Contents

1. Introduction and Who Guideline applies to

Familial breast cancer typically occurs in people with an unusually high number of family members affected by breast, ovarian or a related cancer. If more cases of breast, ovarian or a related cancer are seen in a family than would be expected by chance alone, this can be a sign that genes have caused or contributed to its development. Breast cancer in people who have a family history of breast, ovarian or a related cancer may need different management from that in people without a family history of these cancers. This is because of differences in the future risk of developing contra-lateral breast cancer, the risk of other tumours in the body e.g. ovarian cancer and the risk to other relatives.

This guideline describes the classification and care of people at risk of familial breast cancer. It provides recommendation for genetic testing surveillance and risk reduction and treatment strategies for people without breast cancer who are at increased risk because of a family history of breast, ovarian or a related cancer This guideline also covers people with a diagnosis of breast cancer and/or family history of breast, ovarian or a related cancer. It makes recommendations on genetic testing thresholds, surveillance, risk reduction and treatment strategies (nice.org.uk/guidance/cg164 Nov 2023). This is an update from the 2004/6 guidelines. It also includes additional guidance for very high-risk women or people as set out in 2020 by the NHS Breast Screening programme.

These guidelines are intended for use by all clinical geneticists/familial breast cancer nurses and cancer genetic/ genetic counsellors involved in risk assessment and counselling of clients

with breast cancer, a family history of breast and / or ovarian cancer.

2. Recommendations, Standards and Procedural Statements

2.1 Family history-taking in specialist genetic clinic

A third-degree family history should be taken in a specialist genetic clinic for a person with no personal history of breast cancer, if this has not been done previously.
For accurate risk estimation, the following are required:

- Age of death of affected and unaffected relatives
- Current age of unaffected relatives.

Confirming the family history:

In general, it is not necessary to validate breast cancer-only histories (via medical records/cancer registry/death certificates). However, this is preferable to ensure the management is accurate.
If substantial management decisions, such as risk-reducing surgery, are being considered and no mutation has been identified, clinicians should seek confirmation of breast cancer- only histories (via medical records/cancer registry/death certificates).

- Where no family history verification is possible, agreement by a multidisciplinary team should be sought before proceeding with risk-reducing surgery.
- Abdominal malignancies at young ages and possible sarcomas should be confirmed in specialist care.

2.2 Communicating cancer risk and carrier probability:

- People should be offered a personal risk estimate but information should also be given about the uncertainties of the estimation.
- When a personal risk value is requested, it should be presented in more than one way (for example, a numerical value, if calculated, and qualitative risk).
- People should be sent a written summary of their consultation in a specialist genetic clinic, which includes their personal risk information.

Information and support:

- Effective care involves a balanced partnership between patients and healthcare professionals. Patients should have the opportunity to make informed choices about any treatment and care and to share in decision making.

- To ensure a patient–professional partnership, patients should be offered individually tailored information, including information about sources of support (including local and national organisations).

1. National Hereditary Breast Cancer Helpline
2. YOU TUBE channel, www.**youtube**.com/user/**ClinicalGenetics** (Optional)

For people being cared for in a specialist genetic clinic:

- Standard written information as above).
- Information about hereditary breast cancer.
- Information about genetic testing, both predictive testing and mutation finding, including details of what the tests mean and how informative they are likely to be, and the likely timescale of being given the results.
- Information about the risks and benefits of risk-reducing surgery when it is being considered, including both physical and psychological impact.
- People who meet the following referral criteria should be offered a referral to a specialist genetic clinic.

2.3 Offering genetic testing

Offer genetic testing in specialist genetic clinics to a person with if their combined BRCA1, BRCA2 or PALB2 mutation carrier probability is 10% or more and an affected relative is unavailable for testing.

BRCA1, BRCA2 and PALB2 mainstreaming testing is available through trained the gynae-oncology team for patients with high grade serous ovarian cancer without a wider relevant family history of breast, prostate or ovarian cancer. Gene panels for suspected mendelian disease is available if suspected mendelian disease is suspected e.g. Li-Fraumeni, Peutz Jeghers, Cowden or diffuse gastric cancer and lobular breast cancer.

