Guidelines on organising the surveillance of women at higher risk of developing breast cancer in an NHS Breast Screening Programme
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**Organising the surveillance of women at higher risk of breast cancer**

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</table>
## CONTENTS

**AUTHORS**

1

**CONTENTS**

III

**EXECUTIVE SUMMARY**

1

1. **INTRODUCTION**

2

1.1 Aims of the guidance

2

1.2 Background

2

1.3 Provision of screening services in the new NHS

3

1.4 Commissioning of cancer screening

3

1.5 Some key messages from the higher-risk demonstration sites

4

1.5.1 Risk assessment

4

1.5.2 Planning higher-risk screening

4

1.5.3 Delivering higher-risk screening

5

1.5.4 Audit and ‘Right Results’

5

2. **REFERRAL OF APPROPRIATE WOMEN**

6

2.1 Liaison with genetics services

6

2.2 Liaison with oncology services

7

2.3 Liaison with MRI services

7

2.4 MDTs

7

3. **ENTERING WOMEN ONTO NBSS**

9

3.1 Set up

9

3.2 Registration and selecting the protocol

9

3.3 Forms

10

3.4 Creating an higher-risk episode on NBSS

10

3.5 Letters for women undergoing higher-risk screening

11

3.6 Screening clinics

12

3.7 Assessment

12

NHSBSP March 2013
3.8 Closing the episode 12
3.9 Higher-risk reports 13
3.10 National statistical returns 14
3.11 Women moving area or being repatriated to another screening programme 14
  3.11.1 AJ-BSH: Breast Screening History 14
  3.11.2 AJ-BSRS: Higher-Risk Surveillance 14
3.12 Configuration checklist 14

4. TRANSMITTING MESSAGES ON NHAIS 15
4.1 Summary of NHAIS records and reports 15

5. QUALITY ASSURANCE AND QUALITY CONTROL 16
5.1 Quality control 16
5.2 Accreditation 16
5.3 Audit 16
5.4 QA Visits 16

REFERENCES 17

APPENDIX 1: Referral to the NHSBSP for higher-risk screening 18
APPENDIX 2: Repatriation Proforma 19
APPENDIX 3: Leaflet for higher-risk women 21
ORGANISING THE SURVEILLANCE OF WOMEN AT HIGHER RISK OF BREAST CANCER

EXECUTIVE SUMMARY

The Cancer reform strategy, published in 2007, stipulated that the surveillance of women who have been identified as being at high risk of developing breast cancer (according to the criteria agreed by the Advisory Committee on Breast Cancer Screening) should be managed through the NHS Breast Screening Programme (NHSBSP). The aim was to standardise surveillance, to ensure that women are called at appropriate intervals, and to provide high quality screening and assessment.

Women who are currently under surveillance outside the NHSBSP, but who meet the criteria for higher risk breast screening, should be transferred to the NHSBSP. The local breast screening unit is responsible for inviting these women at appropriate intervals and for ensuring that imaging is performed to the required standards.

From April 2013, the NHS Commissioning Board (NHS CB) will commission breast screening services to a standard specification. This specification includes the surveillance of women at higher risk.
1. INTRODUCTION

1.1 Aims of the guidance

The NHS Breast Screening Programme (NHSBSP) is responsible for managing the imaging surveillance of women who are assessed as being at higher risk of developing breast cancer. Their elevated risk may be due to a genetic predisposition to the disease, a significant family history of breast cancer, or previous supradiaphragmatic radiotherapy (e.g. treatment for Hodgkin’s disease).

This guidance sets out the role of a breast screening programme in relation to women at greater than average risk of breast cancer, and describes the organisational arrangements that need to be in place, including appropriate use of the computer system, the National Breast Screening System (NBSS), and the National Health Applications and Infrastructure Services (NHAIS) system.

This guidance is based on staff experiences at three demonstration sites at which higher-risk screening was piloted. It is designed for use within the new organisational arrangements, under which responsibility for screening passes to Public Health England (PHE) and the NHS Commissioning Board (NHS CB). It should therefore be read in conjunction with NHSBSP publication number 53, Organising a breast screening programme.

1.2 Background

The Department of Health’s Cancer reform strategy (2007) recognised a high degree of local variability in protocols for the surveillance of women identified as being at elevated risk of developing breast cancer. The document recommended that all women identified as being at higher risk should be offered the opportunity to have their risk formally assessed and, where appropriate, to discuss their risk management options with a qualified medical professional, in accordance with guidelines published by the National Institute for Health and Clinical Excellence (NICE).

