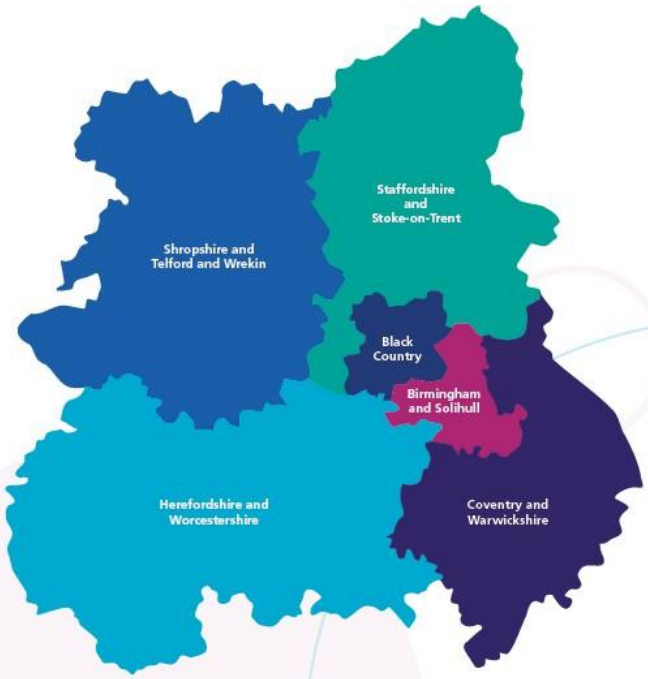
West Midlands Cancer Alliance: Colorectal Cancer Personalised Stratified Follow-up Pathway Guidelines December 2025



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Approved by

This document must be approved by the following people:

Governance	Description	Who	Date
WMCA Colorectal EAG Chair	Approved	EAG chair	10/12/2025
WMCA Clinical Cabinet	Approved	Clinical Cabinet	14 January 2026

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1. Introduction and Purpose of this Guideline

This guideline is for Personalised Stratified Follow-Up (PSFU) for people with a bowel cancer diagnosis. It spans primary and secondary care and covers the care of the individual who has completed their treatment for bowel cancer.

The purpose of this document is to provide best practice details specific to bowel cancer and should be read in conjunction with 'Personalised Stratified Follow Up Guidelines for people with a cancer diagnosis' which provides more detailed general guidelines on the WMCA website.

This document is intended as a flexible resource to help Trusts implement the PSFU pathway for patients with primary bowel cancer.

As a result of increasing incidence and improved survival rates for colorectal cancer, models of follow up with greater emphasis on quality of life and responsibility for the individual have been introduced. This is beneficial both for the patient and for the system as a way of addressing capacity issues within the NHS.

As outlined in the NHS Long Term Plan (2021), the implementation of (PSFU) pathways across all clinically appropriate cancer types is a national priority. This approach aims to enhance cancer care by ensuring timely access to personalised support, underpinned by ongoing holistic needs assessments, structured care planning, and coordinated support services.

The NHS Long Term Plan and Planning and Operational Guidance has placed a strong emphasis on improving the cancer waiting time recovery particularly for the 62-day referral to treatment waiting time standard. The introduction of PSFU will enable the reduction in outpatient activity freeing up clinical capacity to focus on timely patient treatment and care, patient quality outcomes and NHS efficiency.

The purpose of this document is to provide best practice guidance for Trusts, commissioners, clinicians and all others involved in providing person centred follow up after surgical treatment for colorectal cancer. This original model of follow up has been in place since March 2020 and has now been reviewed and updated in 2025 these guidelines are to assist all members of the colorectal multi-disciplinary team (MDT) in understanding the process, ensuring optimum follow up care is provided to all colorectal cancer patients completing treatment.

PSFU should be introduced and clearly explained at the point of diagnosis to ensure patients are informed and engaged early in their cancer pathway. Early preparation is essential to support a the transition to living with and beyond cancer. This approach reinforces the principle that cancer care extends beyond disease management it encompasses holistic support for the individual throughout their cancer journey, addressing both physical and psychological needs. Many patients may experience long-term effects of their cancer, which can emerge shortly after

treatment ends many years later, emphasising the importance of proactive, personalised follow-up.

This document describes 3 levels of follow up investigation – standard, intensive and supportive to allow stratification of patients according to oncological risk in line with the Association of Coloproctology of Great Britain and Ireland (ACPGBI) recommendation.

The document provides guidelines to recommend:

These guidelines recommend the following key components to ensure safe, effective, and person-centred follow-up care for individuals diagnosed with colorectal cancer:

- A safe, robust, user-friendly system is available to enable PSFU, which includes appropriate surveillance with timely reporting and recall if required to facilitate a positive patient experience.
- Every individual is provided with additional information and signposting to enable them to manage and live well with and beyond cancer.
- Every individual is provided with verbal and written guidelines about exactly when and who to contact if they have any concerns in the future.
- Every individual, their GP and the hospital will receive a Treatment Summary (TS) outlining the care and treatment received plus any key information regarding consequences of disease and/or treatment required for Primary Care to facilitate continuity of care in the form of a Cancer Care Review (CCR).
- Timely, safe and appropriate open access back into specialist colorectal services is in place should they be required.

This protocol has been co-designed with the West Midlands Cancer Alliance, the West Midlands Cancer Alliance Colorectal Expert Advisory Group, representatives from local Integrated Care Systems and Primary Care as well as patient and carer involvement throughout.

2. Context

Bowel Cancer Incidence

PSFU for colorectal cancer has been designed to enable post-treatment care based on individual risk profiles, clinical needs, and patient preferences and address the increase in demand for cancer services. This model is particularly relevant given the high and rising incidence of colorectal cancer in the UK.

Bowel Cancer Incidence and demographics in the UK:

- Over 385,000 new cancer cases are diagnosed annually in the UK more than 1,000 per day (2017–2019).

- Bowel cancer accounts for approximately 44,100 new cases each year, making it the fourth most common cancer, representing 11% of all new diagnoses.
- It ranks as the third most common cancer in both females (19,600 cases/year) and males (24,500 cases/year).
- Incidence is highest among individuals aged 85–89, with 43% of cases diagnosed in those aged 75 and over.
- Since the early 1990s, bowel cancer rates have remained stable overall, with a 3% decrease in males and no significant change in females.
- Over the past decade, rates have declined by 6% overall, including a 10% drop in males and 4% in females.
- Projections suggest a further 8% decline in incidence between 2023–2025 and 2038–2040, although annual cases may still reach 47,700 by 2040.
- Socioeconomic factors influence incidence: males in the most deprived quintile have 9% higher rates than those in the least deprived, with **~630 cases/year** linked to deprivation.
- Ethnic disparities exist incidence rates are lower among Asian, Black, and mixed/multiple ethnic groups compared to the White population, though Black males show higher rates than their White counterparts.
- As of 2010, an estimated 230,200 people previously diagnosed with bowel cancer were living in the UK.

https://www.cancerresearchuk.org/health-professional/cancer-statistics-for-the-uk#heading-Zero

3. Implementing the Colorectal Cancer Personalised Stratified Follow Up (PSFU) Pathway

For patients with a colorectal cancer entering a PSFU pathway, the following key components must be in place to ensure safety, support, and empowerment:

These guidelines recommend the following key components to ensure safe, effective, and person-centred follow-up care for individuals diagnosed with colorectal cancer:

- **Holistic Needs Assessment (HNA) and Care Planning**
  All patients should receive a comprehensive HNA and personalised care and support plan (PCSP). This should be accompanied by tailored information and access to appropriate health and well-being support services to empower patients to live actively and well following the completion of their cancer treatment.
- All patients should receive an End of Treatment Summary (EoTs) prior to transitioning onto a PSFU pathway. These tools ensure that care remains tailored to individual needs and supports patients in taking an active role in their recovery and ongoing health.
- **Robust and Accessible Follow-Up System**
  A safe, reliable, and user-friendly system must be in place to support PSFU. This should include appropriate surveillance protocols with timely reporting and recall mechanisms to ensure a positive and reassuring patient experience, including details of any required scans or tests and how these will be arranged.
- **Support for Self-Management**
  Patients should be provided with additional information and signposting to relevant services and resources that enable them to self-manage and maintain wellbeing with and beyond cancer. Personalised care and support planning, including resources for self-management to promote long-term health and wellbeing.
- **Clear Communication Channels.**
  Patients must receive both verbal and written guidance detailing when and how to seek help, including specific contact points within the colorectal care team for any future concerns. Patients should receive clear written information about signs and symptoms that may indicate recurrence or progression of disease. They should also receive guidance on surveillance, including details of any required scans or tests and how these will be arranged.
- **Treatment Summary and Continuity of Care**
  A Treatment Summary/EoTs should be shared with the patient, their GP, and the hospital team. This document should outline the treatment received and highlight any ongoing concerns or potential consequences of disease or treatment. It should support Primary Care in conducting a Cancer Care Review and ensuring continuity of care.
- **Open Access to Specialist Services**
  Timely, safe, and appropriate open access back into specialist colorectal care services must be available for patients who require further assessment or support. This must include rapid access to the colorectal cancer team, including telephone advice and clinical support for any concerns.
- All patients moved onto a Patient Stratified Follow Up (PSFU) should be logged and tracked on the organisations IT system.