Testing should be carried out in keeping with the genomic test directory

In a specialist genetic clinic, use a carrier probability calculation method with demonstrated acceptable performance (calibration and discrimination) to assess the probability of a *BRCA1, BRCA2 or PALB2* mutation. Examples of acceptable methods include CAN RISK and the Manchester scoring system. A newly discovered familial breast and ovarian cancer susceptibility gene, PALB2 has been added in 2021

The vast majority of decisions should be made on the likelihood of identifying a gene change based on either the Manchester Scoring or can risk computer modelling system cross-referenced with the test directory. https://www.england.nhs.uk/publication/national- genomic-test-directories/

If there are problems with using or interpreting carrier probability calculation methods, use clinical judgment when deciding whether to offer genetic testing and discuss this at the weekly clinical meeting. This is based on who would benefit from genetic testing in the family and how the result might be used by relatives for screening and/or preventative surgical decision making.

Offer fast-track genetic testing (within 4 weeks of a diagnosis of breast cancer) only as part of a clinical trial or if clinically it is thought likely to help with surgical decision making.

Surveillance for women with no personal history of breast cancer

NICE guidance (2023) is used for women at moderate and high risk in accordance to 17% and

30% lifetime thresholds for moderate and high risk.
NHS Breast Screening programme guidance is used for women at above 40% risk as set out in appendix 1 and in the referral form below.

2.4 Preventative breast surgery

Discuss the risks and benefits of risk-reducing mastectomy with women with a known or suspected BRCA1, BRCA2, PALB2 or TP53 mutation.

For a woman considering risk-reducing mastectomy, include in the discussion of risks and benefits:

- the likely prognosis of their breast cancer, including their risk of developing a distal
- recurrence of their previous breast cancer
- a clear quantification of the risk of developing breast cancer in the other breast
- the potential negative impact of mastectomy on body image and sexuality
- the very different appearance and feel of the breasts after reconstructive surgery
- the potential benefits of reducing the risk in the other breast and relieving the anxiety about developing breast cancer.

Give all women considering a risk-reducing mastectomy the opportunity to discuss their options for breast reconstruction (immediate and delayed) with a member of a surgical team with specialist skills in oncoplastic surgery or breast reconstruction.

Ensure that risk-reducing mastectomy and breast reconstruction are carried out by a surgical team with specialist skills in oncoplastic surgery and breast reconstruction.

Offer women who have BRCA1, BRCA2, PALB2 or TP53 mutations but who decide against risk-reducing mastectomy, surveillance according to their level of risk.

2.5 Risk-reducing bilateral salpingo-oophorectomy

Discuss the risks and benefits of risk-reducing bilateral salpingo-oophorectomy with women with a known or suspected BRCA1, BRCA2 or PALB2 mutation. Include in the discussion the positive effects of reducing the risk of breast and ovarian cancer and the negative effects of a surgically induced menopause.

The PROCTECTOR study can be considered where the tubes are removed but removal of the ovaries is delayed (new 2021)

Defer risk-reducing bilateral salpingo-oophorectomy until women have completed their family.

Contraindications to risk-reducing surgery for people with a personal history of breast cancer.

Do not offer risk-reducing surgery to people with comorbidities that would considerably increase the risks of surgery.
Do not offer risk-reducing surgery to people who have a limited life expectancy from their cancer or other conditions.

Offer people with invasive breast cancer or ductal carcinoma in situ and a 30% probability of a TP53 mutation, genetic testing to help determine their treatment options.

2.6 Chemoprevention for women with no personal history of breast cancer

Discuss either tamoxifen or raloxifene for 5 years to postmenopausal women with a uterus and at high risk of breast cancer unless they have a past history or may be at increased risk of thromboembolic disease or endometrial cancer. This would be prescribed by the patient's GP.

Healthcare professionals within a specialist genetic clinic should discuss and give written information on the absolute risks and benefits of all options for chemoprevention to women at high risk or moderate risk of breast cancer.

Discussion and information should include the side effects of drugs, the extent of risk reduction, and the risks and benefits of alternative approaches, such risk-reducing surgery and surveillance.

