

## The Jewish Community's NHS BRCA Testing Programme: Information for Cancer Alliances

### Background

In January 2023, NHS England launched a programme to offer genetic testing for BRCA mutations to men and women over 18 years old with Jewish ancestry (at least one Jewish grandparent) in England. Our aim is to identify more people with cancer predisposing genes and enrol them into appropriate surveillance and treatment pathways. This will lead to more cancers being prevented or detected earlier and contribute to the NHS Long Term Plan ambition to diagnose 75% of cancers at an early stage by 2028.

Having a BRCA mutation increases your risk of developing several cancers, in particular breast and ovarian cancer. The programme is important because people with Jewish ancestry have a 1 in 40 risk of carrying a BRCA mutation compared to the general population risk of 1 in 400. Only approximately 11% of BRCA mutation carriers in the Jewish population have been identified to date.

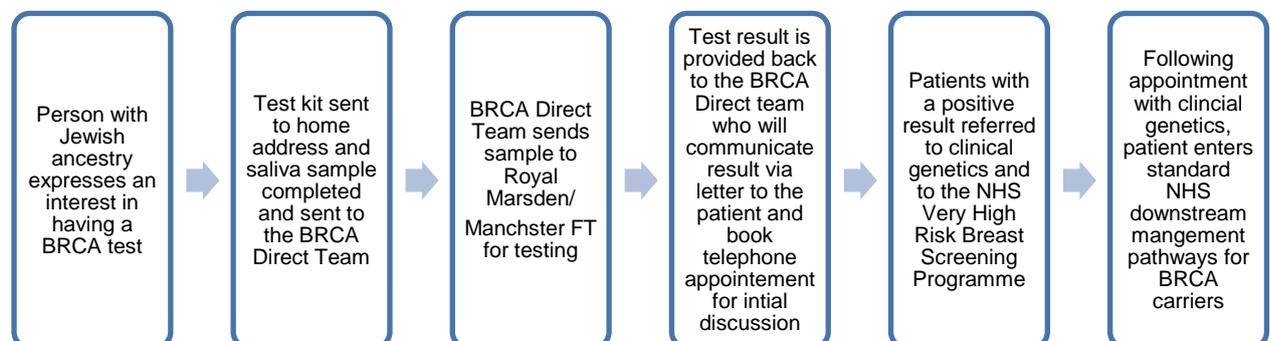
### The testing pathway

All consenting adults will receive full gene testing for BRCA1 and BRCA2 from saliva and will be offered genetic counselling support throughout the testing pathway. This genetic counselling will be managed by the BRCA Direct team at the Institute of Cancer Research and genetic testing will be performed by the Royal Marsden Hospital and Manchester University Foundation Trust, with other labs potentially helping to meet demand as the programme expands.

People who are found to be BRCA carriers will have an appointment via telephone with a Genetic Counsellor who will:

- Refer any female carriers to their local NHS Very High-Risk Breast Screening Programme for regular screening in line with [national guidelines](#).
- Inform the person's GP of the diagnosis.
- Provide information about cascade testing of family members and facilitate those that would like to come forward for testing through the programme.
- Refer all carriers to their local Clinical Genetics service for further discussion around long term risk management, including preventative surgery, chemo preventative drugs and recommend any relevant lifestyle advice (for example the oral contraceptive).

**Figure One: The Testing Pathway**



Genetic Counselling Hotline available throughout the patient journey



## **Engaging the Jewish community**

In collaboration with [Jnetics](#) and [Chai Cancer Care](#), the programme will deliver a national engagement campaign to people with Jewish ancestry to encourage people to take up the offer of a BRCA test. An [information page](#) about BRCA has been created for those interested in the programme and those who want more information on the implications of a positive result and the support services available.

## **Launching the programme and expected impact**

The genetic testing pathway was soft launched in January 2023 and over 2000 people came forward to receive a test. Due to the high demand for this programme, the NHS Cancer Programme is working with service providers across the BRCA testing and surveillance pathway to prepare systems for increased downstream demand before reopening the programme.

For now, those interested in a test are being asked to complete [this expressions of interest form](#) and will be invited to request a test when the testing pathway has reopened. It is expected the programme will cover a period of three years.

Based on activity within the soft launch we anticipate delivery of ~33,000 BRCA tests over the three-year programme resulting in approximately 2,500 BRCA carriers identified, including cascade testing to family members. See Annex A for a further breakdown of anticipated numbers by region.

It is likely the predicted number of BRCA carriers found is an overestimate due the programme inviting the whole Jewish population (rather than only the Ashkenazi population who are at an increased risk of carrying a BRCA mutation compared to the Sephardi population) to participate in the programme and defining Jewish ancestry as having at least one Jewish grandparent. Some Jewish BRCA carriers and their family members have also already been identified (for example in Manchester ~133 Jewish female BRCA carriers have already been found).

We will continue to update and amend our modelling and will share with Cancer Alliances as results from the programme emerge, but for now are keen to ensure services have adequate information to plan for any increased activity within their services.

### **Figure 2: Expected number of tests and BRCA carriers found over the three-year programme**

<b>Total index tests over three years</b>	<b>33,318</b>	
Expected carriers – index cases	833	based on an assumed 2.5% incidence
Expected carriers – cascade testing	1,666	based on a 50% positive rate from 4 cascade tests
<b>Total</b>	<b>2,499</b>	men and women

## **Funding**

The NHS Cancer Programme is funding the delivery of the testing pathway and will also be providing funding to some clinical genetics services where necessary to reflect the increased workload. Funding will not be provided to downstream management services. People will be made aware of standard waiting times for access to downstream management pathways (e.g. clinical genetics). People will also have access to a genetic counselling hotline and can

use the hotline throughout the three-year programme at any stage of the pathway. Patients tested through this programme will be prioritised for treatment in the same way as patients entering the pathway through standard testing routes.

### **Further information**

Anyone interested in participating in the programme should be asked to complete [this expressions of interest form](#). It is recommended that GPs (and other primary care staff) share this link with Jewish patients who are interested in a test or suggest they call the genetic counselling hotline directly to order a test: 020 3437 6001 (the hotline is open Monday to Friday, 9:00am to 5:00pm, with extended hours to 7:00pm on Wednesdays).

Any family members of those who have tested positive should also be referred to the programme for testing via the same approach.

### **Any questions?**

If you would like to support the programme as part of your early diagnosis work please contact [susana.lukic@nhs.net](mailto:susana.lukic@nhs.net) for more information.

### **Annex A**

This table shows the number of BRCA carriers expected to be found per region over the three-year programme. As above, these are likely to be overestimates because we have used a 2.5% conversion ratio which is the risk for Ashkenazi Jews with four Jewish grandparents however this testing programme is also available to Sephardi Jews and those with one or more Jewish grandparents.

If you would like further information about breakdown of numbers within regions and expected numbers that will enter each stage of the downstream pathway (including for screening and surgery which are only available to females), please contact [susana.lukic@nhs.net](mailto:susana.lukic@nhs.net).

<b>Region</b>	<b>Jewish population *</b>	<b>% population</b>	<b>BRCA carriers</b>
North East	4,389	2%	41
North West	33,287	12%	309
Yorkshire and The Humber	9,358	3%	87
East of England	42015	16%	390
West Midlands	4396	2%	41
East Midlands	4314	2%	40
London	145467	54%	1,350
South East	18685	7%	173
South West	7392	3%	69
	<b>269,303</b>	<b>100%</b>	<b>2,499</b>

\*2021 census data