4. The Principles and Purpose of Follow up for Colorectal Cancer

The Purpose of Follow up

The current National Institute of Clinical Excellence (NICE) and ACPGBI guidelines, mandate follow up post colorectal cancer resection with curative intent. As the numbers of patients being diagnosed and treated remain significant, huge numbers of patients are at any one time in follow-up. Some of these patients are extremely unlikely to develop recurrent cancer or suffer the long-term effects of “curative therapy”

The Aims of follow up are as follows:

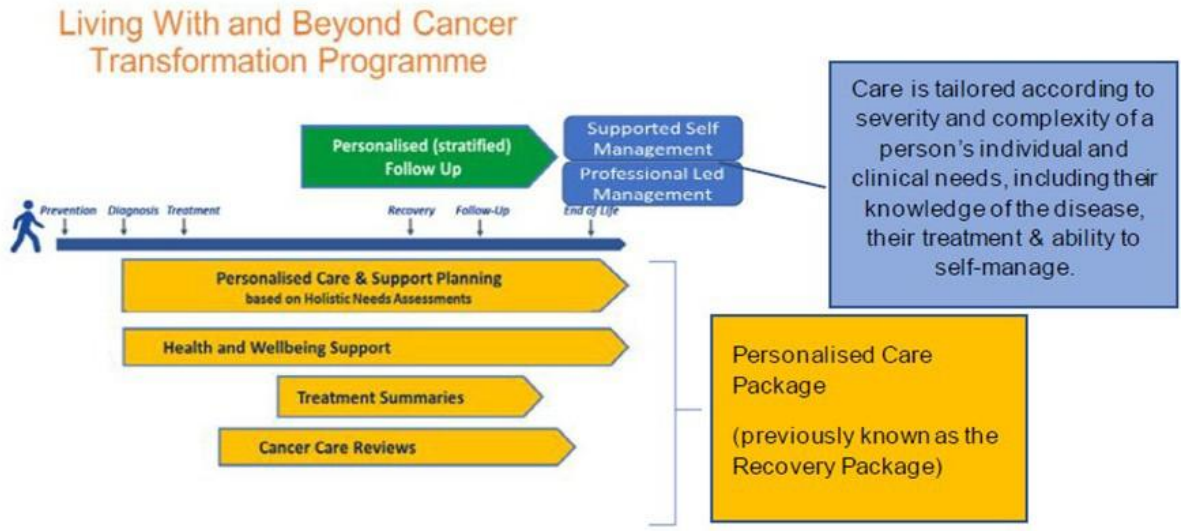
- Cancer Related: to detect recurrent cancer before it is clinically apparent to improve colorectal cancer mortality
- To detect subsequent colorectal cancer/polyps
- Survivorship: to manage the early and late effects of treatment
- Surgical: stomas, hernias, LARS,
- Oncological: diarrhea, neuropathy, weakness
- Psychological: depression, anxiety, isolation

5. Background to Personalised Stratified Follow Up

PSFU is an effective way of adapting care to the needs of patients after cancer treatment, to ensure that the NHS is providing world-class services. The implementation of PSFU pathways tailored to individual needs offers huge benefits to patients and the NHS. Furthermore, PSFU improves patient experience and quality of life for people following treatment for cancer, as well as making services more efficient and cost-effective.

PSFU is designed to support individuals diagnosed with cancer by providing timely access to care and empowering them to self-manage their health. This approach promotes living well with and beyond cancer, placing greater emphasis on quality of life and personal responsibility. PSFU not only benefits patients through tailored support but also helps address capacity challenges within the NHS by ensuring resources are directed where they are most needed.
The diagram below illustrates the programme driving this.

Figure 1 Personalised Care /Living with Cancer Programme



6. Workforce

Workforce planning is essential to the implementation and delivery of a successful Personalised Stratified Follow-Up Pathway.

Organization's need to ensure the workforce is well established and resilient, that workforce planning is prioritised and opportunities for staff to build resilience are embedded within their work.

Staff should have IT and remote monitoring system knowledge, so they can be confident in using and navigating systems and processes accurately and effectively.

Cancer Navigator/ Cancer Support Worker/ Cancer coordinator role:

The safety and quality of the service is dependent on a dedicated coordinator function to organise and manage aspects of the pathway, to facilitate the release and appropriate realignment of CNS clinical time in secondary care and ensure safe support to people from diagnosis.

This role will require specific support, training and development. It is expected that this role will require some clinical knowledge, have a level of communication skills and coordinating the re-entry process and any other contact point within the service.

- Examples of clinical knowledge could include NVQ Level 3 / 4 in health-related subject / equivalent knowledge and experience.

- In addition to clinical knowledge is the ability to show empathy and understand difficulties faced by people affected by cancer, to communicate both verbally and non- verbally on a daily basis with people at all levels as well as accurate written communication and ability to motivate self and others.

This role in primary care may be employed within a practice or across a primary care network e.g.: a social prescriber to support individuals making best use of the Treatment Summary to inform Cancer Care Reviews, coordinating the re-entry process and any other contact point within the service.

Clinical Nurse Specialists: Will need to have the correct time agreed in their job plans to allow the necessary time to be trained and be competent in undertaking HNA's, PSCPs and end of treatment reviews.

This also applies to other Health Care Professionals involved in Personalised Care Planning at various points on the pathway.
Open Access follow up (OAFU) helpline: Trusts may wish to consider a helpline, with without e-mail access, where people can access advice, support and be triaged to virtual or face to face CNS, oncology or surgical clinics if new symptoms develop.

Resources needed for Personalised Stratified Follow Up PSFU.
To ensure effective personalised stratified follow up systems are in place each NHS Trust will have Remote monitoring systems to enable the following to happen:
There should be a designated member of the specialist cancer team such as a Cancer Navigator/Support Worker or Clinical Nurse Specialist who may guide/triage callers who is responsible for ensuring the following takes place:

The scheduling, monitoring and communication of surveillance tests and subsequent results
Scheduling systems to ensure appropriate individuals are contacted with the test results and no individual is 'lost to follow up'.

The nature of the work will change for all members of the Colorectal team. Organisations should demonstrate an understanding of the potential changes in workload that this change will bring, ensure workforce planning is prioritised and introduce the cancer navigator role.

The safety and quality of the service is dependent upon a dedicated navigator and deputy to organise and manage aspects of the pathway. This role is designed to release and appropriately realign CNS clinical time and will require specific support, training and development. It is expected that this role will require some clinical knowledge, coordinating the re-entry process and any other contact point within the service. Colorectal CNS staff will need to have the correct time agreed in their job plans to allow the necessary time to undertake HNAs, care plans and end of treatment reviews.

7. Levels of Follow-up Support

This document outlines the care pathway for individuals diagnosed with colorectal cancer, detailing the levels of personalised stratified follow-up support available to meet their clinical and holistic needs; this includes,

- Supported self-management follow up.
- Professional led follow up (including best supportive care)
- All individuals diagnosed with cancer, irrespective of their risk of recurrence, receive coordinated supportive care with rapid re-entry (open access) to the specialist cancer team as required.

Personalised Stratified Follow-up Pathways

Workforce planning is essential to the implementation and delivery of a successful Personalised Stratified Follow-Up Pathway.

Types of Personalised Stratified Follow Up

The follow up schedule broadly revolves around two central tenets:

I. Oncological risk of recurrence (pathological / radiological staging)
   - Low risk
   - Intermediate risk
   - High Risk
   - Radiotherapy
   - Metastatic Disease

II. Method of Delivery (See figure 5)
   - Supported self-management.
   - Professional led (includes best supportive care)

   See Appendix 3 for further information

8. Current Guidelines for Follow up After Colorectal Cancer Resection

The following illustration represents currently produced guidelines regarding follow up of patients after colorectal cancer resection with curative intent.

