West Midlands Cancer Alliance Early and Locally Advanced Breast Cancer Personalised Stratified Follow Up (PSFU) Pathway Guidelines

Report by : Sandra Smith

Date : November 2025

EAG name	Personalised Care: Breast EAG (Personalised Stratified Follow Up (PSFU)	
Document Title	West Midlands Cancer Alliance Early and Locally Advanced Breast Cancer Personalised Stratified Follow Up (PSFU) Pathway Guidelines	
Published date	January 2026	
Document Purpose	To provide clinical guidance and support to Trust Breast Cancer Clinical Teams for the management Breast cancer patients following diagnosis or completing treatment as appropriate. To support the delivery of the national priorities and objectives for cancer.	
Authors	Sandra Smith, WMCA Programme Manager, EAG Raghavan Vidya, Breast Lead, EAG Jayne Kanwar JK (CNS) Helen Bradlow (CNS) Martin Sintler Consultant Breast Surgeon EAG members/Stakeholders	
Review Date:	January 2028	
Approval Signatures:	Vidya Raghavan **Chair EAG** 	**Clinical Director, West Midlands Cancer Alliance** 

Approved by

This document must be approved by the following people:

Governance	Description	Who	Date
WMCA Breast EAG	Approved	Breast EAG Chair	24 November 2025
WMCA Clinical Cabinet	Approved	Chair	14 January 2026

The controlled copy of this document is maintained by West Midlands Cancer Alliance. Any copies of this document held outside of that area, in whatever format (e.g. paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

Document name:	Terms of reference for West Midlands Cancer Alliance Expert Advisory Groups		
Version	**Date**	**Amendment**	**By**
V0.1	April 2025	• Various changes discussed during initial meeting with CNS	Jayne Kanwar JK (CNS)/ Sandra Smith (SSm)
V0.2	May 2025	• Various changes discussed during group meeting	SSm/Helen Bradlow (CNS)/JK
V0.3	June 2025	Various changes discussed during group meeting	SSm/Helen Bradlow (CNS)/JK
V0.4	July 2025	• Updated	Martin Sintler
V0.5	August 2025	• Updated	SSm
V0.6	August 2025	• EAG members/Stakeholders	SSm/JK CNS
V0.7	October 2025	• Formatting /amendments	SSm/ CNS
V0.8	November 2025	Updated amendments	SSm/ Breast EAG /
V0.9	November 2025	Updated amendments	Primary Care EAG Membership

Table of Contents

Introduction and Purpose of this guideline

This document outlines best practice recommendations for the personalised stratified follow-up for individuals diagnosed with breast cancer. It encompasses both primary and secondary care settings and is specifically designed for patients who have completed treatment for early or locally advanced breast cancer.

Developed to complement the broader Personalised Stratified Follow-Up (PSFU) Guidelines for People with a Cancer Diagnosis, available via the West Midlands Cancer Alliance (WMCA) website, this guidance serves as a practical and adaptable resource for NHS Trusts, Integrated Care Boards (ICBs), and members of the breast multidisciplinary team (MDT). It supports the implementation of the PSFU pathway tailored to the needs of breast cancer patients diagnosed with early and locally advanced breast cancer.

With rising incidence and improved survival rates, PSFU models have evolved to prioritise quality of life, patient empowerment, and system sustainability. These models not only enhance patient experience but also help address capacity challenges within the NHS.

The NHS Long Term Plan identifies the implementation of PSFU pathways across all clinically appropriate cancers as a strategic priority. This includes improving access to personalised care through ongoing holistic needs assessments, care planning, and timely support. PSFU also contributes to reducing outpatient activity, thereby freeing up clinical capacity to focus on timely treatment, improved outcomes, and operational efficiency, particularly in relation to the 62-day referral-to-treatment standard.

Crucially, PSFU should be introduced and discussed at the point of diagnosis. Early preparation helps patients transition smoothly to life beyond active treatment, reinforcing the principle that cancer care extends beyond disease management to encompass the individual's physical, emotional, and psychological wellbeing. Many patients may experience long-term effects after their diagnosis or treatment, which can arise shortly after treatment or years later, making personalised, proactive follow-up essential.

