WE ARE MACMILLAN. CANCER SUPPORT

Manchester Cancer
Colorectal Pathway Board

Colorectal Treatment Summaries –

Hints & Tips (September 2016)

Contents

Introduction 1
When and who? 2
Templates 2
Standardised wording 7
Examples of standardised wording for Colorectal Treatment Summaries 8
Example 1 9
Example 2 12
Example 3 13
Example 4 16
Example 5 18
Example 6 20
Standard Treatment Sumary Covering letter for the Patient 23
Treatment Summary Glossary for the Patient 24
Audits and improvements 25
References 29

Introduction

Treatment Summaries are one of the 4 elements of The Recovery Package along with a Holistic Needs Assessment and care plan, a Health and Wellbeing event and a Cancer Care Review.
The purpose of the Treatment Summary is to describe the treatment that a person has received, its potential side effects, and signs and symptoms of recurrence. It is designed to be shared with the patient and their GP to help inform the GP Cancer Care review and improve dialogue between the patient and GP.

The purpose of this document is to share the learnings from a 12 month project undertaken as part of the Colorectal Pathway Board with aim of improving services for people living with and beyond colorectal cancer and funded by the Macmillan Living with and Beyond Cancer Innovation Fund. From a colorectal pathway perspective 5 of the 11 trusts have started doing Treatment Summaries for their patients and another 2 trusts have developed templates and standardised wording and will be ready to roll them out in the next 3-6 months.

The fundamentals of this document are applicable to all tumour groups when considering implementing treatment summaries. The detailed standardised wording is specific to colorectal

cancer but may be useful for consideration and extrapolation to other tumour groups and provides a baseline for what colorectal will be providing.

When and who?

The Manchester Cancer CNS group determined that a Treatment Summary should be in place for patients at the following point in their follow-up pathway:

- At the end of treatment
- When a patient transition onto a supported self-management
- When a patient transition onto a palliative care pathway.

It may not be necessary to generate a new treatment summary if a relevant treatment summary is already in place, however at the points above it should be checked that a relevant treatment summary is in place. It will depend on each individual patient.

It is the accountability of the MDT to ensure the treatment summaries are provided at the identified points. It should be determined within the MDT who is responsible for generating the summary in the different scenarios appropriate to how that trust is set-up. It may be a consultant responsibility, a CNS responsibility, a joint responsibility for different sections or another healthcare professional's responsibility e.g. could be a radiographer if it is determined that a treatment summary should be generated after a period of long course radiotherapy. What is important is that the MDT understands the purpose and value of the treatment summary and actively supports embedding them into their pathways.

Templates

Different templates exist for compiling and Treatment summary and all contain broadly the same information but offer different benefits.
Macmillan have developed a triplicate pack for generating hand written treatment summaries and provides an option for simply completing a summary on the go and ensures copies are produced at the same time. However, long term this isn't the most efficient way of generating treatment summaries, with electronic systems being preferred.

The hospital system, Somerset Cancer Register, has an option to generate a treatment summary. If Somerset is already in use within a trust this is a good way of ensuring a treatment summary can be provided. Some sections pre-populate using information already contained within Somerset (should be checked for correctness by the person authoring the treatment summary) and the remaining sections allow for free text. This makes it easy to complete at the same time as other sections of Somerset are updated. A downside however is that if an updated treatment summary is required at a later date, then the original version will not be stored within Somerset. A hard copy would therefore need to be printed and held within the patient records to ensure a copy of all versions is held centrally.

A word document of the Macmillan template is available. The value of this is that it can be used as a basis for creating a template that can be used within an Automated Letter System (ALS). This has the benefit that the trust can develop a bespoke template (based on the key principals of the Macmillan template) that is appropriate for their needs, and can be refined and evolved as the treatment summaries get embedded and feedback from authors and users is gained. Further more, using an ALS means that key patient details will automatically self-populate. Using

something such as an ALS may make it easier to embed within current practices as may be perceived to be similar to other hospital documents such as invites and letters and therefore seem a good fit with existing processes. Different healthcare professionals can use the same standard template and if appropriate relevant sections could be dictated if this is an appropriate method to ensure completion.

The Macmillan template is attached below.

WE ARE MACMILLAN. CANCER SUPPORT

Manchester Cancer
Colorectal Pathway Board

Treatment Summary

Insert GP Contact Details ***Insert Trust Logo and Address***

Dear Dr X

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

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

<table>
<tr><td>Diagnosis:</td><td>Date of Diagnosis:</td><td>Organ/Staging
Local/Distant</td></tr>
<tr><td colspan="2">Summary of Treatment and relevant dates:</td><td>Treatment Aim:</td></tr>
<tr><td colspan="2" rowspan="2">Possible treatment toxicities and / or late effects:</td><td>Advise entry onto primary care palliative or supportive care register

Yes / No</td></tr>
<tr><td>DS 1500 application completed

Yes/No

Prescription Charge exemption arranged

Yes/No</td></tr>
<tr><td colspan="2" rowspan="2">Alert Symptoms that require referral back to specialist team:</td><td>Contacts for re referrals or queries:
In Hours:
Out of hours:</td></tr>
<tr><td rowspan="2">Other service referrals made: (delete as nec)

District Nurse
AHP
Social Worker
Dietician
Clinical Nurse Specialist
Psychologist
Benefits/Advice Service
Other</td></tr>
<tr><td colspan="2">Secondary Care Ongoing Management Plan: (tests, appointments etc)

