Surrey & Sussex Cancer Alliance

Guidance for the Implementation of Supported Self-Management Pathways for Early Breast Cancer

Version 0.4

June 2019

Key Inputs (Support)	Name	Role / Organization	Date
Detail inputs that have been sought in developing this document. This will depend on the exact nature of the proposal but could include:			
Clinical assurance			
Operational assurance			
Quality assurance			

Document Control:

Version	Date	Details/provenance/comments	Author	Sent to
0.1	10.12.18	First draft	MT/AP/SB/AW/CZ	SSCA Breast Leads
0.2	14.01.19	Second draft based on comments from LWBC Board and Breast MDM	MB/MT	SSCA LWBC Board
0.3	May 2019	Minor edits	SB	SSCA LWBC Clinical leads
0.4	June 2019	Minor edits	MT	

Surrey and Sussex Cancer Alliance: Guidance for the implementation of Supported Self-Management Pathways in Breast Cancer Patients.

Contents:

Appendices

1. Introduction

In 2015, there was an estimated 2.5 million people living with cancer across the UK. By 2030, that number is estimated to reach around four million. There is increasing evidence that the current arrangements for follow up do not meet all of the needs of those living with the consequences of their cancer, and its treatment. Support for patients living with a cancer diagnosis should be centred on the individual to address their specific needs. Delivered at the right time, in the right way to both support and empower. There is a fundamental difference between living with a cancer diagnosis and living well.

In July 2015, the Independent Cancer Taskforce published their strategy for achieving the best clinical outcomes for cancer in England by 2020. An important component of this strategy is to transform the approach to living with and beyond cancer, and to put patient experience on a par with clinical effectiveness and safety. This is embodied in the Living With and Beyond Cancer agenda for Surrey and Sussex Cancer Alliance, with a focus on Personalised care and Stratified Follow-Up Pathways for patients who have completed active cancer treatment. The National target is for all Trusts to have full implementation of breast cancer personalised (stratified) follow up protocols by March 2020.

The main aims of follow-up after cancer treatment are to monitor for disease recurrence and to ensure patients are provided with information, support and reassurance to enable them to self-manage and live well beyond their cancer diagnosis and treatment. There is little evidence that intensive follow up with regular outpatient appointments in secondary care improves the recurrence detection rate or overall survival. Traditional models of follow up are not only expected to be unsustainable due to increasing pressure on available resources, but also may not completely meet the distinct and variable needs of patients who have completed cancer treatment. There is a need for a culture shift moving away from traditional medical models of care focusing on ill-health towards a patient-centred model focusing on health and well-being which may be delivered across a range of providers as part of a whole system approach.

Stratified Follow-up is a model of aftercare service to ensure individual patients are managed on the best follow-up pathway to address their specific needs. It focuses on promoting wellbeing, recovery and empowerment to provide patients with the information and confidence for self-management. The overall aim is to improve patient experience and quality of care, by implementing a personalised, tailored approach to aftercare for each individual patient.

This document describes the Stratified Follow-Up pathway for early breast cancer patients in Surrey and Sussex, where there are 2 clearly defined follow-up pathways - Shared Care and Supported Self-Management (Fig 1). This document contains guidelines for the implementation of the Supported Self-Management pathway to ensure that:

- Patients will receive the appropriate information and support to enable self-management following completion of their cancer treatment.

- There is a clear, safe and robust system for managing the surveillance programme and on-going care.

- There is capacity for rapid-re-entry into specialist services in the event of any concern raised by the patient or clinical team (including primary care and community services)

This document can be used as a resource to assist individual providers and commissioners to plan, agree and implement Stratified Follow up locally, which may incorporate a whole system approach involving secondary care, primary care and community services.

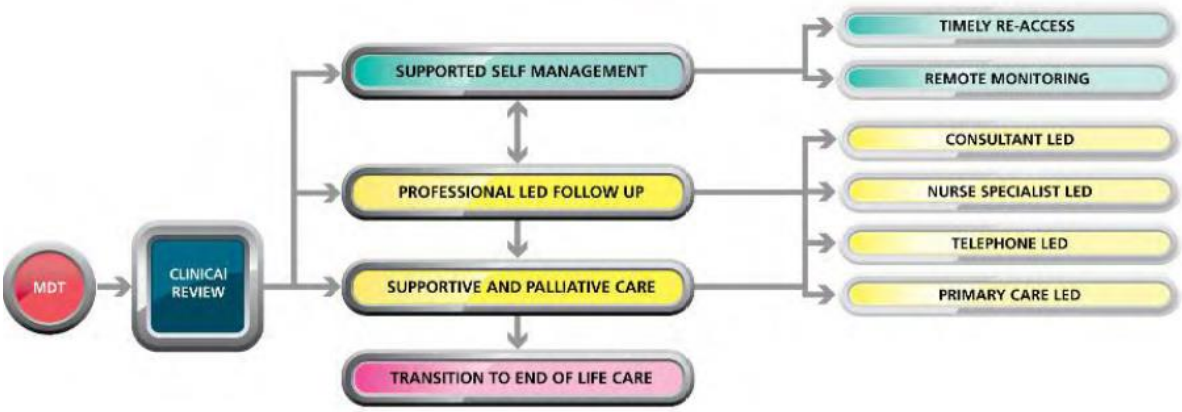

Fig 1: Self-management pathway. NHS Improvement 'How to' guide.