Figure 2

NICE Guideline 2020	Follow up should commence 4 – 6 weeks after curative resection and should consist of: • Minimum 2 computerised tomography (CT) scans within first 3 years • Regular carcinoembryonic antigen (CEA) at least every 6 months in the first 3 years. • Colonoscopy 1 year after initial treatment
ACPGBI 2017 (Leong, Hartley, Karandikar) *Detecting recurrent/metachronous disease /paper 2023 is this still relevant*	• A minimum of two CT scans of the chest, abdomen and pelvis are recommended within the first 3 years of resection. Recommendation grade B. • Regular serum CEA (every 6 months in the first 3 years) could be used in addition to CT with local consensus. Recommendation grade C. • A 'clean' colon should be confirmed by colonoscopy or CT colonography (CTC) at 1 year and subsequently at 5 yearly intervals. Recommendation grade C. • Follow up should cease in elderly or unfit patients by agreement. Recommendation grade D. ***Survivorship*** Cancer survivors should have access to information and support from the point of diagnosis. Recommendation grade D. Individualised care planning, treatment and follow-up plan should be developed for cancer survivors according to their needs, stage of their disease and co-morbidities. These should be communicated with patients and primary care. Recommendation grade D • "*A tailored follow up plan to meet the needs of individuals and stratified according to oncological risk is desirable. This plan may need to be modified during the follow-up process, depending on the presence of any ongoing symptoms or toxicities. The Treatment summary should be generated by the cancer MDT to clarify the individualised follow-up plan for the patient and primary care team. Patients who are unlikely to be*

	*fit for further invasive therapies could be discharged from secondary care with agreement (*ACPGBI 2017).
BSG/ACPGBI/PHE September 2019 check *Post-polypectomy and post-colorectal cancer resection surveillance guidelines*	The key recommendations are: • That patients who have undergone a potentially curative CRC resection should have a clearance colonoscopy within a year of their diagnosis • That once a clearance colonoscopy has been performed in the post-operative period in patients who have had a CRC resection, their next surveillance should be performed after an interval of 3 years. The need for further surveillance should then be determined in accordance with the post-polypectomy high- risk criteria.
Faecal immunochemical testing (FIT) in patients with signs or symptoms of suspected colorectal cancer (CRC): a joint guideline from the Association of Coloproctology of Great Britain and Ireland (ACPGBI) and the British Society of Gastroenterology (BSG)	

9. Minimum Follow-up Schedule

I. Colorectal cancer follow up is the shared responsibility of the specialist team, primary care and the patient. A minimum follow-up schedule should be agreed. It should include at least 2 CT scans of the chest, abdomen and pelvis and a colonoscopy within the first three years after surgery. A completion colonoscopy should be performed as soon as practicably possible in those patients who had an incomplete examination before surgery. Teams may choose to supplement this with regular CEA tests, which may continue for five years post-treatment.

II. The follow up schedule should be tailored according to each patient according to oncological risk.

III. After 5 years, patients may have further surveillance colonoscopies and if not, should be encouraged to join the national screening program. (after 4 years go for FIT for BCS unless under the age of 50 then would book surveillance colonoscopies (Lynch those patients who DMIR if lynch have a slightly more intensive pathway)

IV. Tests should be delivered irrespective of whether a patient is seen in the clinic.

V. The schedule may be conducted in the form of telephone clinics or virtual clinics in place of conventional clinical visits for patients.

Surveillance

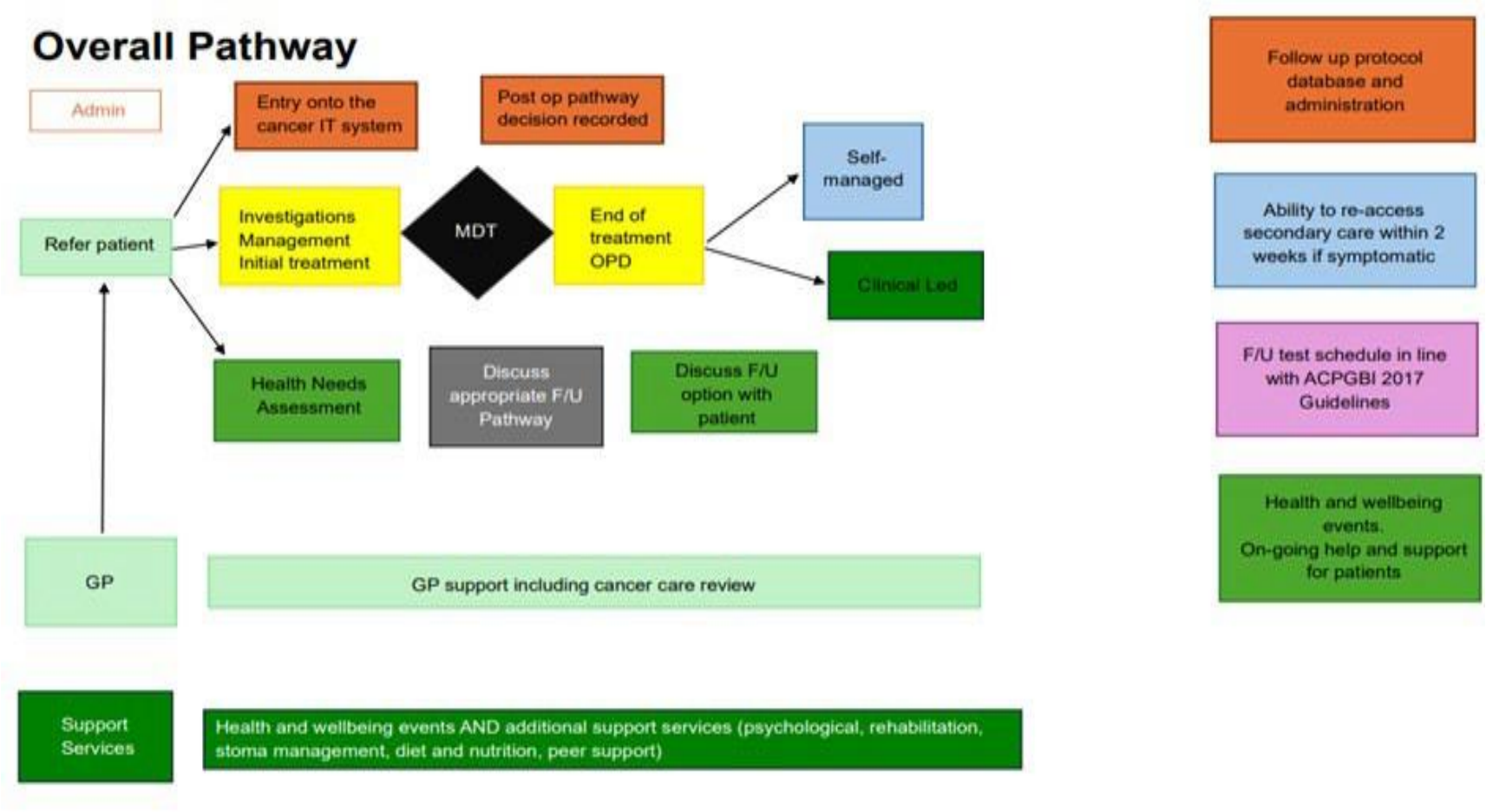
I. Patients who contact any member of the colorectal specialist team with worrying symptoms will be seen by the appropriate team within two weeks and if necessary, the case will be discussed at the MDT meeting.

II. All patients following initial treatment for colorectal cancer, will be given information about self-care and surveillance. A list of symptoms that could be a cause for concern and a contact number for Colorectal CNS will be given as part of the information pack developed by Trusts.

III. Patients should also be given information on symptoms which may indicate recurrence.

10. Personalised Stratified Follow-up Model and Process for the West Midlands

Figure 3 Colorectal Cancer Follow-up Pathway Model



11. Personalised Stratified Follow Up: The Pathway

WMCA Colorectal Cancer Personalised Care Pathway

The care pathway route for all individuals with colorectal cancer is shown in Figure 4 Appendix 10.

Diagnosis and Treatment

The personalised care package comprises of four key components designed to support individuals throughout their cancer journey.

This document recommends all patients diagnosed with a bowel cancer diagnosis, including secondary cancer, receive or are offered a personalised care package made up of:

- Personalised Care and support plan (PCSP) based on a Holistic Needs Assessment (HNA)
- Health and wellbeing support and information (HWBSI)
- Treatment Summary (TS)
- Cancer Care Review (CCR)

At diagnosis, individuals will be informed, at a suitable time for them, about supported self-management and professional-led follow-up pathways; Open Access; and Health and Wellbeing support and information.

Individuals with secondary cancer will be offered personalised care based around the professional-led pathway follow up model.

The Multidisciplinary Team (MDT), following the decision on treatment recommendation, will record the clinically stratified decision in the individuals notes.