Do not offer tamoxifen or raloxifene to women who were at high risk of breast cancer but have had a bilateral mastectomy.

Inform women that they should stop tamoxifen at least:

- 2 months before trying to conceive
- 6 weeks before elective surgery.

3. Education and Training

None

4. Monitoring Compliance

None

5. Supporting References

Clinical genetics referral form
BRCA1, BRCA2 and PALB2 mutation testing guidelines
Familial breast cancer NICE guidelines; nice.org.uk/guidance/cg164
NICE guidelines training pack, implementation plan and breast screening leaflet

6. Legal Liability Guideline Statement

Guidelines or Procedures issued and approved by the Trust are considered to represent best practice. Staff may only exceptionally depart from any relevant Trust guidelines or Procedures and always only providing that such departure is confined to the specific needs of individual circumstances. In healthcare delivery such departure shall only be undertaken where, in the judgement of the responsible healthcare professional' it is fully appropriate and justifiable - such decision to be fully recorded in the patient's notes

7. Key Words

The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs.
As part of its development, this policy and its impact on equality have been reviewed and no detriment was identified.

Contact and review details			
Guideline Lead (Name and Title) Approval Date: Author: Julian Barwell Consultant in Clinical Genetics			**Executive Lead** Chief Medical Officer
Details of Changes made during review:			
Date	**Issue Number**	**Reviewed By**	**Description Of Changes (If Any)**
April 2024	**4**	Dr Julian Barwell – Consultant in Cancer Genetics Vanita Jivanji – Senior Genetic Counsellor Dr Pradeep Vasudevan Hos	No changes to guidance NICE CG 164 link updated Approval record updated Format of guideline updated in line with Trust recommendations Approved by: Clinical Genetics Case and Cancer Review Group UHL Women's Quality & Safety Board: April 2024

Appendix 1: Referral to the NHSBSP for very high-risk screening

	Referral to the NHSBSP for very high-risk screening
Section A: To be completed by the referrer	Patient Details Name: Click or tap here to enter text. NHS No: Click or tap here to enter text. Address: Click or tap here to enter text. DOB: Click or tap here to enter text. Postcode: Click or tap here to enter text. Telephone No: Click or tap here to enter text. Mobile: Click or tap here to enter text.
	Referrer Name: (i.e. Geneticist / geneticist nominee, Oncologist, BARD)Click or tap here to enter text. Address (with postcode): Click or tap here to enter text. Referee name: (i.e. alternative BSS service) Click or tap here to enter text. Address: Click or tap here to enter text.
	Please indicate relevant family history members with age of diagnosis, relationship and attach copy of genetics letter indicating level of risk. Click or tap here to enter text.

Section B: To be completed by Genetics/Oncology/BARD	*Please tick imaging requested*			
	Risk Click or tap here to enter text.	**Age** Click or tap here to enter text.	**Surveillance Protocol** Click or tap here to enter text.	✓
	BRCA carriers and equivalent			
	BRCA1 ☐	BRCA2 ☐	Risk equivalent, not tested ☐ (Evidence of 10 year risk required)	
	Other gene mutation ☐ *(please state)*	PALB2 ☐ PTEN ☐ Other Click or tap here to enter text.	STK11 ☐ CDH1 (E-Cadherin) ☐	
		25 to 29	MRI (with 8%, 10 year risk)	☐
		30 to 39	MRI	☐
		40 to 50	MRI + mammography	☐
		51 to 70	Mammography +/- MRI	☐
	TP53 (Li-Fraumeni)	20 to 70	MRI	☐
	A-T homozygotes	25 to 70	MRI	☐
	Radiotherapy to breast tissue – irradiated when	25 to 70	MRI	☐

	aged between 10-19 years			
	Radiotherapy to breast tissue – irradiated when aged between 20-29 years	30 to 39 40 to 50 51 to 70	MRI MRI +/- mammography Mammography +/- MRI	☐ ☐ ☐
	If Radiotherapy to breast tissue, was this for….	Hodgkins Lymphoma ☐ Other Click or tap here to enter text.	Non-Hodgkins Lymphoma ☐	
	I can confirm that the woman has been informed that her details will be shared with the NHS Breast Screening Programme for the purpose of screening invitations when she becomes eligible. Signed: Role: Click or tap here to enter text. Date: Click or tap to enter a date. Print name: Click or tap here to enter text.			