A subsequent publication, Improving outcomes: a strategy for cancer (2011) reported that the NHSBSP was in a position to manage the surveillance of women at higher risk across England and to ensure a consistent and high-quality service that conforms with rigorous national standards. The report concluded that surveillance with digital x-ray mammography and magnetic resonance imaging (MRI) should be provided to women at higher risk where appropriate.

In January 2012, the Advisory Committee on Breast Cancer Screening agreed a set of imaging protocols for a selected group of women at elevated risk of breast cancer. These have now been published as NHSBSP Publication no 74, Protocols for the surveillance of women at higher risk of developing breast cancer. Further recommendations on the surveillance of other groups of women at higher risk of the disease will be issued in due course.

Referrals into the NHSBSP should only be via:

- a genetics service
- a local family history service, situated in an oncology department
• an oncologist (in the case of women treated with supradiaphragmatic radiotherapy)

1.3 Provision of screening services in the new NHS

Launching in April 2013, PHE will be an executive agency of the Department of Health. Its chief executive will be accountable to the secretary of state for health. The national office of the NHS Cancer Screening Programmes and screening Quality Assurance (QA) teams will sit within PHE, under the Health and Wellbeing directorate. This directorate will be accountable for the development of a modern health and wellbeing service, supporting local authorities and the NHS to deliver improvements and reduce inequalities in the nation’s health. Two of the objectives of the new directorate are:

• to provide advice to commissioning bodies and QA teams about some NHS services, such as screening programmes
• to support and assure the quality of the screening programmes

A section 7a agreement between the secretary of state for health and the NHS CB will enable the NHS to fund national screening programmes from the ring-fenced public health budget. The NHS CB will be accountable for ensuring the delivery of improvements to the service against specific indicators.

1.4 Commissioning of cancer screening

The NHS CB will commission cancer screening to standard specifications agreed with the Department of Health. The specifications are based on current best practice, and will include higher-risk screening.

Public health expertise will be seconded to the NHS CB, and will sit with area teams who are responsible for the commissioning of public health programmes. Ten area teams will lead on specialised commissioning across England.

The QA teams within PHE will provide local authority directors of public health with information and expert advice on the performance of the programmes, allowing the latter to fulfil their obligation to scrutinise and challenge the screening services.

Each screening programme is expected to have in place arrangements for managing those women who live in their catchment area and who meet the eligibility criteria for higher-risk screening, according to the service specification. These women must be referred for higher-risk screening by a genetics service or an oncology service. Direct referrals from GPs will not be accepted. The referring service is responsible for ensuring that women are informed of the reason for their referral into the higher-risk screening programme.

Higher-risk screening necessitates arrangements with an MRI service that meets the relevant MRI technical standards. The MRI service could be housed in the same hospital as the NHSBSP screening service, or at a different hospital (for example, mammography screening could be provided by the responsible screening service and MRI provided by a single regional centre). Arrangements for MRI must be specified in local contracts for services.

The section below summarises some key learning points from the three demonstration sites. More information can be found in the publication Managing
women at higher risk of developing breast cancer in the NHSBSP: case studies from the demonstration sites.³

1.5 Some key messages from the higher-risk demonstration sites

1.5.1 Risk assessment

Women at higher risk should be referred via local genetics or oncology services. Risk assessment is the responsibility of the referrer, but all such assessments must be up-to-date, and aligned with current guidance. The referral document must clearly state the woman’s level of risk according to the current agreed protocol for higher-risk screening.

GPs must understand the referral pathways. Services should remember that many GPs have only one higher-risk patient on their list, and that they may therefore be unfamiliar with current guidance.

1.5.2 Planning higher-risk screening

Genetics and oncology services must be made aware of NHSBSP protocols. Only women who match the eligibility criteria should be entered into the higher-risk screening system. The whole team (including clinical, nursing, clerical, and MRI staff from breast screening, genetics and oncology services) should meet and plan the most appropriate patient pathways for the local facilities.

Initially, it may be preferable to limit the number of individuals in the higher-risk screening team. A named team member working in the screening programme must be identified to take overall responsibility for the coordination of activities. This should be someone with a thorough understanding of the service, who can answer questions, send reminders, and so on.

Effective communication will ensure coordination between the patient and genetics, oncology, breast screening, and local MRI services. Dedicating a member of the clerical staff to this task may be beneficial. He or she may require additional training to develop an understanding of both MRI and higher-risk cases and to devise an information sheet for frequently asked questions. The improvements in communication resulting from the creation of this post should prevent failed appointments.