.</td></tr>
<tr><td colspan="3">Required GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening)</td></tr>
<tr><td colspan="3">Summary of information given to the patient about their cancer and future progress:</td></tr>
<tr><td colspan="3">Additional information including issues relating to lifestyle and support needs:</td></tr>
</table>

WE ARE MACMILLAN. CANCER SUPPORT

Manchester Cancer
Colorectal Pathway Board

Completing Doctor: **Signature:** **Date:**

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

System 1	**(5 digit codes)**	**All other systems**	**Version 3 five byte codes (October 2010 release)**
Diagnosis:		**Diagnosis**	
Lung Malignant Tumour	XaOKG	Malignant neoplasm of bronchus or lung	B22z.
Carcinoma of Prostate	X78Y6	Malignant neoplasm of prostate	B46..
Malignant tumour of rectum	XE1vW	Malignant neoplasm of Rectum	B141.
Bowel Intestine	X78gK	Malignant neoplasm of Colon	B13..
Large Bowel	X78gN	Malignant neoplasm of female breast	B34..
Female Malignant Neoplasia	B34..	Malignant neoplasm of male breast	B35..
Male Malignant Neoplasia	B35..		
Histology/Staging/Grade:		**Histology/Staging/Grade:**	
Histology Abnormal	4K14.	Histology Abnormal	4K14.
Tumour grade	X7A6m	Tumour staging	4M…
Dukes/Gleason tumour stage	XaOLF	Gleason grading of prostate Ca	4M0..
Recurrent tumour	XaOR3	Recurrence of tumour	4M6..
Local Tumour Spread	X7818		
Mets from 1°	XaFr.	Metastatic NOS	BB13.
Treatment		**Treatment**	
Palliative Radiotherapy	5149.	Radiotherapy tumour palliation	5149.
Curative Radiotherapy	XalpH	Radiotherapy	7M371
Chemotherapy	x71bL	Chemotherapy	8BAD.
Radiotherapy	Xa851		
Treatment Aim:		**Treatment Aim:**	
Curative procedure	Xallm	Curative treatment	8BJ0.
Palliative procedure	XaiL3	Palliative treatment	8BJ1.
Treatment toxicities/late effects:			
Osteoporotic #	Xa1TO	At risk of osteoporosis	1409.
Osteoporosis	XaELC	Osteoporosis	N330.
Infection	Xa9ua		
Ongoing Management Plan		**Ongoing Management Plan**	
Follow up arranged (<1yr)	8H8..	Follow up arranged	8H8..
Follow up arranged (>1yr)	XaL..		
No FU	8HA1.	No follow up arranged	8HA..
Referral PRN	8HAZ.		
Referrals made to other services:		**Referrals made to other services:**	
District Nurse	XaBsn	Refer to District Nurse	8H72.
Social Worker	XaBsr	Refer to Social Worker	8H75.
Nurse Specialist	XaAgq		
SALT	XaBT6		
Actions required by the GP		**Actions required by the GP**	

Tumour marker monitoring	Xalqg	Tumour marker monitoring	8A9..
PSA	Xalqh	PSA	43Z2.
Osteoporosis monitoring	XalSd	Osteoporosis monitoring	66a..
Referral for specialist opinion	Xalst		
Advised to apply for free prescriptions	9D05	Entitled to free prescription	6616.
Cancer Care Review	Xalyc	Cancer Care Review	8BAV.
Palliative Care Review	XalG1	Palliative Care Plan Review	8CM3.
Medication:		**Medication:**	
New medication started by specialist	XEOhn	Medication given	8BC2.
Medication changed by specialist	8B316	Medication changed	8B316
Advice to GP to start medication	XaKbF		
Advice to GP to stop medication	XaJC2		
Information to patient:		**Information to patient:**	
DS1500 form claim	XaCDx	DS1500 completed	9EB5.
Benefits counselling	6743.	Benefits counselling	6743.
Cancer information offered	XalmL	Cancer information offered	677H.
Cancer diagnosis discussed	XalpL	Cancer diagnosis discussed	8CL0.
Aware of diagnosis	XaQly		
Unaware of prognosis	XaVzE		
Carer aware of diagnosis	XaVzA		
Miscellaneous:		**Miscellaneous:**	
On GSF palliative care framework	XaJv2	On GSF Palliative Care Framework	8CM1.
GP OOH service notified	Xaltp	GP OOH service notified	9e0..
Carers details	9180.	Carer details	9180.

Standardised wording

To ensure consistency of the information provided to patients, it is good practice to develop as much standardised wording for the completion of Treatment Summaries as is possible. This should be reviewed and agreed to by the MDT. This can be added to or amended as required but provides a consistent approach.

Examples of standard wording for colorectal treatment summaries, along with a covering letter and patient glossary are shown at the end of this section.

A Manchester Cancer Colorectal CNS group and Pathway Board initiative has led to the development of a guidance document detailing the management options and referral pathways for patients experiencing gastrointestinal consequences following colorectal cancer treatment (1). The document also aims to improve the identification of those people experiencing GI late effect.
As part of this guidance document, it recommends that 4 trigger questions should be asked to specifically identify patients with possible late gastrointestinal effects, inline with Macmillan recommendations. Suggested wording has therefore been developed to ensure that patients who are on a self-managed pathway are aware of the potential for late GI effects and can self-assess to help identify symptoms. Further more it aims to act as a prompt for the GPs and can be raised as part of the Cancer Care Review

The following suggested text should therefore be included in colorectal treatment summaries for both patient and GP information and is in line with Macmillan recommendations (2):

- Gastrointestinal (GI) consequences are common in patients who have received treatment for colorectal cancers and may be experienced during treatment, immediately post-treatment, or many years later.