2. Purpose

The purpose of this document is to set out the guidelines for Stratified Follow Up for patients who have completed treatment for early breast cancer. It will define the Supported Self Management pathway, roles and responsibilities of staff in regard to Supported Self Management follow up and the system for monitoring compliance and improvement.

3. Eligibility for Supported Self-Management

The key consideration for entry into the Supported Self-Management Follow-Up pathway is the patient's ability to self-manage. All patients who have completed treatment for early breast cancer could be considered for entry into Supported Self-Management. However, the final decision regarding entry should be conducted in collaboration with the patient.

Exclusion Criteria:

- Patients who are unable to self-manage - this will be a joint decision between the patient and health care professional.
- Patients on clinical trials*

*For patients participating in clinical trials, follow-up will be determined by the clinical trial protocols. Patients taking part in trials will still access and benefit from the end of treatment clinical review and Health and Wellbeing information and support (Section 4.4).

It is recommended that the decision for entry into Supported Self-Management should be confirmed and agreed by the Multidisciplinary Team (MDT).

4. Stratified Follow-Up Process

4.1 End of Treatment Clinical Review

At the end of treatment, all patients should receive an ‘End of Treatment’ clinical review with their Consultant or Breast Care Nurse. During this appointment, there should be a discussion between the Clinical team and the patient regarding which form of follow up would best meet their needs.

The decision regarding method of follow up should be formalised and included in the Treatment Summary which should be completed by the Clinical team and sent to the patient and GP (Appendix III). The Treatment Summary should include a personalised plan for future mammographic surveillance and endocrine treatment (if relevant).

It is recommended that the patient is provided with verbal and written information regarding the following:

- Possible treatment toxicities, including late and long term consequences of treatment
- Alert symptoms or signs that require re-access to the specialist team
- Breast awareness, including self-examination techniques
- Information about communication about future mammograms and results
- DEXA scans
- Dates associated with anti-cancer medication/ hormone therapy and common side effects of treatment
- Contact names and numbers of the Supported Self-Management clinical team and helpline
- Health and Wellbeing information and support
- Any local self-help groups and useful contact numbers for other organisations e.g. Macmillan Cancer Support, Breast Cancer Care

Further information can be found in Appendix II.

Patients should be offered a Breast Care Nurse Consultation within 3-6 months of their end of treatment. This is an important opportunity to conduct a Holistic Needs Assessment review, which will guide any additional information, support or signposting required at this point. The model of delivery may vary according to the individual patient’s needs and provider choice, but may be in the form of a:

- Face to face consultation e.g. small group session or one-to-one
- Telephone consultation

4.2 Shared Care Pathway

Patients on a Shared Care Pathway will be booked for routine outpatient clinic appointments in Secondary Care, according to local protocol and individualized to their diagnosis and needs. Surveillance investigations will be organised according to local and national guidelines (Section 5).

It is important for patients on the Shared Care Pathway to have the same information and support as patients in Supported Self-Management to ensure they are able to highlight any concerning symptoms and access the specialist team quickly. They should also benefit from access to any Health and Wellbeing events.

4.3 Supported Self-Management Pathway

Patients on the Supported Self-Management Pathway will not be booked for routine clinic appointments. They will have access to a helpline (telephone/email) and are encouraged to contact this number/address as needed for any concerns. Patient contacts via the helpline should be answered and triaged promptly. Outcomes may include:

- Face-to-face consultant appointment within 2 weeks
- Face-to-face nurse-led appointment (where appropriate)
- Advice to contact GP
- Advice to attend Emergency Department (where appropriate)
- Telephone advice
- Signposting support to other agencies/departments (e.g. AHP, Psychology)

Contact outcomes should be documented clearly in the patients' notes and any electronic databases as required.

Surveillance investigations will be organised according to local and national guidelines. There should be a robust and safe mechanism for remote ordering of investigations and tracking of results (Section 5).