Planning should include the production of letters and information for all stages of the pathway. National leaflets and letters will also be developed in due course.

A reporting schedule should be agreed for local audit purposes, e.g. an annual review of outcomes, and a quarterly review of screening activity (including identification of the women invited). A Crystal report should be made available to facilitate audit-related activities.

A separate KC return is being developed to allow national audit of women in the higher-risk screening programme. It is envisaged that this will be available from October 2013 for the reporting year 2011-2012. As with the existing KC62 audit, the new return must be run by the programme on a regular basis throughout the year to resolve queries and identify missing outcomes.
1.5.3 Delivering higher-risk screening

Screening should be offered only to women who are resident in, or registered within, the local screening service area. Other women should be repatriated to their local screening service.

Good quality mammograms should be available when MRI is being reported. Use of the Image Exchange Portal (IEP), or another suitable image sharing system, should be explored. All staff within the screening service will need some level of training in higher-risk screening. For example, reception staff should be aware that a new group of women is eligible for screening and that some of these women may be younger than participants in the routine screening programme.

There must be close liaison between MRI services and the NHSBSP screening centres to coordinate:

- release of reports to GPs
- second-look ultrasound
- MRI-guided biopsies
- discussion of cases at the multidisciplinary team (MDT) meeting

1.5.4 Audit and ‘Right Results’

It is important to ensure that the referring service maintains an up-to-date list of women referred, which can be checked against the records held in the NHSBSP. These crosschecks should be performed on a regular basis.

The screening team needs to establish a strategy for ensuring that mammography and MRI are performed within a suitable timeframe. Initially, it may be helpful to review all cases at the MDT’s screening meeting, to ensure that there are no outstanding issues.

If the MRI service is not at the same site as the mammography screening service, processes must be agreed between the two services for sending appointments and returning results in a timely manner. There should be a clear protocol outlining the lines of communication and responsibility between the two services.
2. REFERRAL OF APPROPRIATE WOMEN

Women who are eligible for the higher-risk programme must be referred appropriately, via a letter to the director of screening, or via a proforma (see, for example, Appendix 1).

The screening programme must establish links with their local genetics and oncology services. They must also ensure that only women in their catchment area are entered onto the NBSS system. If a women at elevated risk of breast cancer is found to be from another catchment area, the specialist service should be advised where to send her referral for higher-risk surveillance (an example repatriation proforma is available at Appendix 2). The director of screening is responsible for checking and accepting referrals.

Before she enters the higher-risk screening programme, a woman must have an opportunity to discuss the value of surveillance with a specialist. This conversation must cover the benefits and harms of screening.

If a woman meets the NHSBSP eligibility criteria for higher-risk screening but is already included in a surveillance programme within the Trust, a local decision will need to be taken about when to move her to the new system. Once she is transferred to the NHSBSP, she will be part of the screening programme, which is monitored and evaluated on an ongoing basis.

If a woman is under surveillance for breast cancer within an existing programme, but does not meet the eligibility criteria for NHSBSP higher-risk surveillance, a local decision must be taken on whether it is appropriate for her to continue in that programme. The woman must be included in this decision-making process. If screening is discontinued, she should be advised that she will be called for routine screening at the appropriate age, but that she should report any concerns or changes to her breasts to her GP.

2.1 Liaison with genetics services

Each screening office should develop links with genetics and oncology services, with the aim of ensuring that the correct women are referred and the right information about test outcomes is sent back to the referrer.

The status of some women may change once they are entered into the NHSBSP programme:

- some women will choose to have risk-reducing mastectomies and will therefore be ceased from the programme
- some women may decide not to continue with screening
- some women will experience a change in their risk level, which may mean that their imaging protocol needs to be adjusted.

These changes in a client’s history should be logged. Regular contact with genetics and oncology services to review and audit client lists should be agreed. A woman who has had a negative genetics test is not eligible for more intensive screening, but her family history may be assessed and may be found to give her equivalent risk status.
Any changes to the woman’s protocol on NBSS must be agreed with the director of screening.

2.2 Liaison with oncology services

Links will need to be established with the oncology or radiotherapy service to agree a pathway for the referral for women who have had supradiaphragmatic radiotherapy when under the age of 30. This pathway should also facilitate the exchange of important information between services.