1. Context

Breast Cancer Incidence

PSFU for breast cancer has been designed to enable post-treatment care based on individual risk profiles, clinical needs, and patient preferences and address the increase in demand for cancer services. This model is particularly relevant given the high and rising incidence of breast cancer in the UK, where approximately 56,800 new cases are

diagnosed annually—more than 150 each day. Breast cancer remains the most common cancer among UK females, while it is relatively rare in males, with around 390 cases per year. Incidence is notably highest in individuals aged 90 and above, and nearly a quarter of diagnoses occur in those aged 75 and older. Since the early 1990s, rates have increased by 18%, with a projected rise to nearly 69,900 cases annually by 2040. Socioeconomic and ethnic disparities further complicate the landscape: incidence is 14% lower among women in the most deprived areas, yet around 3,000 cases annually are linked to lower deprivation. Ethnic variation is also significant, with lower rates observed in Asian, black, and mixed-ethnicity women compared to white women, although black women face a disproportionately higher risk of aggressive triple-negative breast cancers. PSFU aims to address these complexities by moving away from a one-size-fits-all model, ensuring that follow-up care is both equitable and responsive to the diverse needs of breast cancer survivors.

See publications for more information.
Cancer Incidence by Broad Ethnic Group(link is external)
Breast cancer statistics | Cancer Research UK
Breast Cancer Risk: Disparities That Affect Black Women

Breast Cancer Personalised Stratified Follow-Up (PSFU)

To help address growing outpatient capacity challenges, the implementation of PSFU has been identified as a strategic priority within the NHS Long Term Plan. PSFU enables the safe and effective reallocation of routine follow-up appointments, allowing clinical teams to focus resources on new referrals and individuals with more complex needs. This model has already been successfully embedded across several cancer pathways, including prostate, colorectal, endometrial, and breast cancer and is now considered standard practice.

NHS England has advised that Integrated Care Boards (ICBs), commissioners, and Cancer Alliances work collaboratively to plan and deliver PSFU as part of routine service provision with a focus on identified priority pathways, this includes the breast pathway. National guidance suggests that up to **1 million outpatient slots** could be repurposed through widespread PSFU adoption, helping to optimise clinical capacity while maintaining high-quality care.

2. Implementing the Breast Cancer Personalised Stratified Follow Up Pathway

For patients with breast cancer entering a PSFU pathway, the following key components must be in place to ensure safety, support, and empowerment:

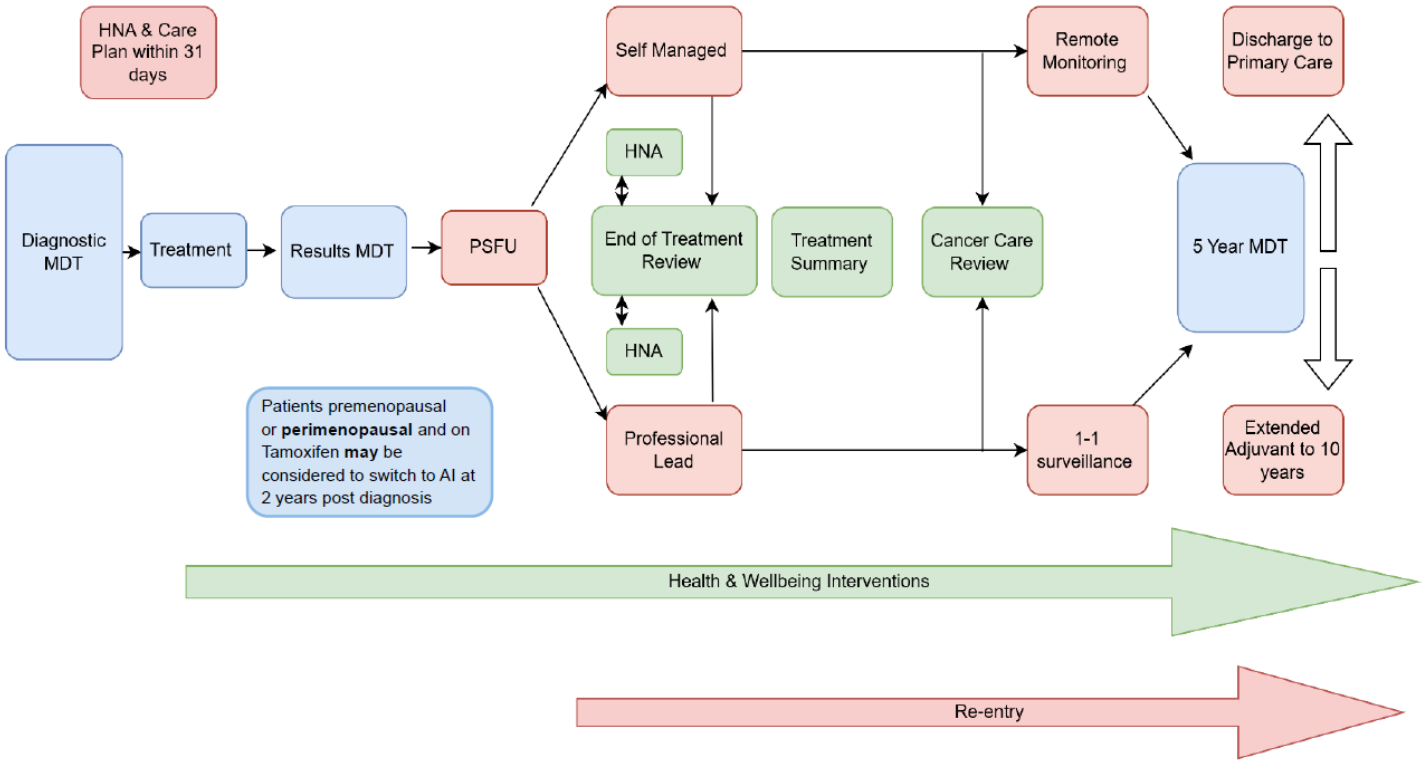
These guidelines recommend the following key components to ensure safe, effective, and person-centred follow-up care for individuals diagnosed with early and locally advanced breast cancer:

- **Holistic Needs Assessment (HNA) and Care Planning**
  All patients should receive a comprehensive HNA and personalised care and support plan (PCSP). This should be accompanied by tailored information and access to appropriate health and wellbeing support services to empower patients to live actively and well following the completion of their cancer treatment.
- All patients should receive an End of Treatment Summary (EoTs) prior to transitioning onto a PSFU pathway. These tools ensure that care remains tailored to individual needs and supports patients in taking an active role in their recovery and ongoing health.
- **Robust and Accessible Follow-Up System**
  A safe, reliable, and user-friendly system must be in place to support PSFU. This should include appropriate surveillance protocols with timely reporting and recall mechanisms to ensure a positive and reassuring patient experience, including details of any required scans or tests and how these will be arranged.
- **Support for Self-Management**
  Patients should be provided with additional information and signposting to relevant services and resources that enable them to self-manage and maintain wellbeing with and beyond cancer. Personalised care and support planning, including resources for self-management to promote long-term health and wellbeing.
- **Clear Communication Channels**.
  Patients must receive both verbal and written guidance detailing when and how to seek help, including specific contact points within the breast care team for any future concerns. Patients should receive clear written information about signs and symptoms that may indicate recurrence or progression of disease. They should also receive guidance on surveillance, including details of any required scans or tests and how these will be arranged.

- **Treatment Summary and Continuity of Care**
  A Treatment Summary/EoTs should be shared with the patient, their GP, and the hospital team. This document should outline the treatment received and highlight any ongoing concerns or potential consequences of disease or treatment. It should support Primary Care in conducting a Cancer Care Review and ensuring continuity of care.
- **Open Access to Specialist Services**
  Timely, safe, and appropriate open access back into specialist breast care services must be available for patients who require further assessment or support. This must include rapid access to the breast cancer team, including telephone advice and clinical support for any concerns.
- All patients moved onto a Patient Stratified Follow Up (PSFU) should be logged and tracked on the organisations IT system.

3. Recommended PSFU Breast Cancer Pathway

Personalised Stratified Follow-up Pathway for Early and Locally Advanced Breast Cancer Patient



4. Workforce Planning

Workforce planning is essential to the implementation and delivery of a successful PSFU pathway.

Departments planning to implement PSFU should undertake a workforce planning exercise to ensure successful delivery of this pathway. This is to ensure that patients can be fully supported remotely and have ease of access to advice or to be seen when required. Breast cancer care navigators and cancer care coordinators can help to manage and organise the pathway to release and realign clinical time of clinical nurse specialists (CNS) to areas of priority.

Breast cancer CNSs routinely carry out HNA and end of treatment reviews for all patients; however, dedicated time and resources must be made available for CNSs to support patients who choose to pursue a PSFU pathway.

For personalised care templates (see appendice1) for HNAs and end of treatment review examples. In the future, some of this work may also be supported with automation.

Personalised Care and Support Planning

A HNA and a personalised care and support plan (PCSP) that will be completed at both diagnosis and at the end of active treatment, forms an integral part of the routine assessment process. (see appendix 1 & 2)

Following treatment, the MDT will determine the most appropriate follow-up pathway, either clinician or self-managed, based on clinical criteria outlined in section 8.