4.4 Health and Wellbeing

Health and Wellbeing information and support is an important component of Stratified Follow up. The main aims are to promote healthy living and provide individuals with the information and confidence to enable them to lead as normal and active life as possible after their cancer treatment. It is also aimed at increasing awareness of the local facilities, supportive care and opportunities that are available to them and their families.

The provision of Health and Wellbeing information and support will vary according to locally agreed models and patient need, but may be in the form of:

- One-to-one appointments
- Rolling programmes e.g. 'Moving On' course
- Group events – these can be scheduled at regular intervals and which patients may have an open invitation to attend if they choose to do so. These events are often a good opportunity for interaction between patients and carers, clinicians, clinical nurse specialists, allied health professionals and complementary therapists. It is also possible to include market stalls of local health promotion services or voluntary agencies.

It is recommended that the core content of Health and Wellbeing information and support include the following:

- Advice on health promotion to support healthy living and reduce risk of recurrence. This can include topics such as physical activity, nutrition, healthy weight management and smoking cessation.
- Advice on adjusting to life after treatment
- Information on signs and symptoms of recurrence, and potential consequences of treatment
- Support to ensure patients have confidence and skills to manage their condition. Examples include referral to rehabilitation and psychological support services, signposting to local support groups

- Information and access to financial and benefits advice
- Specific issues relevant to cancer type and how to access to support e.g. lymphoedema, body image and sexual function
- Vocational rehabilitation

4.5 Discharge from Stratified Follow up

At the end of five years from the point of entry onto either the Supported Self Management or Shared Care pathway, the patient will be considered for discharge back to primary care.

It is recommended that all patients planned for discharge from follow up should be reviewed and discussed by the MDT to confirm if any on-going treatment is indicated (e.g. extended endocrine therapy) and if any further surveillance investigations are required.

The MDT-agreed individualised discharge plan should be sent to both the patient and the GP.

5. Surveillance Investigations

All patients should have their surveillance investigations recorded on a secure, electronic database. There is a requirement for developing and implementing a robust mechanism for monitoring of investigations, including ordering, checking and tracking of results.

All patients should have at least 5 years of annual mammograms commencing on the anniversary of their diagnosis (unless the consultant indicates otherwise). After 5 years of mammography surveillance, patients will transfer back to the NHS breast screening programme. For younger patients, annual mammographic surveillance should continue until they reach the age of 50 years, at which point they can be discharged back to the NHS screening programme.

A safe mechanism of requesting and tracking mammogram results should be developed and implemented. Results should be sent directly to the patient and GP. If results are reported as abnormal, there should be a robust process for notifying the patient and rapid re-access to specialist care for further assessment/investigations.

Patients will be aware of when their mammography surveillance is due from their Treatment Summary letter. There should be a robust mechanism for tracking and identifying patients who have missed their appointments. It is recommended that each provider should clearly outline which team member is responsible for resolving any issues in relation to missed appointments.

There may be cases where additional surveillance imaging (e.g. MRI) is indicated. This should be discussed and agreed by the MDT at the point of entry to Stratified Follow up, and clearly documented in the patient’s Treatment Summary.

Bone health monitoring (with bone density scans) should be organised according to local and national guidelines.

6. Clinical Governance

This document is offered by Surrey and Sussex Cancer Alliance as a common framework for use in all provider sites. This document will be reviewed annually or following significant change to the recommendations. Local implementation must be subjected to individual Trusts' internal governance processes and reviewed according to local policies. Where a system wide approach exists across providers, a clear governance framework should be agreed across the whole pathway with clearly defined roles and responsibilities.

The named Clinical leads from each provider site will be responsible for the clinical governance of the Stratified Follow up pathways and for monitoring the effectiveness of this protocol, reviewing and updating it as necessary in according with current legislation and practice.

7. Roles and responsibilities

There are clear responsibilities that need to be covered to support the implementation and delivery of stratified follow up including shared care and supported self-management pathways. These responsibilities should be clearly defined as part of the development of locally agreed pathways and documented to attribute to roles within individual organisations.

Chief Executive
The Chief Executive has ultimate responsibility for governance arrangements and therefore for ensuring that there are robust processes in place for follow up of patients after potentially curative cancer treatment. The Chief Executive delegates this responsibility through the Medical and Nursing Directorates.

Clinical Leads
Clinical leads in all provider sites will retain overall responsibility for the patient's follow up pathway and wellbeing, and are required to review their practice against national recommendations/best practice. Clinical leads are responsible for approving any local amendments to the follow up pathways.

Clinical Teams
Clinical teams will ensure that the patients are suitably prepared, equipped and supported to manage their follow up. The roles and responsibilities for each member of the clinical team are shown in Table 1.

Cancer Services Team
Cancer Services teams will support the implementation and audit of processes associated with the Stratified Follow up pathways, ensuring targets for recruitment, satisfactory patient experience and adherence to protocols.