- In order to identify possible GI concerns, which may require assessment and management, the following 4 trigger questions should be asked by the GP at the Cancer Care Review and by the patient themselves on a yearly basis:

The four trigger questions:

1. Are you woken up at night to have a bowel movement?
2. Do you need to rush to the toilet to have a bowel movement?
3. Do you ever have bowel leakage, soiling or a loss of control over your bowels?
4. Do you have any bowel symptoms preventing you from living a full life?

If a “yes” is answered to any of the questions you should contact your CNS using the contact details on this Treatment Summary.

Examples of standardised wording for Colorectal Treatment Summaries

Note: The suggested wording recently developed to ensure that patients are aware of the potential for late GI effects and can self-assess to help identify symptoms is not reflected in the examples shown below. The individual trusts are updating their templates to reflect this.

Example 1

Alert symptoms that require referral back to specialist team:

- Diarrhoea for more than 2 weeks not relieved by loperamide/codeine
- Blood per rectum
- Further change in bowel function
- Abdominal pain that persists for longer than 4 weeks and does not respond to simple analgesia

Secondary care ongoing management plan:
EITHER for Stage I and good Stage II, as determined in MDT:
Routine follow-up in consultant surgical clinic, then moving to nurse-led clinic at 3, 6, 9, 12, 18, 24, 30, 36, 48, 60 months after bowel resection. Note – Chemotherapy and/or further bowel surgery may affect at what point you enter this follow-up schedule.
Blood tests at 3,6,9,12,18,24,30,36,48,60 months and CT at 12 and 24 months
In general, colonoscopy at 12 months, then 5 yearly. The timing of colonoscopy and frequency may vary depending on the findings at initial colonoscopy eg. if a patient has polyps removed, a repeat colonoscopy earlier than 5 years may be required.

OR for 'bad' Stage II and Stage III, as determined in MDT:
Routine follow-up in consultant surgical clinic, then moving to nurse-led clinic at 3, 6, 9, 12, 18, 24, 30, 36, 48, 60 months after bowel resection. Note – Chemotherapy and/or further bowel surgery may affect at what point you enter this follow-up schedule.
Blood tests at 3,6,9,12,18,24,30,36,48,60 months
CT at 12, 24 and 36 months, the precise timing of the 12 month CT scan varies depending on chemotherapy regimes and may be earlier than 12 months within the first year after surgery and after completion of chemotherapy.
In general, colonoscopy at 12 months, then 5 yearly. The timing of colonoscopy and frequency may vary depending on the findings at initial colonoscopy eg. if a patient has polyps removed, a repeat colonoscopy earlier than 5 years may be required.

OR for Liver Resection
Routine follow-up in consultant surgical clinic, then moving to nurse-led clinic at 3, 6, 9, 12, 18, 24, 30, 36, 48, 60 months after bowel resection. Note – Chemotherapy and/or further bowel surgery may affect at what point you enter this follow-up schedule.
Blood tests at 3,6,9,12,18,24,30,36,48,60 months
CT 6 monthly for 2 yrs then at 36, 48, 60 months
In general, colonoscopy at 12 months, then 5 yearly. The timing of colonoscopy and frequency may vary depending on the findings at initial colonoscopy eg. if a patient has polyps removed, a repeat colonoscopy earlier than 5 years may be required.

Or for TAMIS – Draft wording
2-3 week follow-up in clinic to explain histology and for post-op check then routine follow-up in consultant surgical clinic moving to nurse-led clinic at 3, 6, 9, 12, 18, 24, 30, 36, 48, 60 months after bowel resection

Flexible sigmoidoscopy at 3, 6, 9, 18, 24, 36 months after surgery

Colonoscopy at 12 months and then every 5 years. The timing of colonoscopy and frequency may vary depending on the findings at initial colonoscopy eg. if a patient has polyps removed, a repeat colonoscopy earlier than 5 years may be required.
MRI rectum at 3, 6, 12, 24 and 36 months after surgery

Blood tests at 3, 12, 24, and 36 months

CT scans of chest, abdomen and pelvis at 12 and 24 months.

NB This will have to change when we move over to stratified management self-support etc.

Secondary care ongoing management plan (tabulated):
EITHER for Stage I and good Stage II, as determined in MDT:

TEST	TIME FROM DATE OF SURGERY										
	3 Months	6 Months	9 Months	1 Year	18 Months	2 Years	30 Months	3 Years	4 Years	5 Years	6 Years
Bloods	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
CT Scan				✓		✓					
Colonoscopy				✓							✓

Note: The timing of colonoscopy and frequency may vary depending on the findings at initial colonoscopy, eg:- if a patient has polyps removed, a repeat colonoscopy earlier than 5 years may be needed.

OR for 'bad' Stage II and Stage III, as determined in MDT:

TEST	TIME FROM DATE OF SURGERY										
	3 Months	6 Months	9 Months	1 Year	18 Months	2 Years	30 Months	3 Years	4 Years	5 Years	6 Years
Bloods	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
CT Scan				✓		✓		✓			
Colonoscopy				✓							✓

Notes:

- The precise timing of the 12 month CT scan varies depending on chemotherapy regimes and may be earlier than 12 months within the first year after surgery and after completion of chemotherapy.
- The timing of colonoscopy and frequency may vary depending on the findings at initial colonoscopy, eg:- if a patient has polyps removed, a repeat colonoscopy earlier than 5 years may be needed.

