



# Northern Cancer Alliance Breast Cancer Stratified Follow Up Clinical Review and Surveillance Guidelines

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## INTRODUCTION

This document provides regional guidelines to complement existing National Institute for Health and Care Excellence (NICE) and NCA tumour specific guidance. This guideline does not override the individual responsibility of healthcare professionals in making decisions appropriate to the circumstances of the individual patient.

It is not anticipated that the guidelines will cover all clinical situations in all patients, but where unusual circumstances exist, it is expected that such treatments would be discussed in the appropriate MDT.

The guidelines will be reviewed on an annual basis. Where new treatments are introduced between revisions they will be added as an addendum to the current guideline.

Supported directed access offers a more effective approach to after-care than traditional medical models of follow-up which has the potential to reduce costs and improve patient satisfaction. Evidence for this model is based on the work undertaken by the National Cancer Survivorship Initiative in 2011. This aligns with the national strategy for implementation of patient-initiated follow-up (PIFU) pathways.

Patients with breast cancer will be considered for PIFU assuming they meet the inclusion criteria below.

## AN OVERVIEW OF STRATIFIED FOLLOW-UP

Stratified follow-up can lead to a reduction of routine appointments in a patient's pathway. Following treatment, aftercare is discussed with the patient and the appropriate pathway assigned. Patients may move between pathways as their needs change.

The pathways are as follows:

**Supported self-management (PIFU):** Patient led follow-up where the individual receives support and interventions to empower them to self-manage their health outside of a hospital setting. They receive surveillance tests but do not have routine clinic appointments.

This pathway is suitable for all breast cancer patients treated with curative intent. If an individual develops problems related to their treatment and once these are controlled, they can re-enter a PIFU pathway. Similarly, if they have suspicious symptoms and following investigation no disease is detected, they can also re-enter a PIFU pathway.

At the present time individuals should remain in PIFU for a period of 5 years.

**Hospital led face-to-face/telephone follow up:** Clinician led follow up where the individual will receive surveillance tests as per the clinical guidelines. Clinic appointments are scheduled as required and can be face to face or telephone consultations, and with a Doctor or Nurse Specialist.

This arrangement should be reviewed regularly and when appropriate the individual can be transferred to PIFU. Local arrangements as to where follow-up takes place should be considered i.e. following adjuvant radiotherapy people are referred-back to their surgical team for follow-up which can continue following implementation of these guidelines. Individual choice should also be offered as to where this takes place i.e. local hospital or centre.

**Supportive/end of life care services:** Clinician led with palliative care input as required, when no further treatment options are available, attending hospital appointments is

potentially difficult for people. Transfer of care to the G.P. and palliative care services should be discussed and the G.P. made aware of this discussion. Community palliative care teams should be involved with the consent of the individual.

The results will be reviewed by appropriately qualified or trained staff and the patient and GP informed of the results. This information may trigger a recall of the patient back to specialist services as required.

Patients suitable for stratified follow up should be offered a 1:1 appointment with a Cancer Nurse Specialist (CNS) at the end of their primary treatment to explain how stratified follow up works and to ensure the patient knows how to contact the service if there are any concerns or symptoms in between surveillance testing. This could be done at the same time as the end of treatment summary and review of the Holistic Needs Assessment (HNA).

A system must be developed for rapid re-entry of patients to the specialist cancer service as required.

## **PATIENT SELECTION CRITERIA FOR STRATIFIED FOLLOW UP**

### **Inclusion Criteria:**

- All patients who have been treated with curative intent are eligible for this pathway

### **Exclusion criteria:**

- Under 18 years at diagnosis
- Patients on clinical trials where the protocol requires clinical review
- Patients whose holistic needs assessment suggests that they are not yet ready to self-manage their aftercare

The option of PIFU should be available for all individuals who are clinically disease free however, this pathway is not suitable for everybody and some may continue to need hospital-based aftercare.

Any individual participating in a clinical trial should be followed-up as per trial protocol.

Following the multidisciplinary meeting (MDT) individuals should be reviewed and made aware of their future management plan. Decisions regarding stratified follow-up can be discussed in the MDT but are only confirmed when a discussion has taken place with individuals. The chosen pathway is then documented in the medical notes and should be communicated to the G.P, preferably via the treatment summary. Regardless of follow-up pathway all individuals should be offered a treatment summary and holistic needs assessment with their CNS or community service if available.

## **MINIMUM FOLLOW UP SCHEDULE**

Following the end of treatment there will be:

- A review of the HNA
- A comprehensive information booklet be given to the patient which advises them of their planned follow up, access back into the service and support services available
- Completion of the end of treatment summary clearly stating the method of follow up and sent to the patient and their GP
- Information supplied regarding health and wellbeing
- Confirmation of booking of planned investigations and how results will be received

A minimum follow up schedule should be agreed and communicated between the specialist team, Primary Care and the patient. The follow-up schedule may be conducted in the form of telephone clinics or virtual clinics in-place of conventional face-to-face clinics for patients.