Table 1. Roles and Responsibilities of Clinical Team

Role	Responsible person
Determining type of follow up for each individual patient Identifying patients suitable for Supported Self Management and referring to Support Worker for registration Completing the Treatment Summary	Clinician reviewing patient at end of treatment
Ensuring patients are adequately prepared for Stratified Follow up	Breast Care Nurse

Ensuring surveillance investigations are organized and carried out according to schedule Sending reminders to patients who have missed surveillance investigations Ensuring patient and GP (*) are informed of results of investigations	Support Worker
Reviewing surveillance investigation results and taking appropriate action	Support Worker Breast Care Nurse
Reviewing patient calls on the Helpline and taking appropriate action	Support Worker Breast Care Nurse
Monitoring compliance with protocols and reviewing deviations from the pathway	Clinical Lead

*GPs will not be expected to action abnormal surveillance investigations while patients are in the stratified follow up pathway

8. Evaluation and Monitoring

The individual providers will monitor any incident, complaint or claim arising out of Stratified Follow up, ensuring that these are investigated and processes reviewed if necessary.

Metrics should be agreed for each follow up pathway to include baseline measures, which should be collected prior to implementation to enable measurement of improvements at a later date. These may include the following:

- New cancer diagnosis: Follow up ratios
- 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 virtual or telephone clinics for follow up patients and average number of cancer patients reviewed per clinic

There should be a mechanism for robust data collection of measures to demonstrate the effectiveness of the Stratified Follow Up pathway. It is recommended that auditing of the pathway should be conducted within 3 months of implementation, and subsequently on an annual basis provided there are no significant adjustments required. Key aspects of the pathway to be audited may include the following:

- Treatment Summaries are being completed and communicated to patient and GP
- All patients are receiving surveillance investigations in a timely manner
- Results of investigations are being communicated to patient and GP in a timely manner
- Results of investigations are being acted upon appropriately
- Completion rate of Holistic Needs Assessment (HNA)
- Response time and outcomes from Supported Self-Management telephone helpline
- Number of patients offered or attending a supportive Self-Management event.

It is recommended that user feedback is obtained to evaluate patient satisfaction with the Stratified Follow up pathways, an example of a patient questionnaire is shown in appendix IV. It is also recommended that health related quality of life and wellbeing is regularly measured while patients are on the Stratified Follow up pathways. Examples of Patient Reported Outcome Measures (PROMS) tools which could be considered include:

EORTC QLQ-C30

Description: A questionnaire which assesses quality of life of cancer patients. It comprises 30 questions which focuses on functional (physical, cognitive, emotional and social), specific symptoms (fatigue, pain, and nausea and vomiting), global health and quality of life domains. A tumour specific module is also available as required.
Permission/Licensing: Permission required. There is no fee for academic use. Permissions obtained via the EORTC website.
Website: 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. There is a condition-specific subscale for breast cancer (**FACT-B**).
Permission/Licensing: 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/

EQ-5D-5L: A standardized 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.
Permission/Licensing: Requires written consent of the EuroQol Executive Office. Registration form can be completed electronically via the EuroQol website
Website: http://www.euroqol.org/