All patients diagnosed, with early or locally advanced breast cancer will receive comprehensive information regarding their diagnosis, treatment options, and the recommended follow-up pathway. This will include:

- An explanation of the re-entry process should symptoms or concerns arise.
- Details of available support services and self-management tools.
- A clear outline of surveillance and screening protocols, including annual mammography, throughout the five-year follow-up period.

5. End of Treatment and Follow-up

At the end of treatment (chemotherapy, surgery, radiotherapy, immunotherapy), all patients will receive a single end of treatment review with a member of the cancer team. It is recommended

that this appointment is scheduled at around 3-6 months to coincide with the end of treatment HNA. At this appointment the patient will receive personalised information about their planned follow-up and surveillance. A Treatment Summary will be generated following this meeting and be sent to the patient, their GP and held within the individual's hospital notes.

During this appointment, it is expected that the patient will be provided with verbal information, and have access to either on-line or printed information, regarding the following, this will include:

- Possible treatment toxicities/consequences of disease and/or treatment:
- A personal plan for future mammographic surveillance, bone density scans and bisphosphonate need.
- an explanation of the process for receiving appointments for mammographic surveillance and results.
- Breast awareness and symptoms that require re-access to the Specialist Team
- Key symptoms that require re-access to the specialist team.
- Contact name, phone number and working hours of the breast specialist team.
- Exercise, nutrition and weight management.
- Health and Wellbeing support and how to access relevant services.
- Any local self-help groups and useful phone numbers (e.g. Macmillan Cancer Support, Breast Cancer Care, Maggies, Breast Cancer Now, Penny Brohn).

At the conclusion of the end of treatment review, patients will be transferred onto either the professionally led or self-managed pathway.

The Breast MDT will decide the frequency and responsibility of follow ups on the professional led pathway.

6. Identifying patients suitable for PSFU

- Identify patients who may be suitable for self-managed follow up is considered taking into account (e.g. the patients understanding and capacity, including frailty and care needs and ability of the care team to support PSFU).
- Where possible discuss and document in the MDT, if the patient is suitable for PSFU
- Patients meeting the criteria as per this guideline shall have an informed discussion in clinic to determine best pathway for the patient including shared decision making.

Eligibility for Entry onto Self-Managed Follow Up Pathway

All early and locally advanced breast cancer patients who have completed treatment will be considered for entry onto the self-managed follow up pathway. This empowers individuals with the knowledge and skills to self-manage their condition. They do not receive any further outpatient appointments (OPA) unless further investigations or support is required.

Some patients may not be appropriate for self-managed care:
Patients not suitable for self-managed care include the following;

- The patient is unable to manage self-manage due to physical, cognitive, communication or emotional reasons.
- Patients with co- morbidities that may require closer monitoring.
- Patients who require reconstruction surgery; (these patients may be eligible for PIFU as well as oncoplastic monitoring)
- Following the shared decision, there is mutual agreement not to enter the self-managed follow up pathway.
- Patients deemed inappropriate by the MDT because of oncological concerns or non-engagement.

If deemed unsuitable for the self-managed pathway then a professional follow-up pathway is prescribed, in which individuals continue to have face to face, phone, or email contact with the specialist team.

For individuals participating in clinical trials, follow-up will be determined by the clinical trial protocol. All individuals taking part in trials will still access and benefit from the end of treatment review and health and wellbeing interventions.

Patients who are gene carriers can enter the self-managed follow up pathway. They will require individualised information and support, with access to the breast team as required. They will be transferred to the Family History team for further imaging if under 60 on completion of their follow up.

Patients with a significant family history (but who are not gene carriers) who have developed cancer can enter the self-managed follow up pathway and receive the standard 5 year follow-up, or until they reach the age of 50. They should then be referred to the family history team (not all sites have a family history team) if no further surveillance or treatment is required.

Patients will have their suitability for entering the self-managed follow-up pathway considered at the MDT at which their results are discussed. Those who are not eligible will be recorded as not appropriate for self- managed follow-up on their MDT proforma within the cancer IT system and will continue on the professional led follow-up pathway at a frequency determined by the MDT. A copy will be placed in the patient's notes as appropriate.

7. Documentation for PSFU

- Written information should be provided to the patient about their diagnosis, treatment and PSFU
- The outcome of the PSFU discussion should be documented in the patient medical record and on the IT system
- Where possible, the patient should be moved to a PSFU pathway and provided with written information on what the route of contact is, if there are any concerns during the designated follow up period, as per current national guidance.
- Where possible, patients should be seen by a breast cancer CNS prior to entering PSFU to provide education on self-monitoring and to undertake the holistic needs assessment. This also provides a named point of contact, if there is a concern.
- Advice should be given on how often to check for signs and symptoms.
- A separate letter documenting the PSFU should be forwarded to the patient's GP with the contact details and length of follow-up. This can be auto generated where possible.