The national office of the NHS Cancer Screening Programmes will shortly issue a separate protocol to cover the identification of women who meet the NHSBSP criteria, who have previously had supradiapragmatic radiotherapy, and who are currently in a surveillance programme outside of the NHSBSP.

Lists of affected women should be checked regularly against lists of referrals, and against women entered onto the NBSS system. A named lead, responsible for checking these lists, should be identified.

An annual audit must be conducted by the local programme to validate new referrals, and to check that all eligible women on oncology lists who wish to participate in the higher-risk screening programme have been invited.

2.3 Liaison with MRI services

Most of the woman who are referred for MRI will need imaging on an annual basis. A local system must be established to send the details of women who require MRI from the screening programme to the identified MRI services.

The MRI appointment can only be made once the mammography appointment has been arranged. Mammograms must be taken before the MRI scan is conducted, as it is important to ensure that x-ray images are available when MRI is performed. Mammography could be performed either in the screening programme or at the centre performing the MRI. In either case, all results must be entered onto the appropriate NBSS. This will allow consistent monitoring and reporting, correct allocation of Next Test Due date (NTD), and will ensure that messages are routinely sent to the NHAIS system (see section 4.0).\textsuperscript{12}

2.4 MDTs

Higher-risk women who require assessment should be discussed at the screening programme MDT before any action is taken.
Figure 1  Information flow
3. ENTERING WOMEN ONTO NBSS

Once a women’s referral has been checked by the director of screening, it can be entered onto NBSS. An NTD will then be allocated. **Referrals should not be entered more than 12 months before the test is due.** This reduces the risk of the woman’s history changing before her first higher-risk screening appointment.

If a woman is being transferred from another service, then her risk status should be confirmed before she is entered onto NBSS. An example referral proforma is shown in Appendix 1.

The steps below describe how to enter a women onto the system.

3.1 Set up

Before entering a woman onto NBSS, it is necessary to set up:

- the referrers, and referral services, in SACMS/SACMR. This function is used to record the referrers used by the screening programme. Once a code entry has been created, it may not be deleted as there may be references to it on the main client files. It can, however, be disabled to prevent further use on the system. The Maintain Referrers function is accessed from the menu option SAD, submenu option SACM, submenu option SACMR. The selection screen will be displayed.

- the equipment in SACMU/SACMN. This function is used to record the types of MRI equipment used by the screening programme. Once a code entry has been created, it may not be deleted as there may be references to it on the main client files. It can, however be disabled to prevent further use on the system. The MRI Equipment Maintenance function is accessed from menu option SAD, submenu option SACM, submenu option SACMN. The selection screen will be displayed.

3.2 Registration and selecting the protocol

The woman can now be registered on the system and a ‘PROTOCOL’ record can be created in TREE VIEW. This can only be done by staff who have Special Individual Privileges (SIP). Any deviation from the protocol should be logged in the comment field (for example, if a woman was able to undergo mammography but not MRI because she has a pacemaker fitted, this should be recorded). Once the PROTOCOL record has been set up, the NTD can be set.
Organising the surveillance of women at higher risk of breast cancer

10

Figure 2 Clinical record: PROTOCOL (highlighting the NTD)

3.3 Forms

Under the SASP2/SIF1/SIF2 Client Forms are the options MRI Screening Request Form, MRI Assessment Form, MRI Screening Form and Ultrasound Screening Form. The forms can be printed blank, part-filled, or filled. The MRI forms are based on NHSBSP Publication No 68, *Technical guidelines for Magnetic Resonance Imaging for the surveillance of women at higher risk of developing breast cancer.*

3.4 Creating an higher-risk episode on NBSS

A higher-risk episode is created by selecting H under Type. When H is selected, the window shows the client’s NTD date, Screening Protocol, and Age at NTD. Checkboxes for SCR-FILM (screening mammogram), SCR-MRI (screening MRI) and SCR-USS (screening ultrasound) indicate the empty records that will be created for this episode. The SCR-FILM and SCR-MRI boxes are filled in automatically, according to the client’s Screening Protocol and Age at NTD. However, it is possible to change the default procedures if they are not appropriate for the client, though in such cases it is necessary to make an entry under Deviation Reason.
Organising the surveillance of women at higher risk of breast cancer

### Figure 3  Non batch referral

#### 3.5 Letters for women undergoing higher-risk screening

Once a higher-risk episode has been created, each NBSS letter type (‘task’) can house standard and higher-risk versions of the standard letters. Where higher-risk letters have already been uploaded, NBSS automatically prints them when a higher-risk episode is flagged (type H). The standard letter will be printed if type H is not selected, or if there is no higher-risk version of the letter available. Most screening offices will only create higher-risk versions of invitation and discharge letters, but for the sake of flexibility, NBSS allows a higher-risk version of every letter type to be created.

