Cheshire & Merseyside Cancer Alliance

Protocol for Supported Self-Management in the follow up of Breast, Colorectal and Prostate cancer

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Executive Summary

The number of people living with and beyond a cancer diagnosis in England is set to rise from 2 million in 2010, to almost 4 million in 2030[1]. 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[2].

Traditional out-patient consultations do not provide the best environment to allow holistic and personalised care planning. Furthermore, the culture of education and rehabilitation seen in other long term conditions such as cardiac, diabetes, and respiratory medicine have not yet been fully embraced in cancer services.

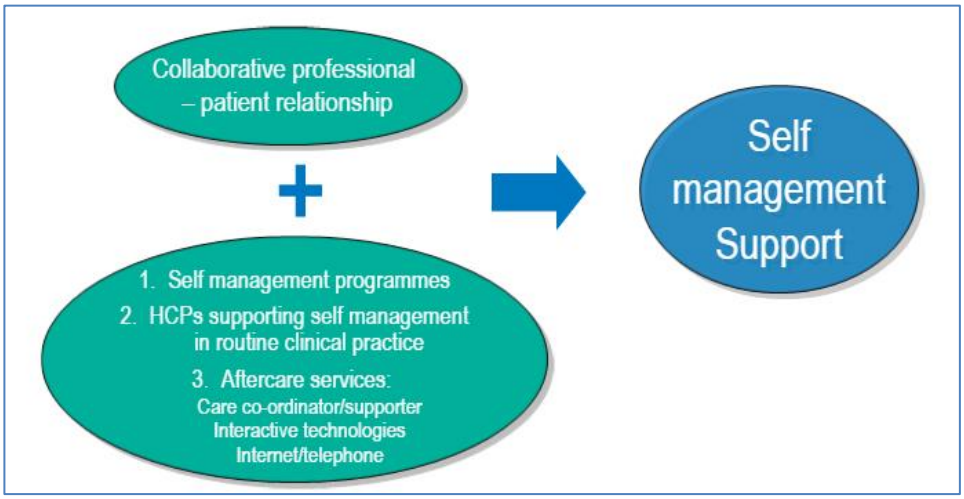
This protocol has been developed to support the redesign of aftercare services for patients who have undergone treatment for breast cancer, colorectal cancer, and prostate cancer. These services utilise a model of supported self-management, in which the educated patient manages their follow-up, continuing to receive all regular evidence based surveillance investigations, but only attending for face to face clinical review if triggered by a patient's concern or abnormal test result.

The basic principles that underpin supported self-management for follow-up are:

- Patients and professionals work collaboratively to form personalised care plans
- There is a programme of appropriate patient education, supported by written information and access to online portal for those who are IT enabled
- There is consistent implementation of self-management support interventions
- All clinical evidence-based surveillance investigations continue unchanged
- Robust systems are in place to ensure tracking and monitoring of investigation requests and results
- There is fast track re-entry for clinical review if required

[1] Maddams J et al. 'projections of cancer prevalence in the United Kingdom, 201-2040. *Br. J. Cancer 107:1195-1202 (2012)*

[2] Maher EJ, Makin W. Life after cancer treatment- a spectrum of chronic survivorship conditions. *Clin. Oncol.19, 743-745 (2007)*



1 Introduction

1.1 Overview of the importance and role of the protocol

The main purpose of follow-up after cancer treatment is to monitor for disease recurrence, manage any side effects related to treatment and provide information, support and reassurance for patients. Many clinicians believe that following up patients who are essentially well is neither clinically beneficial, nor cost effective.[3]

There is little evidence that intensive follow up improves overall mortality[4]. The majority of recurrences are detected either by patients themselves or by investigations which can be planned and undertaken without a patient having to attend an outpatient clinic.

Limited clinical resources mean the provision of routine follow-up may lengthen waiting times for new referrals, compromising the efficiency of diagnostic services and reduce the time available to deal with patients who have complex clinical needs.

Supported Self-Management Follow Up (SSM FU)

This is a model whereby patients manage their own follow-up, with back up from the clinical team as needed, in order to limit risk and ensure a satisfactory patient experience.

This includes the following elements:

- Assessment of individual patients to identify suitability for SSM FU.
- The patient is prepared and supported to enable recovery to a healthy lifestyle, and preparation for all the potential consequences of their disease and treatment.
- Exit interview/workshop to ensure patient appropriately prepared with information and education
- Detailed written information is provided, also available online.
- Clear protocol for re-entry into service if required.

[3] Kimman ML et al. Follow up after curative treatment for breast cancer: why do we still adhere to frequent outpatient visits? *Eur. J. Cancer 43, 647-653 (2007)*
[4] Tjandra J, Chan MK. Follow up after curative resection of colorectal cancer: a meta-analysis. *Dis. Colon Rectum 50 (11) 1783-1799*

- Treatment summary sent to GP outlining patient's discharge from treatment into SSM FU.
- Routine follow up investigations continue as before with robust tracking mechanism managed by support worker and reviewed by appropriate clinician
- Standard clinical follow up for those not suitable for SSM FU or participating in clinical trials.

1.2 Scope of Protocol

- All patients with breast cancer, colorectal cancer, and prostate cancer who have been assessed as appropriate for SSM FU.

- Experience suggests that this should be 65% of all patients treated for breast cancer, 50% of prostate patients & 50% of colorectal patients.

- All medical, nursing, AHP, management and support staff involved in the care of patients with breast cancer, colorectal cancer and prostate cancer.

1.3 Purpose of the Protocol

The purpose of this protocol is to:

- Define duties and responsibilities of staff in regard to SSM FU.
- Specify the tumour specific pathways for SSM FU
- Outline a system for monitoring compliance and improvement.
- Aim to achieve a shift in aftercare for breast, colorectal, and prostate patients undergoing treatment from the current model of routine outpatient clinic follow up to informed and prepared patients self initiating contact with health services when necessary.
- Aim to achieve a reduction in clinic based follow-up appointments
- Promote personalisation of care based on effective assessment and care planning
- To achieve greater flexibility and responsiveness for the clinical teams providing breast, colorectal, and prostate cancer services while increasing the new to follow-up patient ratio.

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1.4 Definitions

Definitions of words and terms used within this protocol are outlined below:

- Self-Management
  - Awareness & active participation by the person in their recovery, recuperation & rehabilitation to minimize the consequences of treatment & promote survival, health & wellbeing (Co-Creating Health –The Health Foundation)

- Supported Self-Management
  - What health services do in order to aid and encourage people living with a long term condition to make daily decisions that improve health related behaviours & clinical, & other outcomes. (Co-Creating Health –The Health Foundation)

2 Related Policies/Guidelines

The Protocol for Supported Self-Management for Breast, Colorectal and Prostate Cancer Follow-up is linked with, and must be read in conjunction with, the following policies/guidelines:

- Cheshire and Merseyside Strategic Clinical Networks Guidelines for Holistic Needs Assessment
- Cheshire and Merseyside Strategic Clinical Networks Key Worker Guidelines
- Cheshire and Merseyside Strategic Clinical Networks Clinical Guidelines for the Management of Breast, Colorectal, and Prostate Cancer

These guidelines available at: http://www.cmscnsenate.nhs.uk/strategic-clinical-network/our-networks/cancer/

3 Roles and Responsibilities

- **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 treatments. The Chief Executive delegates this responsibility through the Medical and Nursing Directorates.

