London Cancer:
Early Breast Cancer Stratified Follow-Up Implementation Resource Pack

December 2014
Final Version 1.0
1. Background & Introduction

A key London Cancer priority is to reduce variation in order to improve patient experience and outcomes for individuals living with or beyond cancer. Across London Cancer, there are currently considerable differences in follow-up policies to support individuals who have completed their cancer treatment. The Living with and Beyond Cancer Board is working collaboratively with our pathway boards and partner trusts to drive and support the shift from clinician-led and largely hospital-based models of follow-up to an evidence based, stratified model that addresses the unique needs of the individual living after a cancer diagnosis.

In 2011, a stratified follow-up model for individuals with cancer was developed and successfully tested by NHS Improvement as part of the National Cancer Survivorship Initiative (NCSI). The model has been recommended for implementation by the NCSI in the ‘Living with and Beyond Cancer: Taking Action to Improve Outcomes’ document published in March 2013.

Stratified follow-up is an approach to steering individuals onto the best follow-up pathway to address their specific needs. It has a focus on promoting wellbeing, recovery and empowerment to provide individuals with the information and confidence to have an active role in their care. The overall aim of the approach is to improve patient experience and outcomes, and quality of care, by tailoring aftercare and embedding supported self-management within the cancer pathway.

The move toward stratified follow-up is consistent with The Model of Care for Cancer Services (Commissioning Support for London, 2010) which recommends a transition to personalised assessment, information provision and care planning. The rationale for this shift is that there is no evidence that traditional follow-up consisting of regular appointments in secondary care provides the most effective care or best means to detect disease recurrence. In addition, longer life expectancy combined with more intensive treatments are resulting in increasing numbers of individuals living with consequences of treatment, which may manifest years after treatment ends (Macmillan 2013). These consequences of cancer need to be addressed by an effective model of aftercare.

This document is a resource to assist trusts to plan and implement stratified follow-up at local level. The templates contained within the appendices may be sourced as word documents on the London Cancer website: http://www.londoncancer.org/cancerprofessionals/breast/breast-pathway-documents/

2. Key features of a stratified follow-up

The National Cancer Survivorship Initiative advises that individuals are assessed to determine which tier of follow-up would best meet their needs. Individuals deemed at low risk of recurrence and late effects (physical and psychosocial) are encouraged towards supported self-management, those at medium risk receive planned, co-ordinated care and those at high risk receive complex care from specialist services.

Overall key features of stratified follow-up:

- Enables people who are willing and able to undertake self-management to do so in a safe and supported manner.

- Incorporates NCSI Recovery Package interventions (Holistic Needs Assessment and care plan, Treatment Summary, Health and Wellbeing event) to improve outcomes and co-ordination of care.
• Improves patient experience by eliminating anxiety and stress induced by attending unnecessary appointments.

• Rapid re-entry into the specialist cancer service as required. This reassures individuals that they are able to access appropriate, named support quickly should they need it, without having to go via their GP. The ability to re-access services quickly and easily has been shown to be crucial to the confidence of people undertaking supported self-management, and consequently to the long term success of a supported self-management programme.

• Removal of routine follow-up appointments from the pathway. Routine surveillance mammography is still completed at set intervals. However, these do not require the individual to automatically see a hospital doctor or nurse to receive their results. The individual is sent an appointment for the tests. The results will be reviewed by an appropriately qualified staff member and the patient is informed of the results by letter, phone, or in person (as per clinical judgement). Recall back into specialist services is effected via the 2WW system.

3. Understanding, evaluating and learning from national pilots

In 2011 NHS Improvement supported, coached and facilitated stratified pathway development and implementation in 14 test communities in England for the National Cancer Survivorship Initiative. Lessons learned from the test sites:

• Staff were supportive of stratification – they thought it was valuable for all patients as it allowed those that were self managing to be empowered to move on with their lives, while those on professionally led pathways or still in treatment benefited from additional time with consultants.

• Most staff stated that patients positively received the concept of self-management if it was fully explained and introduced at an appropriate point so that it did not contrast with their expectations for follow-up care. Several nurses advised that only new patients should be moved on to a self-management pathway.

• Monitoring was extremely important for patients as a key safety measure. For those patients on a supported self-management pathway, their greatest concerns were related to their cancer returning, and recognising the signs and symptoms of cancer recurrence.

• Patients reported that the knowledge that an appropriately trained health professional reviewed their scan or blood test results was often the reassurance they needed to enter a supported self-management pathway.

• Cultural barriers – many staff acknowledged that the new stratified pathways required a very different way of working and thinking for all concerned. Self-management requires a shift from a culture of dependency and reliance on professionals towards self-reliance and responsibility.
There were a number of factors that stood out as being particularly important for care coordination within a supported self-management follow-up pathway:

- Remote monitoring reassured patients that problems would get picked up; this served as a welcome safety net.
- Assessment and care planning was seen as crucial to effective care coordination by staff and charity contacts. Patients were less vocal about this, simply because not all of them had gone through this process at the time of the interviews. However, where it had happened, patients seemed positive about the care plan – they thought it was useful and a comfort to them.
- Equally hand held records didn’t seem to feature strongly for the patients interviewed; however, where they did have them, they could see the benefit for care coordination and their own peace of mind.
- The central role of the CNS for many patients suggests that even where patients are self managing, the responsibility for managing whatever care may be needed has not entirely shifted to the patient.
- IT solutions to ensure that individuals don’t ‘fall through the net’.

There are a number of things that may need consideration for a fuller shift towards self-management, including:

- The broader cultural changes around how healthcare is provided, part of which is a shift from a traditional medical model, focusing on ill health, towards a model focusing on health and wellbeing. This brings with it broader challenges around how these cultural changes are implemented and operationalised, and how they filter through to staff and individuals with cancer.
- This then has implications for how staff and individuals with cancer see their own role in how care is provided and received. It requires consideration of how attitudes and awareness may be shifted in moving from a system where treatment and care is done to patients to a system where care is delivered in partnership with the individual.
- The challenges around this cultural shift towards self-management were particularly pertinent during the transition from treatment to aftercare, requiring patients to adjust from “being taken care of” to taking on responsibilities themselves. Therefore, it is essential that patients’ expectations be managed early on in the assessment and care planning process to increase their confidence in self-managing once they complete treatment.
- Clear communication around new approaches to care and what this means for all involved is important. As part of this, being more explicit about the respective roles and responsibilities could ensure that each party is aware of what is expected of them. However, making patients’ responsibilities clear to them needs to go hand in hand with building their confidence to handle their own condition.
- Similarly, further training with staff to build their own confidence in this changing role may prove beneficial.
- Longer-term implementation of the programme assists the transition – so key principles that will enable self-management (including needs assessment, care plans, education and learning etc.) are embedded further.
- Finally, staff identified a need for a different approach to resourcing – nurses in particular suggested that resources may need to be moved around the system.
4. Progress with developing stratified pathways within London Cancer

In 2014/2015, the Living with and Beyond Cancer Board is supporting the breast, colorectal and urology pathway boards and partner trusts to develop and implement a stratified model of follow-up. Each board has developed a subgroup which is taking forward development of a stratified pathway and trust resource pack on a tumour-specific basis.

5. The Early Breast Cancer Stratified Pathway

In March 2014, the Breast Pathway Board convened and tasked a sub-group to take this work forward. A pathway and guidelines have subsequently been developed. (Appendix A). In addition to the development of the pathway, the group developed a suite of documents to provide to trusts as a resource to implement locally. Please refer to the appendices below for the following:

- **Appendix B**: Draft business case for developing stratified follow-up
- **Appendix C**: Patient information leaflet on supported self-management
- **Appendix D**: IT Functionality Requirements and Options Appraisal document
- **Appendix E**: GP information leaflet on supported self-management
- **Appendix F**: GP clinical template letter – includes treatment summary, endocrine treatment options and bone health monitoring guidance

The subgroup is also in the process of identifying two beacon sites to pilot the introduction of the stratified pathway with early breast cancer patients.
References


Acknowledgements

Thank you to all of the sub-group members who assisted in the development of this new stratified follow-up pathway. We acknowledge the input and expertise of all the members of this sub-group and the Breast Pathway Board whom participated in the development process.

We also acknowledge the Parapet Breast Unit at Heatherwood and Wexham Park Hospitals NHS Foundation Trusts who provided us with permission to localise their excellent guidelines.

