

Supplemental material

APPENDIX 6: Family-oriented leaflet explaining the meaning of ‘no findings’ in the context of the study

My Child’s Testing *Did Not* Find Any Genetic Changes

What does this result mean?

- Testing did not find any changes (variants) in the tested genes that can cause cancer
- As no genetic changes were found in your child, your (parent) samples were not checked

This result ***does not*** exclude a genetic cause, given the following

- There is a small chance that your child has a genetic change that cannot be found with current testing methods
- A genetic change may have been found but we do not know what it means – these are not reported
- There may be genetic causes of cancer that we have not yet discovered and were not checked with this testing

Will the PREDICT Study re-check my child’s testing?

- The PREDICT Study Team *may* re-check your child’s sample if new genetic causes of cancer are discovered during the study period
- Your child’s doctor will update you if the result changes, but the chance of this is low

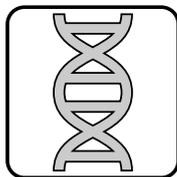
What is the chance of another childhood cancer happening in our family?

- Your child’s cancer could be a ‘one-off’ event, also known as a *sporadic* cancer
- This usually means the chance of a close family member getting the same cancer is ***not*** high
- *However*, this can depend on your child’s cancer type and family history
- An appointment with a clinical cancer genetics service might be useful
- *Most* children *do not* need to be referred and so your child’s doctor will discuss with you if this is recommended

We have been referred to a clinical cancer genetics service – what does this involve?

- They will look at your child’s health history and family tree in more detail
- In *rare* cases, more genetic testing might be useful
- Genetic testing by a *clinical* service can sometimes use different testing methods to a *research* study

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What are some important points to keep in mind?**We may discover new cancer genes over time**

- Ask your child's doctors every 3-5 years during their long-term follow-up if a referral to a clinical genetics service is needed
- Once your child is an adult, they can seek updated advice from their doctor/GP if planning a family

**Family history information can change over time**

- Update your child's doctor about any family history changes
- This *may* change the recommendations given by your child's doctor

Who can I contact if I have more questions?

- If you would like to discuss your child's testing in the PREDICT Study further, your child's doctor can arrange for you to speak to a PREDICT Study Genetic Counsellor
- Genetic Counsellors are specially trained health professions who can provide information about genetic testing and genetic results
- You can also contact the PREDICT Study Team by email: schn-predict@health.nsw.gov.au