Patient Information

All patients can contact their Breast Care Team as needed with any concerns via a dedicated contact number:

- Patients will not have annual outpatient appointments.
- Patients will have annual mammograms scheduled by the breast team for 5 years with the results sent to them. They will return to the NHS Breast Screening Programme once the 5yrs are complete and the patient is >50;
- If they are under 50years old then they will continue with annual mammography until they reach 50.
- MRI surveillance will be used as per guidelines.
- Will receive hormone therapy, bisphosphonates and bone health monitoring as per national and local guidelines.
- May move to professional led follow-up if it is appropriate and mutually agreed.

At any point during the 5-year self-managed follow up pathway, patients may be contacted to be offered access to any relevant clinical trials or new treatments that may become available.
Individuals who are on the professional led follow-up:

- Will have follow up surveillance with outpatient appointments that are individualised to their diagnosis/needs.
- May be subsequently transferred to self-managed pathway if appropriate and mutually agreed.

Health and Wellbeing Intervention and Moving forward Programme

All patients will have access to health and wellbeing support. This support may be in the form of an event where there is education and support sessions aimed to provide individuals with the information and reassurance to build confidence, they are established to enable them to lead as normal and active life as possible after their cancer treatment. These sessions may also aim to increase awareness of the local facilities, supportive care and opportunities that are available to them and their family.

Signposting to other existing known local health and wellbeing support services for cancer and other long-term conditions can also be offered as health and wellbeing interventions and will promote collaboration between service providers to ensure sustainability of this essential element of supported self-care.

In summary, Health and Wellbeing intervention may be delivered as:

- 1:1 appointments.
- Rolling programmes (such as the 6-weekly Macmillan HOPE Programme);
- Group events which are scheduled at regular intervals throughout the year, and which individuals may have an open invitation to attend if they choose to do so. They give opportunity for interaction between patients and carers, clinicians, clinical nurse specialists, allied health professionals, and complementary therapists. These might also include market stalls of local health promotion services or voluntary agencies.
- Signposting and access to local services for cancer or long-term condition health and wellbeing management.
- Online tools and support.

10. Discharge from the Breast Cancer PSFU Pathway

At the end of 5 years breast cancer patients will be reviewed in a 5-year MDT to update any ongoing treatment regimes in light of latest evidence. Any plans from this review will be actioned and both the patient and the GP will be informed of any recommendations for ongoing treatment or that the patient has been discharged from the hospital's care.

a. Remote Monitoring

All patients will have their surveillance investigations recorded on a remote monitoring system. This system will hold the information required to manage follow-up investigations - ordering,

checking and recording of results. It will also record dates of HNAs, end of treatment reviews, Health and Wellbeing Intervention attendance and invites for each individual.

A remote monitoring system should be:

- Easy to use and compatible with a Trusts current IT system.
- Secure and safe (regularly backed up etc.).
- Accessible throughout a Trusts IT system.
- Able to record and distribute the metrics needed for comparison of other sites. Easily adaptable to future changes in care.
- Suitable for other cancer-specific Living with and Beyond Cancer (LWBC) programmes implemented across the Trustor.

Mammography surveillance requests will be recorded. All patients will have 1 mammogram per year for 5 years up to the 50th birthday unless the MDT indicates otherwise.

After 5 years of mammography surveillance, patients will then transfer back to the NHS breast screening programme. Patients not yet old enough for national screening will continue to have yearly surveillance managed on the cancer IT system until they reach 50.

A safe and secure system of managing mammography bookings, attendance and results is required. It is recommended that the electronic database generates a list of who needs mammography. The request will then be made and an appointment sent to the patient. Results will be reviewed, and unremarkable results (normal result with no further action) will be sent directly to the patient, GP and recorded onto the cancer IT database. Unexpected results will be discussed at the next available MDT to formulate a plan and the patient then contacted (preferably by phone). Any missing results will be followed up to ensure all patients receive their surveillance. It is expected that patients will be able to access results directly via a letter or a web-based portal.
A robust system needs to be in place to ensure patients who have died or moved into a new geographical area during their surveillance period are not sent for.

Other surveillance such as bone health and breast MRI for those at high genetic risk will be recorded and managed on an individual basis.

Patients will be aware of when their mammography surveillance is due from their Treatment Summary.