- **Clinical Leads**

Clinical leads in all tumour sites will retain overall responsibility for the patient's well-being, taking NICE guidance into account and reviewing their practice against recommendations/best practice. In addition, Clinical Leads will approve any local amendments to the example follow up pathways.

- **Clinical teams**

Clinical teams will ensure that the patients are suitably prepared and equipped to manage their follow-up and understand the process for rapid return if necessary. More detailed responsibilities are shown below in Table 1.

- **Cancer Services Team**

Cancer Services teams will support the implementation and audit of processes associated with the SSM FU pathway, ensuring targets for recruitment, satisfactory patient experience and adherence to protocols.

Table 1: Roles and Responsibilities of Clinical Team

Role	Responsible person
Identifying patients suitable for SSM FU and referring to Support Worker for registration (must be documented in notes and end of treatment summary) This must include type and frequency of	Clinician reviewing patient at end of treatment

investigations, and (in the case of prostate) the target range for PSA	
Ensuring patient is adequately prepared for SSM FU and attends exit interview/workshop	Support worker and Clinical Nurse Specialist
Ensuring surveillance investigations are scheduled and carried out in a timely fashion	Support worker
Sending reminders to patients who have missed surveillance investigations or are overdue	Support worker
Reviewing surveillance investigation results and taking appropriate action	Clinical Nurse Specialist via “virtual clinic”
Reviewing incoming messages and health MOTs from patients	Support worker and Clinical Nurse Specialist
Ensuring patient and GP are informed of results of investigations	Support worker
Monitoring compliance with protocols and reviewing deviations from the pathway	Lead Clinician

4 Process for Monitoring Compliance/Effectiveness

The treating Trust will monitor any incident, complaint or claim arising out of SSM FU ensuring that these are followed up and processes reviewed if necessary. Any such incidents will be shared (anonymised) with the appropriate network groups so that lessons learned can be utilised across all participating sites.
In addition, key aspects of the pathway will be audited as shown in Table 2.

Table 2: Monitoring SSM FU Protocol

Element of Protocol to be monitored	Tool/Method	Frequency	Who will undertake	Where results will be reported
All patients in SSM FU are recorded and appropriate surveillance tests organised	Cross check of Tracker tool against Somerset, back up database and clinical records	Monthly	Support Worker	
All patients in SSM FU are receiving investigations in a timely manner and these are being acted upon appropriately	Audit of 10% of cases in SSM FU	Quarterly	Clinical Nurse Specialist	
Results being communicated to patient and GP in a timely manner	Audit of 10% of cases in SSM FU	Annually	Support worker	
Patient satisfaction (to include response time to patient concerns/messages)	Survey of patients in SSM FU	Annually	Clinical Nurse Specialist	
Completion rate of Health MOT	Audit of records on Tracker	Quarterly	Support Worker	

5 Recommendations for recording activity

National Tariff Payment System guidance for 2017/18 and 2018/19 states that new models for non-face to face follow up should be incentivised to increase the adoption of technology. Although reference costs are available, it is suggested that providers and commissioners should agree local prices for such activity.

A consistent approach to recording activity associated with the pathways across Cheshire and Merseyside is recommended. Tariffs will need to be negotiated through the normal contracting routes however key elements of the pathway lend themselves to existing coding structures.

There are two national codes for ‘virtual’ i.e. non-face to face follow ups which are:

National Codes:
National Code Description

NF2FFA- Outpatient First Non Face to Face

NF2FFUP- Outpatient Follow Up Non Face to Face

The local codes that could be used are constructed as follows:

A non-face to face outpatient follow up attendance that is single professional and non-consultant led would be
OPFUPNFTFSPNCL

If all the ‘attendances’ are single professional then that part could be left out e.g. OPFUPNFTFNCL

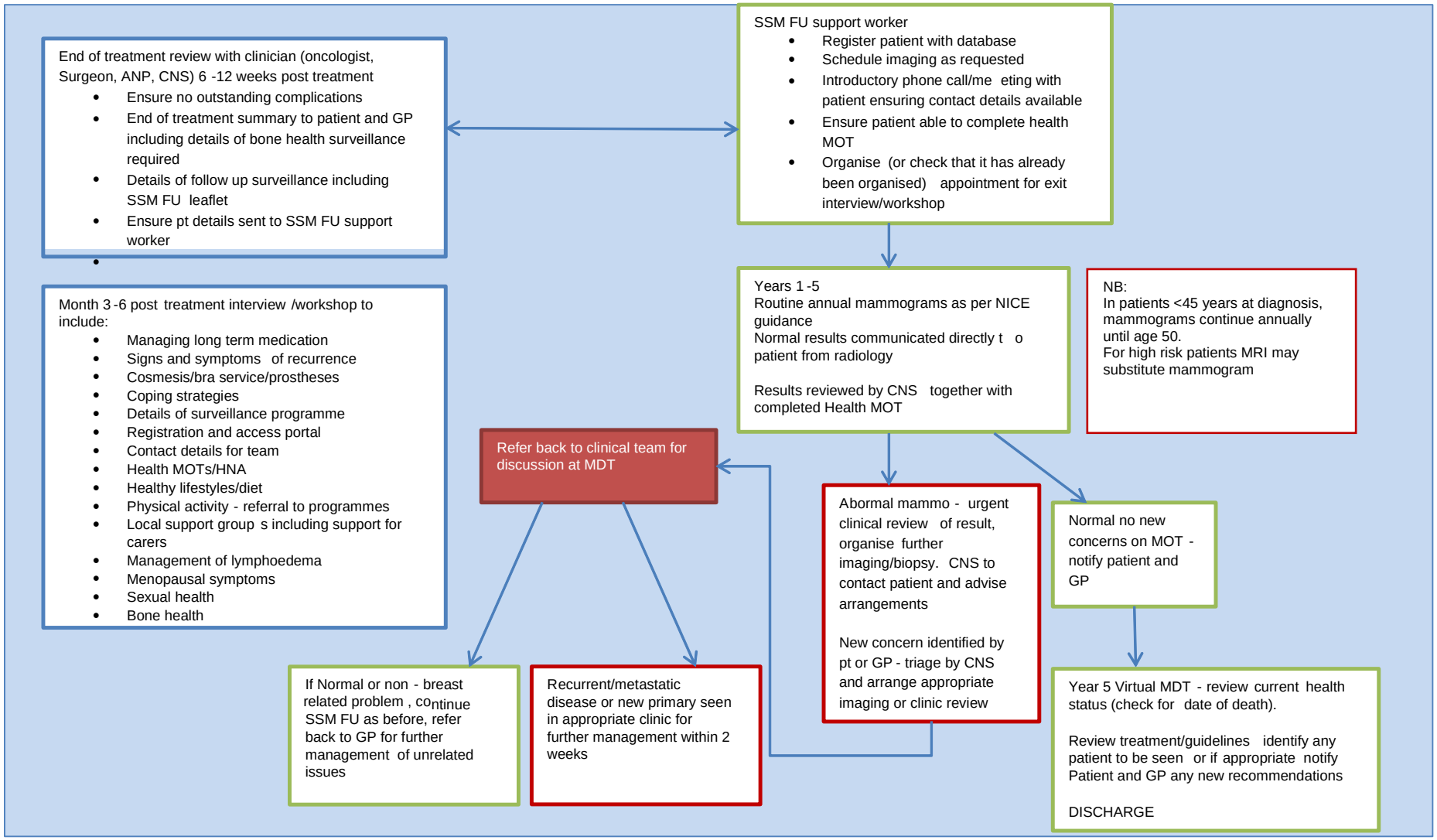
6 Arrangements for review of this protocol