Or for Liver Resection

TEST	TIME FROM DATE OF SURGERY										
	3 Months	6 Months	9 Months	1 Year	18 Months	2 Years	30 Months	3 Years	4 Years	5 Years	6 Years
Bloods	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
CT Scan		✓		✓	✓	✓		✓	✓	✓	
Colonoscopy				✓							✓

Note: The timing of colonoscopy and frequency may vary depending on the findings at initial colonoscopy, eg:- if a patient has polyps removed, a repeat colonoscopy earlier than 5 years may be needed.

Or for TAMIS - Draft

TEST	**TIME FROM DATE OF SURGERY**										
	3 Months	6 Months	9 Months	1 Year	18 Months	2 Years	30 Months	3 Years	4 Years	5 Years	6 Years
Bloods	✓			✓		✓		✓			
CT Scan				✓		✓					
Colonoscopy				✓							✓
Flexible Sigmoidoscopy	✓	✓	✓		✓	✓		✓			
MRI Scan	✓	✓		✓		✓		✓			
Note: The timing of colonoscopy and frequency may vary depending on the findings at initial colonoscopy, eg:- if a patient has polyps removed, a repeat colonoscopy earlier than 5 years may be needed.											

Required GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening):
None

Summary of information given to the patient about their cancer and future progress:
Box that the individual consultant has to write

- Usually actioned after all other sections completed (Colorectal FUp Co-ordinator to monitor actioned)
- Some Consultants may also include more detail in ‘Comments’ box after *Possible treatment consequences and/or late effects* (on first page)

Additional information relating to lifestyle and support needs:
An invitation to the Health and Wellbeing clinic is offered within a year of surgery. This provides an opportunity to learn more about living well with and beyond cancer. Advice on diet, exercise, late effects of treatment, finance and support networks is available.
Information about the local bowel cancer support group is provided at diagnosis and the HOPE (Help Overcoming Problems Effectively) course is offered at the first nurse-led clinic appointment which is run by the CNS (Clinical Nurse Specialist).

Example 2

Comments
Operation –
Consultant -
Other referrals –

Alert symptoms:

Refer back if any change in bowel habit or unexplained bleeding occur and in addition if there is unexplained weight loss or abdominal pain

Secondary care:

Follow up appointments maybe at the hospital or over the telephone for up to 5 years post diagnosis. This will include regular scans and endoscopic surveillance and sometimes blood tests. Follow up appointments during this time will be for as long as the patient and doctor/nurse feel they are useful and the risks of the tests aren't greater than the risk of the cancer coming back.

GP requirements

None

Summary of info:

Given to patient at time of diagnosis - Personal care file containing:
Macmillan book Understanding Colon/Rectal Cancer,
Support and Financial help booklet and leaflet,
Introducing Role of Colorectal Key Worker,
'What happens now' booklet,
Information Prescription leaflet,
Free prescription leaflet,
Holistic Needs Assessment check list and
Contact cards.
At discharge from hospital given:
Booklets on diet and 'Good Bowel Health',
Returning home after surgery leaflet and Regaining Bowel Control leaflet.
Outpatient appointment: The intention of treatment and the treatment summary have been discussed with the patient.

Additional info: Advice on diet, exercise, late effects of treatment, finance and support networks is available and provided at diagnosis and throughout patients pathway as required. Information is available for activity and exercise programmes - Walking for Health and Macmillan Active Manchester

Example 3

Palliative

Your patient has now completed their palliative treatment for colorectal cancer and a summary of their diagnosis, treatment and ongoing management plan is outlined below. The patient has a copy of this summary.

<table>
<tr><td>Diagnosis:</td><td>Date of Diagnosis:</td><td>Organ/Staging
Local/Distant</td></tr>
<tr><td colspan="2">Summary of Treatment and relevant dates:
[delete as appropriate]
Stent
Defunctioning colostomy</td><td>Treatment Aim:

Best supportive care/symptom control</td></tr>
<tr><td colspan="2" rowspan="2">Possible treatment effects:

Following a stent it is common to have:
• Loose frequent stools
• Difficulty controlling the bowels
• Bleeding from the back passage

These symptoms should improve, please contact the colorectal keyworker for advice and guidance</td><td>Advise entry onto primary care palliative Gold Standards Framework (GSF) or supportive care register
Yes</td></tr>
<tr><td>DS 1500 application completed
Yes/No/Unknown
Prescription Charge exemption arranged
Yes/No</td></tr>
<tr><td colspan="2" rowspan="2">Alert Symptoms that require referral back to specialist team:
There is a slight risk that the stent may become loose and move position causing a perforation or obstruction. If the tumour starts to grow through the stent this can also lead to a further obstruction.
• Rectal bleeding that is not settling
• Severe pain
• Bowels stop working properly causing bloating and vomiting

At risk of Metastatic Spinal Cord Compression (MSCC) Yes/No
If Yes has the MSCC leaflet been given Yes/No
Please contact the colorectal keyworker for advice</td><td>Contacts for re referrals or queries:
Colorectal key worker:
Consultant's secretary</td></tr>
<tr><td rowspan="2">Other service referrals made:

District Nurses
Community Specialist Palliative Care Team
Hospice
Day Hospice
Macmillan Information Centre
Macmillan Benefits Advisor</td></tr>
<tr><td colspan="2">Secondary Care Ongoing Management Plan: (tests, appointments etc)</td></tr>
<tr><td colspan="3">Required GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening)</td></tr>
<tr><td colspan="3">Summary of information given to the patient about their cancer and future progress:</td></tr>
<tr><td colspan="3">Additional information including issues relating to lifestyle and support needs:</td></tr>
</table>

Please take this document with you to your GP practice appointment where your diagnosis and cancer care will be reviewed with you.

