Colorectal Cancer Stratified Follow-Up Implementation Resource Pack

June 2018

FINAL
# Contents

1. Background & Introduction .................................................................................................................. 3
2. Key features of a stratified follow-up ................................................................................................. 3
3. Understanding, evaluating and learning from national pilots .............................................................. 4
4. Progress with developing stratified pathways within UCLH Cancer Collaborative ......................... 6
5. The Colorectal Cancer Stratified Pathway ......................................................................................... 6

**References** .......................................................................................................................................... 6

**Acknowledgements** ............................................................................................................................... 7

Appendix A: Colorectal Cancer Stratified Follow-Up Pathway Guidelines ............................................. 9
1. Introduction and Purpose of this Guideline ......................................................................................... 11
2. Stratified Follow-Up: Overview of the pathway .................................................................................. 11
3. Eligibility for Entry onto Supported Self-management Pathway ...................................................... 12
4. Stratified Follow-Up: The Process ....................................................................................................... 12
5. Surveillance Investigations .................................................................................................................... 16
6. Clinical Governance ............................................................................................................................. 16
7. Re-accessing Specialist Services as required ..................................................................................... 17
8. Evaluation ............................................................................................................................................. 17
9. Guideline Monitoring ............................................................................................................................ 19

**References** .......................................................................................................................................... 19

**Acknowledgements** ............................................................................................................................... 20

Appendix I: Definitions ............................................................................................................................... 20
Appendix II: Stratified follow-up pathway for colorectal cancer patients ............................................. 21
Appendix III: Roles and Responsibilities ............................................................................................... 23
Appendix IV: Alert Symptoms .................................................................................................................... 25
Appendix V: Surveillance Test Schedule .................................................................................................. 26
Appendix VI: Patient Questionnaire Example .......................................................................................... 27
Appendix VII: Colorectal Cancer Stratified Follow-Up Subgroup Members ........................................ 32
Appendix B: Draft Business Case for Developing Stratified Follow-up ................................................. 33
Appendix C: Patient Information Leaflet on Supported Self-management .............................................. 41
Appendix D: IT Functionality Requirements and Options Appraisal document ....................................... 44
Appendix E: GP Information Leaflet on Support Self-management ...................................................... 50
Appendix F: GP Clinical Template Letter – Includes Treatment Summary ........................................... 53
Appendix G: Whittington Health Standard Operating Procedure ........................................................... 58
1. Background & Introduction

A key UCLH Cancer Collaborative priority is to reduce variation in order to improve patient experience and outcomes for individuals living with or beyond cancer. Across the Collaborative, 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 UCLH Cancer Collaborative website https://www.uclh.nhs.uk/OurServices/ServiceA-Z/Cancer/NCV/LC/Pages/Colorectalpathwayboard.aspx

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 will still be 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 within two weeks.

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 co-ordination 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 co-ordination 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 co-ordination and their own peace of mind.
- The central role of the Clinical Nurse Specialist (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 for 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 UCLH Cancer Collaborative

The Living with and Beyond Cancer Expert Reference Group is supporting the breast, colorectal and urology pathway boards and partners 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 Colorectal Cancer Stratified Pathway

The pathway and guidelines have been developed (Appendix A). In addition to the development of the pathway, a suite of documents has been developed to provide to trusts with 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
- **Appendix G**: An example of a local colorectal stratified follow-up standard operating procedure from Whittington Health

References


National Institute for Excellence (2011) Improving Outcomes in Colorectal Cancer, manual update

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 Colorectal 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: Colorectal Cancer Stratified Follow-Up Pathway Guidelines
## Contents

1. Introduction and Purpose of this Guideline .......................................................... 11
2. Stratified Follow-Up: Overview of the pathway ...................................................... 11
3. Eligibility for Entry onto Supported Self-management Pathway ................................ 12
4. Stratified Follow-Up: The Process ........................................................................ 12
5. Surveillance Investigations ..................................................................................... 16
6. Clinical Governance ............................................................................................... 16
7. Re-accessing Specialist Services as required ........................................................ 17
8. Evaluation ............................................................................................................... 17

References .................................................................................................................. 19

Acknowledgements .................................................................................................... 20

Appendix I: Definitions ............................................................................................... 20
Appendix II: Stratified follow-up pathway for colorectal cancer patients ...................... 21
Appendix III: Roles and Responsibilities .................................................................... 23
Appendix IV: Alert Symptoms .................................................................................... 25
Appendix V: Surveillance Test Schedule ..................................................................... 26
Appendix VI: Patient Questionnaire Example ............................................................ 27
Appendix VII: Colorectal Cancer Stratified Follow-Up Subgroup Members .................. 32
1. Introduction and Purpose of this Guideline

The *London Cancer* Colorectal Pathway Board formed a sub-group to develop a stratified follow-up pathway for the future delivery of colorectal cancer aftercare. The sub-group delivered its final proposed pathway to the Colorectal Pathway Board 12th September 2017. The pathway board, as the ultimate source of colorectal cancer expertise and leadership for *London Cancer* approved the stratified follow-up pathway on 4th December 2017.

This document describes the redesigned stratified follow-up pathway for colorectal cancer patients. It defines the three strata of follow-up support available to this cohort of patients – supported self-management, face-to-face follow-up and end of life care. It 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 colorectal 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 colorectal cancer surveillance programme 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.

These guidelines also describe the roles and responsibilities of health professionals in acute and primary care and the patient across the pathway.

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 Colorectal Pathway Specification* document. For definitions, refer to Appendix I.

2. Stratified Follow-Up: Overview of the pathway

The redesigned stratified follow-up pathway for individuals with colorectal cancer is outlined in Appendix II. The pathway is described from the point of diagnosis, through treatment until living with and beyond the disease or the transition to end of life care.