Section C: To be completed by BSS

Referral accepted for very high risk screening ☐

Referral rejected for very high risk screening ☐

Reason for rejection: Click or tap here to enter text.

Radiologist signature: Date: Click or tap to enter a date.

Please complete details below and copy form to the referrer as receipt of referral.

Radiotherapy referrals: chn-tr.bard@nhs.net Clinical

genetics: referring clinical genetics service

Oncology referrals: to individual oncologist and chn-tr.bard@nhs.net

Woman invited (yes/no)	Click or tap here to enter text.	Woman screened (yes/no)	Click or tap here to enter text.

Authoriser's name: Click or tap here to enter text.

Authoriser's signature:

Date: **Click or tap to enter a date.**

(Referral forms can be authorised by a consultant radiologist, consultant practitioner or breast clinician.)

GOV.UK

1. Home (https://www.gov.uk/)
2. Health and social care (https://www.gov.uk/health-and-social-care)
3. Public health (https://www.gov.uk/health-and-social-care/public-health)
4. Population screening programmes (https://www.gov.uk/health-and-social-care/population-screening-programmes)
5. NHS breast screening (BSP) programme (https://www.gov.uk/health-and-social-care/population-screening-programmes-breast)
6. Breast screening: higher risk women surveillance protocols (https://www.gov.uk/government/publications/breast-screening-higher-risk-women-surveillance-protocols)

1. Public Health England (https://www.gov.uk/government/organisations/public-health-england)

Guidance

Protocols for surveillance of women at higher risk of developing breast cancer

Updated 4 October 2019

Contents

This publication is available at https://draft-origin.publishing.service.gov.uk/government/publications/breast-screening-higher-risk-women-surveillance-protocols/protocols-for-surveillance-of-women-at-higher-risk-of-developing-breast-cancer

The national cancer strategy (https://www.gov.uk/government/publications/the-national-cancer-strategy) requires the NHS breast screening programme (BSP) to manage the surveillance of women at very high risk of developing breast cancer to national standards across England.

This guidance is aimed at BSP providers, commissioners, organisations and individuals who refer women into the very high risk programme. These organisations include genetics services, oncology services and the breast screening after radiotherapy dataset (https://www.christie.nhs.uk/bard) (BARD).

Women at very high risk eligible for screening in the NHS BSP only form part of the high risk group defined by the National Institute for Health and Care Excellence (https://www.nice.org.uk/guidance/cg164) (NICE).

The NHS BSP screens very high risk women with digital X-ray mammography and/or magnetic resonance imaging (MRI) according to the frequencies published in this guidance.

The national breast screening system (NBSS) manages the invitation process and records all outcomes for women screened through the very high risk programme. Breast screening services should not use NBSS for the management of women identified to be outside the very high risk programme. This may include women at moderate risk who are seen within a family history screening service.

1. Revisions to previous guidance

This guidance has been revised to clarify:

- how very high risk is defined in the NHS BSP and how that relates to the NICE definitions
- what is risk equivalent to BRCA1 and BRCA2 carriers
- which women aged 25 to 29 should be included in the very high risk screening programme
- who is entitled to a baseline MRI scan
- who is entitled to very high risk screening following radiotherapy to sites involving breast tissue (formerly referred to as ‘supra-diaphragmatic radiotherapy’)
- when the very high risk screening programme ends

2. Related guidance

Technical guidelines on the use of MRI for the surveillance of women at higher risk (https://www.gov.uk/government/publications/nhs-breast-screening-using-mri-with-higher-risk-women) must be followed.

This includes information relating to physics quality control and guidance for radiologists reporting MRI. There are also practical guidelines (https://www.gov.uk/government/publications/breast-screening-screening-of-higher-risk-women) on setting up and providing screening for women at higher risk.

Guidance on screening very high risk women who are pregnant or lactating (https://www.gov.uk/government/publications/breast-screening-higher-risk-women-who-are-pregnant-or-lactating) is also available.