Personalised Care and Support Plan including Holistic Needs Assessment

A Holistic Needs Assessment (HNA) is a checklist of concerns that cover physical, emotional, practical, spiritual and financial issues. It informs the development of a Personalised Care and Support Plan (PCSP) for the patient following discussions with their specialist colorectal nurse (often a Clinical Nurse Specialist) or key worker, highlighting the most important issues at that time that need to be addressed during or after treatment.

Health and Wellbeing Support and Information (HWBS&I)

All individuals will have access to health and wellbeing support and information at suitable points in the pathway.

End of Treatment Summary /Treatment Summary (TS)

- At the end of treatment (surgery, chemotherapy, radiotherapy), all individuals will receive a single end of treatment review with a CNS. At this appointment the patient will receive personalised information about their planned follow-up and surveillance.
- A Treatment Summary will be generated following this meeting and be sent to the patient, their GP and held within the individual's hospital notes.

- A Treatment Summary (TS) is a document produced by a healthcare professional after a significant phase of an individual's cancer treatment. It is designed to be shared with the person living with cancer and their primary care team, to enable them to manage their health and wellbeing.
- TSs are essential for good quality and safe open access follow-up and effective Cancer Care Reviews. PSFU should not be undertaken without treatment summaries being completed. Key information that needs to be included in these important documents include.

Symptoms Checklist

- NB: People living with cancer and clinicians may differ as to what constitute significant symptoms. People who experience these symptoms may require follow-up by trained staff to support them.
- Key symptoms that require urgent re-access to the specialist secondary care team include:
- During this appointment, it is expected that the patient is provided with verbal information, and that they have access to either online or printed information, regarding the following:

Possible Treatment Toxicities/Consequences of Disease and/or Treatment

- A personal plan for future surveillance, scans and blood tests. This will include an explanation of the process for receiving appointments for scans, other tests and results;
- Key symptoms that require re-access to the specialist team.

Contact Name, Phone Number and Working Hours of the Colorectal Specialist Team.

- Bowel awareness.
- Exercise, nutrition and weight management.
- Health and Wellbeing support and how to access relevant services.
- Any local self-help groups and useful phone numbers
- On conclusion of the end of treatment review, patients will be transferred onto either the professional-led or self-managed pathway.
- The colorectal MDT will decide the follow up schedule according to oncological risk.
- Most patients will be discharged at the end of year four, unless there are ongoing concerns. (concerns about cancer risks for e.g. polyps)

12. Remote Monitoring System (RMS)

To ensure effective personalised follow up systems are in place each NHS Trust will have remote monitoring systems to enable the following to happen:

- There should be a designated member of the specialist colorectal team who is responsible for ensuring the following takes place:

- The scheduling, monitoring and communication of surveillance tests and subsequent results
- Scheduling systems to ensure appropriate individuals are contacted with the test results and no individual is 'lost to follow up'

More information on remote monitoring systems can be found in Appendix 9.

13. Types of Personalised Stratified Follow Up Pathways

Professional Led Follow Up Pathway

The follow up schedule broadly revolves around two central tenets:

Oncological risk of recurrence (pathological / radiological staging)

- Low risk
- Intermediate risk
- High risk
- Radiotherapy
- Metastatic disease

Method of Delivery (See Figure 4)

- Supported self-management.
- Professional led (includes best supportive care)

See appendix 3 for further information.

Patients will have their suitability for entering the self-managed follow up pathway considered at the MDT at which their results are discussed. Those who are not eligible will be recorded as not appropriate for self- managed follow up on their MDT proforma within the cancer IT system and will continue the professional-led follow up pathway at a frequency determined by the MDT. A copy will be placed in the patient notes as appropriate.

Figure 4

Patient pathway for self-managed follow up

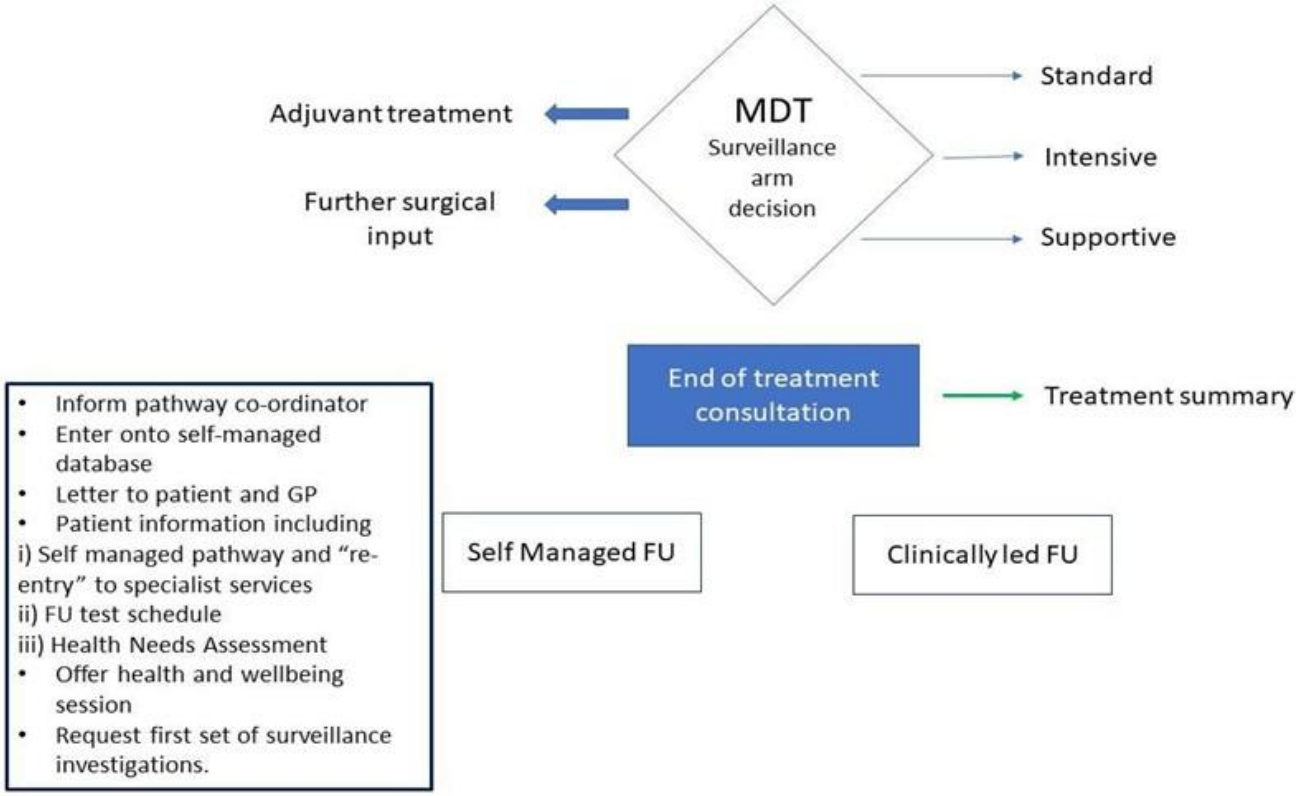


Figure 5: Types of Personalised Stratified Follow-Up Pathways – Method of delivery

Colorectal Cancer Resection & Polyps	**watch and wait – rectal cancer & Best Supportive care**
Supported Self-Management (SSM) Pathway	**Professional Led Pathway (PLP)**
Individuals will not have scheduled outpatient appointments after initial post-operative follow up appointment with the surgeon. Surveillance test results will be communicated by phone/e-mail/ letter unless results indicate the person. needs to be seen. • HNA can be offered when test requests are sent. It may be valuable for the individual to have an annual review with their GP Practice team.	Individuals will have scheduled outpatient. appointments: At these appointments/reviews there will be a review of: • Test and other scan results as appropriate and available • Medication review where appropriate • HNA can be offered.

At the end of Open Access, individuals will be discharged to the care of their GP. A letter from the colorectal team will be sent to the individual and their GP confirming this.	At the end of Open Access, following a review, individuals will be discharged to the care of their GP. A letter from the colorectal team will be sent to the individual and their GP confirming this.
Individuals may move to professional led follow-up if it is appropriate and mutually agreed at any point.	Individuals may move to supported self-management follow-up if it is appropriate and mutually agreed at any point.
All Personalised Follow Up Pathways	
To optimise outcomes both to patients and the healthcare system, GP practices should consider the wider benefits of offering Cancer Care Reviews (CCRs) as best practice. WMCA recommend that Practices continue to provide patients with the opportunity to have a conversation within 12 months of a cancer diagnosis, with the aim to increase their awareness of the support available to them at the practice, as well as signposting/referring them to additional support within the wider local community.	
Individuals will have re-entry to secondary care Open Access (appointment within 2 weeks if clinically urgent) for the length they are on remote monitoring with the specialist team from diagnosis (E.g.: 5 years) for both SSM pathway or PLP. An individual can contact their specialist Colorectal Team as needed with any concerns via a dedicated contact number and or e-mail address advised in the TS	
Individuals will be invited to their surveillance tests, by their specialist colorectal team. This will be clearly documented in the TS clearly stating who is responsible for ordering and reviewing the investigations and when they should be started and stopped	
At any point during the secondary care Open Access individuals may be contacted to be offered access to any relevant clinical trials or new treatments that may become available.	
If recurrent or metastatic disease is found at any time along the pathway the persons results will be discussed with the consultant, referred to the MDT meeting and referred to an alternative clinical pathways as appropriate.	

