FAMILY HISTORY, GENETICS AND BREAST CANCER BRIEFING:

Improving support for women at increased risk

BREAST CANCER NOW

SUMMARY

Women at increased risk of breast cancer are being let down by inconsistent access to services and assessment. Risk assessment pathways are complex and inaccessible for too many women, meaning they are unable to access vital early screening, risk-reducing treatment or support.

By finding women most at risk, providing them with support to reduce their risk and the correct enhanced screening, we can prevent more breast cancers – or diagnose and treat them earlier to save more lives.

To make sure women can access support, we need:

- Integrated Care Boards (ICBs) to plan for, commission and provide sufficient resources to services that support women at increased risk
- NHS England (NHSE) and Department of Health and Social Care (DHSC) to integrate all enhanced screening into the national NHS Breast Screening Programme
- ICBs and trusts to review the pathway and support available for prescribing risk-reducing drugs, and implement best practice more consistently across England to increase overall rates of uptake and long-term adherence
- Building on the successful development and implementation of registers like the National Inherited Cancer Predisposition Register (NICPR), the National Disease Registration Service (NDRS) should collect data on all women at increased risk of breast cancer
- DHSC to support more research into new strategies for identifying people at increased risk of breast cancer and better supporting them to reduce their risk, including through integrating datasets and improving data monitoring in these services

BACKGROUND

Around 1 in 7 women in the UK will be diagnosed with breast cancer in their lifetime.[1] But for some women, their genetics or family history makes them much more likely to get breast cancer.

In the UK, around **2,750–5,500** women are diagnosed with breast cancer due to a gene alteration (like BRCA1 or 2) or a strong family history of breast cancer. This is about 5–10% of all breast cancers.[1]

Evidence suggests around 4% of women are at increased risk of breast cancer in the UK, and this could mean hundreds of thousands of women are at an increased risk.[2]

Women at increased risk are currently classed as:

MODERATE RISK

more than 17% lifetime risk

HIGH RISK

more than 30% lifetime risk

VERY HIGH RISK

more than 40% lifetime risk

Treatments can significantly lower risk. Risk-reducing medication can reduce risk by 30-60% and risk-reducing surgery by 90-95%.[1]

The National Cancer Plan for England made 3 specific commitments to improve people's understanding of their cancer risk and help them reduce it.

National Cancer Plan for England commitments:

- To extend direct-to-patient genetic testing, so that patients with the greatest risk of cancer have faster access to testing and intervention
- By 2035, to use the NHS app to provide personalised risk profiles and prevention advice, based on an individual's lifestyle and genetic data
- To make sure people of Jewish heritage continue to receive BRCA testing, alongside others in high-risk populations

The plan also talks about expanding the role of genomics and personalised, risk-based care even further.

But our evidence shows that the system is already struggling to cope with the demand, with long wait times to access assessment, genetic testing and risk-reducing mastectomies.

BREAST CANCER NOW'S PRIORITIES FOR WOMEN AT INCREASED RISK

This briefing is part of Breast Cancer Now's No Time To Waste campaign. It's our campaign to make sure that everyone with breast cancer is diagnosed quickly and at an early stage.