This protocol is offered by the Cheshire & Merseyside Cancer Alliance as a common framework for use in all participating sites. It must be subjected to Trust internal governance processes and reviewed according to local policies.

The Clinical leads with responsibility for SSM FU will be responsible for monitoring the effectiveness of this protocol, reviewing and updating it as necessary in accordance with current legislation and practice.

It is recommended that this protocol will be formally reviewed by no later than March 2020.

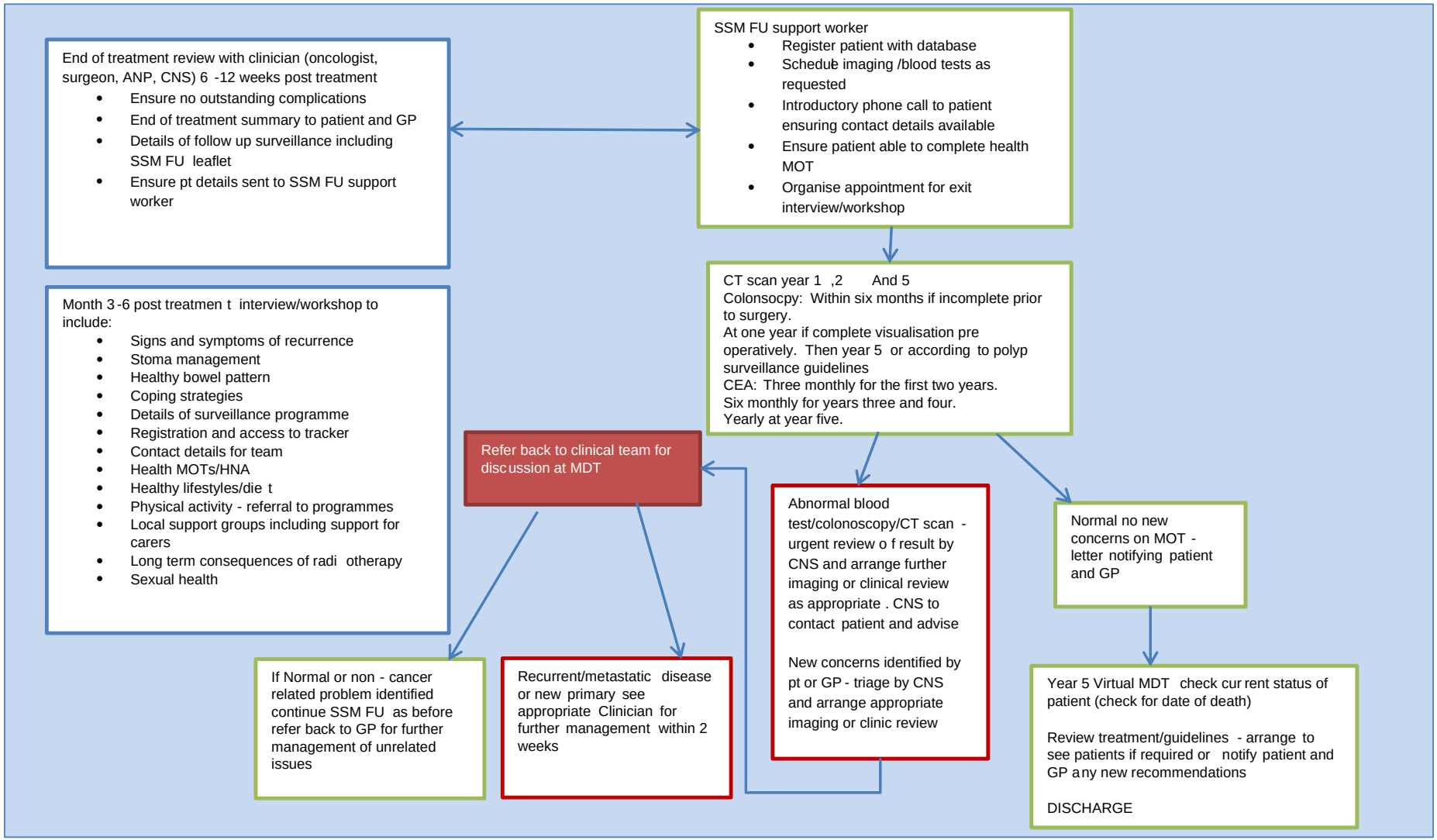
Appendix 1: Example SSM FU Breast Pathway[5] for ALL patients completing treatment with curative intent



[5] Ref NICE Quality Standard 12 https://www.nice.org.uk/guidance/qs12/chapter/quality-statement-10-follow-up-imaging

Appendix 2: Example SSM FU Colorectal Pathway[6]

[6] Ref NICE Quality Standard 8 https://www.nice.org.uk/guidance/QS20/chapter/Quality-statement-8-Follow-up-and-regular-surveillance



Appendix 3: Current schedule of follow-up surveillance tests following curative colorectal cancer treatment

Following multidisciplinary discussion patients will be offered adjuvant chemotherapy where indicated. Follow-up will then be scheduled as follows unless:

- Decision at MDT meeting is made for alternative management.
- Patient has stoma and consultant wishes to review until reversal.
- Patient declines follow-up.
- In clinical trial with alternative protocol.