Method of PSFU – Professional-led or Self-managed

A) Individuals Who Are on the Self-managed Follow-up Pathway

- Can contact their Colorectal Specialist Team as needed with any concerns via a dedicated contact number;
- Will not have annual outpatient appointments;
- Will have standard, intensive or supportive follow up as determined by the MDT after discussion of oncological risk.
- May move to professional-led follow up at any point in time if it is appropriate and mutually agreed;
- During the 3 to 5-year self-managed follow up pathway, patients may be contacted to be offered access to any relevant clinical trials or new treatments that may become available.

B) Individuals who are on the professional-led follow up pathway:

- Will have follow up surveillance with outpatient appointments that are individualised to their diagnosis/needs.
- May be subsequently transferred to a self-managed pathway at any point if appropriate and mutually agreed.

To ensure effective personalised follow up systems are in place each NHS Trust will have remote monitoring systems to enable the following to happen:

Eligibility for Entry - Personalised Supported Self-Management Pathway

At the end of surgical or oncological treatment for colorectal cancer all patients will have an end of treatment consultation. This could be post-operatively for those patients who require no further interventions, post adjuvant therapy or post stoma closure. At this consultation between the patient, colorectal cancer specialist and patients' key worker a joint decision can be made about through which modality patients will engage with surveillance investigations and support services.

All individuals with colorectal cancer who have completed treatment will be considered for entry onto the supported self-management pathway. This empowers individuals with the knowledge and skills to self-manage their condition. Individuals' suitability for entering the supported self-management pathway will be considered at the end of treatment review, if not before at the Colorectal MDT, according to the clinical criteria in Figure 2 section 6.

Those eligible will be recorded as appropriate for supported self-management follow-up on their MDT proforma within the cancer IT system.

A copy will be placed in the individuals notes as appropriate. At the end of treatment review the supported self-management and professional led follow up pathways and the support available is discussed with the individual to help them decide what type of follow up works for them. People may change between supported self-management and professional led pathways in discussion between their specialist team and themselves.

Section 9 and Appendix 15 describes the end of treatment review and what is offered from updated holistic needs assessment, updated personalised care and support plan, a treatment summary, open access to secondary care and health and wellbeing support. It must include who, how and when individuals can access support (E.g.: written advice, online, telephone support etc) including open access to secondary care. For those individuals on the supported self-management follow up pathway no further scheduled follow up appointments in secondary care are required after the end of treatment review except for undergoing planned surveillance tests as specified in Section 6 figure 2.

Eligibility for Entry - Personalised Professional Led Pathway

Individuals' suitability for entering professional led pathway will be considered at the end of treatment review, if not before, according to the clinical criteria in section 5 agreed at the MDT at which their results are discussed. Some individuals identified on the colorectal resection or polyps pathways may not be appropriate for supported self-managed care and will join the professional led pathway. These can include:

- The individual who cannot self-manage due to physical, cognitive, communication or emotional reasons.
- The individual who has co-morbidities that may require closer monitoring.
- Following discussion between the individual and the healthcare professional there is mutual agreement not to enter the self-managed follow-up pathway.
- The individual is deemed inappropriate by the MDT because of ongoing surgical or oncological concerns.
- The individual is in a clinical trial.

The provision of language support services for individuals diagnosed with colorectal cancer whose first language is not English should be considered locally, based on the demographic profile of the population served by each hospital. This ensures equitable access to self-managed follow-up options and support.

Individuals who are not eligible will be recorded as not appropriate for self-managed follow-up on their MDT proforma within the cancer IT system and will continue on the professional led follow-up pathway. A copy will be placed in the individuals notes as appropriate. Section 9 and Appendix 15 describes the end of treatment review and what is offered from updated holistic needs assessment, updated personalised care and support plan, a treatment summary, open access to secondary care and health and wellbeing support. It must include who, how and when individuals can access support (E.g.: written advice, online, telephone support etc)

Clinical Trials

For individuals participating in clinical trials, follow-up will be determined by the clinical trial protocol. It is recommended that at any point during the 5-year follow-up pathway in secondary care, patients may be contacted to be offered access to any relevant clinical trials that may become available.

All individuals taking part in trials will still access and benefit from the end of treatment review and updated holistic needs assessment, updated personalised care and support plan, a treatment summary, open access to secondary care and health and wellbeing support. Information must include who, how and when individuals can access support (e.g. written advice, online, telephone support etc) including open access to secondary care in addition to their scheduled appointments.

Figure 6

Follow up schedule

	Standard Follow Up	Intensive Follow Up	Supportive Follow Up
Length of follow up	At least three years.	Five years.	
CEA	Pre-operatively and every 6/12 months post-op.	Pre-operatively and every 6/12 months post-op.	
CT TAP	Yearly for 3 years.	At 6 months (or after adjuvant treatment), then yearly.	
Colonoscopy or CTC	At one-year post-op or as soon as possible if colon is not fully visualised pre-operatively. Then surveillance scope after three years or as per BSG guidelines.	At 6 months post-op or as soon as possible if colon not fully visualised pre-operatively. Then surveillance scope after three years or as per BSG guidelines.	
Other tests		Consider MRI liver in EMVI + tumours	

- This table is suggested as reference for standard practice and based upon ACPGBI guidelines and current practice within the region. However individual MDTs may have some variations to this regime. MDTs are encouraged to work towards standardising follow-up.
- Other groups of patients may have their follow-up schedule amended by regional tertiary referral centres e.g. Liver Unit or Thoracic Surgery Dept after surgery for metastatic disease.
- The follow up for patients with rectal cancer who have a complete response to treatment and those with polyp cancers is yet to be determined at a national/international level. When such information becomes available or is agreed regionally this can be added to this document.
- Which patients are suitable for which follow up pathway remains the decision of the colorectal surgeon responsible for individual patient care supported by their local MDT. The following is a guide for which patient groups may be suitable for different follow up schedules. However, these are a guide only and each MDT should agree local criteria.

Figure 7

The table below summarises a typical monitoring schedule (with timelines):

Timeline	Action	Who
6 wks /52 wks prior to patient surveillance investigations	Telephone contact with patient to check they are willing and able to attend surveillance investigations. At this point patients can be informed of their appointment date and time.	This telephone contact could be undertaken by the self- managed pathway co- ordinator or the patient's key worker (clinical nurse specialist) or alternating between appropriately trained healthcare professionals.
Within 28 days of test (normal test results)	Results to be reviewed by an appropriately trained healthcare professional and patient informed of results.	This could be by telephone but a letter to the patient and GP would be generated (see template in appendix).
Outpatient clinic within 14 days (abnormal test results)	All Abnormal results reviewed	Responsible Colorectal Specialist and discussed at colorectal MDT
Specialist Clinic within 2 weeks	Patients who develop symptoms in the self-managed follow up must be able to re-access specialist services within 2 weeks	Pathway Co-ordinator
Within timeframe dictated by Treatment Plan for individual patient	The next surveillance tests are requested, and pathway co-ordinator informed of results to update patients records.	Pathway Co-ordinator

14. Discharge from the Colorectal Cancer Follow-up Pathway

After three years in the standard follow-up group, or a minimum of five years in the intensive group, a joint decision should be made with the patient regarding discharge from follow-up care. Once this decision is agreed, a formal letter should be sent to the patient's GP, and the pathway coordinator must be notified to ensure the patient is appropriately removed from the active surveillance pathway.

At the end of their surveillance period, results of colorectal cancer patients will be reviewed by a suitably trained clinician. This is so that any ongoing treatment regimens can be updated considering the latest evidence. Any plans from this review will be actioned and both the patient and the GP will be informed of any recommendations for ongoing treatment or that the patient has been discharged from the hospital's care.

15. Clinical Governance

- Over the duration of follow up, the clinical governance for the follow up pathway lies with the Colorectal MDT Lead and named consultant.
- The responsibility for security and the database, and ensuring its suitability, lies with the Caldicott Guardian, Cancer Lead Clinician and Nurse.