Patients will be informed to contact the specialist team if they do not receive a request for mammography by the end of the month that it is due. It is recommended that the trust have a

system in place to outline which team members will have the responsibility to resolve issues regarding missed mammographic surveillance appointments.

b. Clinical Governance

Over the 5-year duration of the self-managed follow-up pathway, the clinical governance for patients on the professional led follow-up pathway lies with the Breast MDT Lead and named consultant.

For individuals who are on the follow-up pathway, clinical governance is shared between the named Breast Consultant, the Breast MDT Lead.

The responsibility for security and the database, and ensuring its suitability, lies with the Caldicott Guardian, Cancer Lead Clinician, Clinical Nurse Specialist and Lead Cancer Nurse.

c. The 5 Year Multi-Disciplinary Team Meeting (5year MDT)

- To identify and inform patients that no further treatment or extra imaging is required beyond the five-year follow-up.
- To identify and inform patients who may benefit from extended hormone treatment (if a change from an earlier MDT decision).
- To facilitate switching of endocrine treatment for patients who have commenced Tamoxifen and may now be suitable to switch to an Aromatase Inhibitor; This also needs to be at a 2-year point and a mechanism in place for this.
- To identify patients with a significant family history of breast cancer who may require additional screening beyond five years or the age of 50.
- To define when the patient is discharged from person centred follow-up care and inform both the patient and GP that the follow up is complete and they have been discharged from care.
- After discharge, patients presenting with new symptoms must be appropriately referred (see section 11).

All patients who have completed five years of follow-up are eligible for discussion. The 5-year MDT should be held separately to the diagnostic and results MDT and as a minimum should comprise of a core group to include a surgeon, medical oncologist and breast care nurse (BCN).

There needs to be a safe, robust system in place to ensure all patients are booked appropriately onto a 5-year MDT at the appropriate time.

Patients discussed at the 5-year MDT will receive confirmation of the outcome, with a copy sent to their GP.

Patients on extended adjuvant treatment will be discharged after the five-year follow-up. Their details will remain on the self-managed follow-up pathway database, and they will be written to when they have completed their endocrine treatment.

Patients on extended adjuvant treatment who have been discharged after the five years should be referred directly back to the managing Oncology team/MDT if there are questions or concerns related to hormone treatment.

11. Re-accessing the Breast Care Team as Required

All patients and their GPs will be aware of how to access the Breast Care Team if concerns arise within the 5 years. Safe robust and sustainable open access systems will be in place to facilitate this.

Patients and their GPs will have contact numbers and guidelines about when and how to access further support. Access will be via the Breast Care Team during the first 5 years of follow up through an open access system. When communicating with the team, the patient will be triaged and either have an appointment made for specific imaging, one-stop clinic, appointment with either a breast surgeon, BCN, oncologist or be recommended to see their GP.

To deliver a robust rapid re-entry pathway, it is essential to ensure there is appointment capacity with the existing symptomatic and oncology clinics.

If a patient is required to have further investigations following their routine mammography surveillance they will be recalled for further imaging or an outpatient appointment after discussion of the imaging in an MDT and seen within 2 weeks.

After discharge back into the care of the GP after 5 years on the PSFU pathway, re- entry will be via a new patient GP urgent cancer referral route into the appropriate pathway.

After discharge back into the care of the GP, the following steps are to be followed for re- entry of patients with systemic symptoms of possible metastatic disease:

- After discharge, patients presenting with new symptoms must be appropriately referred.
- The GP to undertake their normal investigations and checks as appropriate for the patients' symptoms. For localised Breast symptoms e.g. lumps and bumps, GP to refer patients via urgent cancer referral pathway to the Breast Surgical team.
- For patients where the GP feels the cause of symptoms may be metastatic relapse (non-emergency), referral back to the Breast Oncology Team for appropriate guidance and management. For patients with symptoms requiring emergency management, such as unremitting back pain (suspected metastatic spinal cord compression - MSCC) It is recommended that the GP follow normal emergency pathways.

12. Evaluation

- The Trust will complete an audit of the current re- entry process compared to the person-centered follow-up model.
- Trust to provide number of breast cancer patients on the PSFU pathway.
- Comparison of previous and subsequent evaluation from the National Cancer Patient Experience Survey (CPES) will be reviewed.

13. Guideline Monitoring

It is recommended that auditing occurs twelve months following the implementation of these guidelines at Cancer Alliance and Breast Expert Advisory Group level – and then on an annual basis provided there are no significant adjustments required.