Patient provided a copy Y/N

Patient declined a copy Y/N

Surgery

Your patient has now completed their initial treatment for colorectal cancer and a summary of their diagnosis, treatment and ongoing management plan is outlined below. The patient has a copy of this summary.

<table>
<tr><td>Diagnosis:</td><td>Date of Diagnosis:</td><td>Organ/Staging

Local/Distant</td></tr>
<tr><td colspan="2">Summary of Treatment and relevant dates:</td><td>Treatment Aim:
[Delete as appropriate]
Palliative intent
Curative intent</td></tr>
<tr><td colspan="2" rowspan="2">Possible post-surgery effects/late effects:
[Delete as appropriate]
Colon surgery – It is common to have altered bowel function and loose stools following this surgery. This should settle in time.
Rectal surgery - It is common to have altered bowel function and this can take several months to settle down. This may include:
• Urgency and frequency of stools
• High stoma output
• Tenesmus (feeling or urge to open bowels)
• Leakage of stool from the bottom

Please contact the colorectal keyworker if you need advice and guidance.</td><td>Advise entry onto primary care palliative or supportive care register

No</td></tr>
<tr><td>DS 1500 application completed
Yes/No/Unknown
Prescription Charge exemption arranged
Yes/No</td></tr>
<tr><td colspan="2">Alert Symptoms that require referral back to specialist team:

• Abdominal rectal or pelvic pain that persists for over 4 weeks and is not responding to simple analgesia
• Further changes to bowel function especially diarrhea which is not settling with loperamide
• Rectal bleeding or discharge from the back passage
• Unexplained weight loss

Please contact the colorectal keyworker if you develop any of these symptoms.</td><td>Contacts for re referrals or queries:

Colorectal key worker:

Other service referrals made:</td></tr>
<tr><td colspan="2">Secondary Care Ongoing Management Plan: (tests, appointments etc)
Follow up for up to 5 years.
• CEA blood test at every appointment
• CT chest abdomen and pelvis at 1 year 2 years and 5 years
• Colonoscopy at 1 year and 5 years</td><td></td></tr>
<tr><td colspan="3">Required GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and</td></tr>
</table>

cardiac screening)
Summary of information given to the patient about their cancer and future progress: Personal care file given at the time of diagnosis includes key worker contact details Macmillan Understanding Colon/Rectal Cancer booklets. An information guide to help you find a range of written information and national and local support groups. The ‘Returning Home from Your Bowel Cancer Operation’ booklet is provided on discharge from hospital.
Additional information including issues relating to lifestyle and support needs: All patients are sign posted to local support groups and activities.

Please take this document with you to your GP practice appointment where your diagnosis and cancer care will be reviewed with you.

Patient provided a copy Y/N

Patient declined a copy Y/N

Example 4

Palliative

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>
<tr><td>Diagnosis:</td><td>Date of Diagnosis:</td><td>Organ/Staging -
Local/Distant –</td></tr>
<tr><td colspan="2">Summary of Treatment and relevant dates:</td><td>Treatment Aim:
Best Supportive Care/Symptom Control</td></tr>
<tr><td colspan="2" rowspan="2">Possible treatment toxicities and / or late effects:</td><td>Advise entry onto primary care palliative or supportive care register
No</td></tr>
<tr><td>DS 1500 application completed
No
Prescription Charge exemption arranged
No</td></tr>
<tr><td colspan="2">Alert Symptoms that require referral back to specialist team:
1. Change of bowel habit
2. Unexplained loss of appetite
3. Discomfort in abdomen or back passage (Which persist for more than a month).
4. Unexplained loss of weight</td><td>Contacts for re referrals or queries:
In Hours:
7.30am – 5pm Mon - Fri</td></tr>
<tr><td colspan="2"><u>Secondary Care Ongoing Management Plan:</u> (tests, appointments etc)
USS LIVER CT SCAN COLONOSCOPY
N/A
<u>Appointments</u>/<u>CEA Blood Tests</u>
N/A</td><td>Other service referrals made: (delete as nec)
N/A</td></tr>
<tr><td colspan="3"><u>Required GP actions in addition to GP Cancer Care Review</u> <u>(e.g. ongoing medication, osteoporosis and cardiac screening</u>)
N/A</td></tr>
<tr><td colspan="3"><u>Summary of information given to the patient about their cancer and future progress:</u>
N/A</td></tr>
<tr><td colspan="3"><u>Additional information including issues relating to lifestyle and support needs:</u>
N/A</td></tr>
<tr><td colspan="3"><u>Recommendations:</u>
To have at least 30 minutes of moderate exercise (brisk walking or swimming) on most days of the week, discuss with your doctor first, especially if you are not used to regular exercise or have any other health problems.</td></tr>
</table>

Self–managed patients

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>
<tr><td>Diagnosis:</td><td>Date of Diagnosis:</td><td>Organ/Staging –
Local/Distant –</td></tr>
<tr><td colspan="2">Summary of Treatment and relevant dates:</td><td>Treatment Aim:

To Identify and detect any signs of recurrence of cancer early enough so it can be treated.</td></tr>
<tr><td colspan="2" rowspan="2">Possible treatment toxicities and / or late effects:</td><td>Advise entry onto primary care palliative or supportive care register
No</td></tr>
<tr><td>DS 1500 application completed
No