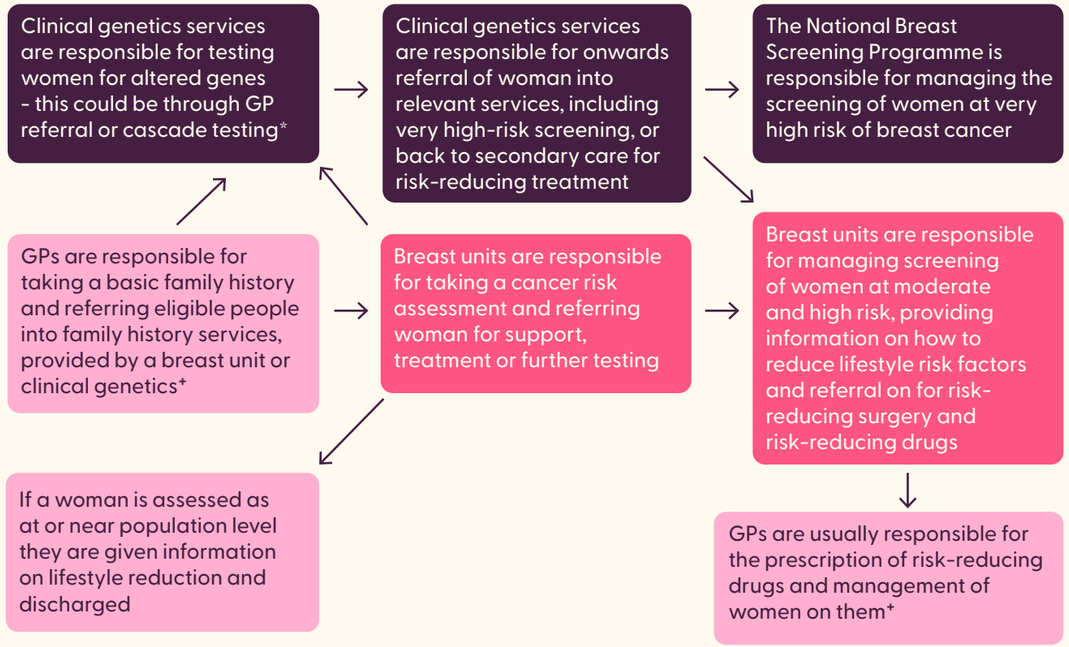
We know screening saves lives – and we're committed to making sure that all women can access a quick and early diagnosis. But we're also committed to making sure that they can receive the right support and care.

By finding women most at risk of breast cancer and providing them with support to reduce their risk and the correct enhanced screening, we can find breast cancers at the earliest stage possible, or even prevent them from developing in the first place.

HOW DID WE CREATE THIS BRIEFING?

- We spoke to a variety of healthcare professionals working in this area
- We held focus groups and interviews with women at increased risk
- We collected data through an FOI (Freedom of Information) request sent to all NHS Hospital Trusts, to find out what support and interventions they provide and how many people are using them

CURRENT PATHWAY



*Cascade testing is when a member of your family has tested positive for a gene variant either after a diagnosis or through a family history risk assessment, and clinical genetics send you an invite for testing.

+Some breast units will manage patients on risk-reducing drugs in areas without a dedicated family history service, all GP referrals are triaged and managed by clinical genetics.

It's vital that women are aware of their risk and are offered the information and treatment needed to help them manage and potentially reduce it. But the current approach to supporting these women is complicated and difficult to navigate. It also mainly relies on women proactively seeking out risk assessment and support.

Research has also shown that more comprehensive risk calculation tools that take into account other factors like lifestyle identify more women as at increased risk[3], but their use in practice is inconsistent across different family history services. This means too many women are not accurately being identified as at increased risk. And many more women who are aware of their risk level aren't getting the support they need.

KEY CHALLENGES IN FAMILY HISTORY SERVICES

1. INCONSISTENT CARE

‘Family history’ clinics are specialist services aimed at finding women at increased risk of breast cancer and helping them reduce and manage their risk.

Our FOI data shows significant differences in the way these services run across England, and in the treatments and support offered. And we know from speaking to healthcare professionals that lack of standardisation, failure to set up national pathways and ring-fenced funding is affecting women’s access to care.

Family history clinics are usually run through secondary care, often alongside breast cancer clinics. There’s no formal commissioning or dedicated funding provided for these services. And in some areas, there are no family history services and all referrals go through clinical genetic services.

Healthcare professionals also report that, particularly in smaller and more rural areas, services are often being run by a single, dedicated member of staff. The same member of staff usually also works with people with breast cancer symptoms. This has resulted in very long waits for appointments and access to genetic testing for women in these areas – sometimes over a year.

Women we spoke to also said that the ad hoc approach and delayed care in many places meant they felt they had to constantly advocate for themselves. Many of the women in our focus groups experienced unacceptably long waits to access family history clinics and clinical genetics, with women in some areas waiting over 14 months. Once in family history services, women felt like they were constantly chasing appointments, ringing up services to ask about results and repeating forms and conversations multiple times.