We also acknowledge the London Cancer Alliance who kindly shared their documentation for our group to review and adapt as needed.
Appendix A: Early Breast Cancer Stratified Follow-Up Pathway Guidelines
London Cancer:
Early Breast Cancer Stratified
Follow-up Pathway Guidelines

December 2014
Final Version 1.0
1. Introduction and Purpose of this Guideline

The London Cancer Breast Pathway Board formed a sub-group to develop a stratified follow-up pathway for the future delivery of early breast cancer aftercare. The sub-group met during the period between May 2014 and September 2014 and delivered its final proposed pathway to the Breast Pathway Board on 18th November 2014. The pathway board, as the ultimate source of breast cancer expertise and leadership for London Cancer approved the stratified follow-up pathway on 1st December following opportunity for board members to comment subsequent to the board meeting.

This document describes the redesigned stratified follow up pathway for early breast cancer patients (Appendix I). It defines the two levels of follow-up support available to this cohort of patients – shared care and supported self-management - and outlines which individuals are eligible for entry onto the supported self-management pathway (SSMP) for their aftercare. The document provides guidelines to ensure that:

- All individuals diagnosed with early breast cancer receive personalised information and appropriate support to enable them to live actively and well following the end of their cancer treatment.
- A safe, robust, transparent system is utilised to manage their breast cancer surveillance program and ongoing care.
- Timely, safe and appropriate systems back into specialist services are in place in the event that a concern arises.
- Each individual is provided with verbal and written guidelines about exactly when and who to contact if they have any concerns in the future.

This stratified pathway meets the expectations of the National Cancer Survivorship Initiative and NHS Improvement (Cancer) which are included as references. It is an accompanying document to the London Cancer Breast Pathway Specification document. For definitions, refer to Appendix I.

2. Stratified Follow-Up: The Process

2.1 Diagnosis and treatment:

- Following the decision on treatment recommendation, the MDT will discuss if the individual is eligible for entry onto the self-management pathway (utilising the eligibility criteria outlined in section 3).

- All newly diagnosed early breast cancer patients will receive information about the shared care and supported self-management follow-up options available to support them at the end of treatment. This will include a description of both forms of follow-up with emphasis placed on the fact that they may move between pathways if their needs change during the 5-year follow up period.
2.2 End of treatment and follow-up

- At the end of treatment, all individuals will receive a ‘clinical review OPA’. This is an appointment between the patient and the consultant/breast care nurse where the individual will receive personalised information about their follow-up options and will decide which form of follow-up best meets their needs. The decision regarding which pathway they will enter will be formalised and included in the treatment summary generated by the doctor and sent to the patient. Copies of the treatment summary will also be sent to the GP and held within the individual’s written and electronic hospital notes.

During this appointment, it is recommended that the patient be provided with verbal and/or written information regarding the following:

- Possible treatment toxicities/consequences of treatment
- A personal plan for future mammographic surveillance and endocrine monitoring. This will include an explanation of the process for receiving appointments for mammographic surveillance and results
- Alert symptoms that require re-access to the specialist team
- Contact name and phone number of the breast specialist team and trust helpline
- Breast awareness
- Nutrition and weight
- Health and Wellbeing events
- Any local self-help groups and useful phone numbers (e.g. Macmillan Cancer Support, Breast Cancer Care)

- It is recommended that the GP is sent copies of the same information that is given to the patient. This will provide the GP with the required information to enable them to support the individual in the primary care setting.

- At the conclusion of the clinical review OPA, the patient is transferred onto the supported self-management or shared care pathway. They will also be scheduled to receive an aftercare appointment with their breast care nurse.

- The aftercare appointment: Takes place with the breast care nurse (BCN) three months following the end of treatment. During this appointment the patient receives a review of their:

  - Holistic needs assessment. This will guide which additional information and signposting they are given at this point.
  - Progress on their current follow-up pathway. Does it suit their needs? Do they feel sufficiently confident to move onto the supported self-management pathway (if they are currently on the shared care pathway)?
2.3 Living Beyond Cancer

Individuals that choose the supported self-management pathway (SSMP):

- Can contact BCN as needed with any concerns
- Will not have annual outpatient appointments
- Will have annual mammograms 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 50yrs old then they will continue with annual mammography until the age of screening
- MRI surveillance will be used as per guidelines for known gene carriers
- Will receive hormone therapy and bone health monitoring as per national and local guidelines

At any point during the 5-year follow-up pathway, patients may be contacted to be offered access to any relevant clinical trials that may become available

The individuals who choose the shared care pathway:

- Will have follow up surveillance with outpatient appointments that are individualised to their diagnosis/needs

2.3.1 Health and Wellbeing Events

All patients will be offered a health and wellbeing event. Health and wellbeing events are patient education and support sessions which aim to provide individuals with the information and confidence they require to enable them to lead as normal and active life as possible after their cancer treatment. They also aim to increase awareness of the local facilities, supportive care and opportunities that are available to them and their families.

The Health and Wellbeing events may be delivered as:

- **1:1 appointments** conducted with individuals at the end of treatment
- **Rolling programmes** (such as the 6-weekly Macmillan HOPE events)
- **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

It is recommended that the core content of Health and Wellbeing events is as follows:

- Expert advice on **health promotion** - to minimise risk of recurrence and support healthy living. Specifically this will include: being physically active, nutrition, healthy weight management, and smoking cessation. To include information/support to effect behavioural change.
- **Support** to ensure that individuals have the confidence and skills to manage their condition themselves as far as possible – i.e. referral to rehabilitation and psychological support services and signposting to local support groups or buddy services
- Advice on **adjusting to life after treatment** – addressing fears of cancer recurrence
- Information on **signs and symptoms of recurrence** and **potential consequences of treatment**. All events should clearly convey and reinforce the methods to activate fast-track access back into the system if there are any concerns regarding new symptoms or recurrent disease
• Information and access to financial and benefits advice
• Specific issues relevant to the individual’s type of cancer. For example lymphoedema – early detection and management, body image & sexual functioning
• Vocational rehabilitation

The aftercare appointment with the BCN may be tailored to fulfil the function of a health and wellbeing event. However, evidence from National Cancer Survivorship Initiative health and wellbeing pilot sites revealed that many patients benefited from group sessions\(^1\). Specifically the pilots demonstrated that:

- The informal atmosphere of group events enhanced the delivery of the Health and Wellbeing messages
- The combination of using professionals and volunteers at the Health and Wellbeing group sessions was effective
- Participants valued the group discussions - this assisted to address issues of isolation and to validate what is ‘normal’ to experience and feel for a person affected by cancer. This differentiates the clinics from traditional forms of follow-up such as outpatient appointments

2.3.2 Discharge from the Stratified Follow-up Pathway

At the end of 5 years from transfer onto follow-up, the individual will be reviewed in a virtual MDT in order to update any ongoing treatment regimes in light of latest evidence. Any plans from this review will be actioned and a letter will be sent to both the patient and the GP to inform them of any recommendations for ongoing treatment or that the patient has been discharged from the trust stratified follow-up pathway.

3. Eligibility for Entry onto Supported Self-management Pathway

All early breast cancer patients will be considered for entry onto the breast supported self-management pathway unless:

- The individual is unable to self-manage due to physical, cognitive or emotional reasons
- The individual chooses not to enter the supported self-management pathway

For individuals participating in clinical trials, follow-up will be determined by the clinical trial protocols. All individuals taking part in trials will still access and benefit from the clinical review OPA, aftercare appointment and health and wellbeing events.

Patients will have their suitability for entering the supported self-management pathway considered at the last MDT at which they are presented. Those who are not eligible will be recorded as

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not appropriate for SSMP on their MDT proforma within the cancer IT system. A printed copy will be placed in the patient notes as appropriate.

The final decision regarding entry onto the supported self-management pathway is conducted in collaboration with the patient.

4. **Surveillance Investigations**

All patients will have their surveillance investigations recorded on the cancer IT database. This database will hold the information required to manage follow up investigations - ordering, checking and results recording.

4.1 Mammography surveillance requests will be recorded on the cancer IT database at data entry following diagnosis. All patients will have 5 years of mammography on the anniversary of diagnosis (unless the consultant indicates otherwise).

4.2 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 screening age.

4.3 A safe system of checking mammography required each month will be developed and implemented. It is recommended that the electronic database generates a monthly list of who needs mammography. The mammography request will then be made and an appointment sent to the patient. Results will be sent directly to the patient and GP and these results will be recorded onto the cancer IT database. Any missing results will be followed up to ensure all patients receive their surveillance.