16. Re-accessing the Colorectal Specialist Team as Required

A. All patients and their GPs will be aware of how to access the Colorectal Specialist Team if concerns arise within the surveillance period. Safe robust and sustainable open access systems will be in place to facilitate this.
B. Patients and their GPs will have contact numbers and guidelines about when and how to access further support. Access will be via the Colorectal Specialist Team through an open access system.
C. To deliver a robust rapid re-entry pathway, it is essential to ensure there is appointment capacity with the existing colorectal and oncology clinics.
D. If a patient is required to have further investigations following their routine surveillance, they will be recalled for further imaging or an outpatient appointment after discussion of the imaging in an MDT and seen within 2 weeks.
E. After 3 or 4 years, at the end of the follow up schedule; any re- entry will be via a new patient GP referral into the appropriate urgent cancer referral pathway or routine pathway.

17. Equality and Health Inequalities Impact

- There is an impact assessment within the general PSFU guidelines. In the context of colorectal cancers specialist teams should be aware that research studies have shown that:
- People with increased socioeconomic deprivation (unemployed, non-skilled occupational class or lower levels of education) were more likely to decline to participate in telephone follow up, suggesting that patient acceptability needs to be further assessed in these groups.
- People who are non-English speakers are at particular risk of being marginalised (Kumarakulasingham et al 2019), Kumarakulasingam goes on to indicate this can be reduced through:
    - Education sessions with their family/carers and
    - Knowledge of the local community and its demographics can be helpful in planning services. Each Trust should have available language support in place.
- Availability of interpreting services can enable people to participate in PSFU

18. Evaluation

A. It is expected that the Quality of Life and Living with and Beyond metrics will be used to evaluate the implementation of Personalised Stratified Follow Up.
B. Comparison of previous and subsequent evaluation from the National Cancer Patient Experience Survey (CPES) will be reviewed in relation to aspects of the Personalised Care Package.

19. Guideline Monitoring

It is recommended that auditing occurs twelve months following the implementation of these guidelines at Cancer Alliance and Colorectal Expert Advisory Group level and then on an annual basis provided there are no significant adjustments required.

20. References

Armes, J. et al. (2009) Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. J. Clin. Oncol. 27, 6172–6179

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Palin, J. Ryrie, I. Smith, L. Khanna, M. Pralat, R. (2011) Evaluation of Health and Wellbeing Clinics: Final Report

21. Acknowledgements

Thank you to all the West Midlands Cancer Alliance Colorectal Expert Advisory Group, patient advocates and sub-group members who assisted in the development of this Personalised Stratified Follow Up pathway and guideline document. The Cancer Alliance acknowledges the input and expertise of all the members of these groups who have participated in the development process.

22. Definitions

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

Cancer Care Review (CCR): A CCR is a conversation that is carried within Primary Care with the cancer patient.

Co-design: Collaborative method of design engaging with all key stakeholders involved in service provision and those using the service.

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: The end of treatment is defined as the conclusion of all active treatment required by an individual following a diagnosis of cancer. This may be after surgery alone or following a combination of therapies (excluding adjuvant endocrine therapy) but precedes the period known as ‘follow up’. The patient will be presented with a Treatment Summary – see definition below

Health & Wellbeing Intervention (HWBI): Health and Wellbeing interventions are any support or education events or programmes that enable the transition from treatment for cancer to supported self-management. They can range from one-to- one information sessions to group sessions on a variety of topics designed to help with the emotional and practical aspects of life with and beyond cancer.

Holistic Needs Assessment (HNA): A Holistic Needs Assessment is a checklist of concerns that cover physical, emotional, practical, spiritual and financial issues ensuring each area is addressed and a care plan created for those identified as needing specific support. The care

plan offers suggestions to manage the concerns including signposting to other services or information services that can help.
An HNA can be offered at key points during the pathway to meet the needs of the individual.

Personalised Stratified Follow Up (PSFU): A model of follow-up in which the clinical team and the person living with cancer decide the best form of aftercare based on the individual's clinical and personalised needs. Individuals enter either a professional led or self-managed follow up pathway. The Personalised Stratified Follow Up pathway extends 5 years from the point of diagnosis.

Personalised Approach: A personalised approach means that any person that receives care or support will have choice and control in determining the shape of that support based on what is important to and for them.

Professional-led Follow Up 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.

Self-managed Follow Up Pathway: 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.

Shared Decision Making: Shared decision making is a collaborative process that allows the individual and the responsible health care professional to make health care decisions together in the person's best interest, based on evidence-based practice and taking into account the person's values and preferences.

Stratified Follow Up: A model for managing how individuals are followed up after completion of treatment; depending on their risk of disease recurrence.

Treatment Summary (TS): A Treatment Summary is a document produced by the Doctor or Specialist Nurse at the end of active treatment for cancer. The Treatment Summary details the diagnosis, stage and any relevant pathology information. It also includes any surgery, chemotherapy, radiotherapy or any other therapies that the person may have received during the treatment phase. It is followed by specific information on signs and symptoms of recurrence as well as significant consequences of disease and/or treatment. This is important as this information may be needed later by long-term survivors who may develop issues. A treatment summary and an HNA develop the Cancer Care Review.

The document is shared with the Patient and the Primary Care team to facilitate ongoing supported self-management.

23. Appendices

Appendix 1: Personalised Care

Personalised Care All patients will have an HNA and Personalised care support plan embedded as part of the normal assessment process at diagnosis and at the end of treatment; Following the decision on treatment recommendation, the Multi-Disciplinary Team (MDT) will discuss which follow up pathway the individual is eligible for; professional-led or self-managed follow up utilising the criteria outlined in section 3;

All newly diagnosed colorectal cancer patients will receive information about their diagnosis, treatment options and subsequent follow up pathway at the end of treatment. This will include a description of the re-entry process, the support and tools available to enable self-management and explanation of the ongoing surveillance and screening that will occur during the 3 to 5 years follow up period;

All patients will be transferred onto the jointly agreed follow up pathway at the end of treatment.

Holistic Needs Assessment

An HNA is a simple questionnaire completed by the person affected by cancer that assesses the physical, practical, emotional, spiritual and social needs of the individual and ensures these needs are met in a timely and appropriate way.

All patients will have an HNA embedded as part of the normal assessment process within 31 days of diagnosis (before treatment commenced) and at the end of treatment.

This requires consideration of the timing of the assessment in relation to the patient's journey, enough time to reflect and consider their own needs and feelings and an appropriate environment to undertake the questionnaire;

The HNA will inform the development of a short-term care plan following discussions with their Colorectal CNS or key worker at the point of diagnosis, highlighting the most important issues at that time that need to be addressed during treatment;

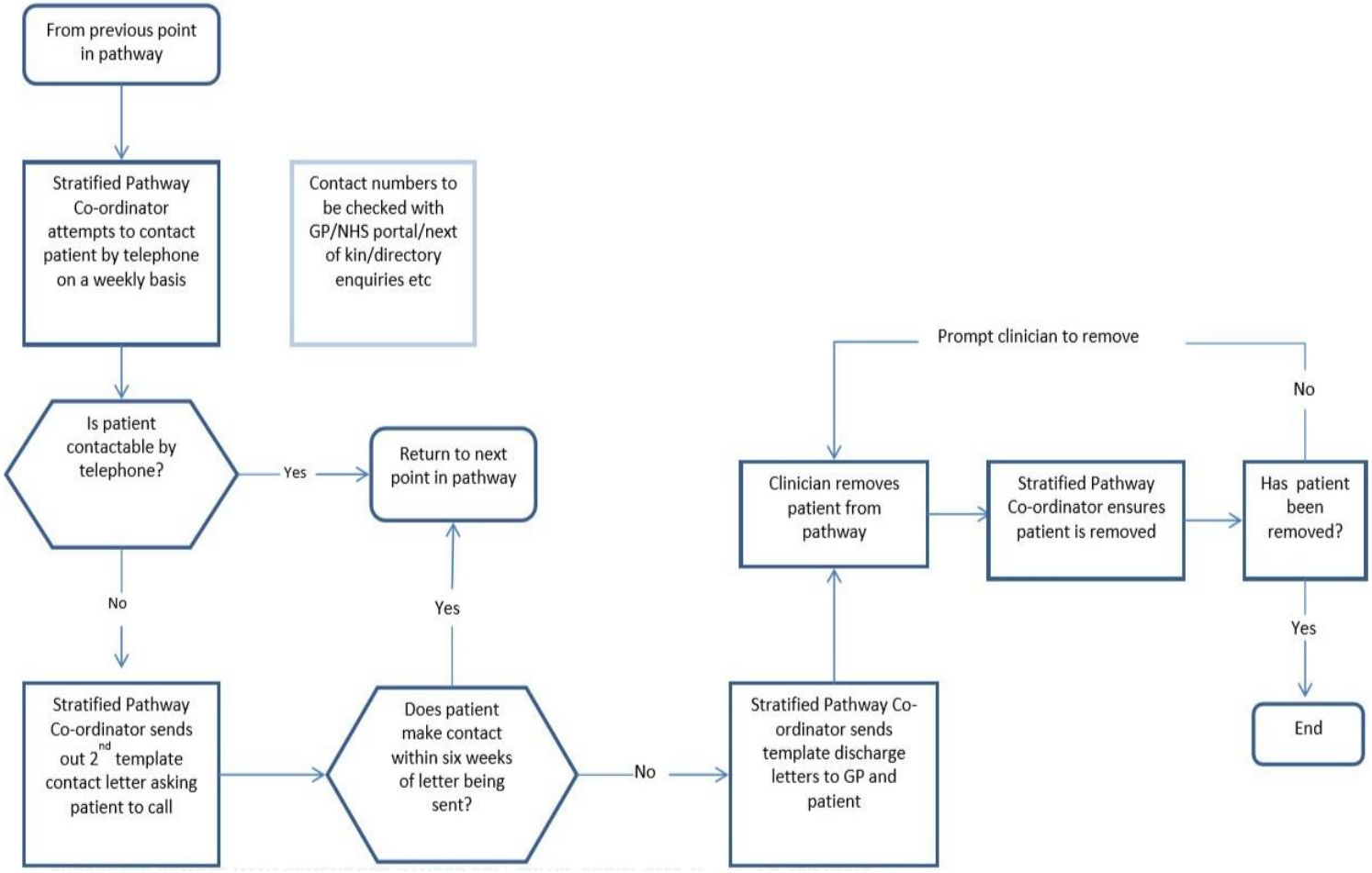
A review of the care plan will occur following the HNA at the end of treatment;