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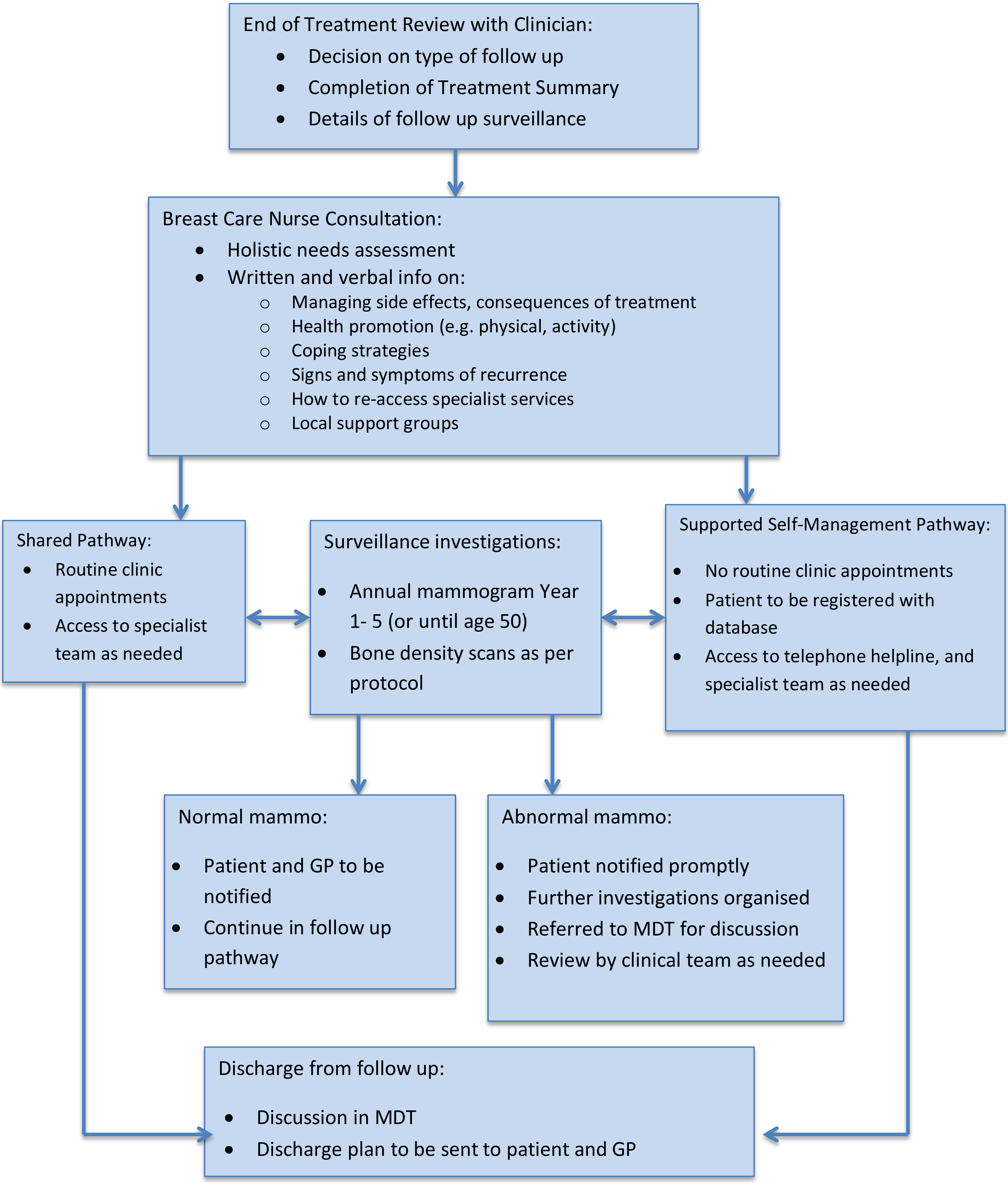
We also acknowledge the Early Breast Cancer Stratified Follow-Up Subgroup of London Cancer North and East Alliance, and the Macmillan Living with and Beyond Cancer Merseyside and Cheshire Team who kindly shared their documentation and provided us with permission to utilize and adapt their excellent guidelines as needed.

Appendix I

Stratified Follow up Pathway for Breast Cancer Patients



End of Treatment Review with Clinician:

- Decision on type of follow up
- Completion of Treatment Summary
- Details of follow up surveillance

Breast Care Nurse Consultation:

- Holistic needs assessment
- Written and verbal info on:
  - Managing side effects, consequences of treatment
  - Health promotion (e.g. physical, activity)
  - Coping strategies
  - Signs and symptoms of recurrence
  - How to re-access specialist services
  - Local support groups

Shared Pathway:

- Routine clinic appointments
- Access to specialist team as needed

Surveillance investigations:

- Annual mammogram Year 1- 5 (or until age 50)
- Bone density scans as per protocol

Supported Self-Management Pathway:

- No routine clinic appointments
- Patient to be registered with database
- Access to telephone helpline, and specialist team as needed

Normal mammo:

- Patient and GP to be notified
- Continue in follow up pathway

Abnormal mammo:

- Patient notified promptly
- Further investigations organised
- Referred to MDT for discussion
- Review by clinical team as needed

Discharge from follow up:

- Discussion in MDT
- Discharge plan to be sent to patient and GP

Appendix II

Guidelines for Patient Information Leaflets

Guidelines for Early Breast Cancer Supported-Self management follow up patient information leaflet.

These guidelines should be used to support each provider develop a clear and informative patient leaflet that will provide the patient with additional information once they have moved into Open access follow up. It should not replace any face to face appointments but be a reference to give the patient brief information on how Open Access follow works, what is an involved and contact for accessing additional support. This leaflet should be given to the patient during their last clinic appointment.

Introduction

The introduction should explain what open access follow up is, why the hospital uses open access follow up and why they have been assigned this type of follow up.

How open access works

Explain the process within the provider organisation including appointments and timescales and who they are with.

Information to given at Open access follow up appointment

To advise the patient what information will be given, in addition to this leaflet, at the end of treatment and how this will be delivered.