The pathway has three strata of follow-up:

- **Supported self-management pathway (SSMP):** Patient led follow-up where the individual receives support and interventions to empower them to self-manage their health. They receive surveillance tests but do not have routine clinic appointments
- **Face-to-face follow-up:** Clinician led follow-up. The individual will receive surveillance tests as per the London Cancer schedule. Clinic appointments are scheduled as required.
• **Supportive/end of life care services**: Clinician led with palliative care input as required.

Once an individual has finished first definitive treatment they will be reviewed by the clinical team and stratified onto the supported self-management pathway – or the face-to-face follow-up pathway if they are not eligible/unable to self-manage. This will be recorded in Somerset/Infophlex and the GP will be notified of the intended follow-up regime. They will be monitored on the appropriate pathway for five (or seven, following surgical intervention for single liver or lung metastasis with no follow-up at the tertiary centre) years. Those who are on the SSMP will then be discharged into primary care, with contact numbers if they require rapid access back into secondary care. Individuals receiving face-to-face follow-up will be reviewed and their needs for ongoing support by secondary care will be reviewed by the Multidisciplinary Team (MDT). Individuals may move between pathways as per their individual and clinical needs. For information on the roles and responsibilities of health professionals, teams, and the patient themselves, please refer to Appendix III.

### 3. Eligibility for Entry onto Supported Self-management Pathway

All colorectal cancer patients will be considered for entry onto the colorectal 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 end of treatment outpatient appointment (OPA) - 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 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. Stratified Follow-Up: The Process

#### 4.1 Diagnosis and treatment:

- Following the completion of first definitive treatment and review of histology, 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 individuals newly diagnosed with colorectal cancer will receive information about the treatment they will receive and how they will be supported during and after the end of treatment.

• This will include a description of both face-to-face and supported self-management follow-up options with emphasis placed on the fact that they may move between pathways if their needs change during the follow-up period.

• Individuals will receive a holistic needs assessment around diagnosis. This will be reviewed whenever their needs change.

• In the initial post-operative period, patients found to have a single liver or lung metastasis will enter into seven-year pathway in accordance with the London Cancer Colorectal Pathway Specification from the date of diagnosis of the metastasis.

4.2 End of treatment and follow-up

• At the end of treatment, all individuals will receive an ‘End of Treatment OPA’. This is an appointment between the patient and the Consultant/colorectal CNS in which the individual will have their holistic needs reviewed and they will receive personalised information regarding their follow-up options. It is recommended that the patient be provided with verbal and/or written information regarding the following:

  o Possible treatment toxicities/consequences of treatment
  o A personal plan for future surveillance monitoring. This will include an explanation of the process for receiving appointments for these tests and the method of results being communicated to them
  o Alert symptoms that require re-access to the specialist team. Please see list in Appendix IV.
  o Contact name and phone number of the colorectal specialist team and trust helpline (if the trust has a helpline)
  o Colorectal awareness
  o Nutrition and weight
  o Health and Wellbeing Events (HWBE)
  o Any local self-help groups and useful phone numbers (e.g. Macmillan Cancer Support, Beating Bowel Cancer)

• The decision regarding which pathway they will enter will be formalised within this End of Treatment OPA and will be 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.

• At the conclusion of the End of treatment OPA, the patient is transferred onto the supported self-management or face-to-face follow-up pathway. They will also be scheduled/offered opportunity to attend a HWBE.
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.

4.3 Living Beyond Cancer

Individuals who are eligible and choose the supported self-management pathway (SSMP):

- Can contact their colorectal CNS as needed with any concerns.
- Will not have routine outpatient appointments.
- Will receive surveillance tests as per the London Cancer Colorectal Pathway Specification (Appendix V).
- Will have a full colonoscopy conducted within one year of diagnosis (if not received at time of diagnosis) and every five years thereafter until aged 80.

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

The individuals who choose the face-to-face follow-up pathway or who are not eligible for the supported self-management pathway:

- Will have a schedule of follow-up surveillance tests, and outpatient appointments that are individualised to their diagnosis/needs.
- Will have their eligibility for entry onto the SSMP revisited during each OPA. If a patient persistently does not attend follow-up appointment, this is an opportunity to discuss/offer SSMP as an alternative means of follow-up for them.

4.3.1 Health and Wellbeing Events

All individuals will be offered a Health and Wellbeing Event (HWBE). Health and Wellbeing Events are education and support sessions that 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. HWBEs also increase awareness of local services, supportive care and opportunities that are available to patients 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 and sexual functioning.

- **Vocational rehabilitation**.

The end of treatment appointment with the Consultant/CNS 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 sessions¹. 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.

### 4.3.2 Discharge from the Stratified Follow-up Pathway

At the end of five years from the point of entry onto either the SSP or face-to-face pathway, the individual will receive their five-yearly CT (chest-abdomen-pelvis).

- **If their results are normal**, they and their GP will receive a letter of discharge to primary care. These individuals will remain on five-yearly colonoscopy surveillance as per local protocols.

- **If their results are abnormal**, they will be moved to the face-to-face follow-up pathway for further investigations.

---

Individuals who have had surgical resection of solitary liver or lung metastases will remain on the pathway for seven years.

5. **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.

5.1 Surveillance requests will be recorded on the cancer IT database at data entry following diagnosis. All patients will have five years of tests on the anniversary of diagnosis (unless the consultant indicates otherwise).

5.2 A safe and robust system of checking surveillance tests will be developed and implemented. It is recommended that the electronic database generates a monthly list of individuals who require surveillance tests. The test requests will then be made and appointment information sent to the patients. 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 test results.

5.3 Patients will be informed of their surveillance test schedule from their end of treatment summary letter and their personal surveillance schedule. Patients will be informed to contact the specialist team if they do not receive a request for surveillance 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 surveillance appointments.

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

6. **Clinical Governance**

Over the five-year duration of the follow-up pathway, the clinical governance responsibility for patients on the face-to-face and supported self-management pathways lies with the named clinician working in conjunction with the MDT (CNS and radiology).
7. Re-accessing Specialist Services as required

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

7.1 Patients and their GPs will have written contact numbers and guidelines regarding concerning symptoms requiring input from the specialist team. Access will be via the Colorectal CNS during the first five years and thereafter via a GP referral.