It is recognised that an HNA should be done at any point in the pathway where there is a change in treatment or issues identified by the patient or healthcare professional, with a care plan generated and acted upon.

It is recognised that the HNA can be done by any member of the MDT and must include appropriate triage. Appropriate time should be allocated to staff to enable time for triaging HNAs and managing the findings;

The care plan should be completed by the CNS in communication with the patient;

Appendix 2: Pathway for those patients who are “uncontactable”



Appendix 3: Developing a Personalised Stratified Follow-up Strategy

The Clinical Advice for the Commissioning of the Whole Bowel Cancer Pathway from the Colorectal Cancer Clinical Expert Group includes the following:

Clinical Review and Surveillance - Stratified Follow-up

Self-Management Follow Up

Those patients with good social support and minimal long-term effects of their treatment should be suitable for self-managed follow-up. Patients with stomas, bowel function, and other late effects of treatment (surgical or chemotherapy) may initially need planned hospital follow-up or in the community by trained staff. The frequency of follow up investigations delivered either remotely or in secondary care will depend upon the risk of recurrence and should be intended to pick up recurrence before symptoms develop.

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

Self-managed follow up involves reduction of routine appointments from the pathway. Routine surveillance tests will still be completed as indicated. The results will be reviewed by appropriately qualified or trained staff and the patient and GP informed of the results. This information may trigger a recall of the patient back to specialist services as required.

Patients should be offered a 1:1 appointment with the clinical nurse specialist (CNS) at the end of primary treatment to explain how stratified follow up works and to ensure the patient knows how to contact the service if there are any concerns or symptoms in between surveillance testing. (This could be done in the same session as the end of treatment HNA).

Appendix 4: National Health & Wellbeing Being Checklist

(Insert Embedded Doc)

Appendix 5: Equality & Health Inequalities Impact Assessment

(Insert Embedded Doc)

Appendix 6: Example Content for Trust PSFU Patient Information

Appendix 7: RMS

It is recommended that the Trust RMS has clear standard operating procedures outlining:

- The minimizing of risk to losing individuals
- The resolution of issues regarding missed surveillance tests
- That safety netting is in place to ensure contact is not made with individuals who have died or moved out of area.
- How to contact newly registered individuals who qualify for surveillance monitoring
- The responsibilities of other healthcare professionals in the event of an abnormal result in the absence of the clinician responsible.

Generally, it is recommended that the RMS is:

- Easy to use and compatible with a Trusts current IT system.
- Secure and safe (regularly backed up etc.)
- Accessible throughout a Trusts IT system
- Able to record and distribute the metrics needed for comparison of other sites.
- Easily adaptable to future changes in care
- Suitable for other Living with and Beyond Cancer programmes in the Trust
- Able to support a patient portal going forward

The required functionality of remote monitoring is listed below

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 store 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
10)	To record the outcome of any event or test
11)	To provide standard and ad hoc reporting and routine monitoring function and be amenable to clinical audit
12)	To be NHS and HL7 compliant with secure access
13)	To use a common file format for all data export to be able to import the data into local IT systems if required.

Source: https://www.slideshare.net/NHSImprovement/effective-followup-testing-risk- stratified-pathways-cancer (Page 15)

System implementation should comply with the NHS Digital clinical risk management requirements for health IT systems shown below:

- Compliance with standards DCB0129 and DCB0160 is mandatory under the Health and Social Care Act 2012
- DCB0129: Clinical Risk Management: its Application in the Manufacture of Health IT Systems - more information here
- DCB0160: Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems - more information here

The standards relate to clinical risk management and comprise:

- A specification, which defines the requirements and conformance criteria to be met by the user of the standard - how these requirements are met is the responsibility of the user, for example the NHS Trust implementing digital RMS
- Implementation guidance, which provides an interpretation of the requirements and, where appropriate, defines possible approaches to achieving them.

Remote monitoring system

- All patients will have their surveillance investigations recorded on a remote monitoring system. This system will hold the information required to manage follow-up investigations - ordering, checking and recording of results. It will also record dates of HNAs, end of treatment reviews, Health and Wellbeing Intervention attendance and invites for each patient.
- It is expected that the remote monitoring system will require initial investment and on-going finance, however, is integral to the running of a self-governed service to minimise the risk of losing patients or missing results.

A remote monitoring system should be:

- Easy to use and compatible with a Trusts current IT system.
- Secure and safe (regularly backed up etc.).
- Accessible throughout a Trusts IT system.
- Able to record and distribute the metrics needed for comparison of other sites. Easily adaptable to future changes in care.
- Suitable for other cancer LWBC programmes in the Trust.

A safe and secure system of managing CT scan, CTC and colonoscopy bookings, attendance and results is required. It is recommended that the electronic database generates a list of who needs investigations. The request will then be made, and an appointment sent to the patient. Results will be reviewed, and unremarkable results will be sent directly to the patient, GP and recorded onto the cancer IT database. Unexpected results will be discussed at the next available

- MDT to formulate a plan and the patient then contacted (preferably by phone). Any missing results will be followed up to ensure all patients receive their surveillance.
- Patients will be aware of when their surveillance tests are due from their Treatment Summary. Patients will be informed to contact the specialist team if they do not receive a request for their tests or scans 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.

Appendix 8: List of Available Resources

Figure 8 lists some resources available to help clinicians with possible cancer symptoms and long-term consequences.

Figure 8: Resources for clinicians to help with possible cancer symptoms

Gateway C	https://www.gatewayc.org.uk/gwc-cancer-map/
CRUK interactive Desktop Easel	https://www.cancerresearchuk.org/health-professional/diagnosis/suspected-cancer-referral-best-practice/nice-cancer-referral-guidelines#NICE_implementation1
CRUK Infograph Poster	https://www.cancerresearchuk.org/sites/default/files/nice_infographic_poster_m arch2016.pdf Or can be ordered: https://publications.cancerresearchuk.org/search?p=7)
Macmillan Clinical Decision Support	https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/prevention-early-diagnosis-programme/cancer-decision-support- tool.html#280141
Lymphoma Action	https://lymphoma-action.org.uk/

Figure 9 lists some support to help individuals around health and wellbeing support and information. Good practice would be to remind individuals of the support available to them nationally and locally.

Figure 9: National Resources for Individuals Around Health & Wellbeing Support

Good practice: Remind individuals of health and wellbeing support and information available nationally such as websites, and in their local community including support groups in addition to local GP practice resources e.g.: Social prescriber	
Cancer Care map directory	https://www.cancercaremap.org/ Can help individuals living with cancer to find local cancer care services in their area.
Macmillan Cancer Support	https://www.macmillan.org.uk/ Provides advice and patient information on bowel cancer. Includes an online community and support line.
NHSE PSFU handbook 2020	NHS England » Implementing personalised stratified follow-up pathways

Appendix 9: The Benefits of Personalised Stratified Follow Up

For Patients:

Access to higher quality care that:
- Is personalised and tailored to people's specific needs and conditions
- Is based on what matters to people and their individual strengths, needs and preferences
- Helps to detect and manage cancer-related psychosocial problems
- Provides more support for those with complex needs
- Helps people find services that meet their individual needs, and
- Increases the proportion of people continuing to have surveillance tests (i.e. fewer 'lost to follow up').