The Print Letter option in Figure 2 can be used to generate an introductory letter, containing a summary of the client’s protocol. This option is only available if the office has already linked a Crystal Report to the letter task PROTO1. For convenience, an example letter, ProtocolLetterExample.rpt, is distributed with the release. This can be copied to a new filename, and customized according to the needs of each office.

Files housed under Professional Letter and Label Templates can include the referrer's name and address, and a protocol description copied from the PROTOCOL record associated with a higher-risk episode. The new embedded fields are not available under Legacy Letters or Labels because there were not enough letters in the alphabet to include the new fields.

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**NBSS March 2013**

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**Used when deviating from standard protocol e.g. where a woman cannot have MRI due to a pacemaker.**

**Only on 'H' (higher risk) episodes.**
3.6 Screening clinics

Screening mammogram appointments for higher-risk clients are booked into screening clinics in the usual way. Local arrangements between the screening office and MRI service determine how MRI appointments should be booked. As the MRI appointments have to be arranged at a specific time in the woman’s cycle, it is advisable to book this appointment first, and then the mammogram afterwards, to ensure that the mammographic x-ray images are available at the time of the MRI appointment (see section 2.3). Women requiring MRI need to be entered onto the Radiology Information System as well as the appropriate NBSS.

NBSS does not record MRI referrals or MRI appointments, but SIF1 can be used to print an MRI Screening Request Form that combines screening referral and results reporting. MRI services are expected to return screening results using this form. If the screening outcome is abnormal, this form will also be used to return assessment results.

3.7 Assessment

Unlike mammography screening, MRI screening and MRI assessment can be performed at the same time. The screening office must use SS/SIP to record the SCR-MRI (screening MRI) and then create an ASS-MRI (assessment MRI) to record the ‘abnormal’ result (where applicable).

Where MRI-guided biopsy is required, this may take place on another date and could even be performed at another Trust. Such appointments would be arranged by the MRI service, and their outcome reported back to the breast screening service. A histology record must then be created on NBSS, using the same format as that employed for other biopsies.

3.8 Closing the episode

SS/SIP is used to close a higher-risk NBR episode. NBSS gives a warning on episode closure if the procedures used to screen the woman differ from the procedures associated with her protocol. The system also automatically updates the woman's NTD when the episode is closed. A warning will be given if the woman's age at NTD is outside the range covered by her current protocol. This will prompt the user to move the woman to another protocol or to withdraw her from the higher-risk programme. If the woman is to switch to triennial screening, the office will withdraw her from the higher-risk programme.

A screening office can continue to recall a woman for higher-risk screening after the age of 50 by continuing to create H episodes for her.

NHAIS screening batches will include women over the age of 50 who are still being screened under the higher-risk programme. To cater for this, when the system creates an episode for a woman who is still on the higher-risk programme, Batch Completion will show a warning. The office will then check whether the woman is still at elevated risk and confirm whether she should be transferred to triennial screening. If the woman is still on the higher-risk programme, the office will close her batch episode with the new closure code, HR – On higher risk.

The screening office can stop a woman from appearing on the NTD List (a list of the higher-risk women due to be recalled for screening) by withdrawing her from the
Organising the surveillance of women at higher risk of breast cancer

higher-risk screening programme. If the office does not withdraw the woman, she will continue to appear in the NTD list.

3.9 Higher-risk reports

SPNTD, Print NTD List is a new menu option that allows users to print the NTD List. The function is analogous to SPRCL, Print Recall List, for short-term recall women. SPNTD appears in the SOM menu under the SP Prints Menu submenu. The report includes clients according to their NTD date and shows the higher-risk programme Comment from Figure 2, if present.

Figure 4 SPNTD list

SASP8, Missing MRI and USS Results is a new menu option to list missing MRI and ultrasound screening results. The existing function SASP5, Session Print - Missing Results Report, lists missing screening film results for higher-risk clients. SASP8 appears in the SOM menu under the SASP Session Print Requests submenu.