7.2 If a patient is on the SSMP and is required to have further investigations following their routine surveillance tests, they will be recalled as per local trust policy. Patients will be informed of this possibility at their end of treatment clinical appointment. Patients on the personalised clinical follow-up pathway will be seen in clinic for a review within two weeks and further investigations ordered as required. It is recommended that trusts identify a clinic for these patients to attend to ensure rapid access when required.

8. Evaluation

8.1 It is recommended that user feedback is conducted by a postal questionnaire which is sent to all patients three months following the End of Treatment OPA. The aim of the questionnaire is to establish if patients’ needs have been met. (Refer to Appendix VI for an example of a patient questionnaire.)

8.2 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 colorectal 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

8.3 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 - Patient Reported Experience Measures (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

8.4 It is recommended that measurement of the health related quality of life and wellbeing of colorectal 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 wellbeing. Originally validated in a general cancer population, it has condition-specific subscales to complement it, including one for colorectal cancer (FACT-C).
  - **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 five dimensions: mobility, self-care, usual activity, pain/discomfort, and anxiety/depression. The instrument comprises two 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:** [https://euroqol.org/](https://euroqol.org/)
9. 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) Colorectal Pathway Specification


National Institute for Health and Care Excellence (2011) Improving Outcomes in Colorectal Cancer, manual update


Acknowledgements

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

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

Appendix I: Definitions

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

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

End of Treatment OPA: The final outpatient appointment with a member of the consultant team and/or the Colorectal CNS after the individual’s treatment is completed.

Face-to-Face 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.

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 face-to-face pathway or a supported self-management pathway. The stratified follow-up pathway extends five (or seven) years from the point of entry.

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 colorectal 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 Colorectal Cancer Patients
Stratified Follow-up Pathway for Colorectal Cancer

1. **Diagnosis**
   - MDT
   - Treatment decision
   - Further Needs Assessment conducted

2. **Treatment**
   - MDT
   - Pre-operative short course radiotherapy and surgery
   - Pre-operative chemotherapy and surgery
   - Surgery
   - Neo-adjuvant chemo
   - Supportive and/or palliative care

3. **MDT**
   - Joint medical and nursing End of Treatment OPA
   - OPA includes clinical review
   - Treatment summary being completed, and surveillance test diary being given to patient
   - Patient is then stratified onto appropriate pathway: Surveillance tests conducted as per London Cancer schedule

4. **Support**
   - Supported self-management
   - Face-to-face follow-up
   - Education, support services and optimization for self-management
   - boots onto health and Wellbeing (<6 weeks of surgery)
   - Transition to end of life care
   - Consider referral to primary care for follow up +/- palliative care referral

5. **Surveillance**
   - Surveillance tests as per London Cancer schedule
   - Frequency of OPAs as per international and clinical need

6. **Results**
   - Normal result
   - Abnormal result

7. **Follow-up**
   - Results to patient & GP by appointment
   - Self-management

---

Care coordination

---

*Area within the green lines is expanded in the 'stratified follow-up pathway for eligible colorectal cancer patients' diagram. This area covers a time span of 5 years (or 7 years for patients with solitary liver or lung metastases which have been excised).*
Appendix III: Roles and Responsibilities
Follow-up pathway for colorectal cancer: Roles and responsibilities

**Diagnosis and Treatment**
- Process referral
- Entry onto cancer IT system
- Decision recorded on IT cancer system
- Pre-op radiology

**End of treatment & living beyond cancer**
- Preparation of treatment summary and invitation to aftercare appointment
- If abnormal result, patient recalled for review
- CEA Colonoscopy CT CAP
- If normal result
  - Results to GP & Patient
  - Follow up schedule as per London Cancer pathway specification. Then five-yearly colonoscopies as appropriate

**End of Treatment OPA**
- Joint medical and nursing appointment
- Treatment summary completed
- Surveillance test schedule given to patient
- Stratified follow-up decision made in collaboration with patient
- Individual is then transferred to appropriate pathway

**Face-to-face follow-up**
- Supported Self management: Patient led follow-up / support determined by need
- Ongoing support and helpline for patients

**MDT**
- Investigations diagnosis and treatment
- MDT includes: Radiology, Screening, Medical, Patient, CNS, GP, Support services

**Support services**
- Health and Wellbeing Events AND additional support services (Psychological, rehabilitation, diet and nutrition, exercise, peer support, stoma management)

**GP Support**
- Includes cancer care review within 6 months of diagnosis and referral back to appropriate specialist team, as required

**Patient info**
- Describes available follow-up options

**HNA**
- Discuss follow up options with patient
- HNA reviewed as needed

**Process**
- Patient engaged throughout and self-referral to appropriate specialist, as required

At end of 5 or 7 years, if results normal, discharge to primary care. If abnormal refer to MDT.
Appendix IV: Alert Symptoms

Symptoms checklist

It is recommended that this is given to all patients as a means of highlighting symptoms that should trigger obtaining advice from the Colorectal CNS. Much of this can be assessed over the phone, with the patient being asked a detailed history, regarding onset duration, exacerbating and relieving factors and any action already taken. Then given advice +/- signposted to their GP.