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

4.5 Patients will be aware of when their mammography surveillance is due from their end of treatment summary letter and their personal plan. 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.
5. **Clinical Governance**

Over the 5-year duration of the follow-up pathway, the clinical governance responsibility for patients on the shared care pathway lies with the breast MDT. For individuals who are on the supported self-management pathway, clinical governance lies with radiology.

6. **Re-accessing Specialist Services as required**

All patients and their GP’s will be aware of how to access the specialist team if concerns arise. Safe robust systems will be in place to facilitate this.

6.1 Patients and their GP’s will have written contact numbers and guidelines about when and how to access further support. Access will be via the BCN during the first 5 years and thereafter via a GP referral.

6.2 If a patient is required to have further investigations following their routine mammography surveillance and they are on the SSMP pathway, they will be recalled via the 2WW process. Patients will be prepared for this possibility at their aftercare appointment. Patients on the shared care pathway will be seen in clinic for a review within 2 weeks and further investigations ordered as required.

7. **Evaluation**

7.1 It is recommended that user feedback is conducted by postal questionnaire which is sent to all patients 3 months post the aftercare appointment. The aim of the questionnaire is to establish if the patients’ needs have been met. (Refer to Appendix III for an example of a patient questionnaire)

7.2 Baseline measures/process mapping: Establishing baseline measures prior to implementation is critical to enable measurement of improvements at a later date. Recommended data for collection includes:

- **New cancer diagnosis**: Follow up ratios for breast patients
- Number of **Surgical** outpatient clinics per week
- Number of **Oncology** outpatient clinics per week
- Number of **cancer patients** seen at each outpatient clinic
- Average number of new **cancer patient** slots per clinic
- Average number of follow up **cancer patient** slots per clinic
- Number of telephone clinics to follow up cancer patients. Average number of cancer patients reviewed at each telephone clinic.
• Number of virtual clinics to follow up cancer patients. Average number of cancer patients reviewed at each virtual clinic.
• Readmission rates for cancer patients

7.3 On-going measures: Establishing the data collection and measures to be utilised to demonstrate effectiveness also needs to be agreed prior to implementation. Data on all or some of the following would be useful:
• Reduction in outpatient attendances
• Improved patient experience (PREMS)
• Patient Reported Outcome Measures (PROMS)
• No. of calls to helpline or clinical nurse specialist from patients post treatment
• Cancer waiting times
• Number/ % of Patients with a care plan
• Number/% of Patients who receive a Treatment Summary at end of treatment
• Number of patients enrolled to a supported self-management pathway
• Patients’ narratives/stories

7.4 It is recommended that measurement of the health related quality of life and wellbeing of early breast cancer patients is assessed approximately one year post entry onto the stratified model of follow-up. PROMS tools to consider:

- **EORTC QLQ-C30**
  
  **Description:** A questionnaire which assesses the quality of life of cancer patients. It comprises 30 questions which focuses upon functional (physical, cognitive, emotional, and social); specific symptom (fatigue, pain, and nausea and vomiting); global health and quality-of-life domains. A tumour specific module is also available as required.
  
  **Permissions/Licencing:** Permission required. There is no fee for academic use. Permissions obtained via the EORTC website.
  
  **Website:** [http://groups.eortc.be/qol/eortc-qlq-c30](http://groups.eortc.be/qol/eortc-qlq-c30)

- **FACT G:** A general quality of life instrument intended for use with a variety of chronic illness conditions. It assesses the functional status of patients with specific cancer diagnosis. The sub-scales included within the questionnaire are as follows: physical, social/family, emotional, and functional well-being. Originally validated in a general cancer population, it has condition-specific subscales to complement it, including one for breast cancer (FACT-B).
  
  **Permissions/Licencing:** Permission for use is obtained by completing a user agreement on the FACIT website. There is no fee for use of the tool
  
  **Website:** [http://www.facit.org/](http://www.facit.org/)

- **EQ-5D-5L:** A standardised instrument for use as a measure of health-related quality of life and of health outcome. The measure has 5 dimensions: mobility, self-care, usual activity, pain/discomfort, and anxiety/depression. The instrument comprises 2 parts: respondents rate their health on the dimensions/levels as well as record an overall assessment of their health on a visual analogue scale.
Permissions/Licencing: Requires written consent of the EuroQol Executive Office. Registration form able to be completed electronically via the EuroQol website
Website: www.euroqol.org

8. Guideline Monitoring

It is recommended that auditing occur three months following the implementation of these guidelines at trust level – and on an annual basis provided there are no significant adjustments required.
References


London Cancer (2014) Breast Pathway Specification


Acknowledgements

Thank you to all of the sub-group members (named in Appendix IV) who assisted in the development of this new stratified follow-up pathway. We acknowledge the input and expertise of all the members of this sub-group and the Breast Pathway Board whom participated in the development process.

We also acknowledge the Parapet Breast Unit at Heatherwood and Wexham Park Hospitals NHS Foundation Trusts who provided us with permission to localise their excellent guidelines.
Appendix I: Definitions

**Aftercare Appointment:** 45min booked clinic appointment with the patient’s breast care nurse (BCN). It is scheduled 3 months following the clinical review outpatient appointment (OPA) taking place.

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

**Clinical Review OPA:** The final outpatient appointment with a member of the consultant team and/or the BCN after the individual’s treatment is completed. Hormone treatment will continue beyond this.

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

**Stratified 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 shared care pathway or a supported self-management pathway. The stratified follow-up pathway extends 5 years from the point of diagnosis.

**Shared Care 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.

**Supported self-management pathway (SSMP):** 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.

**Treatment Summary:** The NCSI treatment summary template is completed by the medical team at the end of primary treatment. It includes information on possible treatment toxicities and /or consequences of treatment, signs and symptoms that require referral back to a specialist team, an ongoing management plan, and a summary of information given to the individual about their cancer and future progress and any required GP actions to support the patient. Copies are sent to the GP and provided to the patient when they are discharged. The treatment summary can be automatically generated on the two main cancer information systems Somerset and InfoFlex.
Appendix II: Stratified follow-up pathway for early breast cancer patients
Appendix III: Patient Questionnaire Example

Patient Questionnaire about follow up, after treatment ends, for breast cancer patients cared for by insert trust name

At the insert trust name, we are changing how we care for individuals who have early breast cancer once they have completed their treatment. These changes are in line with national guidelines (NHS Improvement Cancer and the National Cancer Survivorship Initiatives) and with what cancer patients have reported best meets their needs. It is important to us that we receive feedback from you to determine if we are meeting your needs - and what we need to do to continue to improve the care we give.

Please could you take a few minutes to complete this questionnaire?

Your answers will remain anonymous and will only be used by the trust to guide service improvements.

1. Do you have the contact details for your breast care nurse?
   Yes □    No □

2. After your end of treatment clinical review outpatient appointment with the doctor or breast care nurse, did you receive a letter detailing your diagnosis, treatment and what scans or treatment you will need in the future?
   Yes □    No □

3. Do you feel you were given an adequate explanation of this letter by the doctor?
   Yes □    No □

4. Have you had the opportunity to discuss this letter in your aftercare appointment with your breast care nurse?
   Yes □    No □

5. Please comment about the contents of this letter below, if you feel able to.
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
6. Did you receive a holistic needs assessment assessment with your Breast Care Nurse at your aftercare appointment?
   Yes □ No □ don’t know □

7. Do you feel the holistic assessment was useful for you?
   Yes □ No □ don’t know □ not applicable □

8. Please comment about the holistic assessment below, if you feel able to.

   __________________________________________
   __________________________________________
   __________________________________________
   __________________________________________

9. Over the past six months, how many times have you contacted your GP practice for advice or support with issues relating to your cancer, or your treatment for cancer?
   Not at all □ 1-2 times □ 3-5 times □ 6-10 times □ More often □

10. How confident do you feel about managing your health?

    Very Confident □
    Fairly Confident □
    Not very confident □
    Not at all confident □
    Don’t know □

11. Do you have all the information, advice or support you need to help you manage your health?
    Yes □ No □ not sure □
12. What other information, advice or support do you need to help you manage your health?
______________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

13. Do you have all of the information and advice that you need about the effects of your treatment?
   Yes □      No □       not sure □

14. How confident do you feel about who to contact if you have a query or concern, if at all?

   Very Confident □
   Fairly Confident □
   Not very confident □
   Not at all confident □
   Don’t know □

15. Were you offered the opportunity to be on the supported self-management pathway?
   Yes □      No □       I don’t know □

16. If yes to question 15 then did you choose to go on the supported self-management pathway?
   Yes □      No □       I don’t know □       not applicable □

If you feel able, please could you share any further comments or thoughts you have about the end of treatment information and appointment with your Breast Care Nurse?
___________________________________________________________________________
___________________________________________________________________________
Thank you for taking the time to complete this questionnaire, we value your comments and they will be used to guide service improvement in the future.