14. References

Armes, J. et al. (2009) Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. J. Clin. Oncol. 27, 6172–6179

Breast Cancer Risk: Disparities That Affect Black Women
https://www.verywellhealth.com/breast-cancer-risk-black-women-6740824

Cancer Research UK https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/breast-cancer#breastcs0

Department of Health, Macmillan cancer support and NHS improvements (2011) Living with & Beyond Cancer: Taking Action to Improve Outcomes (an update to the 2010 The National Cancer Survivorship Initiative Vision)

Department of Health – Quality health (2012) Quality of life of cancer survivors in England, report on a pilot survey using Patient Reported Outcome Measures PROMS

Maddams, J. Utley, M. and Moller, H (2012) Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J. Cancer 107, 1195-1202

National Cancer Survivorship Initiative (2011), Evaluation of adult cancer aftercare services (2011) Ipsos MORI

National Institute for Excellence (2011) Improving Outcomes in Breast Cancer, manual update NHS Improvement Cancer (2012) Innovation to Implementation: stratified pathways of care for people living with or beyond cancer. A "how to guide"

Palin, J. Ryrie, I. Smith, L. Khanna, M. Pralat, R. (2011) Evaluation of Health and Wellbeing Clinics: Final Report

15. Definitions

Cancer IT System: The local cancer database (Somerset, Infoflex or Dendrite).

Cancer Care Review (CCR) A CCR is a conversation that is carried within Primary Care with the cancer patient.

Co design: Collaborative method of design engaging with all key stakeholders involved in service provision and those using the service.

Eligibility Criteria: An agreed description of the safety and appropriateness of entry onto the supported self-management pathway for individuals with early breast cancer.

End of Treatment: The end of treatment is defined as the conclusion of all active treatment required by an individual following a diagnosis of cancer, this may be after surgery alone or following a combination of therapies (excluding adjuvant endocrine therapy) but precedes the period known as 'follow-up'.

The patient will be presented with a Treatment Summary – see definition below

Health & Wellbeing Intervention (HWBI): Health and Wellbeing interventions are any support or education events or programmes that enable the transition from treatment for cancer to supported self-management. They can range from one-to-one information sessions to group sessions on a variety of topics designed to help with the emotional and practical aspects of life with and beyond cancer.

Holistic Needs Assessment (HNA): An Holistic Needs Assessment is a checklist of concerns that cover physical, emotional, practical, spiritual and financial issues ensuring each area is addressed and a care plan created for those identified as needing specific support. The care plan offers suggestions to manage the concerns including signposting other services or information services that can help.
An HNA can be offered at key points during the pathway to meet the needs of the individual.

Personalised Follow Up: A model of follow-up in which the clinical team and the person living with cancer make a decision about the best form of aftercare based on the individual's clinical and personalised needs. Individuals enter either a professional led or self-managed follow up pathway. The Personalised Follow Up pathway extends 5 years from the point of diagnosis.

Personalised Approach: A personalised approach means that any person that receives care or support will have choice and control in determining the shape of that support based on what is important to and for them.

Professional Led Follow Up Pathway: The follow-up pathway in which individuals with cancer continue to have face to face, phone, or email contact with the specialist team as part of continuing follow up.

Self-managed Follow Up Pathway: The follow-up pathway in which patients are empowered with the knowledge and skills to self-manage their condition. They are given information about the symptoms to look out for and who to contact if they notice any of these alert symptoms, future scheduled tests, and how to contact the specialist breast team if they have any concerns. They do not receive any further OPA unless further investigations or support is required.

Shared Decision Making: Shared decision making is a collaborative process that allows the individual and the responsible health care professional to make health care decisions together in the person's best interest, based on evidence-based practice – taking into account the person's values and preferences

Stratified Follow Up: A model for managing how individuals are followed up after completion of treatment; depending on their risk of disease recurrence.

Treatment Summary (TS): A Treatment Summary is a document produced by the Doctor or Specialist Nurse at the end of active treatment for cancer. The Treatment Summary details the diagnosis, stage and any relevant pathology information. It also includes any surgery, chemotherapy, radiotherapy or any other therapies that the person may have received during the treatment phase. It is followed by specific information on signs and symptoms of recurrence as well as significant consequences of disease and/or treatment. This is important as this information may be needed at a later date by long term survivors who may develop issues. A treatment summary and an HNA develop the Cancer Care Review.

The document is shared with the Patient and the Primary Care team to facilitate ongoing supported self-management.

