The ROYAL MARSDEN
NHS Foundation Trust

NHS England

NHS
North Thames
NHS Genomic Medicine Service Alliance

The Jewish Community's NHS BRCA Testing Programme

- NHS England is offering genetic testing of the BRCA1 and BRCA2 genes to people with Jewish ancestry
  - For this programme, "Jewish ancestry" refers to people with at least one Jewish grandparent
  - People with Jewish ancestry are more likely to have BRCA gene faults
- BRCA gene faults increase the risk of certain cancers, for which extra screening and preventative options can help
- Please review this booklet to learn more

If you would like to proceed with genetic testing, follow the instructions on the back cover to:

- ❑ complete a genetic test consent form
- ❑ complete a personal details form
- ❑ collect a saliva sample
- ❑ return your forms and sample from your local post office

If you have any questions or would like to discuss further, please contact us:

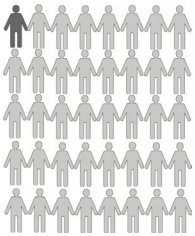
Genetics Helpline: +44 20 3437 6001
Monday to Friday, 9:00am to 5:00pm
With extended hours to 7:00pm on Wednesdays

ICR The Institute of Cancer Research
Queen Mary University of London
Jnetics
chai cancer care
together we can cope

Overview

Why is this genetic test being offered to people with Jewish ancestry?

- Gene faults in the BRCA1 and BRCA2 genes are more common in people with Jewish ancestry (particularly Ashkenazi)
  - Gene faults are also referred to as “pathogenic variants,” “gene alterations” or “mutations”



1 in 40 Ashkenazi Jews have a BRCA gene fault

- In the Ashkenazi Jewish population, approximately 1 in 40 people have a BRCA gene fault
- In the Sephardi Jewish population, approximately 1 in 140 people have a BRCA gene fault
- By comparison, in the general UK population, approximately 1 in 200-250 people have a BRCA gene fault

Why is this genetic test helpful?

- This genetic test can identify if you have a gene fault in BRCA1 or BRCA2
- BRCA gene faults increase the risk for certain types of cancer
- Learning if you have a BRCA1 or BRCA2 gene fault can:
  - open cancer risk management options for you
  - open cancer risk management options for your relatives
  - provide information for family-planning

Who might benefit from different genetic testing services?

- If you already know there is a gene fault in your family, you may wish to be referred directly by your GP to your local clinical genetics service for testing and support
- If you have already had cancer you are still eligible to participate in this programme. However, you may also be eligible for additional genetic testing, and you may wish to discuss this with your GP.

Cancer Risk

If you have a BRCA gene fault, it does **not** mean that you will definitely get cancer, but it does mean you have a **higher chance** for certain cancers.

- **The main cancers caused by BRCA1 and BRCA2 gene faults are female breast cancer and ovarian cancer**
- The tables below show the detailed cancer risks for females and males. Ranges are given, as the risk to each individual depends on multiple factors including family history.

Female Cancer Risk Over Lifetime (to age 80)			
Cancer	General population	With **BRCA1** gene fault	With **BRCA2** gene fault
Breast	11.5%	**72% (65-79%)**	**69% (61-77%)**
Ovarian	1.5%	**44% (36-53%)**	**17% (11-25%)**
Pancreatic	1.0%	Not elevated	2% (1-4%)

Male Cancer Risk Over Lifetime (to age 80)			
Cancer	General population	With **BRCA1** gene fault	With **BRCA2** gene fault
Breast	Less than 0.1%	0.4% (0.1-1.5%)	4% (2-8%)
Prostate	12.5%	Not elevated	27% (21-35%)
Pancreatic	1.0%	Not elevated	3% (2-5%)

- The values in brackets indicate the range of risks (95% confidence intervals)
- BRCA1 and BRCA2 gene faults are not associated with childhood cancers, except in very rare cases where a child has faults in *both* copies of their gene.

Sources: Cancerresearchuk.org; UKCGG BRCA1 Germline Pathogenic Variant Carriers Management Guidelines for Healthcare Professionals; UKCGG BRCA2 Germline Pathogenic Variant Carriers Management Guidelines for Healthcare Professionals

Managing Cancer Risk

Learning if you have a BRCA gene fault can allow you to proactively manage your cancer risk**. If you are found to have a gene fault, you will be able to discuss the management options below and more with your clinicians.** They can provide more individualised information to support you in making the decisions best for you.

• Female Breast Cancer Risk

There are two main options for managing breast cancer risk if you have a BRCA gene fault:

Enhanced (extra) breast screening.
This includes regular MRI and/or mammograms, starting from a younger age. The intention is to pick up any breast cancer at an early stage.

Surgery
Removal of the breast tissue upfront makes the risk of a breast cancer developing very low. This surgery is called a risk-reducing mastectomy.

• Ovarian Cancer Risk

There is currently no proven effective screening for ovarian cancer. Therefore, women with BRCA gene faults are offered surgery to remove the ovaries and fallopian tubes. This makes the risk of developing ovarian cancer much lower. This surgery is called a risk-reducing salpingo-oophorectomy. The surgery is typically performed after a woman has completed her family.