(Questionnaire adapted from Parapet Breast Unit at Heatherwood and Wexham Park Hospitals NHS Foundation Trusts)
Appendix IV: Early Breast Cancer Stratified Follow-Up Subgroup Members

- Sharon Cavanagh (Chair) – Living with and Beyond Cancer and AHP Lead, *London Cancer*
- Rebecca Roylance – *London Cancer* Breast Pathway Director and Consultant Medical Oncologist, Barts Health NHS Trust
- Patricia Dean – Patient Representative
- Katie Sutton - Macmillan Project Lead-Cancer Follow-Up Redesign, University College of London Hospital NHS Foundation Trust
- Claire Grainger – Breast Cancer Nurse, Princess Alexandra Hospital
- Kate Kavanagh - Cancer Commissioning Manager (BHR & West Essex) NEL Commissioning Support Unit
- Antony Pittathankal – Consultant Breast Surgeon, Clare Stephens – General Practitioner, Barnet
- Alex Clayton-Jolly - Consultant Radiologist, Barking, Havering and Redbridge University Hospitals NHS Trust
- Rob Stein – Consultant Medical Oncologist, University College London Hospitals NHS Foundation Trust
- Ros Crooks – Consultant Breast Radiologist, Whittington Hospital NHS Trust
- Sarah How – Pathway Manager, *London Cancer*
- Philip Lunn - Divisional Operations Director, Homerton Hospital
Appendix B: Draft Business Case for Developing Stratified Follow-up
Draft Business Case

Self-management pathway - Cancer Services

Executive Summary

The primary purpose of follow-up is to detect for cancer recurrence and identify and treat late effects of treatment. The traditional model follows a standard regime of outpatient appointments and surveillance tests over several years. Patients can be seen by any member of the clinical team.

Increasing incidence of cancer (currently 3% per year) alongside increased survival rates are putting huge pressure on outpatient resources and impacting on the quality and efficiency of services provided. Both patients and professionals have identified that many appointments are unnecessary, add no value and incur unnecessary costs for patients.

The (insert team) have reviewed their current clinical pathways and propose the introduction of a self-management or open access pathway option for low risk patients, offered soon after the completion of treatment and when the short term effects of treatment have subsided. Key enablers to support this pathway are an effective assessment process to identify and manage individual needs and a remote monitoring system to ensure surveillance tests are safely monitored.

A number of options were considered to support this approach:

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<thead>
<tr>
<th>Option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do nothing</td>
</tr>
<tr>
<td>2</td>
<td>Supported self-managed pathway - specialist monitors surveillance tests</td>
</tr>
<tr>
<td>3</td>
<td>Self-managed pathway - primary care monitors surveillance tests</td>
</tr>
<tr>
<td>5</td>
<td>Self-managed pathway - external provider monitors surveillance tests</td>
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Option 2 is the preferred option. This option is favoured over other models because:

- it offers higher patient safety. Robust IT solution built specifically for this purpose ensures no patients slips through the net;
- higher rates of referral to open access pathway expected as patient remain under specialist watch rather than primary care or external service;
- easier access to MDT or specialist advice for equivocal or abnormal results;
- patients more likely to accept self-management pathway choice if remaining under ‘specialist supervision’; and
- the do nothing option will rapidly need new resources (consultant sessions and outpatient space) as demand exceeds capacity.

Benefits of a specialist led open access pathway:

**To patients:**
- Follow-up model based on choice;
- Reduced personal costs associated with outpatient attendances;
- More rapid re-access/recall to specialist if needed

**For providers:**
- Improved access times for new referrals;
- Increased time in clinic for those with complex needs;
- Fewer overbooked clinics; and
- Released outpatient capacity.

**For commissioners:**
- More effective use of local outpatient capacity;
- Improved quality of service for local population;
- Improved communication between specialist and community teams;
- Safer service - fewer patients ‘lost to follow up’; and
- Monitoring surveillance tests remains under ‘specialist watch’.

This solution is expected to take 6 months to implement. Investment in a remote monitoring system and other qualitative initiatives are required to safely implement this option. The pathway will offer a return on investment within (insert time).

The capital costs of set up is (insert year 1 capital costs) and has (£ insert) on-going revenue implications.

This proposal has the full support of (insert directorate and or commissioning group).
1. Introduction

This business case proposes the introduction of a supported self-management pathway within (insert cancer specialty areas). This solution requires investment in a remote monitoring solution and a more formalised approach to needs assessment and care planning to ensure that patients offered this pathway are informed and confident to manage their condition without regular face to face contact with the specialist team. The solution enables the release of outpatient capacity and aligns with the local strategy to improve the efficiency and effectiveness of outpatient services.

2. Background Information

There are estimated to be around 2 million (2008) people in the UK living following a diagnosis of cancer. This number is rising by approximately 3% per annum and expected to reach 3 million by 2030 as incidence increases and survival rates improve.

Locally as the number of (insert specialty) cancer survivors increase, so does the number of patients requiring follow up. Without a change in approach further significant investment in resources (clinical, space, support teams) will be required.

The quality, innovation, productivity and prevention agenda calls upon all organisations within the health service to identify and implement more efficient ways of working. Providers and commissioners are required to work across health systems to reduce unnecessary use of resources.

With regard to cancer follow up, while some appointments are clinically indicated, a large proportion are not required and alternative models of care can be delivered whilst still complying with NICE Guidance (Insert reference).

Supporting patients to self-manage develops their ability to actively participate in their follow-up care empowering and building confidence so they have the ability to make decisions concerning their recovery within a supported environment. Patients on an open access pathway are more likely to act promptly to report concerns than those on traditional follow up who often wait for an appointment before reporting abnormal signs.

3. Current position

(Insert trust) sees approximately (insert no:) new referrals per annum. Following treatment the follow up regime involves (insert number) follow up attendances over (insert number) years. There are approximately (insert number) patients in follow up. The annual cost to commissioners of follow up within this specialty is (insert).

On-going surveillance tests (insert) are timed to coincide with follow up appointments where the results are shared with the patient. The health care professional discusses the result with the patient and confirms when the next test and follow up appointment is due. After (insert number) years, surveillance tests cease and the patient is discharged to primary care.
4. Proposed service change

Studies within NHS Improvement test sites\(^1\) and elsewhere have found that with appropriate investment in quality initiatives such as needs assessments and care plans, information and education, approximately (75% breast, 45% colorectal, 30% prostate) of patients are suitable for a supported self-management pathway.

The *(insert directorate)* proposes the same approach. At the end of treatment or at each follow up appointment patients will be triaged, based on agreed criteria, to either a supported self-management pathway or continue to be followed up by the specialist team. For patients stratified to a self-managed pathway, surveillance tests will be scheduled and monitored remotely with results conveyed to the patients and their GP without the need for a face to face appointment.

At the time of decision to transfer to a self-management pathway the patient will be ‘enrolled’ to a remote monitoring system. Patient dataset and diagnostic data will be drawn into the remote monitoring solution from trust existing IT systems. The health care professional will ensure information such as diagnosis, treatment history and other relevant information such as co-morbidity or social circumstances are recorded. They will enter the date/s that the surveillance test is next due setting individual upper limits where appropriate to do so. The next test due date is reset each time a test is completed.

Operationally the responsibility for managing this group of patients rests with the *(insert specialty)* MDT with delegated responsibility under protocol to the *(insert role e.g. Clinical Nurse Specialist)* for the day to day management of patients.