SIL, Print Lists can be used to print screening results for higher-risk referrers or referring services. The options RFR - Referrer Reports and RFL - Referrer Labels are available in SIL if SAMM parameter Referrer Sort is set to R - Referrer or S - Referring Service. The RFR referrer’s report is similar to the GPR report produced for GPs/GP practices.
3.10 National statistical returns

National reports have been developed for submission to the NHS Health and Social Care Information Centre. These will monitor on an annual basis the numbers of women going through the higher-risk screening programme and their outcomes.

3.11 Women moving area or being repatriated to another screening programme

The new screening office treats a transfer in the same way as a new referral.

3.11.1 AJ-BSH: Breast Screening History

When a woman moves into a new screening office area, as a result of moving to a new authority or GP practice, her breast screening history must be transferred to the new screening office. The analysis job on the NHAIS system for this transfer is AJBSH.

3.11.2 AJ-BSRS: Higher-Risk Surveillance

The AJ-BSRS function produces a report detailing those women who have been determined to be at higher risk of developing breast cancer, and who are due to be screened according to their higher-risk NTD date.

The old office can use SS Client Registration to record the woman’s new screening office. The NTD list will show the message ‘Transferred to X’ when it is run for the month she is due. The transferred woman will cease to appear in the list the following month.

An example proforma for women repatriated to another screening programme is shown in Appendix 2.

3.12 Configuration checklist

The following table lists the actions that a screening office needs to take in order to configure NBSS to record higher-risk screening.

<table>
<thead>
<tr>
<th>Action</th>
<th>Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change ‘referrer’ sort to ‘R’ or ‘S’ if referrer reports are required in SIL</td>
<td>SAMM</td>
</tr>
<tr>
<td>Set up referring service codes</td>
<td>SACMS</td>
</tr>
<tr>
<td>Set up referring clinician codes</td>
<td>SACMR</td>
</tr>
<tr>
<td>Assign specialty ‘AA’ to clinicians who authorise higher-risk screening</td>
<td>SACMP</td>
</tr>
<tr>
<td>Set up MRI service clinician codes with profession RL (for entering SCR-MRI records)</td>
<td>SACMP</td>
</tr>
<tr>
<td>Set up MRI service location codes (for entering SCR-MRI records)</td>
<td>SACML</td>
</tr>
<tr>
<td>Set up MRI equipment codes (for entering SCR-MRI records)</td>
<td>SACMN</td>
</tr>
<tr>
<td>Set up ultrasound equipment codes (for entering SCR-USS records)</td>
<td>SACMU</td>
</tr>
<tr>
<td>Create and link higher-risk versions of invitation and discharge letters</td>
<td>SLL</td>
</tr>
<tr>
<td>Create and link a higher-risk PROTO1 introductory letter, if required</td>
<td>SLL</td>
</tr>
</tbody>
</table>
4. TRANSMITTING MESSAGES ON NHAIS

Inbound NHAIS screening batches will include women over the age of 50 who are still being screened under the higher-risk programme.

The NBSS’s Batch Completion shows a warning when an episode is created for a woman who is still in the higher-risk programme. If a warning appears, the screening office must check whether the woman is still at an elevated risk of getting breast cancer, or whether she should be transferred to triennial screening (see section 3.8). If the woman is still on the higher-risk programme, the office can close her batch episode with new closure reason ‘HR – On higher risk’.

STO, Transmit Data, sends higher-risk notifications to NHAIS (data type 147). These messages tell NHAIS that a woman is on the higher-risk surveillance programme, so that NHAIS can inform her new screening office of her risk status if she moves to a new area. NBSS generates a SMAC entry to trigger a higher-risk notification when a woman’s Current Status or NTD date is changed (provided that she is already flagged as a participant in the higher-risk programme).

Higher-risk NBR episodes (type H) are sent to NHAIS via higher-risk (type H) batches, in the same way as other NBR episodes.

4.1 Summary of NHAIS records and reports

NHAIS is able to:

- record a woman’s risk status and higher-risk NTD date (on BH screen or via NBR transfer)
- record new H episodes, via NBR or on the SE screen
- report women whose higher-risk NTD date is due (AJ-BSRS)
- integrate higher-risk screening (normally up to the age of 50) with existing breast screening for 47-73 year olds
- transfer H status, higher-risk NTD and history to the new NHAIS system
- report H status for women moving to a new area and a new screening office
- include higher-risk status in reports, screens and downloads
- allow users to view a woman’s HR status, NTD and episodes via Open Exeter
5. QUALITY ASSURANCE AND QUALITY CONTROL

As higher-risk surveillance is part of the specification for screening, QA of this service will be included in routine QA activities.