However some of these symptoms combined with telephone triage may necessitate an outpatient appointment

- Change in bowel habit (lasting more than one week)
- Blood in or on the stool
- Blood on wiping
- Mucous on or mixed with the stool
- Recurrent new onset abdominal pain, again not just a single episode
- Weight loss
- Increasing tiredness
- Loss of appetite
- Weight loss for no reason
- Abdominal swelling or tenderness
### Appendix V: Surveillance Test Schedule

<table>
<thead>
<tr>
<th>Year</th>
<th>Month</th>
<th>Date</th>
<th>Investigations</th>
<th>Recommended health care provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>6</td>
<td>weeks</td>
<td>• CEA</td>
<td>Hospital</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Post-op follow-up in clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• HNA if not for chemotherapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Treatment summary / diary completed</td>
<td></td>
</tr>
<tr>
<td>1-2</td>
<td></td>
<td></td>
<td>• Health and Wellbeing Event/session offered</td>
<td>Hospital Colorectal Nurse Specialist</td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
<td>• CEA</td>
<td>Hospital Colorectal Nurse Specialist</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• CT CAP</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Colonoscopy if not complete pre-op</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• HNA if received chemotherapy</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Clinic, telephone or virtual assessment</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td></td>
<td></td>
<td>• CEA</td>
<td>Hospital Colorectal Nurse Specialist</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Colonoscopy</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Clinic or telephone assessment</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>18</td>
<td></td>
<td>• CEA</td>
<td>Hospital Colorectal Nurse Specialist</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• CT CAP</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Clinic, telephone or virtual assessment</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td></td>
<td></td>
<td>• CEA</td>
<td>Hospital or primary care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Clinic, telephone or virtual assessment</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>30</td>
<td></td>
<td>• CEA</td>
<td>Hospital or primary care</td>
</tr>
<tr>
<td>36</td>
<td></td>
<td></td>
<td>• CEA</td>
<td>Hospital Colorectal Nurse Specialist</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• CT CAP</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Clinic, telephone or virtual assessment</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>48</td>
<td></td>
<td>• CEA</td>
<td>Hospital or primary care</td>
</tr>
<tr>
<td>5</td>
<td>60</td>
<td></td>
<td>• CEA</td>
<td>Hospital or primary care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• CT CAP</td>
<td></td>
</tr>
</tbody>
</table>

Then five-yearly colonoscopies, if fit.
Appendix VI: Patient Questionnaire Example
Patient Questionnaire about follow up, after treatment ends, for colorectal cancer patients cared for by insert trust name

At the insert trust name, we are changing how we care for individuals who have colorectal cancer once they have completed their treatment. These changes are in line with national guidelines (NHS Improvement Cancer and the National Cancer Survivorship Initiative) 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 Colorectal CNS?
   - Yes □
   - No □

2. After your end of treatment clinical review outpatient appointment with the doctor or Colorectal CNS, 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 colorectal care nurse?
   - Yes □
   - No □

5. Please comment about the contents of this letter below, if you feel able to.
   _________________________________________________________________
   _________________________________________________________________
   _________________________________________________________________
   _________________________________________________________________
   _________________________________________________________________

28
6. Did you receive a Holistic Needs Assessment with your Colorectal Care Nurse at your aftercare appointment?
   Yes □     No □   Don’t know □

7. Do you feel the Holistic Needs 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, 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 Colorectal 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 VII: Colorectal Cancer Stratified Follow-Up Sub-group Members

- Sharon Cavanagh (Chair) – Macmillan Integrated Cancer Programme, Living with and Beyond Cancer and AHP Lead, UCLH Cancer Collaborative
- Pauline McCulloch – Colorectal Lead Nurse Academic Department of Coloproctology Nursing, Homerton University Hospital NHS Foundation Trust
- Katie Sutton - Macmillan Project Lead, Cancer Follow-Up Redesign, University College of London Hospital NHS Foundation Trust
- Jonathan Wilson - Consultant Laparoscopic Colorectal and General Surgeon, Whittington Health NHS Trust
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 terms 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:

<table>
<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>
</tr>
</tbody>
</table>

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 slip 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 six 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 people in the UK living following a diagnosis of cancer (2008). 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 healthcare professional discusses the result with the patient and confirms when the next test and followup 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\(^2\) 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></td>
<td>The standardised follow-up model of care continues with surveillance tests at the hospital before/at time of clinic visits. Limited opportunity exists for needs assessments after treatment completion and consequent referral to support services. Patients remain dependent on the specialist team. Increased pressure on access times for new and follow-up appointments and reduced time for those with complex needs. Increasing volume of unnecessary appointments. Potential for patients to be lost to follow up.</td>
</tr>
<tr>
<td>2</td>
<td>Specialist led open access</td>
</tr>
<tr>
<td></td>
<td>For low risk patients an open access pathway allows the specialist to schedule and monitor surveillance tests without the need for face-to-face appointments. An initial assessment of needs, a care plan and treatment summary helps to improve knowledge, understanding of disease and on-going surveillance plan. There is no impact on primary care. Rapid re-access systems to specialist if required.</td>
</tr>
</tbody>
</table>

---

\(^2\) NHS Improvement - Stratified Pathways of Care – from Concept to Innovation. Executive Summary. May 2012
Primary care led follow up

Low risk patients are assessed at end of treatment and 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.

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>Weight</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 waits</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>TOTAL</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>
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/five 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.

---

<table>
<thead>
<tr>
<th>Admin and clerical support - Band 3 (2 hours per week)</th>
<th>£1,400.00</th>
<th>£1,400.00</th>
<th>£1,400.00</th>
<th>£1,400.00</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lost income through reduced OP tariff cost</td>
<td>£0.00</td>
<td>£3,000.00</td>
<td>£4,000.00</td>
<td>£5,000.00</td>
</tr>
<tr>
<td><strong>Total Costs</strong></td>
<td><strong>£24,400.00</strong></td>
<td><strong>£15,400.00</strong></td>
<td><strong>£16,400.00</strong></td>
<td><strong>£17,400.00</strong></td>
</tr>
<tr>
<td><strong>Benefits (to providers)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opportunity costs - released slots for new activity</td>
<td>£0.00</td>
<td>£10,400.00</td>
<td>£15,000.00</td>
<td>£20,000.00</td>
</tr>
<tr>
<td><strong>Total benefits</strong></td>
<td><strong>£0.00</strong></td>
<td><strong>£10,400.00</strong></td>
<td><strong>£15,000.00</strong></td>
<td><strong>£20,000.00</strong></td>
</tr>
<tr>
<td><strong>Net Cash Flow</strong></td>
<td><strong>£24,400.00</strong></td>
<td><strong>-£5,000.00</strong></td>
<td><strong>-£1,400.00</strong></td>
<td><strong>£2,600.00</strong></td>
</tr>
<tr>
<td>PV</td>
<td>1</td>
<td>0.96</td>
<td>0.93</td>
<td>0.90</td>
</tr>
<tr>
<td>NPV</td>
<td>-£24,400</td>
<td>-£4,800.00</td>
<td>-£1,302.00</td>
<td><strong>£2,340.00</strong></td>
</tr>
</tbody>
</table>