5. Option Appraisal  The following options for offering a self-managed pathway have been considered

<table>
<thead>
<tr>
<th>Option</th>
<th>Description and key issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do nothing</td>
</tr>
<tr>
<td>2</td>
<td>Specialist led open access</td>
</tr>
</tbody>
</table>

\(^1\) NHS Improvement - Stratified Pathways of Care - from Concept to Innovation. Executive Summary. May 2012
3  Primary care led follow up

Low risk patients are assessed at end of treatment are referred to primary care who schedule and monitor all test results. Requires on-going investment in education as treatment and salvage options change. Potential for patients to be ‘lost to follow up’. Often lacks consensus amongst GPs, patients and specialist teams. Capacity issues in primary care.

5  External provider

Low risk patients are assessed attend of treatment and referred to a private contractor who will schedule and monitor all surveillance test results on behalf of primary and specialist services. Requires clear specification and monitoring to ensure safety and quality of service. May not be popular with patients. This option has been removed as no example available.

6. Preferred non-financial option

Based on the following criteria the preferred non-financial option is (insert preferred option).

Options were scored 1-5 (as a team insert your own assessment scores and weightings).

<table>
<thead>
<tr>
<th>Key Criteria</th>
<th>Weighting</th>
<th>Option 1 Do Nothing</th>
<th>Option 2 Specialist led</th>
<th>Option 3 GP led</th>
<th>Option 4 Other provider</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Score</td>
<td>weighted score</td>
<td>Score</td>
<td>weighted score</td>
<td>Score</td>
</tr>
<tr>
<td>Clinical safety</td>
<td>35</td>
<td>3</td>
<td>105</td>
<td>etc</td>
<td></td>
</tr>
<tr>
<td>Impact on cancer</td>
<td>25</td>
<td>1</td>
<td>25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient experience</td>
<td>20</td>
<td>1</td>
<td>25</td>
<td>etc</td>
<td></td>
</tr>
<tr>
<td>Access to specialist</td>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient choice</td>
<td>10</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>100</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

7. Benefits appraisal

The following is an example only. The same cost benefits analysis is required for each option. Seek help from local finance to complete.

7.1 Option 2

<table>
<thead>
<tr>
<th>Year</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IT set up*</td>
<td>£10,000.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IT interface*</td>
<td>£5,000.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Licences and server</td>
<td>£2,000.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IT maintenance and development</td>
<td>£5,000.00</td>
<td>£5,000.00</td>
<td>£5,000.00</td>
<td>£5,000.00</td>
<td></td>
</tr>
<tr>
<td>Remote Monitoring - CNS band 7 (2.5 hrs. per week)</td>
<td>£2,500.00</td>
<td>£2,500.00</td>
<td>£2,500.00</td>
<td>£2,500.00</td>
<td></td>
</tr>
<tr>
<td>Needs assessment and care planning - CNS grade 7 (4hrs per week)</td>
<td>£3,500.00</td>
<td>£3,500.00</td>
<td>£3,500.00</td>
<td>£3,500.00</td>
<td></td>
</tr>
</tbody>
</table>
Admin and clerical support - Band 3 (2 hours per week) | £1,400.00 | £1,400.00 | £1,400.00 | £1,400.00  
Lost income through reduced OP tariff cost | £0.00 | £3,000.00 | £4,000.00 | £5,000.00  
**Total Costs** | **£24,400.00** | **£15,400.00** | **£16,400.00** | **£17,400.00**  
Benefits (to providers) |  
Opportunity costs - released slots for new activity | £0.00 | £10,400.00 | £15,000.00 | £20,000.00  
**Total benefits** | **£0.00** | **£10,400.00** | **£15,000.00** | **£20,000.00**  
Net Cash Flow | £24,400.00 | -£5,000.00 | -£1,400.00 | £2,600.00  
PV | 1 | 0.96 | 0.93 | 0.90  
NPV | -£24,400 | -£4,800.00 | -£1,302.00 | £2,340.00  

NB. The IT costs will depend on the remote monitoring solution selected for which a separate business case may be required.

7.2 Assumptions *(draft examples)*

- the current follow up regime is consistent across all specialty clinicians;
- there is 80% take up of needs assessment at end of treatment;
- ....% of total new patients are stratified to self-management pathway in year 1; released OP capacity is available to offer new services/opportunities;
- some released capacity used to extend clinic times for complex patients;
- no medical staff savings (through released OP slots) transferred to nursing budget; surveillance tests costs covered through block contract not within OP tariff;
- commissioners wish to purchase new activity; and
- no costs have been included for education events or self-management programmes.

The introduction of a specialist led self-managed pathway supported by remote monitoring systems offers quality, safety and efficiency benefits for patients and commissioners. Whilst there will be a consequent reduction in income to provider organisations there will also be opportunity costs arising from released capacity to the wider benefit of the local population.

7.3 Funding source – *(if applicable)* either known or suggested should be identified and an indication of the certainty of funding being made available when required.

7.4 Other benefits of the specialist led self-management pathway

Patient experience and quality:

- longer appointment times available for those with complex needs;
- reduced personal cost to patients associated with outpatient appointments (average £350/5 years); and
- personalised information and education, written care plans and treatment summaries support self-management and increase self-confidence.

Operational Efficiency:

- Released capacity will improve access times for new referrals;
- Potential for application within other specialties in future.

**Staff benefits:**
- Fewer overbooked clinics with less pressure on staff;
- Increased capacity and satisfaction to deliver high quality care to those with complex needs; and
- Increased training opportunities for junior medical staff in managing complex patients.

8. **Risks Analysis**

The following risks and mitigating actions have been identified

<table>
<thead>
<tr>
<th>Ref:</th>
<th>Risk Description</th>
<th>Probability</th>
<th>Impact</th>
<th>Risk score</th>
<th>Mitigation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>No new activity is commissioned as outpatient capacity is released.</td>
<td>1</td>
<td>4</td>
<td>4</td>
<td>Demand for new services increasing. Unless capacity released additional consultant post required within 3 years</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Commissioners will transfer monitoring of tests to primary care in the future.</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>Investment in IT will be utilised to support other specialties where primary care monitoring is not suitable</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Etc</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

9. **Project management arrangements**

Once business case approval is agreed a small project team will be established led by (insert named project lead). Members will reflect the IT component of the project as well as clinical and operational staff representatives. Patients will be co-opted to advise on process and documentation to support system. The project will report to (insert appropriate steering group) group.

Baseline data and on-going measures will be collected to ensure the changes proposed have made an improvement to the patient experience and efficiency of services. A project initiation document will be developed. (Insert high level plan with key components and milestone dates as appendix)

The new pathway will be operational within (insert time based on resources available) of approval to proceed.

10. **Conclusions and recommendations**

The introduction of self-management pathways will improve the efficiency and effectiveness of follow up care for cancer patients. Enabled by a robust remote monitoring solution it will release significant outpatient capacity. The recommendation for a specialist led self-management pathway is cost effective and meets the needs of commissioners.
Appendix C: Patient Information Leaflet on Supported Self-management
Why have you given me this leaflet?
You have been given this leaflet to explain supported self-management follow-up which Trust Name has put in place for patients who have been treated for breast diseases, including cancer.

What is supported self-management follow-up?
Supported Self-management is a new type of follow-up at Trust Name. It is where routine, clinical examination type 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 have you introduced supported self-management?
We have introduced supported self-management follow up as it has been shown to be better for patients. It means that you don't have to make unnecessary trips to the hospital at times when you are feeling perfectly well.

Patients often find traditional clinical appointments are a source of anxiety and can lead to them being tempted to put off reporting worrying signs and symptoms if a routine clinical appointment is 'not too far away.'

Also, it's been proved that new problems are unlikely to be picked up by clinical examination alone. Most are identified by patients themselves, in between routine appointments.

Is TRUST NAME the only hospital to have supported self-management follow-up?
No (although it may be called different things in different places). More and more hospitals across the country are changing the way patients are followed up after treatment for breast cancer. For example, Hillingdon and Addenbrookes Hospitals have ‘patient-led follow-up’, and have been rolling it out successfully for many years.

What information will I be given?
In addition to this leaflet, you will have a consultation at the end of your treatment 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 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
- The process your breast care nurse will follow if you need to be booked back into clinic at any time in the future.

Will I still be able to access the breast service in the event of concerns?
Yes. You can call the breast care nurses 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 you will be called back by your breast care nurse within XX hours. 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. These will be organised via your GP who will receive clear instructions on what you need.

**How the Helpline works**
At the end of your treatment, you will have a special consultation with your doctor or breast care nurse. During this appointment, they will explain exactly how the Helpline works, teach you the signs and symptoms that you need to watch out for and give you the direct telephone number on which you can contact her with any symptoms or concerns.