Prescription Charge exemption arranged
No</td></tr>
<tr><td colspan="2">Alert Symptoms that require referral back to specialist team:
1. Change of bowel habit
2. Unexplained loss of appetite
3. Discomfort in abdomen or back passage (Which persist for more than a month).
4. Unexplained loss of weight</td><td>Contacts for re referrals or queries:
In Hours:
7.30am – 5pm Mon - Fri</td></tr>
<tr><td colspan="2">Secondary Care Ongoing Management Plan: (tests, appointments etc)
USS LIVER CT SCAN COLONOSCOPY</td><td>Other service referrals made: (delete as nec)

N/A</td></tr>
<tr><td colspan="3">Required GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening)
Requires CEA (Carcinoembryonic Antigen) Blood Test every 6 months.
We will notify patient to book appointment for blood test when it is due.</td></tr>
<tr><td colspan="3">Summary of information given to the patient about their cancer and future progress:
Colorectal information leaflet, Macmillan Cancer Information Booklet., Follow Up Surveillance Investigation Plan, Support Group Dates.</td></tr>
<tr><td colspan="3">Additional information including issues relating to lifestyle and support needs:
Regular Exercise/Remain Active
Smoking cessation if applicable, alcohol within safe limits, healthy eating.</td></tr>
<tr><td colspan="3">Recommendations: To have at least 30 minutes of moderate exercise (brisk walking or swimming) on most days of the week – discuss with your doctor first, especially if you are not used to regular exercise or have any other health problems.</td></tr>
</table>

Example 5

Post operative advice following bowel surgery

Alert Symptoms that require referral back to specialist team

Symptoms to look out for on discharge;

- Abdominal pain, swelling, pelvic or lower back pain.
- Rectal bleeding or increase in mucus/slim or discharge from the back passage. Anal /Rectal pain or discomfort.
- New redness and swelling or discharge from your wound.
- Your bowel habit and function will be altered but increase watery stools that are not settling or constipation that is not resolving.
- Pain on having bowels opened via your rectum or stoma (if you have a stoma)
- Night sweat/ temperature

Right Sided Surgery

Anastomotic leak, collection, constipation, diarrhoea, wound infection.

Post operatively following a right hemi colectomy it is common to have altered bowel function and loose stools. As we have removed a length of colon we have reduce the amount of colon that can pull water out of the liquid stool to bulk it up.

Left Sided Surgery

Anastomotic leak, collection, constipation, high output stoma, diarrhoea, wound infection.

Post operatively following a left hemicolectomy or anterior resection the patient will have altered bowel function (If anastomosed). It takes time for bowel function to settle down and return to its normal pattern. The surgery to remove the tumour can alter/lead to a number of things:

1. **Reduced storage capacity of rectum - can cause urgency to go and frequency of visits to the toilet.**
2. **High output stoma**
3. **Tenesmus (feeling or urge to open bowels)**
4. **Leakage of stool from your bottom (incontinence).**

It is important to remember that the changes to your bowel function after surgery are normal and should improve over the 12 week period following your discharge from hospital. It can take time for the body to readjust to a section of the bowel being removed. This means that you may find your stool is very loose or watery. If this is more than three to four times a day then we may advise taking medication such as Loperamide or Codeine Phosphate. Please contact us for advice and guidance. Reduced colon length to absorb water – can cause loose stools/diarrhoea. If you feel that you are not coping or managing these changes please contact your Colorectal Nurses for help and advice.

Long term symptoms;
Unplanned weight loss, loss of appetite, passing blood or mucus that is new and changed.

(TAMIS/TART and DXT +/- Papillon alert symptoms still to be developed)

Secondary Care Ongoing Management Plan:

5 year F/U (for patients under 80 with curative intent)

The patient will be followed up on the colorectal cancer follow up. They will be seen at regular intervals by the colorectal nurse specialists. The 5 year follow up includes regular clinic appointments. These are at 6 weeks, 3 months and then 6 monthly for 5 years with CT scans 6 monthly for the first 3 years then annually at year 4 and 5. There will be a completion endoscopy at a year to visualise the entire large bowel if this has not already been undertaken, and again at 5 years prior to being discharged back to the GP. There will be blood test to check LFT, U&E and the CEA every 6 months. At all appointments the patient holistic needs will be assessed and referrals made to the wider MDT as appropriate. The clinic will look at the patients' health and wellbeing needs.

6 monthly F/U/ Palliative

The patient will be followed up on the colorectal cancer follow up. They will be seen at regular intervals by the colorectal nurse specialists. The 6 monthly follow up includes regular clinic appointments. The appointments are booked on individual patients needs but they are usually 6 monthly but as previously stated depend on patients needs. The appointments include assessment of these patients individual needs at each clinic appointment. Tests are organised dependent on the patients symptoms and their comorbidities and ongoing health issues. This is done in consultation with the consultant. The clinic will look at the patients' health and wellbeing needs.

Extralevator abdoperineal excision. 5 year F/U

The patient will be followed up on the colorectal cancer follow up. They will be seen at regular intervals by the colorectal nurse specialists. The 5 year follow up includes regular clinic appointments. These are at 6 weeks, 3 months and then 6 monthly for 5 years with CT scans 6 monthly for the first 3 years then annually at year 4 and 5.there will be a completion endoscopy at a year to visualise all the large bowel if this has not already been undertaken, and again at 5 years prior to being discharged back to the GP. There will be blood test to check LFT, U&E and the CEA every 6 months. At all appointments the patient holistic needs will be assessed and referrals made to the wider MDT as appropriate. The clinic will look at the patients' health and wellbeing needs. .Due to these patients having permanent stomas the stoma team and colorectal nurses link in to offer on-going support for physical as well as body image and psychological issues.