• Pancreatic and Prostate Cancer Risk

The increase in risk for these cancers is much lower. Research studies are underway for screening for pancreatic cancer. Similarly, there have been recent prostate cancer screening research studies (which use PSA blood tests). You may be able to participate in screening within a research study for these cancers.

Results

There are three possible results of the genetic test:

- **Gene fault found**

This result indicates that you have a higher risk for the types of cancer described previously. You will be referred to your local clinical genetics team to discuss your cancer risk management options fully. Your clinician will also discuss implications for your family members.

- **No gene fault found**

This result means that no increased cancer risk was identified. Your cancer risk is likely the same as other people your age. You should still participate in routine cancer screening offered to all people through the NHS (for example, mammograms for women over 50) and pay attention to any symptoms.

If you have a strong personal or family history of cancer, you should report this history to your GP. They may refer you to clinical genetics for consideration of further consultation and additional genetic testing.

- **Variant of Uncertain Significance (VUS) Found**

This is a very infrequent result. A VUS means that the laboratory identified a rare alteration in the gene, but they cannot classify this as either harmful or not harmful with our current information. Usually, as research advances, these alterations are reclassified as not harmful. Therefore, a VUS is treated the same as when no gene fault is found.

Management of Data and Samples

To understand and classify gene alterations, we need to compare information about the genetic alterations we have found nationally across the NHS and internationally (without sharing any patients' names). Sometimes, with new information, we will reclassify a gene alteration. You may be recontacted in the future if new information about the classification of your gene alteration becomes available.

Normal NHS laboratory practice is to store DNA samples, as they may be used for future analysis (for example if additional gene tests are required) and/or to ensure that other testing (for example that of family members) is accurate and of high quality.

Results Notification

- Your results will be ready in approximately 6 to 12 weeks
- You will be notified of your results by post
- Your result letter will have a front sheet so that you may choose when to read your result

- Should you wish to have support from a genetic counsellor whilst reading your result, you could telephone the genetics helpline (+44 20 3437 6001)

If you have a gene fault:

- You will be given a follow-up telephone appointment for within a week to speak with a genetic counsellor from this programme. If you prefer, you may telephone the genetics helpline and speak to a genetic counsellor sooner, and at a time of your choosing.
- You will also be referred to your local clinical genetics unit for further consultation and ongoing management
- Additional support is available from Chai Cancer Care and Jnetics (see Additional Information on page 7)

- All participants will receive a copy of their test report. A copy will also be sent to your GP (unless you decline this)

Implications for Relatives

- If you have a BRCA gene fault, your relatives (in England) can access NHS England genetic testing to see if they also have the gene fault. If they do, they may choose to access risk management options such as extra screening or surgery.
- Sharing of genetic information in your family can be done in discussion with you or through a process that will not personally identify you.
- Both men and women can have and pass down BRCA gene faults. Every time a person with a BRCA gene fault has a child, there is a 50% chance (1 in 2) that the gene fault is passed on to the child.
- Some individuals or couples choose to have genetic testing before family planning. There are additional reproductive options (for example, pre-implantation genetic testing) available to couples if one or both partners has a BRCA gene fault. These options help couples to avoid passing on the gene fault to their children.

Genetic Testing and Insurance

The insurance industry differentiates between a predictive genetic test and a diagnostic genetic test

- If you have not had a cancer, the BRCA1/BRCA2 genetic test is termed a **predictive test**. Insurance companies cannot ask you to disclose the results of predictive genetic tests for the majority of policies.
- If you have had a relevant cancer, the BRCA1/BRCA2 genetic test is termed a **diagnostic test**. Insurance companies may ask you for the results of your genetic test if you open a new life, income protection or critical illness insurance policy. Any policies already in place will not be affected.
- You can find more information about insurance from the Association of British Insurers
  - www.abi.org.uk/data-and-resources/tools-and-resources/genetics/genetic-testing/

Additional Information

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Alternatively, you may contact us by email at jewishbrca.programme@nhs.net

Additional information and support are also available from:

- Jnetics (jnetics.org/brca-explained)
  - A cross communal charity dedicated to the prevention and diagnosis of Jewish genetic disorders
- Chai Cancer Care (0808 808 4567 or chaicancercare.org)
  - Expert support services for any member of the Jewish community affected by cancer or identified as having a BRCA gene fault.
- Jewishbrca.org
  - Website with additional resources related to BRCA testing

To Proceed with Genetic Testing, Please Complete the Steps Below

❑ Consent Form

- Review and sign the Genetic Test Consent Form

❑ Personal Details Form

- Fill in the requested information on the Personal Details Form

❑ Saliva Sample

- Wait at least 30 minutes after eating or drinking before sample collection
- Wash your hands thoroughly
- Rinse your mouth well with water to clear away any food
- Fill the tube with your saliva up to the line
- Screw on the lid and check it is tight
- Wash your hands again thoroughly
- Write the date of saliva collection on the adhesive label, then stick the label on the saliva collection tube
- Place the labelled saliva collection tube into the transport tube, making sure the transport tube is shut tightly
- Place the transport tube into the small padded envelope

❑ Post from a Post Office

- Place both forms and the packaged saliva sample in the pre-paid plastic mailing bag
- Take the package to your local post office. You may find your nearest post office at: www.postoffice.co.uk/branch-finder
- This package may NOT be posted using a street post box

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or email jewishbrca.programme@nhs.net