If you need to ring this number, please leave a short message including your **name, hospital number and telephone number** on the answer phone. This is checked regularly from Monday to Friday between 9am and 5pm and you will be phoned back by the breast care nurse **within XX hours.**

Your breast care nurse will talk through with you the symptoms or concerns that you have and decide with you whether you need to be brought back into clinic or have any further diagnostic tests. If she feels this is necessary then you will be offered a clinic appointment within 14 days of phoning the Helpline.
Living with and Beyond Cancer Board

IT Remote Monitoring System: Functionality requirements and options appraisal

Sharon Cavanagh
July 2014
Introduction

Integral to the successful implementation of stratified model of follow-up is the setting up of a robust IT remote monitoring system. Remote monitoring assists the specialists to schedule and review surveillance tests for patients who have completed treatment for cancer, without the need for a face to face outpatient appointment to convey the result. Its primary role is to support low risk patients treated with curative intent who are suitable to be supported on a self-managed pathway. Therefore, a key enabler for testing and implementing stratified pathways of care is access to a safe reliable IT system that enables clinicians to schedule and monitor surveillance tests (such as mammograms, CT scans, colonoscopies).

Functionality requirements of the remote monitoring system

Stratified follow-up national pilot sites have identified the required functionality of IT systems to ensure that remote monitoring can effectively take place. The system needs to house sufficient information to enable the clinician to manage the patient without the need to access case notes.

Other functions of the system are as follows:

1. To pull patient data set information from PAS via the local cancer information system
2. To pull test results from local diagnostic IT systems
3. To store key diagnostic and key patient history data
4. To log any relevant treatment history during monitoring period including a log of patient contacts
5. To set individual patient range/tolerances for specific tests
6. To schedule tests based on user definable follow up schedules
7. To hold a range of template letters to enable communication of results to patients and GPs by post or electronically
8. To include an alert system that identifies test results for review, due dates exceeded or test result that exceed tolerance
9. To provide a summary history and treatment page with test results shown numerically and graphically to record the outcome of any event or test
10. To provide standard and ad hoc reporting and routine monitoring function and be amenable to clinical audit
11. To be NHS and HL7 compliant with secure access
12. To use a common file format for all data export to be able to import the data into local IT systems if required

Options Appraisal

In addition to defining the functionality, NHS Improvement developed an options appraisal for services to make local decisions with regards to how to best take this forward. This information was published in 2013 in a document titled ". We have outlined these options below:

Option 1 - Use functionality within existing IT systems

Many IT systems have scheduling and monitoring systems available within them and may only require small adjustments to accommodate the needs for remote monitoring. IT leads or system providers will be able to provide advice on the local system capability. For example, CIMS (Clinical Information Management Systems) who supply InfoFlex have developed remote monitoring capability within their system.

Pros
• Existing familiarity of use with staff.
• Fewer interface requirements than other options.
• On-going support through existing service contracts.
• Send and receive data capability.
• Flexibility to suit local needs, e.g. audit.
• Speed of implementation.
• Less likely to require business case approval.

Cons
• May require additional licenses.
• Existing staff often do not utilise local IT system.
• System provider consultancy costs to support implementation.

Option 2 – Develop a bespoke remote monitoring solution

This suits organisations where there is local IT development team skill and capacity or local restrictions on use of external software.

Pros
• Local ownership and development.
• Fit with existing IT architecture.
• No external maintenance costs.

Cons
• Long lead in time for development (allow three months from approval and three months to test and implement).
• Existing IT workload can delay development and implementation.

Option 3 – National Cancer Survivorship Initiative (NCSI) solution

NHS Improvement, North Bristol NHS Trust (NBT), Royal United Hospital Bath and national clinical advisors have developed a remote monitoring solution to support prostate and colorectal cancer. Both modules are designed to interface with the local cancer registry and diagnostic systems such as pathology, radiology and endoscopy systems. Within each module the specialist can view all their patients with a diagnosis of prostate or colorectal cancer. Once selected for enrolment to a self-managed pathway, the specialist enters diagnostic details, treatment and relevant drug therapy, comorbidity and any other relevant information. Test results are automatically drawn into the modules and displayed numerically, graphically or as text. Standard outcome letter templates are generated from the system to send to the patient and the GP. Maintenance and development of the NCSI system is available to sites through a service level agreement (currently £5,000 per annum) with North Bristol NHS Trust. Assistance with local installation is also available on request.

Pros
- Available to any NHS organisation.
- Capable of interface with any IT system.
- No license issues.
- Remote installation of system including any future upgrades.
- Recent upgrade (March 2013).

Cons
- Importing external solutions may not align with local IT strategy.
- Requires server capacity.
- ‘Virtual clinics’ are still required on PAS to capture activity data.
- Annual cost of £5000.

Option 4 – Primary care solution

Examples exist of primary care based IT systems for monitoring surveillance tests. Whilst these have not been tested by the NCSI there are systems available as an option for those considering a primary care based solution.

Pros
- Care transferred closer to home.
- Potential reduction in cost to commissioners.
- Releases maximum capacity within secondary care.

Cons
- Not viable by individual practice due to the small patient numbers. A clinical commissioning group option might be feasible.
- Professional education required to establish and maintain disease knowledge base.
- Reaching GP consensus to manage surveillance tests.
- Less immediate access to specialist for advice on abnormal or equivocal results.
- Manual entry of enrolment data.
Option 5 – National breast screening system (NBSS) – mammography only

Set up a parallel recall system for breast cancer patients who require annual mammograms. This is the same as, but separate to, the national breast screening programme and mirrors the model set up for managing high risk familial patients who require annual rather than three yearly mammograms.

Pros
- Excellent clinical governance.
- Very low risk of patients being missed as processes, system and staff involved are the same as those delivering the national breast screening service.

Cons
- Limited use as does not link to radiology information systems.
- Set up and license costs.
- Implementation more difficult for non-screening sites.
- System cannot be adapted without NBSS approval.
- Unsuitable for use through mobile units.

Contact: David Soloman at Temenos for further information on this option dsolomon@temenos. Temenos are the IT suppliers for the national breast screening system.
Why are you sending me this leaflet?
You are being sent this leaflet because your patient, after having treatment for breast cancer at our hospital, has had their follow-up clinical review appointment with one of our consultants and a breast care nurse, and has been started on a supported self-management (SSM) follow-up pathway.

What is supported self-management follow-up?
It is a new form of follow-up at Trust Name. Supported self-management replaces routine, clinical examination type appointments with a system where patients can call us if they have a problem and don’t have to come to hospital at times when they are feeling well.

Why are you changing to supported self-management follow-up?
We have changed our system of follow-up because it is better for patients. It enables them to be more in charge of their own follow-up and prevents unnecessary hospital visits at a time when they may feel perfectly well. Patients often report that traditional clinical examination type follow-ups are a source of anxiety and can lead to them being tempted to put off reporting symptoms of concern if a routine clinical appointment is “not too far away”. Also, evidence shows that most recurrences are identified by patients themselves in between routine appointments.

Are you the only hospital to have a supported self-management model of follow-up?
No (although it may be called different things in different places). More and more hospitals across the country are changing the way patients are followed up after treatment for breast cancer.

What information has my patient been given?
They have had a consultation which covered the following topics:
- Their diagnosis
- The treatment they had and some of the possible side effects
- Signs and symptoms to report
- Being body and breast aware
- Arrangements for mammograms and bone density scans (if appropriate)
- Where to find further help and support,
- They have also been given written information on these topics.

Will my patient still be able to access the breast service?
Yes. Patients will be able to call the dedicated Helpline (XXXXXXXXX) if they have any queries or problems, and they are encouraged to do so. This telephone number is monitored regularly between 0900 and 1700, Monday to Friday and the patient will be phoned back by a breast care nurse within timescale of leaving a message. If the breast care nurse feels that it would be appropriate for the patient to come back to clinic to be seen, an appointment will be offered within 14 days of the telephone call.

How does this affect me?
It is unlikely that you will need to do anything different than you would already do for your patients after they have completed treatment for breast cancer. The attached letter and treatment summary gives details of the medication that you will need to continue to prescribe for your patient, as well as any additional tests that you may need to arrange for them.

Will my patient continue to have routine mammograms?
Yes. Unless it has been otherwise specified on the letter we have sent you, they will need annual mammograms for at least 5 years. At the end of 5 years, they will rejoin the standard NHS Breast Screening Programme, or if they are still below 50 years, they will continue to have annual mammograms until they reach 50, when they will join the national screening programme.