Screening should be suspended during pregnancy until about 3 months after cessation of lactation, due to the high density of the lactating breast inhibiting interpretation of images. If not breast feeding, MRI should be postponed until 3 months post-partum.

3. Accessing very high risk screening

Referrals into the NHS BSP should be through:

- a genetics service by a consultant geneticist or an appropriately trained individual nominated by them
- an oncologist (in the case of women who received radiotherapy to sites involving breast tissue). For the small number of women who received radiotherapy to sites involving breast tissue for cancers other than lymphoma, oncologists are advised to contact Breast Screening After Radiotherapy Dataset (BARD) (chn-tr.BARD@nhs.net) to confirm eligibility for very high risk screening
- BARD: for women who received radiotherapy to sites involving breast tissue during treatment for lymphoma

3.1 Referrals by genetics services or oncology centres

Women who meet the very high risk criteria should be referred to their local breast screening service.

Typically, you should refer to a named high risk coordinator or director of breast screening. Referrals should contain all the necessary information to demonstrate the individual meets the very high risk criteria and should be made using an NHS BSP referral form (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/830844/BSP_very_high_risk_referral_form.odt).

On receipt, each referral must be reviewed to make sure the inclusion criteria have been evidenced. This review must be completed by a consultant radiologist, consultant practitioner or breast clinician experienced in the full range of triple assessment.

Once a referral has been accepted, the woman needs to be appropriately identified as very high risk on BS Select and NBSS. You should scan and upload documentation on to her BS Select record. See more detailed information regarding these processes (https://www.gov.uk/government/publications/breast-screening-screening-of-higher-risk-women).

3.2 Referrals by BARD

BARD (https://www.christie.nhs.uk/bard) identifies all women in England below the age of 36 who have been treated with radiotherapy for lymphoma to sites involving breast tissue.

Women in this group who were treated with radiotherapy between the ages of 10 and 29 are referred into the NHS BSP very high risk programme.

Women are identified from cancer registries and then cross matched against information held at radiotherapy treatment centres to determine eligibility for inclusion in the NHS BSP for very high risk screening.

BARD sends details (NHS numbers) of these women who fulfil very high risk criteria to NHS Digital to determine if they are already on the BS Select call/recall system.

BARD will write to a woman's GP to confirm screening remains appropriate and, if so, will send services a completed referral form. The service then issues an invitation for screening. This invitation must include the BARD patient information leaflet. This will be sent to the service from BARD directly with the referral or is available online.

The service must subsequently confirm with BARD:

- that the referred woman has been invited
- if and when the referred woman attended screening, using the referral template (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/830844/BSP_very_high_risk_referral_form.odt)

4. Threshold for screening women in the very high risk programme

The NHS BSP screens women at very high risk of breast cancer due to:

- a (usually proven) genetic mutation
- having received radiotherapy to breast tissue during treatment for Hodgkin and non-Hodgkin lymphoma

The NICE familial breast cancer guidelines (https://draft-origin.publishing.service.gov.uk/government/publications/breast-screening-higher-risk-women-surveillance-protocols/www.nice.org.uk/guidance/cg164/chapter/recommendations) categorise women at increased risk of breast cancer as moderate or high.

Only a subset of those defined by NICE as being at high risk reach the very high risk group threshold used in the NHS BSP. This has previously been set at 8 times the relative risk of women in the general population.

To differentiate between the NICE and NHS BSP guidance, very high risk is defined by the NHS BSP as:

- women with a lifetime risk of 40% or greater due to a specific genetic abnormality in the woman or her family
- those receiving radiotherapy to breast tissue during treatment for Hodgkin and non-Hodgkin lymphoma between the ages of 10 and <30
- a small number of women who received radiotherapy to breast tissue during treatment for

cancers other than lymphoma

5. How to calculate women at very high risk

A woman is considered to be at very high risk if she has a test result that demonstrates a genetic abnormality that would confer a 40% to 95% lifetime risk of breast cancer.