CT Scan. (Chest and abdomen)	**CEA.**	**COLONOSCOPY**
1 year post op 2 years post op 5 years post op	3 monthly for the first 2 years. 6 monthly for years 3 and 4. Yearly at year 5. .	Within 6 months if incomplete prior to surgery. At 1 year if complete visualisation pre operatively. In the case of polyps: according to BSG polyp surveillance guidelines

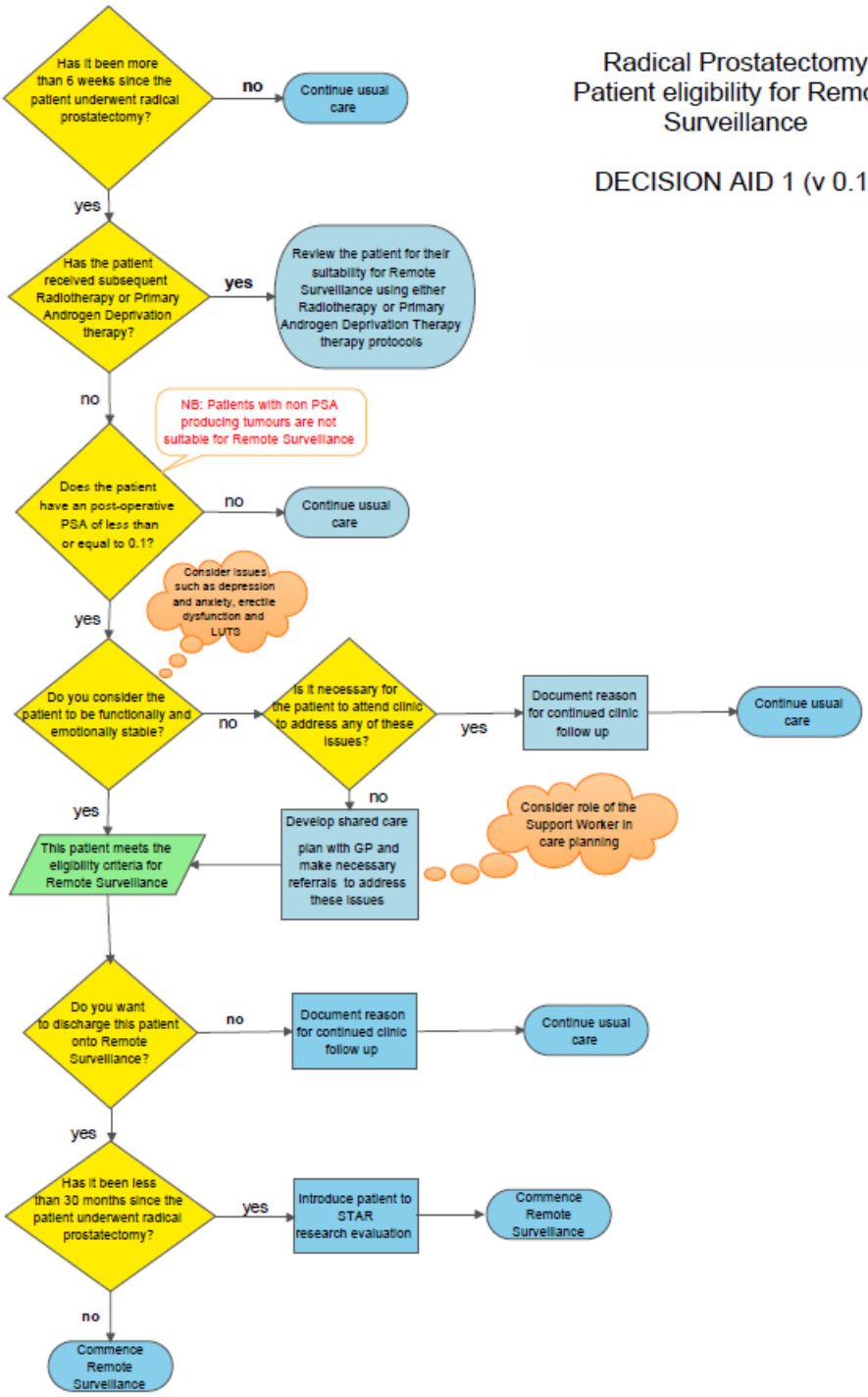
Appendix 4: Example SSM FU Prostate Pathway[7] (adapted from TrueNTH STAR protocol)

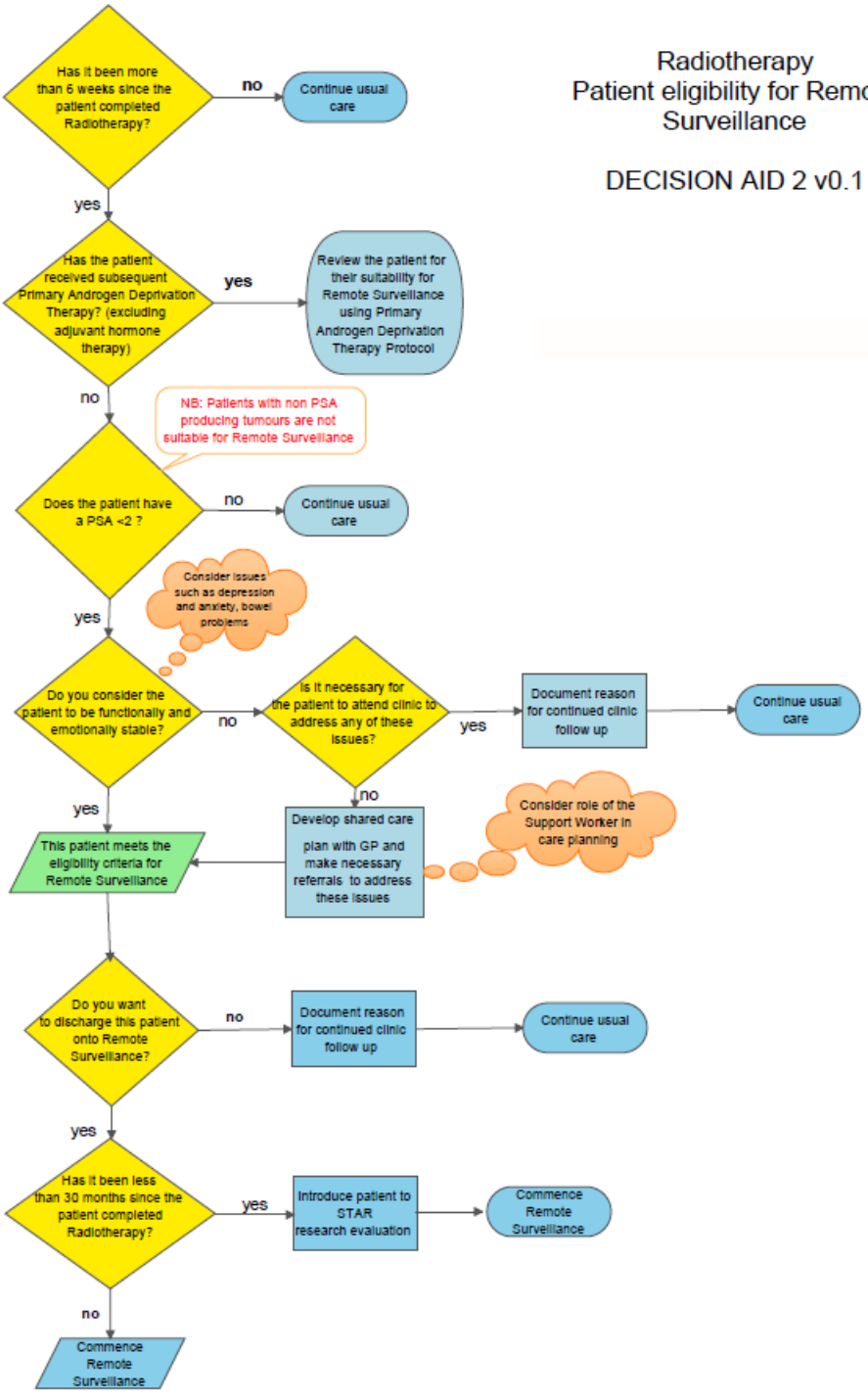
PROTOCOL	ELIGIBILITY	MONITORING		RECALL

[7]Ref NICE Prostate Cancer: Diagnosis and Management CG175 https://www.nice.org.uk/guidance/cg175/ifp/chapter/Follow-up