*NB. The IT costs will depend on the remote monitoring solution selected for which a separate business case may be required.*
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</th>
<th>Probability</th>
<th>Impact</th>
<th>Risk score</th>
<th>Mitigation</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>
</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 specialities where primary care monitoring is not suitable</td>
</tr>
<tr>
<td>3</td>
<td>Etc</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.
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 colorectal 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 surveillance tests, 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 colorectal cancer. For example, Broomfield Hospital in Essex 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 about specific symptoms you should report without delay to your colorectal CNS.

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 aware of changes in your body;
- Arrangements for surveillance tests;
- How to use the Helpline which gives you fast access to your colorectal CNS if you need it;
- The process your colorectal CNS 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 colorectal service in the event of concerns?
Yes. You can call the colorectal Clinical Nurse Specialists 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 colorectal CNS 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 tests?

Yes. When you move onto the self-management pathway, you will be given information on the blood tests, colonoscopies and CT scans that you will require for at least five years after your diagnosis. Your CNS will make you aware of how results of the tests will be communicated with you. It is recommended that you contact the specialist team if you do not receive a request for the routine test by the end of the month that it is due.

How the Helpline works

At the end of your treatment, you will have a special consultation with your doctor or Colorectal CNS. 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 them 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 Colorectal CNS nurse within XX hours.

Your Colorectal CNS 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 they feel 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
December 2017
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 blood tests, CT scans, colonoscopies). The Colorectal Pathway Board recommends a sector wide secure web based solution. Such a database would be a facilitator to the implementation of stratified follow-up and would generate the data to assess what further evidence based improvements could be made to the system.

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 results 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
13. Patient portal

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 “Innovation to implementation: Stratified pathways of care for people living with or beyond cancer - A ‘how to guide’”. 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 suits local needs, e.g. audit.
- Speed of implementation.
- Less likely to require business case approval.

**Cons**
- May require additional licences.
- 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 licence 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 £5,000.

**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 – University Hospitals Southampton NHS Foundation Trust (UHSFT) solution**
University Hospitals Southampton NHS Foundation Trust (UHSFT) have developed a patient online solution that enables clinical teams across several cancer care pathways to manage their patients. In many cases this allows their patients to be managed remotely preventing unnecessary outpatient appointments.

The standard solution includes four key functional areas; patient registration, interfacing, patient facing website, clinician facing website. It includes a patient ‘tracker’ for managing a patient along a cancer pathway/protocol. This allows teams to review patients at set or ad hoc times (typically when results/investigations take place). The clinical teams can also access everything else held in the patient record. This service is accessible from any web enabled device (pc, laptop, tablet but not recommended for smartphone).

**Pros**
- Feed data from PAS, Pathology and Radiology systems at remote hospitals into online records so that patients and clinical teams can view it.
- The patient online solution can be implemented for prostate, testicular, breast, colorectal cancer care pathways
- Each patient has their own health record and access to this via the website and the patient registration process. Once logged in the patient will be able to do the following;
  - Access patient information relative to their condition
  - Message their clinical team
  - View their pathology results / radiology reports
  - Take holistic needs assessments
  - Graph lab results (if relevant to tumour site)

**Cons**
- Set up and licence costs
- Configuring system with additional functionality will incur extra development effort and cost.

Contact: Kevin Hamer. Email address: Kevin.Hamer@uhs.nhs.uk
Appendix E: GP Information Leaflet on Supported Self-management
Why are you sending me this leaflet?
You are being sent this leaflet because your patient, after having treatment for colorectal cancer at our hospital, has had their follow-up clinical review appointment with one of our consultants and a colorectal Clinical Nurse Specialist (CNS), 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 surveillance tests 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 colorectal 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 aware of changes in the body
- Arrangements for surveillance tests
- 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 colorectal service?
Yes. Patients will be able to call the dedicated helpline (XXXXXXXXXX) 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 Colorectal CNS within timescale of leaving a message. If the Colorectal CNS 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 colorectal 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 tests?
Yes. Unless it has been otherwise specified on the letter we have sent you, they will need regular CEA tests, CT scans and colonoscopies for at least five years*. At the end of five years from the point of entry onto the pathway, the individual will receive their five-yearly CT (chest-abdomen-pelvis).
- If their results are normal, both you and the patient will receive a letter of discharge to primary care. These individuals will remain on five-yearly colonoscopy surveillance as per local protocols.
- If their results are abnormal, they will have further investigations.
- Individuals who have had surgical resection of solitary liver or lung metastases will remain on the pathway for seven years.

*
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.

<table>
<thead>
<tr>
<th>What you need to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓ Inform the specialist team if any concerning signs or symptoms reported by the patient</td>
</tr>
<tr>
<td>✓ Please encourage your patient to contact the Helpline xxxxxx, if they have any symptoms that could indicate a return of their cancer.</td>
</tr>
</tbody>
</table>

What you need to do

 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 colorectal cancer. These symptoms could indicate a return or spread of the disease and need further investigation.

- Change in bowel habit (lasting more than 1 week)
- Blood in or on the stool
- Blood on wiping
- Mucous on or mixed with the stool
- Recurrent new onset abdominal pain, again not just a single episode
- Weight loss
- Increasing tiredness
- Loss of appetite
- Weight loss for no reason
- Abdominal swelling or tenderness

NB: If your patient experiences any of the following symptoms they should call the Helpline xxxxxx or you can do so on their behalf. The helpline is monitored from Monday to Friday, 9am to 5pm. Patients will be called back within timescale of leaving a message.

