NHS
Greater Manchester
Cancer Alliance

Personalised Stratified Follow up for

Breast Cancers – Standard Operating Procedure

Document Control

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WHICH PROGRAMME / PATHWAY BOARD / GROUP HAS PRODUCED THIS DOCUMENT (IF APPLICABLE)	Breast Pathway Board Breast Nursing and AHP Forum
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HAS AN EQUALITY IMPACT ASSESSMENT BEEN COMPLETED?	No – NA for this document
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1. Purpose

This document provides local guidance for Personalised Stratified Follow Up (PSFU) within the Greater Manchester (GM) and East Cheshire breast cancer pathway.

It applies to all Greater Manchester local units and specialist centres involved in the treatment of patients with a breast cancer. This model of care is aligned with the NHS Long Term Plan for Cancer, NHSE Personalised Care for Cancer Initiative, Phase 3 COVID Recovery Planning, the GM Cancer Plan and NHS 22/23 and 23/24 priorities and operational planning guidance.

2. Introduction

The overall aim of PSFU is to:

- Improve patient experience and quality of life following treatment for breast cancer.
- Ensure the needs of breast cancer patients are met in a more timely manner and they are better informed about breast cancer, treatments, signs of recurrence and any longer-term effects.
- Ensure there is an increased focus on health and wellbeing and individuals are supported to make healthier lifestyle choices and optimise their health and wellbeing.
- Ensure breast cancer services are more efficient and cost-effective by reducing frequency of hospital-based outpatient appointments.

3. PSFU Process

PSFU describes the delivery of personalised ongoing care for cancer patients that supports them towards self-management based on individual risk stratification, needs and preferences rather than the traditional clinic based follow up.

To self-care effectively, patients must have good knowledge, skills and confidence about their condition.

All newly diagnosed breast cancer patients should receive information about their diagnosis, treatment options and subsequent follow-up pathway at the end of treatment, including PSFU. This will include a description of the re-entry process, the support, and tools available to enable self-management and explanation of the ongoing surveillance and screening that will occur during follow up period of 5 years.

All patients will be transferred onto the jointly agreed follow-up pathway at the end of treatment following discussion between the clinician and patient.

To ensure patients are fully informed about their PSFU decision, they should be given specific written information about PSFU for breast cancer. All patients should be given

time to decide if they need to reflect on the information and reassured that they can convert to traditional clinic follow up at any time if they so wish.

Patients should be reassured that they will receive the following to support them:

- Tumour specific written information
- Treatment Summary (TS) should be given/sent after treatment is completed. The TS should be sent to the patient and GP and includes details of the treatment, treatment outcome, symptoms of side effects or recurrence and contact details for the breast Clinical Nurse Specialist (CNS). The most up to date version of the breast cancer Treatment Summary can be found on the Greater Manchester Cancer Alliance website: https://gmcancer.org.uk/cancer-pathway-boards/breast/
- PSFU information leaflet
- Contact details for the CNS
- Reminders/ appointments for routine follow up tests, if appropriate.
- Confirmation of the outcome of those tests
- A discharge letter at the end of the traditional follow up period for their cancer type.

4. Exclusion Criteria

All patients following treatment for breast cancer should be stratified to PSFU unless they meet the following exclusion criteria:

a. Patients who are assessed to lack capacity to self-manage.
b. Patients who are under active treatment for metastatic disease (excluding positive lymph nodes).
c. Patients who are on primary endocrine treatment.