Radical Prostatectomy	• Consider from 6 weeks post-surgery • PSA ≤ 0.1 • Refer to decision aid 1	**Exclude patients with non-PSA producing tumours, patients who are unable to self -manage or are required to attend clinic to manage functional or psychological issues**	• YEAR 1: PSA 3/12 • YEARS 2-5: PSA 6/12 • YEARS 6-10: PSA Annually • PROM 6/12	**Monitoring and recall criteria may be personalised for individual patients. These criteria should be recorded in the " comments" section of the PSA tracking system.**	• PSA > 0.1: telephone, retest 6/52 • PSA > 0.2 or 3 consecutive rises consider recall • New onset LUTS, visible haematuria, bone pain	**Refer to decision aid 5**
Radiotherapy	• Consider from 6 weeks post completion of treatment PSA < 2 • Refer to decision aid 2		EBRT • YEAR 1: PSA 3/12 • YEARS 2-5: PSA 6/12 • YEARS 6-10: PSA Annually Brachytherapy • YEARS 1-2: PSA 3/12 • YEARS 3-5: PSA 6/12 • YEARS 6-10: PSA Annually • NB: late effects		• PSA > nadir + 2 ng/ml , or 3 consecutive rises NB: In the case of "clinical bounce" consider retest 3/12. • Troublesome LUTS, visible haematuria, rectal bleeding, troublesome bowel symptoms, bone pain	
Primary Androgen Deprivation Therapy	• Consider from 3 months post commencement of treatment • PSA has responded to treatment • PSA < 4 • Refer to decision aid 3		• PSA 6/12 • Creatinine, ALP 6/12		• PSA > 4 • Troublesome LUTS, visible haematuria, weight loss, bone pain • Consider testosterone testing on recall	
Watchful Waiting	• Consider commencement of watchful waiting • PSA < 20 and PSA doubling time of > 1 year • Refer to decision aid 4		• PSA 6/12 • U+E, ALP 6/12 • Consider testosterone, LFT and creatinine 6/12		• PSA > 20 or PSA doubling time < 1 year • Troublesome LUTS, visible haematuria, weight loss, bone pain	
Active Surveillance	• Patient has been on active surveillance for at least 12 months. • Patient should have undergone template biopsy, repeat MRI and MDT discussion prior to remote follow up being considered if diagnosed on TRUS. • If diagnosed on primary template, should have had a repeat MRI at 12mths and case rediscussed at MDT meeting • Stable PSA • Patient should be able to self- manage and agreeable to remote follow up		PSA -Years 1 & 2 after diagnosis = 3monthly • Year 3 onwards = 6 monthly **DRE** Annual DRE in consultant clinic for first 5 years then every 2 years		• PSA velocity 1ng/ml per year • Change in DRE/MRI findings. • LUTS/symptoms • Pt request.	