- Diagnosis and medication
- Signs and symptoms to report
- Being body and breast aware
- Treatment and possible side effects (long term and short term)
- Arrangements for annual mammogram and bone density if appropriate
- How to use the help line which gives you fast access to the breast care nurse
- How to see your Consultant if they have concerns
- Access to Health and wellbeing events

Symptoms you may want to report

Provide a list of symptoms that patients should be aware of or reference

Contact

Include details of how the patient contacts the Breast service if they have concerns
Include contact numbers
Opening time
Expected response time
What will happen next?

Mammogram process

Explain the process for notification of annual mammograms
Reason for annual mammogram
How often they will have a mammogram
How they will receive the results

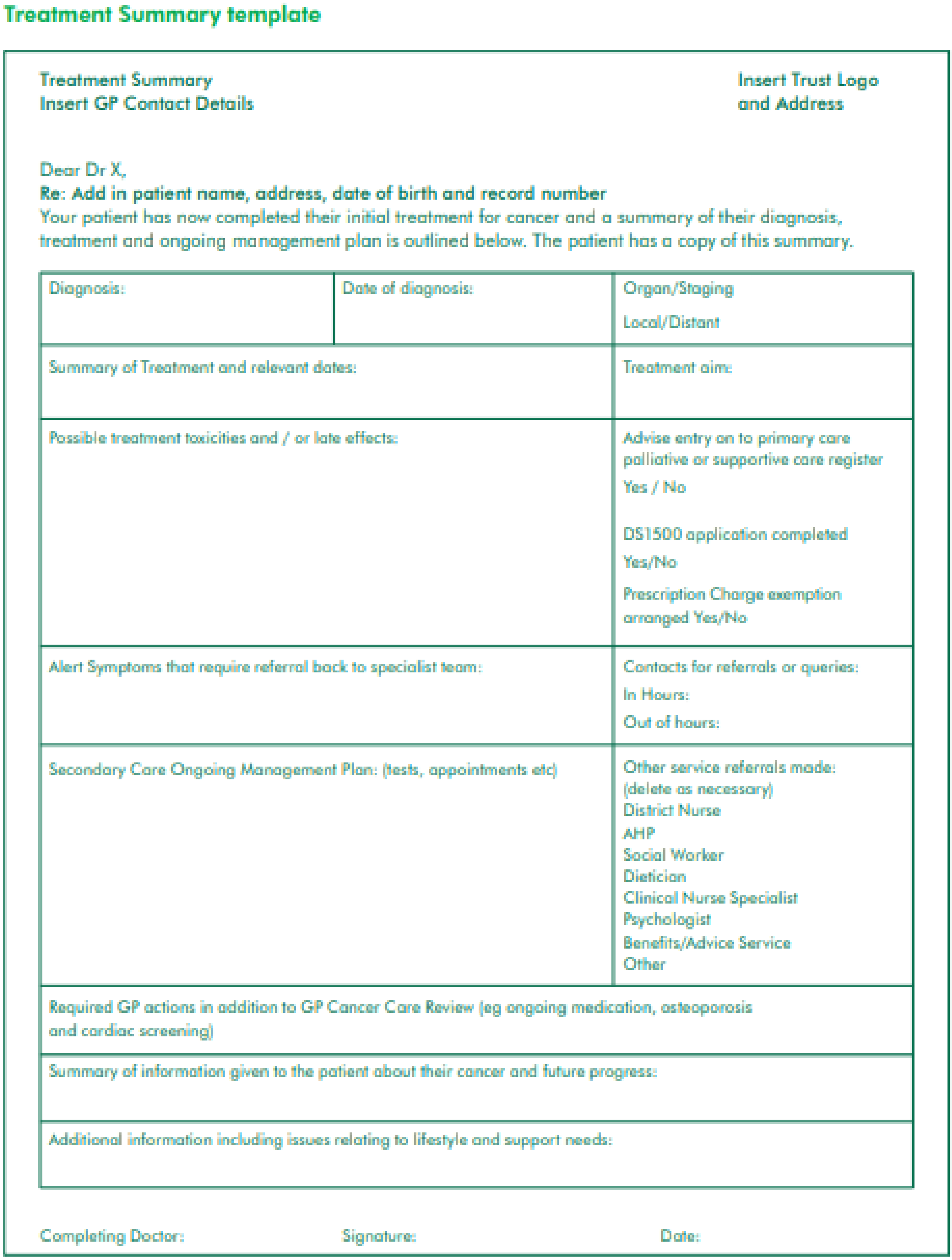
Other tests
Explain what they might be, what tests they could have and why they might have it.
Process for arranging scan

Further help and Support/ Life after treatment
Provide information on local and national support to include and why they might want to contact them:
Emotional support
Financial guidance
Rehabilitation
Lymphopedema
Menopausal
Fertility/sexuality/ body image issues
Support groups
Access to health and wellbeing events