They also reported feeling overwhelmed by family history questionnaires and had difficulty gathering medical information from their families. Some women also reported they didn’t feel comfortable asking family members about their medical history.

The lack of standardisation has resulted in avoidable and unacceptable variation in the way risk assessment is carried out. Across England, different services will use a variety of different tools[4] at different stages of the patient pathway. This has led to **women being assessed at different risk levels based purely on where they live**.

Even across units that use the same tool to assess women’s risk, there’s a lack of training and support for healthcare professionals undertaking risk assessment. There’s also limited guidance about what information to include. This can lead to very different assessments and women being told different things about their risk.

The lack of formal commissioning and guidance, monitoring of performance and dedicated funding is having a serious impact on family history services and the care women are receiving.

SO WHAT NEEDS TO HAPPEN?

- [ ] To improve services and make sure everyone has equal access to services across England, ICBs need to plan for, commission and provide sufficient resources to services that support women at increased risk.

2. UNRELIABLE ACCESS TO AT-RISK SCREENING

Screening is the best way to diagnose breast cancers at an early stage, when they're easier to treat. But evidence has shown that there's **inconsistency of screening provision for women at increased risk – and this is leading to preventable deaths**.[5]

Women at increased risk of breast cancer are eligible to be screened more often and from an earlier age. The specific offer is based on whether a woman is at moderate, high or very high risk.[6]

Screening in England is managed either locally or nationally depending on your level of risk.

Women at very high risk[7] of breast cancer have their screening managed through the National Breast Screening Programme (NBSP), which is funded nationally through NHS England. This means that all women in this programme get the same frequency and type of screening and have their data recorded in a central database. This database can be easily accessed and updated by healthcare professionals, and the programme's performance is monitored.

In contrast, women at moderate or high risk have their screening managed locally by breast units, who are also running clinics for women with suspected breast cancer (symptomatic imaging). Women who attended our focus groups repeatedly spoke about having to chase referrals and invites to screening, in the absence of a formalised screening system.

The National Institute of Health and Care Excellence (NICE)[8] publishes guidance for what screening should be offered to moderate and high-risk women. The NICE guideline has 3 categories of screening. They are:

OFFER
screening that NICE says has a strong evidence base and should be offered to all eligible women within the risk and age category

CONSIDER
screening that NICE says has a weaker evidence base and so a decision about whether to offer it to women in the age and risk category should be based on clinical decision making

DO NOT OFFER
screening that NICE says should not be offered to anyone in that age or risk category

Healthcare professionals have told us this language is vague, that the term "consider" is not properly defined and leads to variation in care that is not based on clinical evidence. While NICE is currently reviewing these guidelines, they have stated that there is no new evidence for screening women at increased risk, so it's not in scope of that review.

Other professional bodies' recommendations on screening for women at increased risk also differ to NICE recommendations. NICE recommends MRI screening for women with gene variants such as BRCA 1 or 2 or PALB2 from the age of 30 only[9]. The UK Cancer Genetics Group[10] (UKCGG) recommends screening from the age of 25 for women with certain gene variants who have a more than 50% lifetime risk.[11] A focus group attendee had experienced this inconsistency within her own family. Although both her and her sister were diagnosed with BRCA 1, she was able to access screening from 25 but her sister was told she would have to wait until she was 30.

FOI data reveals significant variation in the screening being offered to women at moderate and high risk. Of the 77 trusts[12] that responded to our FOI and offer some services, our analysis found that:

4 TRUSTS adhere to the most comprehensive screening offering recommended by NICE.

1 TRUST offers the minimal level of screening recommended by NICE with some additional screening.

31 TRUSTS offer a broad package of enhanced screening that does not fully follow NICE guidance, but which does include many of NICE's recommendations.

28 TRUSTS offer a minimal screening package, less than recommended by NICE.

7 TRUSTS couldn't or did not provide data for this question.

2 TRUSTS provided responses that indicated they only provide some screening, with extra restrictions, but can refer to other trusts where indicated.