5. Patient Pathway/ Process (see Appendix 1)

The patient is fully aware and actively involved in decisions throughout their cancer care pathway; shared decision making with the CNS is an underlying principle of care. The key components of PSFU for patients who have completed their primary treatment for breast cancer include:

a) CNS introduce patients to PSFU early in the pathway ensuring they are fully informed of how they may be followed up after their initial treatment ends.
b) All patients are invited to an end of treatment appointment carried out by a CNS. The treatment summary document is discussed in full with the patient.
c) Patients are empowered to self-manage with information about red flag signs and symptoms to look out for, likely short and long – term effects of treatment,

and tailored support to maintain health and wellbeing in the long term. This is supported by ABCDiagnosis sites of recurrence infographics.

d) The CNS initiates a personalised care and support plan based on a holistic needs' assessment ensuring any ongoing or unmet needs are identified and discussed. This may be started by cancer care coordinators/navigators who can discuss non-clinical concerns.
e) The CNS proactively promotes and encourages health and wellbeing including events, information, and support along with referrals to health, social care, community-based services based on expressed patient needs (as part of personalised care and support plan).
f) If patients highlight symptomatic concerns within the treatment summary appointment, they will be discussed with the patient's allocated consultant and primary Multi-Disciplinary-Team prior to any investigations being requested.
g) The CNS triages and arranges rapid re-access to a consultant clinic for new symptoms or suspected recurrence. Patients have ongoing access to advice and support online and over the telephone as required.
h) The CNS maintains the robust remote monitoring IT system PSFU within InfoFlex/HIVE , from the point of diagnosis and schedules tests such as mammograms, bone density scans and required endocrine blood tests. All failure to attend for tests are actioned as per flowchart (see Appendix 1).
i) The administrator maintains the scheduling of tests ensuring all remotely monitored patients are booked into the relevant virtual clinic to schedule tests and ensures all patients receive notification of tests. The administrator monitors the attendance of tests and ensures the test results of all remotely monitored patients are reviewed by the breast care nurse.
j) Treatment summary documents, patient personalised care and support plans and test results are shared with both the patient and GP.
k) If patients are stratified to PSFU future mammograms are scheduled.
l) All CNSs must complete robust Ionising radiation (medical exposure) regulations (IRMER) training in order to safely request routine mammograms, breast MRIs and DEXA scans that are medically prescribed in MDT. (see Appendix 3).

Following the treatment summary appointment, patients are assessed about suitability to continue PSFU pathway, if not deemed suitable they are scheduled for ongoing routine follow up in a consultant clinic.

6. Patients with a personal diagnosis of breast cancer who are at high risk of developing future breast cancer, including patients with germline pathogenic variants

Patients with a personal diagnosis of breast cancer who have been identified:

- to have a proven germline pathogenic variant in BRCA1, BRCA2, TP53, A-T homozygotes, PALB2, PTEN, STK11 or CDH1 or any other high risk gene variant based on testing in a clinically accredited laboratory, **or**
- as being high at risk of developing a future breast cancer

will be screened according to national guidelines.

6.1. Roles and responsibilities for high risk patients:

a) The CNS completing the treatment summary will check if patient has been identified as having a germline pathogenic variant or has been identified as at high risk of developing future breast cancer by medical staff.

b) If patient qualifies for testing via Greater Manchester breast cancer genetic testing pathway (which is aligned with the eligibility criteria of the National Genomic Test Directory), and testing has not been completed earlier in the patient pathway, the CNS will discuss, complete consent with patient and arrange for blood sample to be taken if patient accepts genetic test (https://gmcancer.org.uk/cancer-pathway-boards/breast/genetic-testing/)

c) All patients that test positive for a germline pathogenic variant must be referred to the regional clinical genetics team (St Mary's Hospital MFT) by breast surgeon.

d) *If* a patient is identified as having a germline pathogenic variant ***(EXCEPT ATM***, ***CHEK 2, Rad 53C and Rad 51D*)*,*** and has not had bilateral mastectomy, ***surgical consultant to refer to VHRNBSP (Very High Risk National Breast Screening Programme) (see Appendix 4&5).*** All other monitoring will remain under the PFSU team (e.g. DEXA, bloods)

e) If ***a patient is identified as having a germline pathogenic*** variant in ATM, CHEK 2, Rad 53C or Rad 51D, ***and has not had bilateral mastectomy,*** surgical consultant to document that they have been classified as eligible for extended mammograms and breast care nurse will request yearly mammograms up to 70 years.

