifically mention the possibility of revealing non-biological parentage if sending parental samples. Explore conception history. Ask if the couple could be related by blood. Document using the Record of Discussion form.
- 3** **Seek support** if you receive an unexpected result.
Clinical Genetics, the laboratory and your Trust's Ethics Committee can provide guidance.
- 4** **Make a plan** before delivering the incidental finding to the family
Contact specialists/Clinical Genetics to ensure you have an understanding of any conditions identified, including their inheritance patterns and any recommended screening, interventions or referrals. Have a plan to share with the patient or family so they know what will happen next e.g. who will contact them and when will this happen?
- 5** Wherever possible, **schedule** a results appointment or call.
This allows families to prepare. Separate appointments can be helpful if results impact family members differently.
- 6** If the patient/family doesn't answer when you call, **leave a message**
Families may be under a lot of pressure. Leaving a message saying when you'll call back (or giving a number for them to call) can help to reduce anxiety.
- 7** Provide the family with **resources** when you deliver the result
Patient information booklets, links to patient support groups and detailed clinic letters help the family to process, remember and explain their result
- 8** **Refer the family to Clinical Genetics** if appropriate
Genetic counsellors can help families understand recurrence risks, reproductive options & facilitate cascade testing

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