Created: 
Review date:
Appendix F: GP Clinical Template Letter – Includes Treatment Summary
Supported Self-management Follow-Up for Colorectal 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 colorectal 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 aware of changes to their body
- Their planned surveillance tests
- 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:

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 Colorectal Team on insert specialist team number

Signed: ..............................................................   Contact Tel no. ...................................
Name (please print) ..............................................................
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>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Local/Distant:</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>
</tr>
</thead>
<tbody>
<tr>
<td>District Nurse</td>
</tr>
<tr>
<td>AHP</td>
</tr>
<tr>
<td>Social Worker</td>
</tr>
<tr>
<td>Dietician</td>
</tr>
<tr>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td>Psychologist</td>
</tr>
<tr>
<td>Benefits/Advice Service</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Summary of information given to the patient about their cancer and future progress:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Additional information including issues relating to lifestyle and support needs:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Completing Doctor:</th>
<th>Signature:</th>
<th>Date:</th>
</tr>
</thead>
</table>
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>Diagnosis:</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>XE1W</td>
<td>Malignant neoplasm of Rectum</td>
<td>B141.</td>
</tr>
<tr>
<td>Bowel Intestine</td>
<td>X78qK</td>
<td>Malignant neoplasm of Colon</td>
<td>B13..</td>
</tr>
<tr>
<td>Large Bowel</td>
<td>X78gN</td>
<td>Malignant neoplasm of female mammo</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>Histology/Staging/Grade:</td>
<td>Histology/Staging/Grade:</td>
<td></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>Treatment Aim:</td>
<td>Treatment Aim:</td>
<td></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>Treatment toxicities/late effects:</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>Ongoing Management Plan</td>
<td>Ongoing Management Plan</td>
<td></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>Referrals made to other services:</td>
<td>Referrals made to other services:</td>
<td></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>Actions required by the GP</td>
<td>Actions required by the GP</td>
<td></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 Plan Review</td>
<td>XalG1</td>
<td>Palliative Care Plan Review</td>
<td>8CM3.</td>
</tr>
<tr>
<td><strong>Medication:</strong></td>
<td></td>
<td><strong>Medication:</strong></td>
<td></td>
</tr>
<tr>
<td>New medication started by specialist</td>
<td>XEOhn</td>
<td>Medication given</td>
<td>8BC2.</td>
</tr>
<tr>
<td>Medication changed by specialist</td>
<td>8B316</td>
<td>Medication changed</td>
<td>8B316</td>
</tr>
<tr>
<td>Advice to GP to start medication</td>
<td>XaKbF</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advice to GP to stop medication</td>
<td>XaJC2</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Information to patient:</strong></td>
<td></td>
<td><strong>Information to patient:</strong></td>
<td></td>
</tr>
<tr>
<td>DS1500 form claim</td>
<td>XaCDx</td>
<td>DS1500 completed</td>
<td>9EB5.</td>
</tr>
<tr>
<td>Benefits counselling</td>
<td>6743.</td>
<td>Benefits counselling</td>
<td>6743.</td>
</tr>
<tr>
<td>Cancer information offered</td>
<td>XalmL</td>
<td>Cancer information offered</td>
<td>677H.</td>
</tr>
<tr>
<td>Cancer diagnosis discussed</td>
<td>XalpL</td>
<td>Cancer diagnosis discussed</td>
<td>8CL0.</td>
</tr>
<tr>
<td>Aware of diagnosis</td>
<td>XaQly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unaware of prognosis</td>
<td>XaVzE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer aware of diagnosis</td>
<td>XaVzA</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Miscellaneous:</strong></td>
<td></td>
<td><strong>Miscellaneous:</strong></td>
<td></td>
</tr>
<tr>
<td>On GSF palliative care framework</td>
<td>XaJv2</td>
<td>On GSF Palliative Care Framework</td>
<td>8CM1.</td>
</tr>
<tr>
<td>GP OOH service notified</td>
<td>Xaltp</td>
<td>GP OOH service notified</td>
<td>9e0..</td>
</tr>
<tr>
<td>Carers details</td>
<td>9180.</td>
<td>Carer details</td>
<td>9180.</td>
</tr>
</tbody>
</table>
Appendix G: Whittington Health Standard Operating Procedure
## SUPPORTED REMOTE MANAGEMENT FOR CANCER FOLLOW UP

### STANDARD OPERATING PROCEDURE (SOP)

[COLORECTAL, BREAST AND PROSTATE CANCER]

<table>
<thead>
<tr>
<th>Reference number</th>
<th>SOP/SL/0393</th>
</tr>
</thead>
<tbody>
<tr>
<td>Version:</td>
<td>1</td>
</tr>
<tr>
<td>Ratified by:</td>
<td>Policy Assurance Group</td>
</tr>
<tr>
<td>Ratification Date:</td>
<td>30 May 2017</td>
</tr>
<tr>
<td>Approval Committee</td>
<td>Surgery and Cancer ICSU Board</td>
</tr>
<tr>
<td>Date Approved:</td>
<td>May 2017</td>
</tr>
<tr>
<td>Date Issued:</td>
<td>30 May 2017</td>
</tr>
<tr>
<td>Executive Owner:</td>
<td>Chief Operating Officer</td>
</tr>
<tr>
<td>Name of Author(s) and Job Title(s):</td>
<td>Karen Phillips, Macmillan Lead Cancer Nurse</td>
</tr>
<tr>
<td>Target Audience:</td>
<td>All staff in Cancer Services</td>
</tr>
<tr>
<td>Review date:</td>
<td>3 years after ratification date 30 May 2020</td>
</tr>
<tr>
<td>Procedural document linked to/Tagged:</td>
<td>Tick as appropriate</td>
</tr>
<tr>
<td>Regulatory Compliance</td>
<td>√</td>
</tr>
<tr>
<td>Organisation-wide</td>
<td></td>
</tr>
<tr>
<td>Directorate/ICSU</td>
<td>Cancer services</td>
</tr>
<tr>
<td>Service</td>
<td></td>
</tr>
<tr>
<td>Shared document</td>
<td></td>
</tr>
<tr>
<td>Keywords</td>
<td>Cancer, self-management, follow-up, stratified</td>
</tr>
</tbody>
</table>