f) If patient has a family history of breast cancer, but is not found to have a germline pathogenic variant or doesn't qualify for genetic testing, surgeon to clarify if patient is eligible for extended mammograms (see section 6.2 and *A*ppendix 6) and document in patient notes.

g) If patients are identified as eligible for extended mammograms the specialist nurse completing their treatment summary appointment will ***schedule*** yearly

mammograms 10 years via InfoFlex/HIVE. After 10 years this will be reassessed, and further yearly mammograms requested, as required, up to the age of 70.

h) All patients, regardless of genetic test result and including those who have had bilateral mastectomy, will be seen for a treatment summary appointment and will be stratified to self-supported management, or consultant follow up, for 5 years.

6.2. Criteria for extending annual surveillance mammograms in patients without a germline pathogenic variant

The criteria for extending annual mammographic follow up age to 69 years old, after a previous diagnosis of breast cancer, in patients without a germline pathogenic variant are:

a) The patient and one first degree relative have been diagnosed with breast cancer with an average (mean) age of less than 50.
b) The patient and two additional relatives (on the same side of the family) have been diagnosed with breast cancer with an average (mean) age (of all three) less than 60 years.*

*One of the members must be a first degree the other a first or second degree. Unless the family history is from the paternal line when it can be two second degree relatives

7. Follow up mammograms/Bone density (DEXA) Scans

The process for follow-up investigations:

a) Patients are invited to attend for routine surveillance mammographic +/- MRI +/- bone density surveillance by mail or through the patient portal of InfoFlex/HIVE, if available at the treating provider and activated by the patient.
b) CNS / pathway navigator checks the results.
c) If reported as normal, a standard letter is sent to the patient.
d) PSFU within InfoFlex/HIVE is updated (including scheduling next review).
e) Abnormal results will be recalled by radiology. Any further investigations e.g. imaging and biopsies will be discussed at the MDT. Results will be actioned from MDT as per local MDT protocol.
f) Patients will receive results of investigations, arising from abnormalities of surveillance imaging, in a format appropriate to the severity of the results and patients' individual needs e.g. face-to-face consultant clinic, telephone clinic or in writing.