NHSBSP publication number 68, Technical guidelines for Magnetic Resonance Imaging for the surveillance of women at higher risk of developing breast cancer, provides standards for equipment, recall rates, and professional conduct. Those providing MRI to the NHSBSP will be assessed against these standards when they begin to offer services, and will be reassessed thereafter on an annual basis.

5.1 Quality control

Standard procedures should be agreed as part of the local breast screening programme’s quality system. Routine audits should be performed to check that these procedures are followed and updated where appropriate. Routine procedures should be developed for:

- accepting referrals from oncology and genetics
- referring women to MRI services
- auditing records
- ensuring that results are transmitted efficiently, in a confidential manner, to the correct parties (the ‘right results’ process)
- annual reconciliation of women held on NBSS with records held by genetics services and oncology referrers

5.2 Accreditation

Each MRI service performing MRI screening should be meeting, or working towards achieving, the relevant technical standards. Commissioners of screening must ensure that MRI services are capable of meeting these standards. Quality Assurance Reference Centres (QARCs) must be provided with evidence from the local breast screening programmes that the MRI provider is able to ensure a high-quality service.

5.3 Audit

Annual audits should take place on the workload and outcomes of higher-risk screening. A national return (KC62 and KC63) is expected from each screening programme, although the numbers of higher-risk cases gathered for these returns are expected to be small. All services should undertake an additional annual audit of their Quality Management System (QMS) to ensure that the guidance governing ‘right results’ is met for higher-risk screening. This is particularly important as the pathways are likely to be complex and to cover multiple organisations.

5.4 QA Visits

All breast screening services are subject to formal triennial QA visits. The process and outcomes of the higher-risk screening programme will be reviewed during the standard visit. The ‘right results’ walkthrough conducted by the QA service will incorporate the entire screening process for both population-based screening and higher-risk surveillance.
REFERENCES


Appendix 1: Referral to the NHSBSP for higher-risk screening

<table>
<thead>
<tr>
<th>Section A</th>
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<tr>
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<tr>
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</thead>
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<tr>
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<td></td>
</tr>
<tr>
<td>Referee name: (i.e. alternative BSS service) Address:</td>
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Please indicate relevant family history members with age of diagnosis, relationship and attach copy of genetics letter indicating level of risk

<table>
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<th>Section B</th>
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<td>Age</td>
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<tr>
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</tr>
<tr>
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<td>MRI</td>
</tr>
<tr>
<td>40-49</td>
<td>MRI + mammography</td>
</tr>
<tr>
<td>50+</td>
<td>Mammography +/- MRI</td>
</tr>
<tr>
<td>TP53 ( Li–Fraumeni)</td>
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<tr>
<td>20-29</td>
<td>MRI</td>
</tr>
<tr>
<td>30-39</td>
<td>MRI</td>
</tr>
<tr>
<td>40-49</td>
<td>MRI + mammography</td>
</tr>
<tr>
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<td>Mammography +/- MRI</td>
</tr>
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<tr>
<td>A-T Heterozygote</td>
<td>40-49</td>
</tr>
<tr>
<td>50+</td>
<td>Mammography</td>
</tr>
<tr>
<td>Supradiaphragmatic radiotherapy irradiated below age 30</td>
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<tr>
<td>30-39</td>
<td>MRI</td>
</tr>
<tr>
<td>40-49</td>
<td>MRI +/- mammography</td>
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<tr>
<td>50+</td>
<td>Mammography +/- MRI</td>
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Signed: Role: Date: Print name

Section C  To be completed by BSS

Referral accepted for higher-risk screening  Referral rejected for higher-risk screening
Reason for rejection Form not completed  Does not meet criteria
Radiologist signature: Date (DD/MM/YYYY)
Organising the surveillance of women at higher risk of breast cancer

Appendix 2: Repatriation proforma

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<tr>
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<td>Mobile:</td>
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Referrer Name: (i.e. Name of Breast Screening Service/Trust referring woman)  
Address (with postcode):

Referee Name (i.e. Name of alternative Breast Screening Service referred to)  
Address (with postcode):

*Please indicate relevant family history members with age of diagnosis, relationship, and attach copy of genetics letter (most recent) indicating level of risk.*

Date higher-risk screening commenced for at the referring BSS:

Has the patient undergone screening compliant with NICE guidelines?: YES / NO

Which clinical genetics or oncology service originally referred the woman?
Please tick imaging required

<table>
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<th>Surveillance Protocol</th>
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<td>MRI</td>
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<tr>
<td></td>
<td>50+</td>
<td>Mammography +/- MRI</td>
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</table>