4 TRUSTS don't provide screening on site as part of their family history service, but do refer patients to other hospitals for screening.

In the trusts who reported not fully following NICE guidance, there was no obvious pattern or rationale for the screening being offered. Trusts also reported using different tools to assess women's risk, which may explain some of this variation.

This variation in advice and lack of clarity in the NICE guidelines is **causing significant inconsistency in the screening offered to women, resulting in geographic inequalities**.

This inconsistency can also lead to challenges for women trying to access screening, including their screening offer changing if they move to a new area.

CLAIRE'S STORY



Claire has a family history of cancer. This led to her being assessed as at moderate risk and getting an annual mammogram where she lived.

But when she moved out of Yorkshire, she had to undergo another risk assessment. This time, she was told she was not moderate risk and would no longer qualify for annual screening. Despite this, she was invited for a screening back in Yorkshire and decided to attend. At this screening she was told she had breast cancer. After her diagnosis, Claire was diagnosed with a BRCA2 gene variant.

SO WHAT NEEDS TO HAPPEN?

Women at moderate and high risk must have access to the enhanced screening they are entitled to, consistently across all areas of England.

- ☑ We're calling on NHSE and DHSC to integrate all enhanced screening into the national NHS Breast Screening Programme.

3. GAPS IN ADVICE, SUPPORT AND FOLLOW UP

As well as earlier and more frequent screening, women at increased risk of breast cancer are entitled to a range of support (based on their risk level) to help them manage and reduce their risk. According to NICE guidance, women should be offered:

Risk level	Lifestyle advice	Risk-reducing drugs	Risk-reducing mastectomy
Population risk	Information to help reduce risk and reassurance	No offer	No offer
Moderate risk	Information to help reduce risk	Information about risk-reducing drugs and referral for prescription if interested	No offer
High risk	Information to help reduce risk	Information about risk-reducing drugs and referral for prescription if interested	Discussion around surgery as a risk-reducing option with relevant women
Very high risk	Information to help reduce risk	Information about risk-reducing drugs and referral for prescription if interested	Discussion around surgery as a risk-reducing option

However, FOI data shows that, like with screening, access to these services is inconsistent:

Overall, only **36 OF THE 77 SERVICES** reported providing all the non-screening options – lifestyle advice, risk-reducing drugs and surgery.

28 SERVICES offered some but not all the non-screening options to women at both moderate and high risk. This may mean they could offer drugs but not surgery, or only high risk women drugs but moderate risk women lifestyle advice.

9 SERVICES could not provide data on this question.

4 SERVICES had offers that provided more options than recommended by NICE (like risk-reducing mastectomy for women at moderate risk).

We also asked trusts if they put in any further conditions or eligibility criteria for accessing support or treatment options. For example, age restrictions, or having to have a certain risk score.

Several trusts said they had further restrictions to access some or all the support available. These included restrictions like completing a more comprehensive personalised risk assessment, clinical team review and discussion, and internal guidelines about what support to offer based on risk.

Women across our focus groups and interviews reported not being offered risk-reducing drugs. And for the few that were, the conversations were not helpful and detailed enough to help their decision making. While drugs were offered to them, **they were not being discussed and managed in a way that met their needs**.

One focus group participant told us "I don't really remember risk-reducing drug treatments being an in-depth conversation. I think it was mentioned as an option and dismissed by the genetics team, and I just went along with it."

Research shows that most women eligible to take risk-reducing drugs are not currently doing so.[13] The failure to properly explain information and support women with their decision may partially explain low take-up.

Risk-reducing drugs can come with side effects. For women who do choose to take risk-reducing drugs, there is little to no follow up and almost no support in managing side effects. Because of this, many women do not complete their full 5-year course of the treatment.[14]

Anecdotally, healthcare professionals have reported that the lack of **clear pathways for prescribing risk-reducing drugs causes issues with access**. In many areas of England, GPs are responsible for the prescription and management of risk-reducing drugs. But they often lack confidence supporting their patients and don't have the experience or training to manage these situations.[15]

There are some areas of the country where different pathways are used to give women access to these medicines.[16] Greater Manchester has introduced a risk-reducing medicine toolkit, aiming to give nurses and GPs in family history clinics the confidence to assess patient risk, discuss treatment options, and manage side effects.[17] All breast services in Greater Manchester can offer risk-reducing medicine to eligible patients, supporting primary care to manage prescribing in the long term.