Useful Contact
Include phone numbers and emails address for
Open access service
Breast Care nurses
Breast screening Service
Dietetics
Physiotherapy
Occupational therapy
Welfare benefits
Chaplain
Information and support centres (local)
Macmillan
Breast Cancer Care

Appendix III

Treatment Summary Template



Treatment Summary template

Treatment Summary
Insert GP Contact Details

Insert Trust Logo
and Address

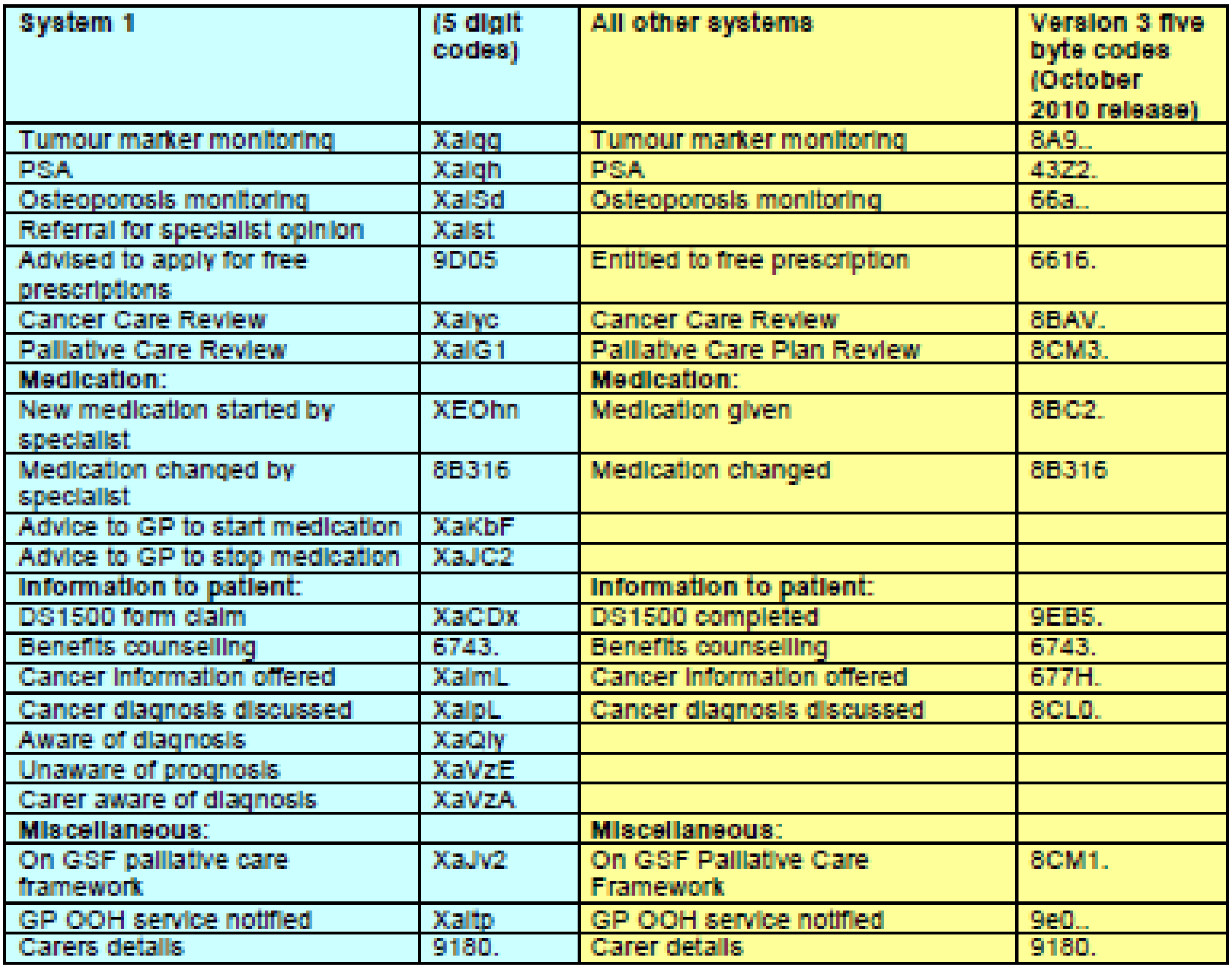
Dear Dr X,
Re: Add in patient name, address, date of birth and record number
Your patient has now completed their initial treatment for cancer and a summary of their diagnosis, treatment and ongoing management plan is outlined below. The patient has a copy of this summary.