Signed  Role

Section C  - To be completed by alternative BSS woman referred to

Referral accepted for higher-risk screening  YES / NO

Date (DD/MM/YYYY)

Name of Director of Screening:

Signature of Director of Screening:

If 'no' please state reason for rejection:

Referring BSS informed?  YES / NO

Woman informed?  YES / NO

Who informed woman and on what date?
Appendix 3: Leaflet for higher-risk women

Breast screening for women with a higher risk of breast cancer

What does ‘higher risk’ mean?
You have been assessed by a specialist in genetics or oncology as being at more risk of developing breast cancer than women in the general population. Women at higher risk of breast cancer are offered breast screening at an earlier age than women from the general population. We call this surveillance screening.

How often will I be offered surveillance breast screening?
You will be offered screening more often than ‘routine’ screening, at least up until the age of 50. For some women, more frequent screening will continue. For others, they will then have routine breast screening, which is every three years.

You may be offered mammography (breast x-rays), MRI (magnetic resonance imaging), or possibly both. It will depend on your age, and the reason for your higher risk of breast cancer. The genetics or oncology specialist will already have let you know what type of screening you can expect to have.

For the general population, women get their first routine screening invitation between their 50th and 53rd birthdays. This age is gradually being lowered, so that women will have had their first screening invitation by their 50th birthday. It will take a while for this to happen everywhere in England.

How will my screening be done?
There are two types of screening technology used for women at higher risk:

Mammography – x-rays of the breasts. You can find out more about mammography in the booklet that comes with your screening invitation, called ‘NHS breast screening’. This booklet is sent to all women invited to NHS Breast Screening, and includes information about the benefits and disadvantages of screening. You can find the booklet on our website here http://www.cancerscreening.nhs.uk/breastscreen/publications/ia-02.html

MRI – magnetic resonance imaging. The MRI scanner is a large tube surrounded by a strong magnetic field, with a platform bed that slides into it. For breast screening, you will be asked to lie face down on the bed. There are cushioned holes for your breasts, and a special rest for your head. MRI involves taking many different images of the breast, which may take a while. During the process, you will be given a small injection in your arm. This contains a liquid which helps different areas of breast tissue to show up on the scans. The whole imaging session usually lasts between 30 minutes and an hour.

Before MRI is carried out, you will be asked some standard questions to ensure your safety. MRI is not suitable for everyone. The questions you are asked will allow screening staff to decide if it is right for you. MRI for breast screening is carried out at specialist centres, as both the equipment and screening staff must meet special specific screening standards.
Is screening suitable for everyone?
There may be certain circumstances that mean screening cannot be carried out. If you have any concerns about whether you can be screened, please contact your local breast screening unit.

What happens when I reach the standard screening age?
Most women will change to being screened every three years. Breast cancers are generally easier to spot in women aged 50 onwards, and they also tend to grow more slowly. This means that you do not need to be screened so often. However, some women will continue to have screening more often than every three years.

If you were previously screened using MRI, you may change to being screened using mammography. This is because mammography is better at detecting breast cancers in older breast tissue. Some women will have MRI as well as mammography. This will be decided by the clinician.

What happens when routine breast screening invitations stop?
Currently, women receive screening invitations up to the age of 70. This is gradually being extended to 73. Once you no longer receive invitations, you can still be screened every three years by booking your own appointments. Simply contact your local screening unit.

What if I notice any changes in my breasts?
No screening method can detect every cancer; and cancer can develop in between screening appointments. If you notice any unusual changes in your breasts, please speak to your GP as soon as possible. Do not wait for your next screening appointment.

Be Breast Aware
- You should know what is normal for you
- Know what changes to look for
- Look at and feel your breasts (in any way that is best for you)
- Tell your GP about any changes as soon as possible
- Go for breast screening when invited (if you decide you want to be screened)

You can read or download our leaflet ‘Be Breast Aware’ at:
http://www.cancerscreening.nhs.uk/breastscreen/publications/be-breast-aware.html

More information:
For more information about NHS Breast Screening, visit our website at:
www.cancerscreening.nhs.uk/breast

You can find out more about breast cancer risks, including family history and genetic risk, on the Cancer Research UK website at:
http://www.cancerhelp.org.uk/type/breast-cancer/about/risks/definite-breast-cancer-risks

This leaflet is available to download in large print at:
www.cancerscreening.nhs.uk/breastscreen/higher-risk.html