Researchers in Cambridge are also piloting a new pathway offering phone and online appointments to provide information about breast cancer risk-reducing medications and

support women with decision-making. But these models are limited to trusts with more funding and resources – usually in major teaching hospitals.

The quality of information provided about lifestyle adjustments also varies, with some women receiving tailored support and others receiving generic advice about lifestyle factors.

Women who attended our focus groups and interviews also reported feeling like there was limited care or information available to help them around the knock-on effects on their lives, particularly the impact on their family and loved ones.

Women also reported struggling with the emotional impact of being told they were at increased risk, and feeling like there was no psychological support available.

While there are tailored support programmes out there, like Breast Cancer Now's Someone Like Me service, these are often not well sign-posted by healthcare professionals and women don't always know about them.

SO WHAT NEEDS TO HAPPEN?

Women must have access to meaningful and tailored support – including support and advice around fertility preservation, how to talk to family members and children who may be affected and information about relevant support groups. They need detailed and informative lifestyle advice on managing and reducing their risk, and access to treatments that can prevent breast cancer.

☑ We're calling on ICBs and trusts across England to review their pathways for prescribing risk-reducing drugs, look to implement changes in practice and provide resources that can improve overall rates of uptake and long-term adherence. This could include:

- Supporting and implementing co-prescribing models
- Offering follow up to women on risk-reducing drugs at 6 months and a year, then follow up subsequently to support better adherence
- Improved training for GPs to help them feel more confident managing patients taking risk-reducing drugs

4. INADEQUATE DATA COLLECTION AND RESEARCH

In England, data is now routinely collected on women with a very high risk of breast cancer through the National Inherited Cancer Predisposition Register (NICPR) and the Breast Screening After Radiotherapy Dataset (BARD) . These registers provide central databases of anyone who has been identified as a known genetic risk carrier, and women who had irradiation to the chest as a child or young adult.

The database is used to track and invite people to very high-risk screening.

But data is not routinely collected or nationally stored on women with a moderate or high-risk of cancer who do not undergo genetic testing or have one of the known genetic risk factors. These make up most women who are at increased risk of breast cancer. This means there isn't a good understanding of the demand for services, and no consistent way of monitoring what provisions women are accessing.

The FOI data found that of the 77 trusts who responded to our request and provided services:

ONLY 16 trusts could provide a full data set of women who had come in for a risk assessment between 2021-2024 and the risk level they were assessed.

51 WERE able to provide data on the total number of patients seen between 2021-2024, but not the risk level.

10 COULD NOT OR DID NOT provide any data at all.

The most common reason trusts gave for not being able to provide data was that it was stored in individual medical records, making it difficult to access.

The lack of centrally held and accessible data makes planning service provision difficult. It also means data cannot be linked up to track outcomes for these women. For example, patient data from at increased risk pathways are not linked to other health data, so we don't know how many women at moderate or high risk go on to be diagnosed with breast cancer. We also don't know what percentage of them take up interventions like risk-reducing surgery or risk-reducing drugs.

The failure to link up this data makes it hard to track the impact of interventions and improve clinical practice. And lack of systematic data collection and monitoring means women could be missed and not get the support they're entitled to.

Cancer risk and genetics is a fast-developing area, so it's also vital that the system enables research, and makes sure practice keeps up with the most recent evidence.

That's why we need a national register that captures and integrates data from all women at increased risk, and fully links up datasets across the entire pathway. This would make it easier to carry out research in this population, as well as learn from high quality, real-time data.

SO WHAT NEEDS TO HAPPEN?

We need to understand the demand for risk assessment and risk-reducing services. And we need to make sure practice is supported by the most up-to-date research.

