The Cancer Screening Trust

CST

Hereditary Cancer Test Information Pack

HEREDITARY CANCER TESTING

A simple saliva sample using genomic DNA to identify genetic variants associated with a predisposition to certain cancers.

WHAT IS HEREDITARY CANCER TESTING?

Hereditary cancer is defined as cancer that has been caused by an inherited genetic variant. The Hereditary Cancer Panel involves testing for inherited genetic variants that are associated with an increased risk of cancer susceptibility.

WHY IS HEREDITARY CANCER TESTING IMPORTANT?

Inheriting certain genetic variants associated with cancer means the lifetime risk is significantly increased. It is estimated that 5-10% of all cancer cases have a genetic variant that leads to cancer susceptibility. (www.informedgenomics.com)

Identifying this allows individuals to find out more about risk management and screening programmes specific to their genetic variant which can aid early cancer detection. Therefore, patients and family members can make informed choices about their health plan.

WHEN IS HEREDITARY CANCER TESTING USED?

A hereditary cancer test is recommended when a genetic cause of cancer is suspected due to the clinical features or the family history includes the following:

- Early age of onset
- Multiple primary tumours
- Multifocal tumour sites
- Bilateral tumour appearance in paired organs
- Same type of tumour in first or second-degree relatives or the same tumour type clustering within a family
- Rare tumour types
- Rare tumours associated with birth defects

You must be over 18 years of age and believe to be at risk of developing cancer, regardless of personal or familial cancer history.

WHAT IS INCLUDED IN THE COMPREHENSIVE HEREDITARY CANCER PANEL?

The 31 gene Comprehensive Hereditary Cancer Panel has been expertly curated using current literature and national testing guidelines to maximise clinical actionability, whilst minimising uncertainty.
The full gene list for this panel is shown in the below table:

Comprehensive Hereditary Cancer Panel	**APC, ATM1, BAP1, BARD1, BMPR1A, BRCA1, BRCA2, BRIP1, CDH1, CDK4, CDKN2A, CHEK22, EPCAM3, HOXB13, MLH1, MSH2, MSH6, MUTYH, NF1, NTHL1, PALB2, PMS24, POLD1, POLE, PTEN, RAD51C, RAD51D, SMAD4, STK11, TP53, VHL**

BENEFITS OF HEREDITARY CANCER TESTING

1. Detects genetic variants associated with a predisposition to certain cancers.
2. Access to genetic counselling to explain test results, associated implications and support networks.
3. Identification of available risk management and screening programmes with earlier access and/or prophylactic treatment.
4. Reduce the risk of developing associated cancers and aid early cancer detection.
5. Enables patients and family members to make informed decisions such as lifestyle changes to reduce your risk.

HOW DO I GET THE HEREDITARY CANCER TEST?

1. An enquiry is made through our website www.thecancerscreeningtrust.co.uk or through a telephone call on 01935 725005.
2. Initial Consultation: one of our team members will call you to find out more about your family history, risk profile and whether the hereditary cancer test is suitable for you.
3. We will send an information pack to your email address, a link to take you to our medical questionnaire to determine your cancer risk profile and a consent form.
4. Once the medical questionnaire and consent form is completed, our clinical team will assess it and be in touch with the next steps.
5. Next, we will send out a complete test kit containing collection tubes for your saliva sample and full instructions for self-sampling.
6. The sample is returned to the laboratory using Royal Mail 48 hour tracked service and analysis takes approximately 20 days.
7. After the sample has been analysed, we will call you with your results and send over the written report to your email address.
8. Full genetic counselling is available for patients to explain test results, the associated implications and to inform relevant support networks.

UNDERSTANDING YOUR RESULTS

There are two types of genetic results you may receive:

- **No clinically significant variants detected**
- **Clinically significant variant(s) detected**

No clinically significant variants detected

- No known pathogenic or likely pathogenic variants were identified in the genes tested which reduces the likelihood you carry a cancer susceptibility variant.

Important to note:

- This doesn't eliminate cancer risk altogether.
- Variants can exist in genes not covered by the panel as well as in genomic regions that fall outside of the scope of testing.
- Not all genes variants that predispose to inherited cancer are currently known.
- This result does not exclude the general background risk of developing cancer.
- Participation in National Screening Programmes and adopting a healthy lifestyle are essential as at least 90% of cancers are sporadic.

Clinically significant variant(s) detected

- A pathogenic or likely pathogenic variant has been detected which is associated with an increased risk of cancer.
- The specific risk can vary depending on the variant and the gene.
- All reported findings will be given by a registered genetic counsellor and are clinically actionable. The results and implications will be explained with an aim to evaluate the cancer risk and explore risk management options and surveillance guidance.
- During this, you will have the opportunity to ask any questions and ensure you understand the information you have been given.
- As the genetic variant can be inherited, at risk family members may also be identified for genetic testing and can sign-post you to relevant information and support networks.

Important to note:

- Not all people with genetic variants develop cancer but there is an increased risk of developing cancer in the future.

Variants of unknown significance

- Sometimes the analysis detects variants of unknown significance: variants where there is either insignificant evidence that they are disease causing or the evidence is conflicting.
- These variants cannot be acted on, therefore they are not reported back to you.
- Due to continued research in this field, our understanding is constantly evolving and in rare instances, a variant may change classification over time.
- If this change is clinically significant, a new report will be issued.

- There may also be occasions where a finding detected in your sample requires further testing to make a full interpretation of your results.
- In these cases, it will be explained in your genetic counselling session and additional investigations required will be discussed.

CONSENT

This is to ensure you understand the benefits, implications and limitations of the hereditary cancer test.
You will also be asked a series of other questions regarding how your DNA and data is stored including limited uses of your DNA for family studies or internal quality control.
It is important to understand that genetic data and DNA will not be shared without your expressed permission, and you can withdraw consent at any time by contacting your test provider.

WHAT IS INCLUDED IN THE FINAL CLINICAL REPORT?

The final clinical report summarises test results by providing:

- Variant interpretation
- Implications of the results
- Recommended actions

If a genetic variant is found, the report will provide the:

- Impact
- Implications
- Recommended actions

Full genetic counselling is available for patients to explain test results, the associated health implications, and to inform relevant support networks for patients and their families.

Following your session, you will also be provided with a written summary of your discussion with the genetic counsellor along with a copy of your test report.

If no clinically significant variant is found, the report will clearly state this.

The routine turnaround time for this testing is approximately 20 days.

It is important to note that not all genetic variants that lead to an increased susceptibility to cancer are associated with a family history.
Inheriting certain genetic variants does not necessarily mean that cancer will develop, but the lifetime risk is significantly increased.

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DATAR CANCER GENETICS

Informed Genomics

CERTIFICATIONS/ACCREDITATIONS OF DATAR CANCER GENETICS INDIA

CAP ACCREDITED 9439695
COLLEGE of AMERICAN PATHOLOGISTS

Certificate No.: MC-4586

TÜV SÜD ISO 27001:2013 93100014

TÜV SÜD ISO 9001:2015 9910015799

CLIA
Accredited Laboratory
Reg. No.: 99D2171983

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