

NHS Jewish BRCA Testing Programme: Information for Cancer Alliances and regional teams

Action for Cancer Alliances

Share with GPs the [registration form](#) link and the genetic counselling hotline number: 020 3437 6001.

Background

On 30 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 for women, 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 250.

Progress to date

The programme has so far been a success. In 2023, 3719 Jewish people returned a saliva sample to be tested, 2488 results have been processed and 76 BRCA carriers found.

All BRCA carriers are referred to their local clinical genetics service for onwards management. The split of BRCA carriers found per clinical genetics unit is outlined in Figure 1 and is in line with what was modelled, with more BRCA carriers found in areas with high Jewish populations.

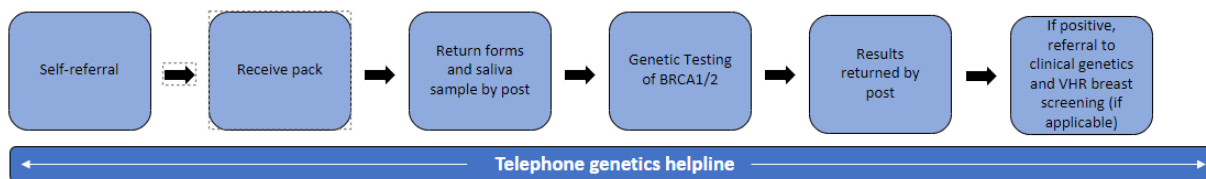
Figure 1: BRCA carriers found to date by clinical genetics unit

Clinical Genetic Unit	Referred patients
Northwick Park	48
Manchester	11
Great Ormond Street	8
Nottingham University Hosp	4
Guy's and St Thomas	3
Cambridge University Hosp	1
St Georges	1

The testing pathway (Figure 2) has been running smoothly. People register for a BRCA test online, a saliva kit is sent to their home address which they return alongside a consent form for genetic testing, one of three labs deliver genetic testing for BRCA1/2 and the result is returned in the post. People are supported throughout the whole pathway with a Genetic Counsellor helpline managed by two NHS Genetics Counsellors.

Figure 2: Genetic Testing Pathway





Full Launch

The full launch of the programme is planned for 31 January 2024 which will include an event at the House of Lords, a BBC news article, and a story in The Jewish Chronicle.

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

Impact

We anticipate delivery of ~33,000 BRCA tests over the three-year programme resulting in approximately 2,500 BRCA carriers identified (Figure 3). This number includes those identified through cascade testing for family members of people diagnosed with BRCA through the programme. We expect to find these people over several years as cascade testing to family members tends to happen over a long period of time. See Annex A for a further breakdown of anticipated numbers by region.

Figure 3: Expected number of tests and BRCA carriers found

Total index tests over three years	33,318	
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
Total	2,499	men and women

We have shared the breakdown of numbers with clinical genetics services, relevant secondary care services and Very High Risk breast screening providers. The ten Very High Risk Breast Screening Providers who it is expected will receive >1 extra referral per month have confirmed they will accept the increased level of referrals. We have also met with impacted secondary care services in London and the North West to inform them of the programme and to prepare them for the anticipated increase in demand as a result of the programme. We are providing funding to all clinical genetics services based on Jewish population to support their services as this is the main service which will see a marked increase in referrals as a result of the programme.

Cancer Alliances are asked to flag with us any questions or services who would like to discuss the programme further.

Further information

Anyone interested in participating in the programme should be asked to complete [this registration 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).

Close 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 for more information.

Annex A

This table shows the number of BRCA carriers expected to be found per region as a result of the three-year programme.

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.

Region	Jewish population *	% population	BRCA carriers
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
	269,303	100%	2,499

*2021 census data