- ☑ Building on the successful development and implementation of registers like the NICPR, the NDRS should collect data on all women at increased risk of breast cancer.
- ☑ DHSC must also support and enable more research into new strategies for identifying people at increased risk of breast cancer and better supporting them to reduce their risk, including through integrating datasets and improving data monitoring in these services.

CONCLUSION

The current system for identifying and supporting women at increased risk of breast cancer is inconsistent and complicated to navigate, leaving too many women without vital access to enhanced screening, risk-reducing treatments and wider support.

Improving pathways and services for people at increased risk will help women reduce their risk and give them the best chance of an early diagnosis, or event prevent breast cancer from developing in the first place. Critically, it could save more lives.

We will work with the DHSC, ICBs and NHS services to make sure all women at increased risk of breast cancer get the care they need.

1. Breast Cancer Now ‘Breast Cancer in The UK 2025: A Compendium’. Available at: https://breastcancernow.org/media-assets/b1mhflrw/bcn_955_breast-cancer-in-the-uk-compendium-2025_final.pdf
2. Evans, Gareth et al ‘Breast Cancer Risk in Young Women in the National Breast Screening Programme: Implications for Applying NICE Guidelines for Additional Screening and Chemoprevention’. Available at: https://aacrjournals.org/cancerpreventionresearch/article/7/10/993/50153/Breast-Cancer-Risk-in-Young-Women-in-the-National. *Estimate based on Cohort data of 4,360 women aged 46-49 years old.
3. Frost. Ruben, 2026, ‘Comparison of NICE criteria with the BOADICEA multifactorial risk model to guide breast cancer 1 risk assessment and referral amongst women under age 50 within primary care’
4. Risk assessment tools can be online tools, such as CANRISK that use an algorithm based system to assess cancer risk or can be tools such as the Manchester score which provides a risk–score based on family history.
5. Evans, Gareth, Available at: Sporadic implementation of UK familial mammographic surveillance guidelines 15 years after original publication | British Journal of Cancer
6. See appendix A for breakdown of screening for women at increased risk as advised by the National Institute for Health and Care Excellence (NICE).
7. Very high risk is defined as women with a lifetime risk above 40%, usually with a confirmed gene variant such as BRCA1/2, and some women who have had prior irradiation to the chest for cancer.
8. NICE is the body responsible for publishing medical guidance in the UK.
9. NICE-https://www.nice.org.uk/guidance/cg164
10. National multidisciplinary body for clinicians working in genetics in the UK. Is responsible for publishing best practice guidance.
11. UK Cancer Genetics Group - https://www.ukcgg.org/information-education/ukcgg-leaflets-and-guidelines/
12. One extra trust did respond saying they offered one very limited screening offering, but no other services at all- they are not included in this data for clarity.
13. Jean Hackett ‘Uptake of breast cancer preventive therapy in the UK: results from a multicentre prospective survey and qualitative interviews’. Available at: https://pmc.ncbi.nlm.nih.gov/articles/PMC6022517/
14. Samual G Smith ‘ Factors affecting uptake and adherence to breast cancer chemoprevention: a systematic review and meta-analysis’. Available at: https://pmc.ncbi.nlm.nih.gov/articles/PMC4803450/#abstract2
15. Sarah Bellhouse, ‘Breast Cancer Risk Assessment and Primary Prevention Advice in Primary Care: A Systematic Review of Provider Attitudes and Routine Behaviours.’ Available at: https://pmc.ncbi.nlm.nih.gov/articles/PMC8394615/
16. Co-prescribing models are models where there is shared responsibility for manging patients on drug regimens/ providing expert advice and guidance to clinicians in primary care. For example, models where prescription through primary care is supported with specialist advice and guidance or where a drug is first
17. Manchester University- Risk Reducing Endocrine Therapy Toolkit. Available at: https://gmcancer.org.uk/cancer-pathway-boards/breast/endocrine-therapy/#endocrinetherapytoolkit Further Information can be obtained through the Greater Manchester Cancer Alliance.

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