What about bone density scans?
If your patient requires bone density scans (DEXAs) this will be indicated in the letter and treatment summary attached. You will need to arrange these locally at the timescales indicated.
What is the document that you have sent me with this leaflet?
We have enclosed a copy of the patient treatment summary to inform you of the medication you will need to prescribe for your patient and the start and finish dates for this. You can keep this for your records. Your patient also has this information.

What you need to do

- Follow the attached endocrine options treatment sheet to ensure your patient continues with the correct medication regime.
- If your patient requires bone density scan, please book these for them. The letter and treatment summary you received with this leaflet will tell you if this is necessary.
- Please encourage your patient to contact the Helpline xxxxxxx, if they have any symptoms that could indicate a return of their cancer.

Signs and Symptoms to report:
The following is a reminder of the signs and symptoms to keep in mind when treating patients who have previously had breast cancer. These symptoms could indicate a return or spread of the disease and need further investigation.

- A lump or swelling in the breast, in the skin after a mastectomy, above the collar bone, in the neck, or under the arm
- Any skin changes, red areas or raised spots on the breast or mastectomy scar
- Nipple discharge
- Development of lymphoedema
- Any new, persistent pain in any part of the body, especially in the back or hips, that does not improve with painkillers
- Unexplained weight loss and a loss of appetite
- A constant feeling of nausea
- Discomfort or swelling under the ribs or across the upper abdomen
- A dry cough or a feeling of breathlessness
- Severe headaches – usually worse in the morning.
- Any abnormal neurology e.g. pins and needles and/or a loss of sensation or weakness in the arms or legs might suggest underlying spinal cord compression and urgent referral to the metastatic spinal cord compression co-ordinator should be considered.

Created: 
Review date:

A New Model of patient Follow-Up after Breast Cancer Treatment

SUPPORTED SELF-MANAGEMENT FOLLOW-UP

Information for GPs

Helpline: (xxxxxxxxxxxxx)

Trust Name

Trust Address
Appendix F: GP Clinical Template Letter – Includes Treatment Summary, Endocrine Treatment Options and Bone Health Monitoring Guidance
Supported Self-management Follow-Up for Breast Cancer Patients

Today’s Date:

Patient Name: ___________________________ DOB: ___________________________

Hospital Number: ___________________________ NHS Number: ___________________________

Dear Dr ……………………………………………………

I am writing to you to let you know that your patient, after having treatment for early breast cancer at [Trust Name], is now on our supported self-management follow-up programme.

They have had a consultation which covered the following topics:
  • Their diagnosis and prognosis
  • The treatment they have had, any ongoing treatment, and possible side effects
  • Signs and symptoms to report
  • Being breast aware
  • Mammograms and MRI scans (for those at high genetic risk)
  • Bone density scans (if required)
  • Where to find further help and support – including how to contact the dedicated helpline if they have any concerns

Please find enclosed a copy of their treatment summary which outlines what was discussed with them. Your patient also has a copy of this.

As part of your patient’s ongoing care, they will need:

☐ Annual mammograms for a period of 5 years. The patient will be contacted directly with an appointment and results fed back to you and the patient directly. At the end of the 5 years of annual mammograms, your patient will return to the normal NHS Breast Screening Programme if they are aged 50 or above. If they are below this age, they will continue to receive annual mammograms until they reach the national screening age.

At any point during the 5-year follow-up pathway, patients may be contacted to be offered access to any relevant clinical trials that may become available.

At the end of 5 years, [insert patient name] will be discussed in a virtual MDT in order to update any ongoing treatment regimes in light of latest evidence. Any plans from this review will be actioned and a letter will be sent to both you and the patient to provide information regarding any changes and to discharge them from the trust supported self-management pathway.

For any queries, please contact our Breast Cancer Team on [insert specialist team number]

Signed: …………………………………………………… Contact Tel no. ………………………………………

Name (please print) ………………………………………………………………………
ENDOCRINE OPTIONS

Your patient is on one of the following treatment regimes. Please follow the prescribing instructions below:

<table>
<thead>
<tr>
<th>Option 1: Premenopausal or postmenopausal but aromatase inhibitor contraindicated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tamoxifen 20 mg OD for 5 years. Start date:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Option 2: Postmenopausal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aromatase inhibitors for 5 years. Start date:</td>
</tr>
<tr>
<td>(usually letrozole 2.5mg od)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Option 3: Postmenopausal*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tamoxifen 20mg OD for 2 years, then 3 years aromatase inhibitors (Exemestane 25mg od)</td>
</tr>
<tr>
<td>Tamoxifen start date:</td>
</tr>
<tr>
<td>End treatment on:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Option 4: Premenopausal at diagnosis, but may become postmenopausal*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tamoxifen for 2.5 years then consider switch to aromatase inhibitors (Exemestane 25mg od). At end of 2.5 years, stop Tamoxifen for 3 months and check LH/FSH to ascertain menopausal status. If patient is pre-menopausal, continue Tamoxifen for 5 years. If patient is post-menopausal, change to Exemestane. Follow prescribing timescales indicated below:</td>
</tr>
<tr>
<td>Tamoxifen start date:</td>
</tr>
<tr>
<td>Exemestane start date</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Option 5: Premenopausal at diagnosis, but may become postmenopausal*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tamoxifen for 5 years and if then aged 47-55, patient should be considered for aromatase inhibitors – Letrozole (extended therapy for 5 years). At end of 5 years, stop Tamoxifen for 3 months and check LH/FSH to ascertain menopausal status. If patient is post-menopausal, change to Letrozole. If remains pre-menopausal, then stop Tamoxifen. Follow prescribing timescales indicated below:</td>
</tr>
<tr>
<td>Tamoxifen start date:</td>
</tr>
<tr>
<td>Start extended therapy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Option 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other – please specify details below:</td>
</tr>
<tr>
<td>............................................................</td>
</tr>
<tr>
<td>............................</td>
</tr>
<tr>
<td>............................................................</td>
</tr>
</tbody>
</table>

*NB – Any patient changing to aromatase inhibitors will need a baseline bone density scan. Please check the bone density result and arrange appropriate investigations / supplementation as necessary |
Postmenopausal Women Receiving an AI (adapted from NCRN Guidelines)

Algorithm for assessment of bone health in patients with breast cancer who are started on an aromatase inhibitor

Risk factor assessment
- Previous fragility #
- Parental history of fragility #
- BMI < 22
- Alcohol > 4 units/day
- Premature menopause
- Rheumatoid arthritis
- Ankylosing spondylitis
- Crohn's disease
- Immobility
- Oral steroids

Blood tests to exclude secondary osteoporosis
- FBC
- UE
- LFT
- Bone profile
- TFT
- Vitamin D

Treat underlying cause as appropriate

Vitamin D replacement
Deficiency (<30)
Load with cholecalciferol 100,000 IU OD for 2/7
Or ergocalciferol 300,000 IU IM stat
Maintenance cholecalciferol 1000 IU OD (<25mcg)
Insufficiency (30-80)
Treat as per maintenance

Lifestyle advice
- Healthy diet: Adequate dietary calcium (700mg/day) and Vitamin D intake (400IU/day)
- Sun exposure (10 mins to face + arms twice/day in summer months)
- Weight-bearing exercise (30 mins three times/week)
- Smoking cessation
- Reduce caffeine intake
- Measures to reduce falls risks

≥75

< 75

RF assessment
DEXA

≤-2.0 or
-1.5 ≤ T < -1.0
MEDIUM RISK

-2.0 < T < -1.0
LOW RISK

Lifestyle advice
Adcal D3 x2/day
Lifestyle advice
Adcal D3 x2/day
Lifestyle advice
Repeat DEXA two years
No further DEXAs
Dear Dr X

Re: Add in patient name, address, date of birth and record number

Your patient has now completed their initial treatment for cancer and a summary of their diagnosis, treatment and on-going management plan are outlined below. The patient has a copy of this summary.