This is an online document. Hard copies and downloaded versions are valid only on the day printed or downloaded. It is the responsibility of staff to verify current status from the Intranet.
Version Control Summary

<table>
<thead>
<tr>
<th>Version No</th>
<th>Description of change</th>
<th>Author</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>New SOP</td>
<td>Karen Phillips</td>
<td>30/3/17</td>
</tr>
</tbody>
</table>

Contents

1.0 Introduction........................................................................................................ 3
2.0 Purpose .................................................................................................................. 3
3.0 Scope ....................................................................................................................... 3
4.0 Duties (Roles and Responsibilities) ................................................................. Error! Bookmark not defined.
5.0 Procedure specific detail ............................................................... Error! Bookmark not defined.
6.0 Contact List .......................................................................................................... Error! Bookmark not defined.
7.0 References ........................................................................................................... 5
8.0 Associated Documents .......................................................................................... 5
9.0 Appendices ............................................................................................................. Error! Bookmark not defined.
10.0 Equality Impact Analysis...................................................................................... 6
1.0 INTRODUCTION

1.1 Stratified follow-up is an approach to steering individuals onto the best 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.

1.2 Implementation of stratified follow-up with a focus on self-management reduces the frequency of hospital based follow-up appointments, ensures GPs have the information they require to provide care in the community (if needed) and supports individuals to live well after treatment.

1.3 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.

1.4 As part of the NCSI we are implementing stratified follow-up within the breast, prostate and colorectal cancer pathways.

2.0 PURPOSE

2.1 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.

2.2 This SOP details the roles and responsibilities of key staff in each tumour group pathway; Consultant, Clinical Nurse Specialist (CNS), Stratified Pathway Co-ordinators.

2.3 The SOP details clear steps within the pathway to follow to ensure that every patient is followed up in locally agreed timeframes and both the patient and primary care are kept fully informed at each stage of the pathway.

3.0 SCOPE

3.1 The SOP is written as a series of flow charts clearly denoting the staff responsibilities and actions.

3.2 The primary tumour groups for stratified follow up are Breast, Prostate and Colorectal. Within each group key staff include Consultant, CNS and Stratified Pathway Co-ordinators.

3.3 Each pathway is individualised depending on the tumour group but the SOP is generic to all three as the same processes and procedures apply.
3.3 The flow chart includes actions for dealing with DNA and measures to take if unable to contact to patient.

4.0 DUTIES (Roles and Responsibilities)

4.1 The Consultant, CNS and Stratified Pathway Co-ordinators must attend the weekly tumour group Multi-Disciplinary Team meeting or send a deputy in their absence.

4.2 The Consultant presents each patient considered eligible for remote management as per inclusion/exclusion guidelines and clinical judgement.

4.3 The Consultant makes formal referral to self-management pathway on ICE and within one week the Stratified Pathway Co-ordinator checks that patient has been added to pathway.

4.4 The Consultant and CNS have an exit clinical appointment with the patient where the follow up plan is fully discussed and explained. The CNS ensures an end of treatment e-HNA is completed along with a Treatment Summary that is agreed with the Consultant and copy given to the patient and primary care.

4.5 The Stratified Pathway Co-ordinators monitor the IT spreadsheet and co-ordinate scheduling of tests, ensuring all patients receive notification of tests.

4.6 The Stratified Pathway Co-ordinators ensure attendance and communicate to the Consultant and CNS that they need to review results.

4.7 All DNA and unable to contact patient are actioned as per flow chart below (appendix 1)

4.8 Once the Consultant has reviewed the test results only they can action if the patient is to remain in remote monitoring and approve on the IT monitoring site.

4.9 If the patient is no longer eligible for remote monitoring they are presented to local MDT for review and treatment plan.

5.0 PROCEDURE SPECIFIC DETAIL

See flowcharts under Appendices

- Stratified Pathway – Adding a patient to the pathway
- Stratified Pathway – Scheduling tests
- Stratified Pathway – Checking test results
- Stratified Pathway – Removing patient from pathway
- Stratified Pathway – DNA/Uncontactable
## 6.0 CONTACT LIST

<table>
<thead>
<tr>
<th>Position</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lead Cancer Nurse</td>
<td>0207 288 3882</td>
</tr>
<tr>
<td>Cancer Service Manager</td>
<td>0207 288 3493</td>
</tr>
<tr>
<td>Breast Oncologist</td>
<td>0207 288 5227</td>
</tr>
<tr>
<td>Colorectal Surgeon</td>
<td>0207 288 5047</td>
</tr>
<tr>
<td>Urology Surgeon</td>
<td>0207 288 5221</td>
</tr>
<tr>
<td>Breast CNS</td>
<td>0207 288 5147</td>
</tr>
<tr>
<td>Colorectal CNS</td>
<td>0207 288 5975</td>
</tr>
<tr>
<td>Prostate CNS</td>
<td>0207 288 5772</td>
</tr>
<tr>
<td>Breast Stratified Follow up Co-ordinator</td>
<td>0207 288 3873</td>
</tr>
<tr>
<td>Colorectal Stratified Follow up Co-ordinator</td>
<td>0207 288 3865</td>
</tr>
<tr>
<td>Prostate Stratified Follow up Co-ordinator</td>
<td>0207 288 3859</td>
</tr>
</tbody>
</table>

## 7.0 REFERENCES

7.1 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. This SOP was written with reference to Stratified Follow up Toolkits that may be sourced as word documents on the London Cancer website.

http://www.londoncancer.org/cancerprofessionals/breast/breast-pathway-documents

http://www.londoncancer.org/cancerprofessionals/urological/urological-pathway-documents


### ASSOCIATED DOCUMENTS

<table>
<thead>
<tr>
<th>Title</th>
<th>Intranet Hyperlink</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Stratified Pathway – Adding a patient to the pathway