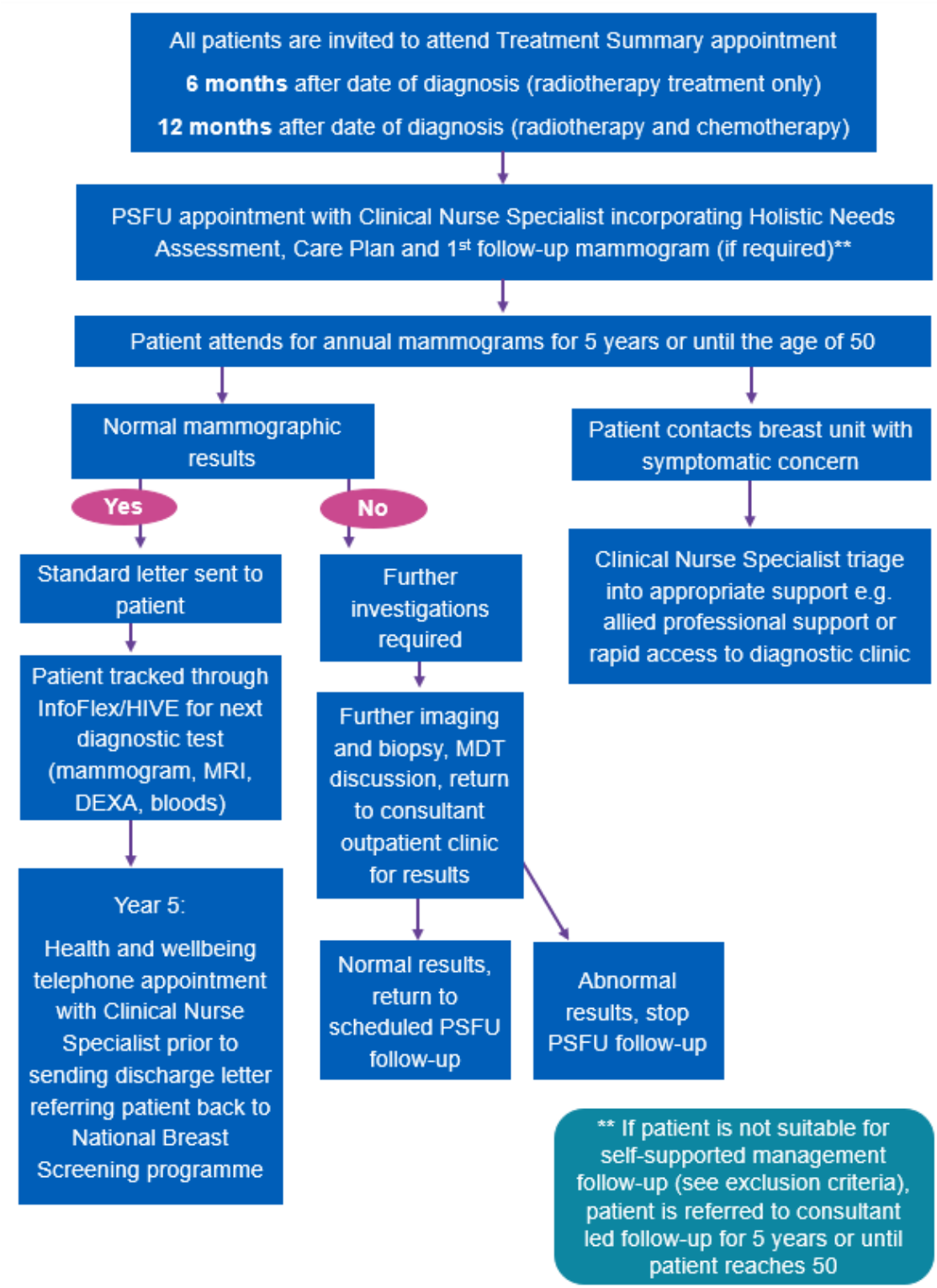
8. Re-accessing the breast specialist team as required

a) All patients and their GPs will be aware of how to access the breast care team if concerns arise within the surveillance period. Re-access routes and contact numbers are provided on the Treatment Summary document.
b) Safe, robust and sustainable open access systems will be in place, with the breast care nursing team acting as the initial contact point.
c) To deliver a robust rapid re-entry pathway, it is essential to ensure there is appointment capacity with the existing breast and oncology clinics.
d) If a patient contacts the breast care team, the CNS will triage the concern into the most appropriate team:
    - If a patient contacts the breast care team with side effects from treatment, the CNS will triage the patient's concerns to allied professional support services where appropriate (e.g. physiotherapy, lymphoedema) or to the patient's consultant surgeon or oncologist, as required.
    - If a patient contacts the breast care team with new breast symptoms, or there is a suspected recurrence, the CNS will request an outpatient consultant appointment or a triple assessment clinic appointment (as per local protocol).