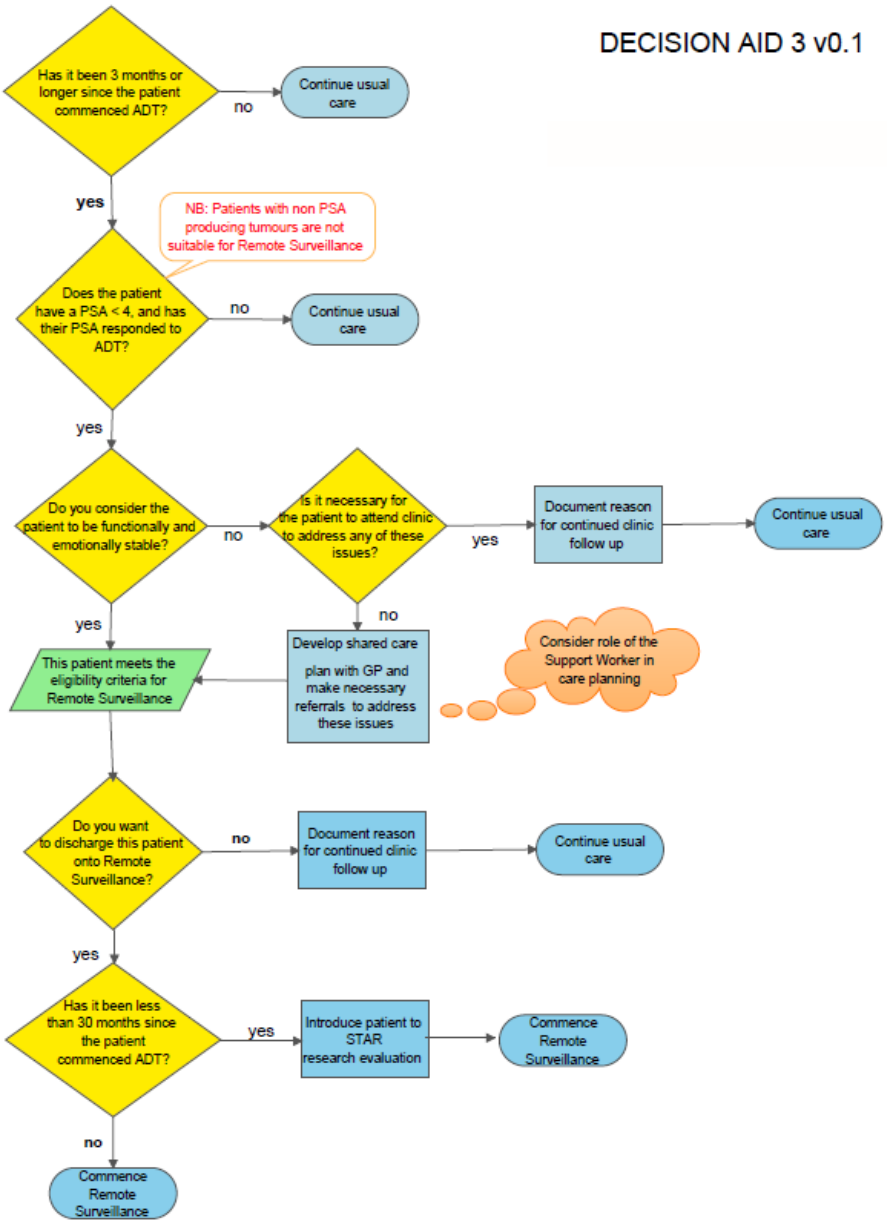
Appendix 5: Prostate Decision Aids

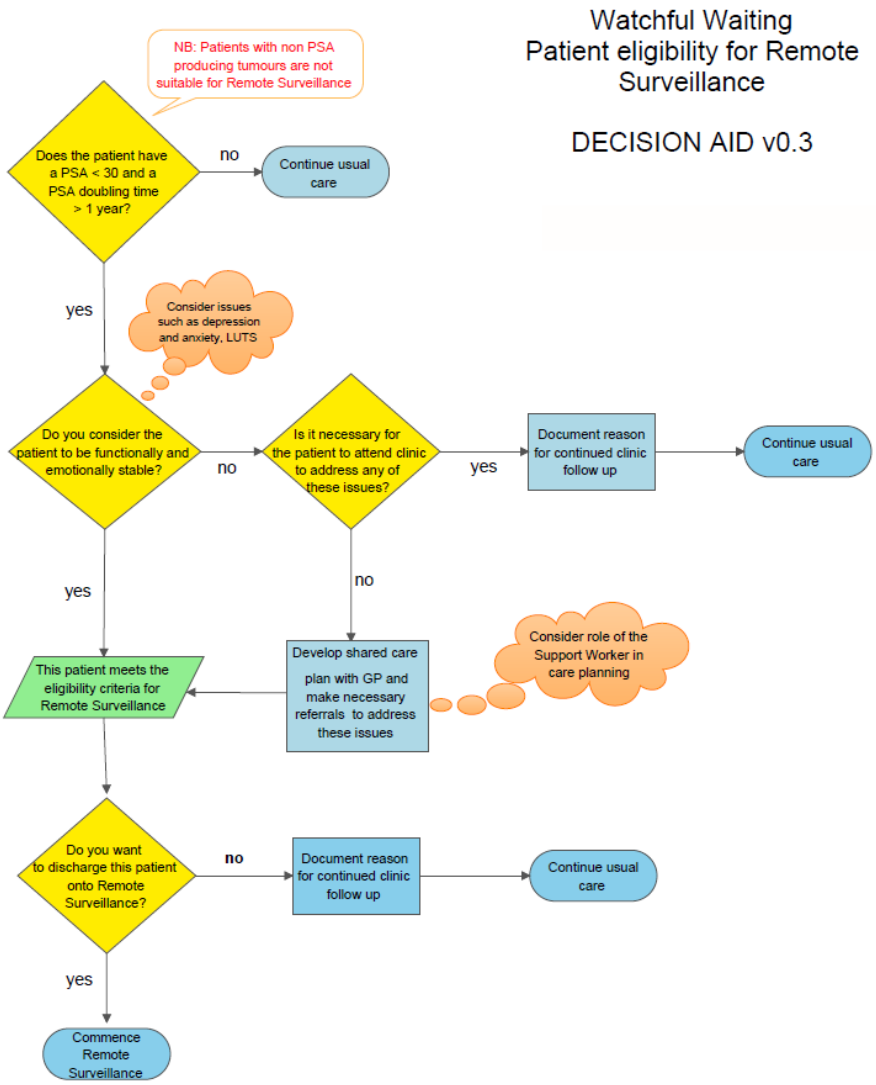


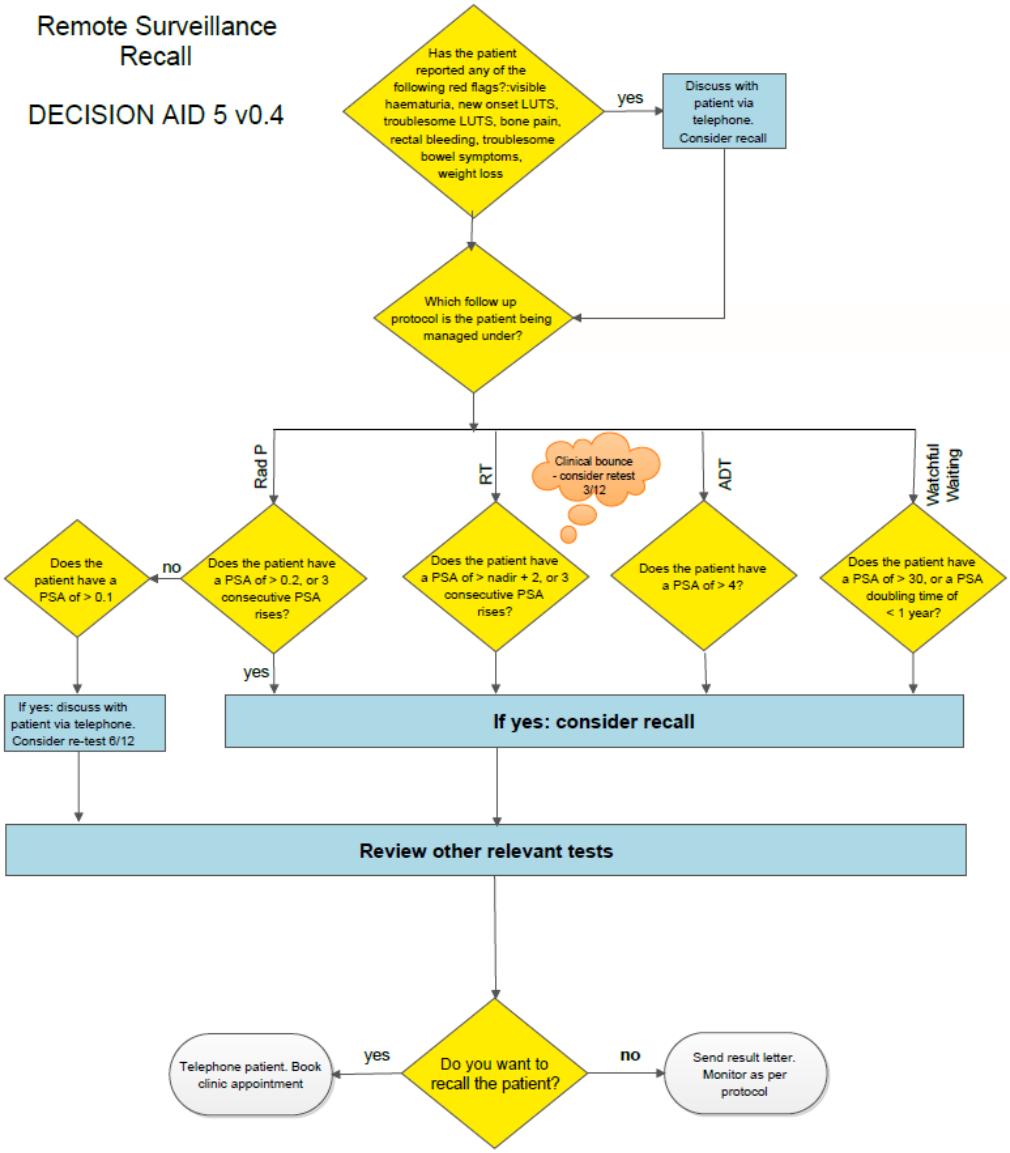

Radiotherapy
Patient eligibility for Remote Surveillance
DECISION AID 2 v0.1
Has it been more than 6 weeks since the patient completed Radiotherapy?
no
Continue usual care
yes
Has the patient received subsequent Primary Androgen Deprivation Therapy? (excluding adjuvant hormone therapy)
yes
Review the patient for their suitability for Remote Surveillance using Primary Androgen Deprivation Therapy Protocol
no
NB: Patients with non PSA producing tumours are not suitable for Remote Surveillance
Does the patient have a PSA <2 ?
no
Continue usual care
Consider issues such as depression and anxiety, bowel problems
yes
Do you consider the patient to be functionally and emotionally stable?
no
Is it necessary for the patient to attend clinic to address any of these issues?
yes
Document reason for continued clinic follow up
Continue usual care
no
yes
This patient meets the eligibility criteria for Remote Surveillance
Develop shared care plan with GP and make necessary referrals to address these issues
Consider role of the Support Worker in care planning
Do you want to discharge this patient onto Remote Surveillance?
no
Document reason for continued clinic follow up
Continue usual care
yes
Has it been less than 30 months since the patient completed Radiotherapy?
yes
Introduce patient to STAR research evaluation
Commence Remote Surveillance
no
Commence Remote Surveillance

Primary Androgen Deprivation Therapy (ADT)
Patient eligibility for Remote Surveillance