1. Does MDT agree to add patient to self management pathway?
   - Yes
     - Stratified Pathway Co-ordinator records patient details in MDT meeting
     - Such information may be able to be recorded on the Somerset Cancer Register
     - Patient booked to attend clinic (by MDT co-ordinator/CNS)
   - No
     - Go to DNA/Uncontactable

2. Does patient attend?
   - Yes
     - Go to scheduling tests
   - No
     - Patient offered follow up on self management pathway

3. Does patient agree to go onto self management pathway?
   - Yes
     - Clinician makes formal referral to self management pathway on ICE
   - No
     - Within one week Stratified Pathway Co-ordinator checks that patient has been added to pathway
     - Has clinician added patient to pathway?
       - Yes
         - Stratified Pathway Co-ordinator sends patient and GP template letter informing them that they have been added to pathway
         - At this point patient is formally discharged from service
       - No
         - Go to DNA/Uncontactable

4. Only if pathway not ended
   - CNS arranges 3 month follow up, for end of treatment eHNA and treatment summary
   - Go to scheduling tests
Stratified Pathway – Scheduling Tests

From adding a patient to the pathway

Repeat process

Stratified Pathway Co-ordinator checks report

Is patient due for one or more tests in six weeks’ time?

Yes

End

No

Stratified Pathway Co-ordinator checks whether patient is alive

Is patient deceased?

Yes

Stratified Pathway Co-ordinator removes patient from pathway on ICE

No

Stratified Pathway Co-ordinator contacts patient to arrange test(s) by letter & phone

No

Stratified Pathway Co-ordinator checks report

Yes

Go to DNA/Not contactable

Does patient attend all test(s)?

No

Stratified Pathway Co-ordinator contacts CNS

Check on a weekly basis

Yes

Stratified Pathway Co-ordinator checks date of test on report

No

Go to DNA/Not contactable

Can Stratified Pathway Co-ordinator book tests?

Yes

Stratified Pathway Co-ordinator requests test on ICE

Page 8 of 12

Only if pathway not ended

Has test been booked?

No

Only if pathway has not ended

Can Stratified Pathway Co-ordinator book tests?

Yes

Stratified Pathway Co-ordinator books test (based on due date); test forms sent out as appropriate

No

Stratified pathway Co-ordinator checks date of test on report

Check on a weekly basis

Yes

Stratified Pathway Co-ordinator contacts CNS

Go to DNA/Not contactable

Does patient attend all test(s)?

No

Stratified Pathway Co-ordinator contacts patient to arrange test(s) by letter & phone

No

Stratified Pathway Co-ordinator checks report

Yes

Go to DNA/Not contactable

Can Stratified Pathway Co-ordinator book tests?

Yes

Stratified Pathway Co-ordinator requests test on ICE
From scheduling tests

Stratified Pathway Co-ordinator shows test results to CNS/clinician

This may happen as part of a weekly meeting with the CNS

Are test results normal?

Yes → CNS phones patient to offer nurse led follow up

No → Patient added to MDT (if appropriate)

Will patient remain on pathway?

Yes → Has patient reached end of pathway?

Yes → Patient and GP sent generic discharge letter → End

No → Patient and GP sent generic letter informing them of when next test(s) are due → End

No → Prompt clinician to remove

Yes → Stratified Pathway Co-ordinator ensures patient is removed

Has patient been removed?

Yes → End

No → Patient added to MDT (if appropriate)
Stratified Pathway – Removing patient from pathway

Patient /GP contacts CNS (at any point during pathway)

Will patient remain on pathway?

Yes

Stratified Pathway Co-ordinator follows clinical instructions
Patient returns to same point on pathway

No

Clinician removes patient from pathway

Prompt clinician to remove

Has patient been removed?

No

Yes

End

Clinician removes patient from pathway

Stratified Pathway Co-ordinator ensures patient is removed

e.g. Patient may be booked to an outpatient clinic as a new patient
(previously discharged when added to pathway)
Stratified pathway – DNA/Uncontactable

From previous point in pathway

Stratified Pathway Co-ordinator attempts to contact patient by telephone on a weekly basis

Contact numbers to be checked with GP/NHS portal/next of kin/directory enquiries etc

Is patient contactable by telephone?

Yes → Return to next point in pathway

No → Stratified Pathway Co-ordinator sends out 2nd template contact letter asking patient to call

Does patient make contact within six weeks of letter being sent?

Yes → Clinician removes patient from pathway

No → Stratified Pathway Co-ordinator sends template discharge letters to GP and patient

Prompt clinician to remove

Has patient been removed?

No

Yes → End

Stratified Pathway Co-ordinator ensures patient is removed

Clinician removes patient from pathway

Stratified Pathway Co-ordinator sends out 2nd template contact letter asking patient to call
10.0 Whittington Health – Equality Impact Analysis Form

Access guidance via this link: http://whittnet/default.asp?c=9308

1. Name of Policy or Service

   Supported remote management for cancer follow up SOP

2. Assessment Officer

   Karen Phillips, Lead Cancer Nurse

3. Officer responsible for policy implementation

   Karen Phillips, Lead Cancer Nurse

4. Completion Date of Equality Analysis 30/3/2017

5. Description and aims of policy/service

   To provide supported self-management to patients for follow-up cancer treatment

6. Initial Screening

   An initial analysis has been carried out to explore whether the SOP is likely to have a detrimental impact in terms of people included in one or more of the following equality categories:
   
   - Race
   - Disability
   - Gender
   - Age
   - Sexual orientation
   - Religion and belief
   - Gender Reassignment
   - Marriage and civil partnership
   - Pregnancy and maternity

7. Outcome of initial screening

   No detrimental impacts

8. Monitoring and review/evaluation

   The Stratified follow up coordinators will monitor IT spreadsheets and provide data for audit for number of patients in stratified follow up to be reported to London Cancer quarterly.

9. Publication of document: Intranet