Diagnosis:	Date of diagnosis:	Organ/Staging Local/Distant
Summary of Treatment and relevant dates:		Treatment aim:
Possible treatment toxicities and / or late effects:		Advise entry on to primary care palliative or supportive care register Yes / No DS1500 application completed Yes/No Prescription Charge exemption arranged Yes/No
Alert Symptoms that require referral back to specialist team:		Contacts for referrals or queries: In Hours: Out of hours:
Secondary Care Ongoing Management Plan: (tests, appointments etc)		Other service referrals made: (delete as necessary) District Nurse AHP Social Worker Dietician Clinical Nurse Specialist Psychologist Benefits/Advice Service Other
Required GP actions in addition to GP Cancer Care Review (eg ongoing medication, osteoporosis and cardiac screening)		
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 <u>exactly</u> as below).

System 1	**(5 digit codes)**	**All other systems**	**Version 3 five byte codes (October 2010 release)**
Diagnosis:		**Diagnosis**	
Lung Malignant Tumour	XaOKG	Malignant neoplasm of bronchus or lung	B22z.
Carcinoma of Prostate	X78Y6	Malignant neoplasm of prostate	B46..
Malignant tumour of rectum	XE1vW	Malignant neoplasm of Rectum	B141.
Bowel Intestine	X78gK	Malignant neoplasm of Colon	B13..
Large Bowel	X78gN	Malignant neoplasm of female breast	B34..
Female Malignant Neoplasia	B34..	Malignant neoplasm of male breast	B35..
Male Malignant Neoplasia	B35..		
Histology/Staging/Grade:		**Histology/Staging/Grade:**	
Histology Abnormal	4K14.	Histology Abnormal	4K14.
Tumour grade	X7A6m	Tumour staging	4M...
Dukes/Gleason tumour stage	XaOLF	Gleason grading of prostate Ca	4M0..
Recurrent tumour	XaOR3	Recurrence of tumour	4M6..
Local Tumour Spread	X7818		
Mets from 1°	XaFr.	Metastatic NOS	BB13.
Treatment		**Treatment**	
Palliative Radiotherapy	5149.	Radiotherapy tumour palliation	5149.
Curative Radiotherapy	XalpH	Radiotherapy	7M371
Chemotherapy	x71bL	Chemotherapy	8BAD.
Radiotherapy	Xa851		
Treatment Aim:		**Treatment Aim:**	
Curative procedure	Xallm	Curative treatment	8BJ0.
Palliative procedure	XalL3	Palliative treatment	8BJ1.
Treatment toxicities/late effects:			
Osteoporotic #	Xa1TO	At risk of osteoporosis	1409.
Osteoporosis	XaELC	Osteoporosis	N330.
Infection	Xa9ua		
Ongoing Management Plan		**Ongoing Management Plan**	
Follow up arranged (<1yr)	8H8..	Follow up arranged	8H8..
Follow up arranged (>1yr)	XaL..		
No FU	8HA1.	No follow up arranged	8HA..
Referral PRN	8HAZ.		
Referrals made to other services:		**Referrals made to other services:**	
District Nurse	XaBsn	Refer to District Nurse	8H72.
Social Worker	XaBsr	Refer to Social Worker	8H75.
Nurse Specialist	XaAgq		
SALT	XaBT6		
Actions required by the GP		**Actions required by the GP**	



System 1	**(5 digit codes)**	**All other systems**	**Version 3 five byte codes (October 2010 release)**
Tumour marker monitoring	XaIqq	Tumour marker monitoring	8A9..
PSA	XaIqh	PSA	43Z2.
Osteoporosis monitoring	XaISd	Osteoporosis monitoring	66a..
Referral for specialist opinion	XaIst		
Advised to apply for free prescriptions	9D05	Entitled to free prescription	6616.
Cancer Care Review	XaIyc	Cancer Care Review	8BAV.
Palliative Care Review	XaIG1	Palliative Care Plan Review	8CM3.
Medication:		**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:		**Information to patient:**	
DS1500 form claim	XaCDx	DS1500 completed	9EB5.
Benefits counselling	6743.	Benefits counselling	6743.
Cancer information offered	XaImL	Cancer information offered	677H.
Cancer diagnosis discussed	XaIpL	Cancer diagnosis discussed	8CL0.
Aware of diagnosis	XaQly		
Unaware of prognosis	XaVzE		
Carer aware of diagnosis	XaVzA		
Miscellaneous:		**Miscellaneous:**	
On GSF palliative care framework	XaJv2	On GSF Palliative Care Framework	8CM1.
GP OOH service notified	XaItp	GP OOH service notified	9e0..
Carers details	9180.	Carer details	9180.

Appendix IV

Patient Satisfaction Questionnaire

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 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
☐ Not applicable

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?

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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.