Example 6

Treatment

Curative – this means where treatment has been given with the intention of curing cancer but this is not a certainty

Palliative – means where either treatment is given to attempt to control cancer or interventions are given to control symptoms but is not able to cure it.

Uncertain – means although treatment has been given there is some uncertainty if a potential cure can be achieved.

Possible treatment consequences and or late effects

For radiotherapy tick the following;

Faecal – urgency, frequency, or incontinence.
Urinary – urgency, frequency, incontinence, poor stream
Changes in sexual function or infertility
Hormonal effects
All patients – tick fatigue
Patients who have had oxaliplatin – tick peripheral neuropathy.

Late effects Comments

Radiotherapy all

The following bowel symptoms may require specialist advice to assess for Gastrointestinal consequences of cancer treatment;
Passing blood from back passage
Waking from sleep to open bowels.
Needing to rush to open bowels, or having accidents
Bowel movements that are pale, smelly and difficult to flush away.
Sometimes radiotherapy can affect how well the bowel copes with certain food types such as lactose; fructose and gluten symptoms of food intolerance may include abdominal cramps, feeling bloated, increased flatulence after eating certain foods.
May cause Pain in the lower back or pelvis when moving around which makes walking very difficult lasting for more than a few weeks. This may require further investigation.

Young women and radiotherapy

Radiotherapy causes early menopause and may require investigation and treatment to help with symptoms.

Women and radiotherapy and pelvic surgery (also the same for radiotherapy only)

Potential late effects include
Lower sex drive,
Changes to sexual sensation,
Vaginal dryness
The vagina may become narrower and less stretchy
Sometimes vaginal bleeding may occur

Women and Pelvic Surgery only
Lower sex drive,
Changes to sexual sensation,
The vagina may be shortened or narrower.

Men and Radiotherapy and pelvic surgery (also the same for radiotherapy or surgery only)
Potential late effects include;
Erection problems
Changes in ejaculation
Changes to sexual sensation
Lower sex drive

All patients who have had surgery
Hernia formation
Adhesions

All patients who have had a stoma
Potential late effects include hernia, skin problems, leakage, bleeding, granulomas, constipation/diarrhoea, retraction, prolapse, stenosis and obstruction.

All patients
May cause difficulties with concentration and memory.

Required GP actions
Young women and radiotherapy
Osteoporosis screening may be required due to early menopause.
Men and radiotherapy
Check testosterone levels may be indicated for patients with lower sex drive.
All pts
Monitoring bowel function and refer for specialist advice if required.
Cancer Care Review

Alert Symptoms that require referral back to the specialist team;

- Diarrhoea for more than 2 weeks not relieved by loperamide/codeine
- Blood per rectum
- Further change in bowel function
- Abdominal pain that persists for longer than 4 weeks and does not respond to simple analgesia.

Secondary Care ongoing Management Plan;
Follow up in the clinic at 6 weeks, 6,12,18,24,30,36,48,and 60 months and CEA blood test.
CT Scan at 6, 12 and 24 months.
If patient has chemotherapy the 6 month CT scan will be performed on completion of chemotherapy which will be later than 6 months
In general a colonoscopy at year 1 and 5 then 5 yearly. The timing of colonoscopy and frequency may vary depending on the findings at colonoscopy

Summary of patient information (suggestions)

Patient is aware of cancer diagnosis and histology results have been discussed and that no further treatment is required.

Additional Information relating to lifestyle and support needs

For potentially curative / uncertain patients

An invitation to the Health and well-being event is offered within 6 months of completing treatment. This provides an opportunity to learn more about living well beyond a cancer treatment. Advice on diet, bowel function, fatigue, managing anxiety and support information is provided at this event.

For palliative patients

Information on the 'living well' programme at the sunflower centre is offered or potentially similar programme locally dependent upon area living.

WE ARE MACMILLAN. CANCER SUPPORT

Manchester Cancer
Colorectal Pathway Board

Standard Treatment Summary Covering letter for the Patient

MainRecipient

MainRecipientAddressLine1
MainRecipientAddressLine2
MainRecipientAddressLine3
MainRecipientAddressLine4
MainRecipientPostCode

Hospital No: PatientFACILNumber Date: CurrentDate
NHS No: PatientNHSNumber User ID: UserID

Dear

I enclose a copy of your Treatment Summary. This details the treatment you have received for your cancer, possible effects of treatment and a follow up plan.

You may find the list of `Abbreviations and Terminology` we have included useful when reading your `Treatment Summary`.

I hope this is helpful to you. A copy of your Treatment Summary has also been sent to your GP.

Yours sincerely

WE ARE MACMILLAN. CANCER SUPPORT

Manchester Cancer
Colorectal Pathway Board

Treatment Summary Glossary for the Patient

Abbreviations and Terminology

We believe in plain speech and try not to confuse you too much with abbreviations or complicated terminology. If there are any terms you do not understand, contact your Key-worker, Nurse or Consultant. In the mean-time, some terms are given below which you may find helpful when reading your 'Treatment Summary'.