<table>
<thead>
<tr>
<th>Diagnosis:</th>
<th>Date of Diagnosis:</th>
<th>Organ/Staging</th>
<th>Local/Distant</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Summary of Treatment and relevant dates:</th>
<th>Treatment Aim:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Possible treatment toxicities and / or late effects:</th>
<th>Advise entry onto primary care palliative or supportive care register</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes / No</td>
</tr>
<tr>
<td></td>
<td>DS 1500 application completed</td>
</tr>
<tr>
<td></td>
<td>Yes/No</td>
</tr>
<tr>
<td></td>
<td>Prescription Charge exemption arranged</td>
</tr>
<tr>
<td></td>
<td>Yes/No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Alert Symptoms that require referral back to specialist team:</th>
<th>Contacts for re referrals or queries:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>In Hours:</td>
</tr>
<tr>
<td></td>
<td>Out of hours:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Secondary Care Ongoing Management Plan: (tests, appointments etc)</th>
<th>Other service referrals made: (delete as nec)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>District Nurse</td>
</tr>
<tr>
<td></td>
<td>AHP</td>
</tr>
<tr>
<td></td>
<td>Social Worker</td>
</tr>
<tr>
<td></td>
<td>Dietician</td>
</tr>
<tr>
<td></td>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td></td>
<td>Psychologist</td>
</tr>
<tr>
<td></td>
<td>Benefits/Advice Service</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Required GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

| Summary of information given to the patient about their cancer and future progress: |
|                                                                                   |

| Additional information including issues relating to lifestyle and support needs: |
|                                                                                  |

Completing Doctor:   Signature:   Date:
GP READ CODES FOR COMMON CANCERS (For GP Use only). Other codes available if required. (Note: System codes are case sensitive so always ensure codes are transcribed exactly as below).

<table>
<thead>
<tr>
<th>System 1</th>
<th>(5 digit codes)</th>
<th>All other systems</th>
<th>Version 3 five byte codes (October 2010 release)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diagnosis:</strong></td>
<td></td>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Lung Malignant Tumour</td>
<td>XaOKG</td>
<td>Malignant neoplasm of bronchus or lung</td>
<td>B22z.</td>
</tr>
<tr>
<td>Carcinoma of Prostate</td>
<td>X78Y6</td>
<td>Malignant neoplasm of prostate</td>
<td>B46..</td>
</tr>
<tr>
<td>Malignant tumour of rectum</td>
<td>XE1vW</td>
<td>Malignant neoplasm of Rectum</td>
<td>B141.</td>
</tr>
<tr>
<td>Bowel Intestine</td>
<td>X78gK</td>
<td>Malignant neoplasm of Colon</td>
<td>B13..</td>
</tr>
<tr>
<td>Large Bowel</td>
<td>X78gN</td>
<td>Malignant neoplasm of female breast</td>
<td>B34..</td>
</tr>
<tr>
<td>Female Malignant Neoplasia</td>
<td>B34..</td>
<td>Malignant neoplasm of male breast</td>
<td>B35..</td>
</tr>
<tr>
<td>Male Malignant Neoplasia</td>
<td>B35..</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Histology/Staging/Grade:</strong></td>
<td></td>
<td>Histology/Staging/Grade:</td>
<td></td>
</tr>
<tr>
<td>Tumour grade</td>
<td>X7A6m</td>
<td>Tumour staging</td>
<td>4M..</td>
</tr>
<tr>
<td>Dukes/Gleason tumour stage</td>
<td>XaOLF</td>
<td>Gleason grading of prostate Ca</td>
<td>4M0..</td>
</tr>
<tr>
<td>Recurrent tumour</td>
<td>XaOR3</td>
<td>Recurrence of tumour</td>
<td>4M6..</td>
</tr>
<tr>
<td>Local Tumour Spread</td>
<td>X7818</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mets from 1°</td>
<td>XaFr.</td>
<td>Metastatic NOS</td>
<td>BB13.</td>
</tr>
<tr>
<td><strong>Treatment:</strong></td>
<td></td>
<td>Treatment</td>
<td></td>
</tr>
<tr>
<td>Palliative Radiotherapy</td>
<td>5149.</td>
<td>Radiotherapy tumour palliation</td>
<td>5149.</td>
</tr>
<tr>
<td>Curative Radiotherapy</td>
<td>XalpH</td>
<td>Radiotherapy</td>
<td>7M371</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>x71bL</td>
<td>Chemotherapy</td>
<td>8BAD.</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>Xa851</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Treatment Aim:</strong></td>
<td></td>
<td>Treatment Aim:</td>
<td></td>
</tr>
<tr>
<td>Curative procedure</td>
<td>Xallm</td>
<td>Curative treatment</td>
<td>8BJ0.</td>
</tr>
<tr>
<td>Palliative procedure</td>
<td>Xail3</td>
<td>Palliative treatment</td>
<td>8BJ1.</td>
</tr>
<tr>
<td><strong>Treatment toxicities/late effects:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Osteoporotic #</td>
<td>Xa1TO</td>
<td>At risk of osteoporosis</td>
<td>1409.</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>XaELC</td>
<td>Osteoporosis</td>
<td>N330.</td>
</tr>
<tr>
<td>Infection</td>
<td>Xa9ua</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ongoing Management Plan</strong></td>
<td></td>
<td>Ongoing Management Plan</td>
<td></td>
</tr>
<tr>
<td>Follow up arranged (&lt;1yr)</td>
<td>8H8..</td>
<td>Follow up arranged</td>
<td>8H8..</td>
</tr>
<tr>
<td>Follow up arranged (&gt;1yr)</td>
<td>XaL..</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No FU</td>
<td>8HA1.</td>
<td>No follow up arranged</td>
<td>8HA..</td>
</tr>
<tr>
<td>Referral PRN</td>
<td>8HAZ.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Referrals made to other services:</strong></td>
<td></td>
<td>Referrals made to other services:</td>
<td></td>
</tr>
<tr>
<td>District Nurse</td>
<td>XaBsn</td>
<td>Refer to District Nurse</td>
<td>8H72.</td>
</tr>
<tr>
<td>Social Worker</td>
<td>XaBsr</td>
<td>Refer to Social Worker</td>
<td>8H75.</td>
</tr>
<tr>
<td>Nurse Specialist</td>
<td>XaAgq</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SALT</td>
<td>XaBT6</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Actions required by the GP</strong></td>
<td></td>
<td>Actions required by the GP</td>
<td></td>
</tr>
<tr>
<td>System 1</td>
<td>(5 digit codes)</td>
<td>All other systems</td>
<td>Version 3 five byte codes (October 2010 release)</td>
</tr>
<tr>
<td>----------</td>
<td>----------------</td>
<td>-------------------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td>Tumour marker monitoring</td>
<td>Xalqg</td>
<td>Tumour marker monitoring</td>
<td>8A9..</td>
</tr>
<tr>
<td>PSA</td>
<td>Xalqh</td>
<td>PSA</td>
<td>43Z2.</td>
</tr>
<tr>
<td>Osteoporosis monitoring</td>
<td>XalSd</td>
<td>Osteoporosis monitoring</td>
<td>66a..</td>
</tr>
<tr>
<td>Referral for specialist opinion</td>
<td>Xalst</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advised to apply for free prescriptions</td>
<td>9D05</td>
<td>Entitled to free prescription</td>
<td>6616.</td>
</tr>
<tr>
<td>Cancer Care Review</td>
<td>Xalyc</td>
<td>Cancer Care Review</td>
<td>8BAV.</td>
</tr>
<tr>
<td>Palliative Care Review</td>
<td>XalG1</td>
<td>Palliative Care Plan Review</td>
<td>8CM3.</td>
</tr>
</tbody>
</table>

**Medication:**

| New medication started by specialist | XEOhn | Medication given | 8BC2. |
| Medication changed by specialist | 8B316 | Medication changed | 8B316 |
| Advice to GP to start medication | XaKbF | | |
| Advice to GP to stop medication | XaJC2 | | |

**Information to patient:**

| DS1500 form claim | XaCDx | DS1500 completed | 9EB5. |
| Benefits counselling | 6743. | Benefits counselling | 6743. |
| Cancer information offered | XalmL | Cancer information offered | 677H. |
| Cancer diagnosis discussed | XalpL | Cancer diagnosis discussed | 8CL0. |
| Aware of diagnosis | XaQly | | |
| Unaware of prognosis | XaVzE | | |
| Carer aware of diagnosis | XaVzA | | |

**Miscellaneous:**

| On GSF palliative care framework | XaJv2 | On GSF Palliative Care Framework | 8CM1. |
| GP OOH service notified | Xaltp | GP OOH service notified | 9e0.. |
| Carers details | 9180. | Carer details | 9180. |