9. Responsibilities and Governance

a) It is the responsibility of the consultant surgeon, CNS and MDT to identify and offer PSFU to appropriate patients. Where a patient has had treatment at a number of different Trusts, follow up will be carried out by the Trust as detailed in the end of treatment responsibilities mapping document. The Trust responsible for the follow up is also responsible for the end of treatment appointment and written summary.
b) If patients or GPs contact the breast care team with symptoms of possible recurrence, they must be offered an appointment for a clinical assessment within the faster diagnostic standard guidance.
c) Appropriate cross cover arrangements for the breast CNSs must be in place to ensure patient contacts are not unduly delayed due to planned/unplanned leave.
d) The responsibility for the installation and security of the digital system, and ensuring its suitability, lies with the Caldicott Guardian, Cancer Lead Clinician and Cancer Lead Nurse of the Provider.
e) It is the responsibility of the breast care team to enrol patients who agree to PSFU onto a secure digital system.
f) Updating the system, routine test requests and patient letters can be delegated to appropriately trained members of the breast care team.
g) The system must contain in-built alerts for routine tests/letters to ensure patients follow up is not missed.
h) It is the responsibility of the recipient of the alerts to action and follow up the alerts.

Appendix 1.0: Breast Patient Stratified Pathway



Appendix 2.0: Ionising Radiation Regulations

https://www.bir.org.uk/media-centre/position-statements-and-responses/guidance-for-non-medical-referrers-to-radiology.aspx

Appendix 3.0: DEXA Scan testing

Baseline DEXA result	Plan for patients on 5yrs Endocrine Therapy	Plan for patients on 10yrs Endocrine Therapy
Normal	No further DEXA required. Requires Vitamin D	Repeat DEXA at year 5 Requires Vitamin D
Osteopenia T-score between 0 and – 2.0	Repeat DEXA in 2yrs. Requires Vitamin D and calcium.	Repeat DEXA in 2yrs. Requires Vitamin D.
Osteopenia T-score between -2.0 and -2.5	Advise bisphosphonate treatment. Requires Vitamin D Repeat DEXA in 2yrs.	Advise bisphosphonate treatment. Requires Vitamin D. Repeat DEXA in 2yrs.
Established Osteoporosis T-score below -2.5	Requires bisphosphonate treatment. Requires Vitamin D. Repeat DEXA in 2yrs	Requires bisphosphonate treatment. Requires Vitamin D. Repeat DEXA in 2yrs.
Receiving Adjuvant IV bisphosphates	No DEXA scan required	DEXA scan at year 5 See above depending on results

Appendix 4.0: Referral to National Breast Screening Programme for High Risk Patients

Breast screening: very high risk women surveillance protocols - GOV.UK

Appendix 5.0: Contact information for Greater Manchester Breast Services

Find breast screening services - NHS

Appendix 6.0: Criteria for extending annual mammographic follow-up age up to 69 years old after a previous diagnosis of breast cancer for patients without a pathogenic variant

1. The patient and one first degree relative have been diagnosed with breast cancer with an average (mean) age of less than 50.
2. The patient and two additional relatives (on the same side of the family) have been diagnosed with breast cancer with an average (mean) age (of all three) less than 60 years.*

   *One of the family members must be a first degree relative, the other a first or second degree. If the family history is from the paternal line, it can be two second degree relatives.

If patient doesn't know exact age of diagnosis, just the decade. E.g. 'mum was in her 50s'. Then we advise using the mid-decade age for calculating the average e.g. '55' for the example above.

Reference: the paragraph in NICE guidelines 1.4.4. and the NICE guidance algorithm. Pragmatically, for our services, this can be implemented without the need to refer to a specialist genetics/tertiary care clinic. If no other criteria for referral to genetics or in house (surgeon led) genomics panel testing is met. As the current genetics wait is 52 weeks, it is not currently practical to comply with the NICE recommendation of a genetics referral for all in this cohort.

The level of proof required for the extended mammograms is a verbal patient report from their recollection of their family history.

These patients will be labelled "eligible for extended mammography" if they are assessed in a surgical breast unit and not "high-risk to avoid confusion with a formal assessment of "high-risk" from tertiary care. Patient will need additional assessment to be considered for contralateral risk reducing surgery.

A patient who has tested negative for the standard breast genomics panel is still eligible for the extended mammograms if the above FH criteria is met.

Appendix 7.0: Follow up for patients with pathogenic variant / eligible for extended mammograms patient that have NOT had bilateral mastectomies