APER/APR	Abdominoperineal excision of rectum and anus.
Anterior resection	Surgery to remove part of the rectum.
Capecitabine	An oral chemotherapy drug used to treat bowel cancer.
CNS	Clinical Nurse Specialist.
Colonoscopy	An endoscopic examination of the whole of the Colon using a camera.
CPEX or Cardio Pulmonary Exercise Test	This is used to assess your overall fitness.
Colectomy	Removal of part of the bowel.
CT	Computer Tomography - a body scan that shows the skeleton and organs in detail.
CTC or CTColon	A body scan that also provides images of the inside of the bowel.
Hemi Colectomy	Removal of part of the bowel.
IrMdG	A combination chemotherapy regime given through a vein using the drugs irinotecan and 5FU.
Laparoscopy	Another word for keyhole surgery. It can be a method of investigation or surgery.
Laparotomy	This is a term for open surgery with larger incision in the abdomen.
Lymphoedema	A chronic (long-term) condition that causes swelling in the body's tissues.
MDT or Multi Disciplinary Team	A team of experts who meet each week to discuss a patient's care.
Neoplasm	Abnormal tissue growth, also called a tumour.
Osteoporosis	A condition that affects the bones, causing them to become weak and fragile and more likely to break (fracture).
OxMdG	A combination chemotherapy regime given through a vein using the drugs oxaliplatin and 5FU.
Peripheral Neuropathy	A term for the nerves in the body's extremities, such as the hands, feet and arms, being damaged.
PET/CT	Another type of body scan. It uses a special contrast that makes certain chemical profiles glow on the scan. It is used to find any abnormalities that may not be picked up on ordinary CT. These will be done at either the Christie or Central Manchester Hospital.
Polyp	**Bowel polyps are small growths on the inner lining of the colon (large bowel) or rectum**
Sigmoidoscopy	An endoscopic examination of the lower bowel, using a camera.
Sigmoid Colectomy	Removal of the Sigmoid colon
Teletherapy	Another term for radiotherapy, an x-ray treatment sometimes given to treat rectal cancer
TAMIS	Trans-anal minimally invasive surgery
TEMS	Trans-anal endoscopic micro surgery. An operation done through the anus (back passage) inside the rectum. It needs no cuts on the outside of the anus or abdomen (tummy).
USS	Ultra Sound Scan - this is mainly used to investigate organs such as the liver, pancreas and kidneys.

Audits and improvements

The implementation of treatment summaries is an iterative process. It is important to start providing patients and GPs with this information, but the optimal way of providing a summary and the most useful text will likely be developed over time. It is therefore important to routinely review the adequacy of the treatment summary template, particularly in its infancy. Getting feedback from those completing the documents as well as patients and GPs is a worthwhile activity to understand the value of the document and how it can be refined / improved. Reviewing the consistency of the summaries produced by different authors is also important to ensure the quality of the treatment summaries.

An example of an audit questionnaire, which can be adapted for both patients and GPs, is included below.

Example Audit Questionnaire: Covering letter

Dear Dr

You may remember receiving an ' Treatment Summary' from me over the last few months relating to your patient , who I have been treating for cancer. A copy of this summary was also sent to the patient and a further copy kept in the hospital notes. The aim of these treatment summaries is to help you and your patient understand the treatment they have had, possible side effects to look out for and their follow-up plan.

I have been using treatment summaries for all my cancer patients over the last 6 months and we are trying to roll this out through the whole department. I would be very grateful if you could spare some time to let me know whether you found the summary helpful, which bits were most useful, which bits were not useful and if there is any extra information you would have liked. In particular, if there is any information I can give you which might help you with your Cancer Care Reviews.

I enclose a questionnaire for you to complete and return. I would really appreciate your input to help change and improve the information I am able to give you. If possible, please can you return this by XXXX.

Yours sincerely,

Dear Mr

You may remember receiving an ' Treatment Summary' from me over the last few months relating to your cancer treatment. A copy of this summary was also sent to your GP and a further copy kept in the hospital notes. The aim of these treatment summaries is to help you and your GP understand the treatment you have had, possible side effects to look out for and your follow-up plan.

I have been using treatment summaries for all my cancer patients over the last 6 months and we are trying to roll this out through the whole department. I would be very grateful if you could spare some time to let me know whether you found the summary helpful, which bits were most useful, which bits were not useful and if there is any extra information you would have liked.

I enclose a questionnaire for you to complete and return. I would really appreciate your input to help change and improve the information I am able to give you. If possible, please can you return this by XXXX.

Yours sincerely,

Example Audit Questionnaire

GP/PATIENT NAME:

1. Did you find your (patients) 'Treatment Summary' helpful? Yes/No (delete as appropriate)

2. How useful did you find each of the following sections? Please mark on the line from 0 (not at all useful) to 10 (extremely useful).

- Summary of treatment and relevant dates

0 (not at all helpful) — 10 (extremely helpful)

- Possible treatment consequences and/or late effects

0 (not at all helpful) — 10 (extremely helpful)

- Comments

0 (not at all helpful) — 10 (extremely helpful)

- Alert symptoms

0 (not at all helpful) — 10 (extremely helpful)

- Secondary care management plan

0 (not at all helpful) — 10 (extremely helpful)

- Summary of information given

0 (not at all helpful) — 10 (extremely helpful)

Additional information relating to lifestyle and support needs.

0 (not at all helpful) — 10 (extremely helpful)

3. Was there any further information you would have liked?

Please comment:

4. Do you think it is useful for your patient/GP to have this information too? Yes/No (delete as appropriate)

Please comment:

5. Have you discussed or used this information in any of the consultations with your patient? / Have you discussed this information with your GP?

Please comment:

6. Any other comments:

Please comment

Thank you for your time and feedback.

References

1. **Manchester Cancer Guidance on managing gastro-intestinal consequences of colorectal cancer and its treatments**
https://manchestercancer.org/find-out-more/pathway-boards/colorectal/

2. **Quick guide for Health Professionals – Managing Lower Gastrointestinal problems after cancer treatment :**
http://be.macmillan.org.uk/Downloads/CancerInformation/ResourcesForHSCP/COT/MAC15384GIquickguide.pdf