Some women may choose not to have genetic testing. In order to avoid a situation where a woman with a known gene mutation in her family is obliged to proceed with predictive genetic testing to access very high risk screening, the following risk assessment process will apply:

If a woman has not been tested, but has a first degree relative with a BRCA1, BRCA2 or TP53 pathogenic gene, she has a 50% chance of carrying this gene. As a result, she will be eligible for very high risk screening up to and including the age of 50.

To access this, confirmation is required from the genetics service that a first degree relative carries a gene mutation. After the age of 50 a previously untested woman will be returned to the routine screening programme.

After the age of 50, a personal test result showing a gene mutation is required to access the very high risk programme. This is due to the residual lifetime risk associated with a gene mutation having fallen by the age of 50, which means a woman with only a 50% chance of carrying this mutation would no longer reach the 40% lifetime risk threshold to access very high risk screening. See more detailed information regarding these processes (https://www.gov.uk/government/publications/breast-screening-screening-of-higher-risk-women).

5.1 How to decide lifetime risk in absence of genetic test

Genetic risk assessment should provide clear confirmation of the level of risk using an NHS endorsed computer risk modelling software programme, BOADICEA (CanRisk) or Tyrer Cuzick. The 10-year risk estimate must be submitted with the referral proforma as evidence that the woman satisfies the appropriate risk at a given age.

Age 25 to 29

Women should have an 8% 10-year risk confirmed by a clinical genetics service (required by the NHS BSP)

Age 30 to 39

Set risk at 30 years and screening if woman meets an 8% 10-year risk confirmed by a clinical genetics service (required by the NHS BSP)

Age 40 to 49

Set risk at age 40 and screening if woman meets a 12% 10-year risk confirmed by a clinical genetics service (required by the NHS BSP)

5.2 Women previously treated with total body irradiation

Women who have previously received total body irradiation are at an elevated risk of breast cancer in

the years following treatment. However, there is insufficient evidence to show that the risk reaches the threshold to qualify this cohort of women for screening in the very high risk programme.

See Tests and frequency of tests for women at very high risk (https://www.gov.uk/government/publications/breast-screening-higher-risk-women-surveillance-protocols/tests-and-frequency-of-testing-for-women-at-very-high-risk).

5.3 Queries over entitlement following previous radiotherapy

Most women who have had radiotherapy fields involving breast tissue at a young age are those receiving treatment for Hodgkin or non-Hodgkin lymphoma. However, other diagnoses may also result in similar radiotherapy treatment fields.

If a woman had radiotherapy involving breast tissue below the age of 36 but it is unclear if she is eligible for very high risk screening within the NHS BSP, contact BARD for advice chn-tr.bard@nhs.net.

6. Screening test

Where indicated, the screening test should be MRI (with or without mammography). If a woman cannot tolerate MRI, she and her lead radiologist should discuss and agree potential alternatives such as wide scanners.

Breast ultrasound is not offered as a screening tool in the NHS BSP based on current evidence.

This differs from current NICE guidance, which states:

Do not routinely offer ultrasound surveillance to women at moderate or high risk of breast cancer but consider it:

- when MRI surveillance would normally be offered but is not suitable (for example, because of claustrophobia)
- when results of mammography or MRI are difficult to interpret

Breast ultrasound is not provided by the NHS BSP as a screening tool. If a woman cannot be screened with MRI, ultrasound should only be carried out following a full discussion regarding the potential benefits and limitations of the test.

6.1 Process before MRI screening

Local protocols should be followed regarding MRI with gadolinium enhancement. There is also Royal College of Radiologists guidance (https://www.rcr.ac.uk/publication/guidance-gadolinium-based-contrast-agent-administration-adult-patients).

6.2 Review of background density

Some of the screening protocols state that women require mammography with or without an MRI. The decision for MRI is based on an annual review of breast density.

Women covered by this guidance should have both procedures up to and including the age of 50. At this point, and annually thereafter, breast density should be reviewed based on current images until a decision is made that MRI is no longer required.

Once the decision is made that a woman no longer needs MRI, her protocol should be updated within the client record on NBSS to show mammography only for her next screening appointment. More

detailed information (https://www.gov.uk/government/publications/breast-screening-screening-of-higher-risk-women) regarding this process is available.