## RECOMMENDED PIFU SCHEDULE AND PROCESS FOR BREAST CANCER PATIENTS

### End of treatment outpatient appointment with the clinical team (within 6-12 weeks post treatment)

After surgery/chemotherapy/radiotherapy is completed patients will attend an end of treatment (or post-treatment) clinic appointment with their clinical team. The clinician will discuss an initial follow up plan with the patient as per the eligibility criteria above and any MDT discussion, and an End of Treatment Summary is completed (patients may have more than one end of treatment appointment/summary, and at different times depending on their treatment schedule).

For patients on an Aromatase Inhibitor (AI), the clinician should state when this should be stopped at the point of transfer to a PIFU pathway. This should be documented in the End of Treatment Summary during the end of treatment clinic appointment, which should be reviewed at the point of discharge to Primary Care at the end of the 5 years by the clinical team, highlighting any changes that need to be monitored/actioned by Primary Care.

### 12 month follow up appointment with the Surgeon and/or Breast CNS

This appointment is around the same time as a patient's first surveillance mammogram at 12 months. During this appointment there is:

- A review of the HNA and end of treatment summary
- A comprehensive information booklet be given to the patient which advises them of their planned follow up, access back into the service and support services available
- A review/update to the end of treatment summary clearly stating the method of follow up shared with the patient and their GP
- Information supplied regarding the next available health and wellbeing event (if applicable)
- Confirmation of booking of annual mammograms for 5 years and how results will be received

### Breast Cancer Follow Up Schedule – for surgical and non-surgical oncology patients

Investigation /Year	0	1	2	3	4	5
Follow Up Appointments	End of treatment appointment	Face-to-face/tele follow up	PIFU	PIFU	PIFU	PIFU
Mammogram	Diagnostic mammogram	Y	Y	Y	Y	Y
DEXA	Y*		Y*			

\*Patients on an Aromatase Inhibitor (AI) will have a DEXA scan at the start of their treatment. It may be recommended that patients have a further DEXA scan to re-check bone mineral density at year 2 or 3 to compare to their baseline scan taken at the start of treatment. This should be clearly stated in the End of Treatment summary including who would be responsible for arranging this and reviewing results.

## **SURVEILLANCE TESTS AND WHEN THE 'CLOCK STARTS'**

All patients following initial treatment for breast cancer will be given information about self-care and surveillance tests. A list of symptoms that could be a cause for concern and a contact number for the Breast CNS Team will be given as part of the information pack developed by Trusts and included in a patient's treatment summary.

Patients who contact any member of the specialist team with worrying symptoms will be seen by the appropriate team within two weeks (in line with 2 week wait) and if necessary, the case will be discussed at the MDT meeting.

As part of a breast cancer patients follow up plan, the hospital clinical team will arrange annual surveillance mammograms and/or other tests (as per the regional guidelines) for 5 years.

It is advised that the 'clock starts' for all patients on a PIFU pathway at the 'date of diagnosis' i.e. a patient will have their 5 yearly mammograms scheduled from this date. It is recognised that this won't be suitable for all patients e.g. those that may still be on active treatment. In these instances, the clinical team may wish to delay the patients first (and subsequent) surveillance mammograms. This should be clearly documented in the End of Treatment summary.

## **DISCHARGE FROM SERVICE**

All patients on a PIFU pathway will be discharged back to the care of their GP at 5 years (unless they are palliative and may be discharged sooner) and will have to re-access the service via their GP. Written information will be given to the patient/GP on the patient's end of treatment summary to advise them regarding this date.

At this point:

- For patients >50 they will receive 3 yearly mammograms as part of the national screening programme
- For patients <50 they will be discharged to the care of their GP. However their surveillance tests (as per the regional guidelines) will be scheduled by the Trusts Radiology Department and will be reported in the same way as standard screening surveillance tests (until they join the national screening programme – this is in-line with NICE guidelines)

Consideration will need to be given to patients who have ongoing medication requirements, who may need additional input from their hospital team prior to discharge. Patients on letrozole (for example) should be contacted in writing by their CNS/member of their clinical at the point of discharge, to confirm when their medication should be stopped. Any correspondence should also be copied to the patients GP.

# APPENDIX

## 1.1 CLINICAL RESPONSIBILITIES AND ROLES

### Stratification

The clinical team / consultant is responsible for identifying patients suitable for supported self-management. The decision should be made based on holistic needs assessment, clinical judgement and discussion with the patient, then recorded appropriately within the Trust clinical systems.

### Stratified Follow up Consultation

The CNS will manage the stratified follow up consultation. They will ensure that the patient is provided with written information, a treatment summary has been completed and a copy has been sent/given to the patient and sent to the GP. A holistic needs assessment will also be carried out and action taken as necessary. All surveillance and scans should be in place and patients are aware of how results will be received.

### Re- access to Services

Patients will receive verbal and written information about how to re access the service if they have a problem or concern at the consultation appointment with the CNS. Patients should contact their clinical team via telephone who will give them verbal advice or arrange a clinic appointment. Patients can also re-access the service via their GP.