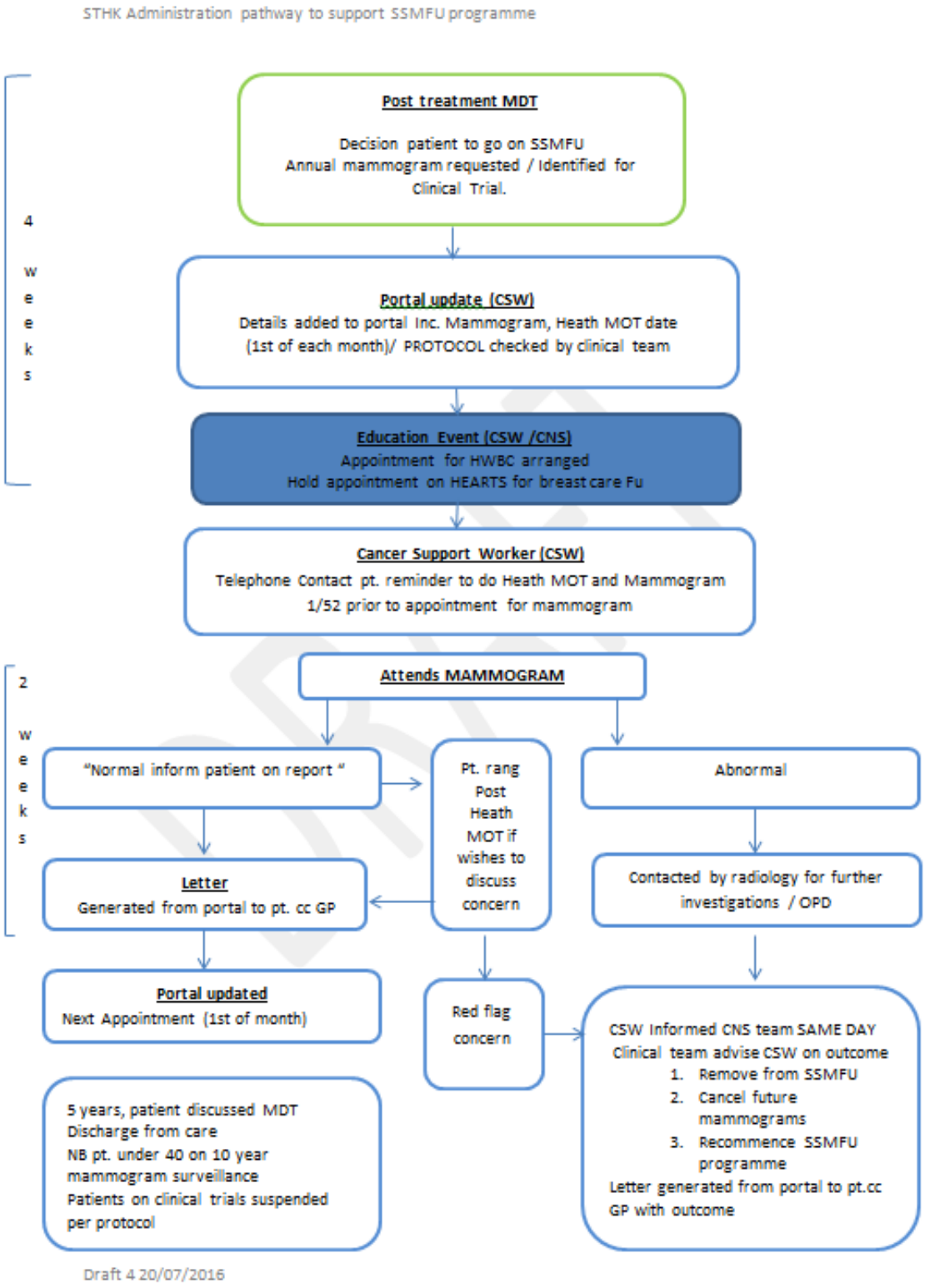
DECISION AID 3 v0.1

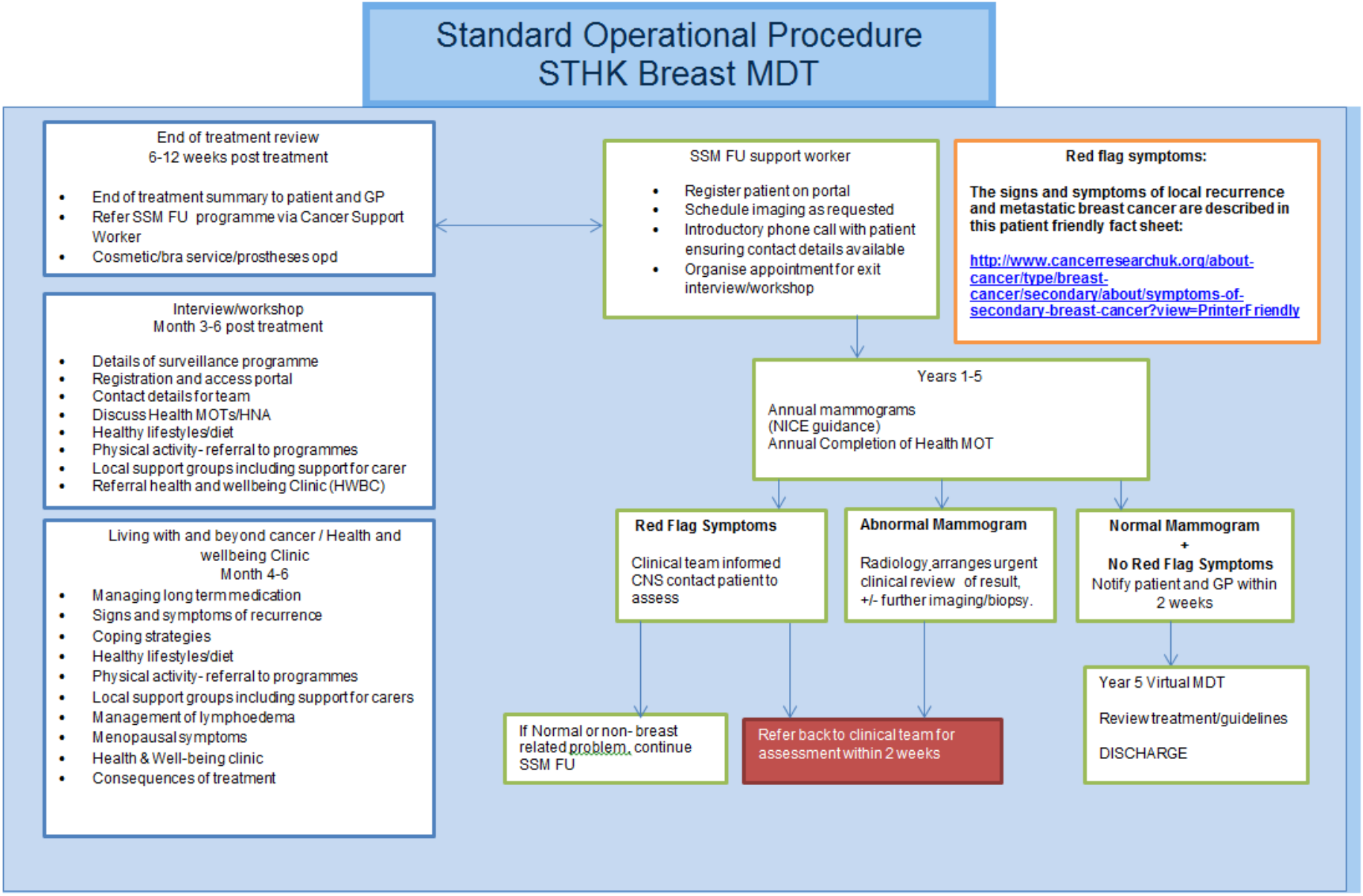



Watchful Waiting
Patient eligibility for Remote Surveillance
DECISION AID v0.3
NB: Patients with non PSA producing tumours are not suitable for Remote Surveillance
Does the patient have a PSA < 30 and a PSA doubling time > 1 year?
no
Continue usual care
yes
Consider issues such as depression and anxiety, LUTS
Do you consider the patient to be functionally and emotionally stable?
no
Is it necessary for the patient to attend clinic to address any of these issues?
yes
Document reason for continued clinic follow up
Continue usual care
yes
no
This patient meets the eligibility criteria for Remote Surveillance
Develop shared care plan with GP and make necessary referrals to address these issues
Consider role of the Support Worker in care planning
Do you want to discharge this patient onto Remote Surveillance?
no
Document reason for continued clinic follow up
Continue usual care
yes
Commence Remote Surveillance


Remote Surveillance Recall
DECISION AID 5 v0.4
Has the patient reported any of the following red flags?:visible haematuria, new onset LUTS, troublesome LUTS, bone pain, rectal bleeding, troublesome bowel symptoms, weight loss
yes
Discuss with patient via telephone. Consider recall
Which follow up protocol is the patient being managed under?
Rad P
RT
Clinical bounce - consider retest 3/12
ADT
Watchful Waiting
Does the patient have a PSA of > 0.1
no
Does the patient have a PSA of > 0.2, or 3 consecutive PSA rises?
Does the patient have a PSA of > nadir + 2, or 3 consecutive PSA rises?
Does the patient have a PSA of > 4?
Does the patient have a PSA of > 30, or a PSA doubling time of < 1 year?
yes
If yes: discuss with patient via telephone. Consider re-test 6/12
If yes: consider recall
Review other relevant tests
Telephone patient. Book clinic appointment
yes
Do you want to recall the patient?
no
Send result letter. Monitor as per protocol

Appendix 6: STHK Breast Process





STHK Supported self-management pathway for breast cancer patients Version 2 01/07/2016

7 Equality Impact Assessment

EQUALITY IMPACT ASSESSMENT TOOL - To be completed for all new/revised policy, procedural and guideline documents.
Equality Impact Assessments (EQIAs) are a way of examining new procedural* documents to see whether they have the potential to affect any one group of people more or less favourably than another. Their purpose is to address actual or potential inequalities resulting from policy development. The duty to undertake EQIAs is a requirement of race, gender and disability legislation.