If the mammogram shows an entirely fatty breast (Birads A (https://www.acr.org/-/media/ACR/Files/RADS/BI-RADS/Mammography-Reporting.pdf)), MRI is unlikely to add value and should not be performed. From the age of 60 onwards, breasts are less likely to require MRI plus mammography, as most breasts are less dense.

6.3 Baseline MRIs for women

A woman newly referred into the programme and meeting the very high risk criteria is entitled to MRI screening even if she is considering risk-reducing surgery. This may help identify malignancy before surgery.

After risk-reducing surgery, a woman can either opt out of the programme by signing a form or the service can cease the woman if there is clinical evidence that bilateral mastectomy has been carried out. Details are available in the opting out of breast screening guidance (https://www.gov.uk/government/publications/opting-out-of-breast-screening), which include copies of the required form.

7. Policy for short-term recalls following screening assessment

Short-term recalls are defined as a further appointment to attend a screening assessment indicated before the normal screening interval (one year).

All women on short-term recall should have previously attended assessment. Short-term recall should not be used as a routine outcome following assessment. Every effort should be made to obtain a definitive diagnosis at initial assessment. Short-term recall should only be made in exceptional circumstances and with fully informed consent as it is associated with significant anxiety.

If recall is within 6 weeks of the original assessment then it should be part of the same episode. If recall is after 6 weeks, it should be logged as a short-term recall episode. The short-term recall should usually be 6 months after the initial assessment of the woman.

8. When very high risk screening stops

Screening should be performed as specified in this guidance.

When a woman reaches 71 years of age routine invitations for very high risk screening will stop. At this stage she is entitled to self-refer for screening. For women in the very high risk programme, this will be annual screening in accordance with her routine screening protocol.

These women should be informed they will need to ask their local screening service directly or their GP can arrange screening for them.

Appendix 3: Tests and frequency of testing for women at very high risk

Contents

1. BRCA carriers and equivalent risks

This group of women at very high genetic risk of developing breast cancer includes:

- BRCA1 carriers
- BRCA2 carriers
- risk equivalent to BRCA carriers not tested [1], but have a first degree relative who has a BRCA1 or BRCA2 genetic mutation
- women who have a mutation in another high risk gene including:
    - PALB2
    - PTEN
    - STK11
    - CDH1 (E-Cadherin)

Age	Test	Frequency of testing
25 to 29 [2]	MRI	Annual
30 to 39	MRI	Annual
40 to 50	MRI + mammography	Annual
51 to <71	Mammography +/- MRI [3]	Annual

2. Women with TP53 (Li-Fraumeni) syndrome

Age	Test	Frequency of testing
20 to <71	MRI	Annual

No mammography tests for this group of women.

3. Women with A-T homozygotes

Age	Test	Frequency of testing
25 to <71	MRI	Annual

No mammography tests for this group of women.

4. Women who have had radiotherapy to breast tissue

4.1 Females irradiated below the age of 10 years

Testing is not applicable to these females.

4.2 Females irradiated between ages of 10 and 19

Age	Test	Frequency of testing
25 to <71	MRI	Annual

Surveillance starts at 25 or 8 years after first irradiation, whichever is the later.

4.3 Females irradiated between ages of 20 and 29

Age	Test	Frequency of testing
30 to 39 [4]	MRI	Annual
40 to 50	MRI +/- mammography	Annual
51 to <71	Mammography +/- MRI [5]	Annual

4.4 Females irradiated between ages of 30 and 35

These women should be referred by GP to local mammography service (non-NHS Breast Screening Programme) as they do not reach the very high risk threshold. Breast screening After Radiotherapy Dataset (BARD) will inform GPs about the need for this and the timing.

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1. Screening for untested women will stop at 50 years. After that, testing will be required to continue in the very high risk screening programme.
2. To qualify for screening under 30 years, women must also have an 8%, 10-year risk at the age when entered (when aged 25 to 29 years).
3. Review MRI annually on basis of background density from 50 years.
4. Surveillance starts at 30 or 8 years after first irradiation, whichever is the later
5. Review MRI annually on basis of background density from 50 years.