Support for self-management that:
- Provides information enabling earlier self- detection of recurrence, progression, or long-term side effects
- Encourages people to contact their healthcare team at any time with any worries or concerns
- Increases people's knowledge and understanding of their condition and situation
- Increases people's overall confidence, health and wellbeing, and
- Encourages lifestyle changes which can help to reduce the risk/impact of cancer recurrence (or new cancers), treatment consequences and comorbidities.

Improves patient experience by:
- Reducing travel to hospital (if on remote monitoring)
- Reducing anxiety through more timely access to results.

For professionals:

- Enhanced continuity of care
- Better triage of queries by support staff
- More responsive access to specialist teams if problems occur
- Improved communication and links with primary care teams (e.g., via End of Treatment Summaries)
- Improved knowledge of management of acute and long-term side effects, and
- Improved knowledge of pathways for referral/ signposting to services and third sector support.

For systems:

- Improves productivity through the redeployment of professionals' time, outpatient capacity* and reduced duplication of surveillance tests
- Supports greater integration of care
- Supports better communication across different care settings
- Reduces demand for unplanned care
- Increases the transparency around costs of cancer follow up, allowing resources to be targeted at patients

Source: NHS Living with and Beyond Cancer – Implementing Personalised Stratified Follow Up Pathways. A Handbook for local health and care systems. March 2020

Appendix 10: Health and Wellbeing Information and Support (HWBiS)

All individuals will have access to health and wellbeing information and support at suitable points in the pathway. This support may be in the form of an event, face to face or online, where there is education and support sessions aimed to provide individuals with the information and reassurance to build the confidence, they require to enable them to lead as normal and active life as possible after their cancer treatment.

These sessions may also aim to increase awareness of the local facilities, supportive care and opportunities that are available to them and their families.

Signposting to other existing known local health and well-being support services for cancer and other long-term conditions can also be offered as health and wellbeing interventions and will promote collaboration between service providers to ensure sustainability of this essential element of supported self-care.

In summary, health and well-being information and support may be delivered face to face or virtually as:

- 1:1 appointment
- Rolling Programme

e.g. the 6-weekly Macmillan HOPE Programme also delivered as an iHOPE course. The Help to Overcome Problems Effectively (HOPE) course concentrates on focusing and rediscovering inner strengths and resilience to help individuals cope emotionally, psychologically and practically. Table 5 shows what the HOPE course covers:

- HOPE Course Content
- Goal setting and action planning
- Looking for solutions to problems
- Stress management (e.g. mindfulness and relaxation)
- Fatigue management
- Identifying your strengths
- Becoming more positive, grateful and appreciating life more
- Healthy lifestyles (e.g. eating more healthily and physical activity)
- Prioritising the important things in life
- Fear of cancer recurrence Body image and sexuality and intimacy
- Communication skills

Source: Macmillan HOPE Programme https://www.macmillan.org.uk/healthcare-professionals/for-your-patients/hope-programme

Group events which are scheduled at regular intervals, face to face or online, throughout the year and which individuals may have an open invitation to attend if they choose to do so. They may be specific to individuals who have had a cancer diagnosis or are open to all who have had a cancer diagnosis. The events provide opportunities for interaction between individuals, carers, clinicians, clinical nurse specialists, allied health professionals, and complementary therapists. These might also include market stalls and/or videos (depending on if face to face or online) of local health promotion services or voluntary agencies. Common area covered in these events include:

- Information about local groups
- Emotional support Finances
- Healthy eating
- Exercise
- Signposting and access to local services for cancer as a long-term condition health and wellbeing management.
- Online support groups
- Online tools and support – examples include: https://www.cancercaremap.org https://www.macmillan.org.uk/Cancer Research UK

These are in addition to locally developed apps. And other local online resources.

A national checklist of health and wellbeing services is available so healthcare systems can identify gaps in provision across cancer pathways and thus to support them in providing consistent information across the health system in different formats. See Appendix B for details.

Appendix 11: Personalised Care

These are in addition to locally developed apps. And other local online resources.

Personalised Care and Support Plan and Holistic Needs Assessment

The Holistic Needs Assessment (HNA) informs the development of a Personalised Care and Support Plan (PCSP) for the individual following discussions with their specialist nurse (often a Clinical Nurse Specialist) or key worker, highlighting the most important issues at that time that need to be addressed during or after treatment.

PCSPs should be completed and agreed by the specialist nurse and the individual. A review of this plan will occur following subsequent HNAs, e.g. at key points in the pathway including at the end of treatment.

An on-line version of the HNA is known as an eHNA (electronic Holistic Needs Assessment).

It is recommended there is a real time recording of the point HNAs are offered and completed in the person's pathway E.g.: at diagnosis, at end of treatment, and number (% of all people diagnosed) of HNAs undertaken. An HNA, also known as a 'concerns checklist' or 'Health MOT', is a simple assessment completed by the person affected by cancer that assesses the physical, practical, emotional, spiritual, and social needs of the person and ensures these needs are met in a timely and
appropriate way.

The HNA requires consideration of the timing of the assessment in relation to the person's journey, enough time to reflect and consider their own needs and feelings and an appropriate environment to undertake the questionnaire. This environment may be at home, in their GP surgery or at the hospital they have been attending for cancer treatment.

HNAs should not be used a tool for identifying side effects of cancer treatment.

All individuals will be offered an HNA as a minimum as part of the normal assessment process from diagnosis through to the end of treatment.

An HNA should also be offered at any point in the pathway where there is a change in treatment, including at the end of treatment, or issues identified by the individual or healthcare professional and the PCSP updated accordingly and agreed with the individual. HNAs can also be offered to individuals undergoing surveillance tests.

The HNA can be undertaken by the individual with support from any HNA trained member of the team, often this is a Clinical Nurse Specialist (CNS), Navigator/Cancer Support Worker, Radiographer or

Allied Healthcare Professional (AHP). Support can also be provided by other healthcare professionals.

Appropriate time should be allocated to staff to enable time for reviewing HNAs and managing the findings.

NHS England and Improvement Implementing Personalised Stratified Follow Up Pathway A handbook for local Health Care Systems March 2020.

Appendix 12: Example content for trust PSFU patient information

N.B. Each Leaflet will include WMCA & Trust Logo

Why have you given me this leaflet?
You have been given this leaflet to explain Personalised Stratified Follow up which **Trust Name** has put in place for patients who have been treated for colorectal cancer.

What is self-managed follow up?
Self-managed follow up is a new type of follow-up that is being introduced at all hospitals. It is where routine, clinical examination appointments are replaced by a system where patients can

call us when they have a problem so that they do not have to come to hospital at times when they are feeling well and symptom-free.

Why has self-managed follow up been introduced?
We have introduced Self-managed follow up as it has been shown to be better for patients in lots of ways.
It means that you do not have to make unnecessary trips to the hospital at times when you are feeling perfectly well and just want to concentrate on living your life.
Patients often find traditional clinical appointments can lead to anxiety and delay reporting worrying signs and symptoms if a routine clinical appointment is 'not too far away.'

Also, it has been proven that new problems are unlikely to happen in line with your appointment time and are identified by patients themselves, in between routine appointments.

It will also mean that you can access support and advice quickly from the right people when you need it, allowing you peace of mind.

You will also get back into the system quickly should this be necessary.

Communication between all the people involved in your care will be better, those in the hospital and outside, such as your GP. This will mean everyone can support you or signpost you on to others who can support you at the right time for you.
What information will I be given?
In addition to this leaflet, you will have an End of Treatment Review with your xxxxx Nurse and will be taught about specific symptoms you should report without delay to your xxxxx Nurse.

- Your diagnosis and medication.
- The treatment you have had and the possible side effects.
- Signs and symptoms to report;
- Arrangements for scans and other tests
- How to use the Helpline which gives you fast access to your xxxx Nurse if you need it
- Advice on Exercise and Nutrition
- Health and Wellbeing support
- Any local support groups and useful contact numbers

Will I still be able to access the colorectal service if I have concerns? Yes. You can call the Colorectal Team 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 if you leave a message, with your name, hospital number and telephone number, in the evening or over the weekend you will be called back by the team on the next working day. 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. Unless it has been otherwise specified at the end of your treatment, you will continue to be called for.