16. Appendices

Appendix 1

Template letters

HNA checklist

HNA checklist 2023.pdf

End of Treatment example

Treatment Summary (UPDATED VERSION)

Appendix 2

Holistic Needs

- A HNA is a simple questionnaire completed by the person affected by cancer that assesses the physical, practical, emotional, spiritual and social needs of the individual and ensures these needs are met in a timely and appropriate way;
- All patients will have an HNA embedded as part of the normal assessment process within 4 weeks following the initial diagnosis (before treatment is commenced) and at the end of treatment.
- This requires consideration of the timing of the assessment in relation to the patient's journey, sufficient time to reflect and consider their own needs and feelings and an appropriate environment to undertake the questionnaire;
- The HNA will inform the development of a short-term care plan following discussions with the patients' breast care nurse or key worker at the point of diagnosis, highlighting the most important issues at that time that need to be addressed during treatment;
- A review of the care plan will occur following the HNA at the end of treatment;
- It is recognised that a HNA should be done at any point in the pathway where there is a change in treatment or issues identified by the patient or healthcare professional, with a care plan generated and acted upon;
- It is recognised that the HNA can be done by any member of the MDT and must include appropriate triage. Appropriate time should be allocated to staff to enable time for triaging HNAs and managing the findings;
- The care plan should be completed by a member of the cancer team (can be a cancer navigator or support nurse) in consultation with the patient;

Appendix 3: Example Content for Trust PFSU Patient Information

N.B. Each Leaflet will include WMCA & Trust Logo

Why have you given me this leaflet?
You have been given this leaflet to explain Personalised Follow-Up which Trust Name has put in place for patients who have been treated for breast cancer.

What is Personalised Follow-Up?
Personalised Follow-Up is a new type of follow-up that is being introduced at all hospitals. It is where routine, clinical examination appointments are replaced by a system where patients can call us when they have a problem so that they don't have to come to hospital at times when they are feeling well and symptom-free.
Why has Personalised Follow-Up been introduced?
We have introduced Personalised Follow-Up as it has been shown to be better for patients in lots of ways.

It means that you don't have to make unnecessary trips to the hospital at times when you are feeling perfectly well and just want to concentrate on living your life.

Patients often find traditional clinical appointments can lead to anxiety and delay reporting worrying signs and symptoms if a routine clinical appointment is 'not too far away.'

Also, it's been proven that new problems are unlikely to happen in line with your appointment time and are identified by patients themselves, in between routine appointments.

It will also mean that you can access support and advice quickly from the right people when you need it, allowing you peace of mind.

You will also get back into the system quickly should this be necessary.
Communication between all of the people involved in your care will be better, those in the hospital and outside, such as your GP. This will mean everyone can support you or signpost you on to others who can support you at the right time for you.

What information will I be given?
In addition to this leaflet, you will have an End of Treatment Review with your Breast Care Nurse and will be taught how to be body and breast aware, including specific symptoms you should report without delay to your Breast Care Nurse.

You will also be given written information in a Treatment Summary on:

- Your diagnosis and medication;
- The treatment you have had and the possible side effects;
- Signs and symptoms to report;

- Being body and breast aware;
- Arrangements for annual mammograms (and bone density scans if appropriate);
- How to use the Helpline which gives you fast access to your Breast Care Nurse if you need it Advice on Exercise and Nutrition
- Health and Wellbeing support
- Any local support groups and useful contact numbers.

Will I still be able to access the breast service if I have concerns?
Yes. You can call the Breast Care Team on the dedicated Helpline telephone number (xxxx) if you have any queries or problems, and you will be encouraged to do so. The helpline is monitored between 0900 and 1700 Monday to Friday and if you leave a message, with your name, hospital number and telephone number, in the evening or over the weekend you will be called back by the team on the next working day. If they feel that it would be appropriate for you to come back to clinic to be seen, you will be offered a clinic appointment, or if necessary, an appropriate diagnostic test within 14 days of your telephone call.

Will I continue to have routine mammograms?
Yes. Unless it has been otherwise specified at the end of your treatment, you will continue to be called for yearly mammograms for at least five years after your treatment, or until you are the right age to join the national NHS Breast Screening Programme. If, as a result of your specific treatment, you do not need to have annual mammograms, you and your GP will be informed about this.

Are there any other regular tests that I may need to have?
Following your treatment you and your GP will be told if you need any additional regular checks, such as bone density scans (DEXA scans). These scans can tell us if you are developing bone thinning which could lead to a condition called osteoporosis.

Appendix 4: Acknowledgements

Acknowledgments

Thank you to all of the West Midlands Cancer Alliance Breast Expert Advisory Group and sub-group members and Patient Advocates who assisted in the development of this Personalised Follow Up pathway and guideline document. The Cancer Alliance acknowledges the input and expertise of all the members of these groups whom participated in the development process.