The word procedural is taken to mean ***all*** *procedural* documents i.e.: Policy, Procedure, and Guideline. (This does *not include Patient Information*)

Document Title	Protocol for supported self-management in the follow up of breast, colorectal, and prostate cancer.	**V. 1. Sept 2016**
Is this a new or revised document?	New	
Area to which document relates Specify whether Trust-wide, Division, Care Group or Department.	Cancer Services Merseyside and Cheshire Cancer Network	
Name of person completing Assessment	Melanie Zeiderman, Programme Lead	

STAGE 1 – INITIAL SCREENING
This stage establishes if the proposed change will have an impact from an **equality perspective** on any particular group(s) of people. See guidance notes on completion.

Does the document affect one group more or less favourably than another on the basis of <u>any</u> of the strands of diversity?	**Positive Impact** **Y/N/Neutral**	**Negative Impact** **Y/N/Neutral**	**Comments –** Give details of concerns and evidence in the boxes below	**Impact Level** N/L/M/H
Age	N	N		
Disability	N	N		
Gender	N	N		
Sexual Orientation	N	N		
Race & Ethnicity	N	N		
Religion or Belief	N	N		
Culture	N	N		
Other e.g. Mental Health, Geographic factors, Economic factors...	Y	N	Reduced hospital visits will impact positively on patients travel time and costs	

Level of impact:
Taking into account the impact level for each group, circle one of the words in the boxes below to identify the overall impact level:

NONE	LOW	MEDIUM	HIGH

Significance
Is the positive / adverse impact significant enough to warrant a more detailed assessment (Stage 2) *A full assessment will usually be required if the level of impact is above 'LOW" as identified above.*

NO *(delete as applicable)*

If no give brief details of any action taken/information gathered to justify this decision:

Or give brief details of how the change will be monitored to assess the impact over a specified period of time:

IF NO POTENTIAL DISCRIMINATION HAS BEEN IDENTIFIED or THE IMPACT IS NOT SIGNIFICANT ENOUGH TO WARRANT A FULL IMPACT ASSESSMENT, PLEASE SIGN AND DATE BELOW.
(NOTE: A full impact assessment should be undertaken if initial screening demonstrates that there could be significant detrimental impact.)
I have assessed this document and found:

- no potential impact on any group

SIGNATURE:

08/09/2016