

TREATMENT SUMMARY HOW-TO GUIDE

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A guide for professionals who want to establish
and implement Treatment Summaries

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Background and introduction

There are currently 2.5 million people in the UK living with and beyond cancer. That number is set to rise to 4 million by 2030, reflecting the increasing incidence of cancer and better survival rates.

Additionally, at least 25% of people living with and beyond cancer will have physical or psychosocial consequences of cancer and its treatment that affects their lives. We also know that more than half (58%) of people living with cancer are not certain who to contact if they have a concern related to their condition^(1, 2, 3).

Therefore, with increasing pressures on cancer services, there is a clear need to adapt and support people to self-manage their condition, enabling better health and care outcomes³. We believe a Treatment Summary will help to do that.



A Treatment Summary, a key component of the Macmillan Recovery Package, aims to increase a patient's understanding of their treatment and encourage better communication between secondary and primary care. It aims to inform General Practitioners and other primary care professionals of any actions they need to take and who to contact with any questions or concerns.

A patient can also choose to use the document to inform other professionals of their treatment, to gain access to services such as travel insurance.

What is the Recovery Package?

The Macmillan Recovery Package is a set of key interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer. The main interventions are: A Holistic Needs Assessment, Care and Support Plan Treatment Summary, Cancer Care Review and a Health and Wellbeing Event.

These interventions, together with information on the consequences of treatment, healthy lifestyle, physical activity as well as work and financial support, aim to help identify and address changing needs throughout a person's cancer experience, from diagnosis onwards, to enable them to live as well as they possibly can.

For more information on the Recovery Package and the tools Macmillan has developed to support delivery please go to www.macmillan.org.uk/recoverypackage



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UK-wide policy drivers



Northern Ireland

As of June 2017, Northern Ireland does not have a Cancer Strategy, however there has been some work to introduce changes within Health and Social Care Trusts based on self-management. One example is the Transforming Cancer Follow Up (TCFU) programme which has now been embedded into cancer services across NI. Currently, over 60% of all breast cancer patients are on a self-management pathway and the programme is undergoing further roll-out in all five Health and Social Care Trusts for a range of cancer types.

Scotland

The Scottish Cancer Strategy's Beating Cancer: Ambition and Action 2016

The ambition of the Scottish Cancer Strategy is 'To help people living with, and after, cancer treatment have access to information, advice and support tailored to their individual needs'.

The strategy mentions 'We will work to ensure that every person with cancer is given a Treatment Summary'. Additionally, the strategy mentions 'We are committed to ensuring that all those who require treatment for cancer should receive that treatment as soon as clinically appropriate and that people are provided with a clear Treatment Summary in a way that is most appropriate for their individual needs'.

 www.gov.scot/Resource/0049/00496709.pdf

Wales

Wales Cancer Delivery Plan for Wales 2016–2020

The plan mentions 'Effective discharge planning and discharge summaries are vital pre-requisites and consideration should be given to all providers applying a common recovery package'.

 gov.wales/topics/health/nhswales/plans/cancer-plan/?lang=en

England


NHS Five Year Forward View

One of the ambitions of the Five Year Forward View is to promote better coordination between primary and secondary care. To help achieve this it says that the NHS in England will 'work in partnership with patient organisations to promote the provision of the Cancer Recovery Package, to ensure care is coordinated between primary and acute care, so that patients are assessed and care planned appropriately'.

 www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

Cancer Strategy for England 2015–2020

The Independent Cancer Taskforce report, *Achieving world-class cancer outcomes: A strategy for England 2015-2020*, recommended that 'NHS England should accelerate the commissioning of services for patients living with and beyond cancer, with a view to ensuring that every person with cancer has access to the elements of the Recovery Package by 2020'. This included 'a treatment summary completed at the end of every phase of acute treatment, sent to the patient and their GP'.

 www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

What is a Treatment Summary?

A Treatment Summary is a document (in the form of a template or letter), produced by secondary care cancer teams, usually following treatment for cancer. It is designed to be shared with the patient, their General Practitioner (GP) and any other professionals the patient may choose, with the aim of highlighting essential treatment information. It includes details of the treatment received, any potential effects of treatment, and signs and symptoms of recurrence. Importantly, it should also highlight any actions for the GP to take. It can also help inform the GP Cancer Care Review and enable the GP's database and records to be kept up to date.

Aims of the Treatment Summary

- To deliver a standard and consistent approach to sharing crucial information between secondary and primary care, that is understandable to the patient without the unnecessary detailed information.
- To make the patient more aware of the potential effects of treatment and signs and symptoms of recurrence.
- To support the discussion a patient can have with their GP as part of their Cancer Care Review.

When and how is it used?

A Treatment Summary is designed to be completed by the hospital clinician after a treatment. This may be following surgery, chemotherapy, radiotherapy, or any other form of treatment. It is then shared with the person living with cancer and sent to their GP. A Treatment Summary can be sent with the standard clinic letter or replace it altogether.

It may also be used when there is a referral from secondary care to community palliative care for symptom control or at other points in the cancer journey, for example, following treatment for recurrence. A Treatment Summary includes details that are relevant to further management and care, for example, any maintenance treatment or ongoing surveillance.

The Treatment Summary should be used alongside a Holistic Needs Assessment (HNA), Care and Support Plan as the two are complementary. While the HNA Care and Support Plan will look at the holistic needs, the Treatment Summary will summarise the treatment given and indicate any ongoing clinical needs.



Sheena, Macmillan Clinical Nurse Specialist in Skin Cancer

Benefits of the Treatment Summary



Benefits of the Treatment Summary for patients

- A Treatment Summary can help a patient understand more about their treatment and potential effects of treatment, which may alleviate some of their concerns. It can also be used as a prompt to act on any concerns they may have. The Treatment Summary also has a space to record contact numbers should they wish to speak to someone about their concerns.
- The patient can also use it to share the information about their treatment with others, such as carers or help access travel insurance.
- Referring to the Treatment Summary during the Cancer Care Review can help patients to feel more confident when talking to their GP about the treatment they have received. They may (depending on the patient) also feel reassured that they are receiving the same information about their treatment as the healthcare practitioners.
- Patients won't have to explain their treatment to the GP, as the GP will be able to get that information from the Treatment Summary.

'People have commented that it helps them bring things to the attention of their GP. They can take it along to show them what they have been told to look out for. They also said it lets their GP know what they have gone through.'

We took a sample to the Patient Involvement Group, who felt it would have been beneficial to them if they had this when their treatment ended. Then, when they had to see a different GP or go to another hospital appointment for something else, they could take it along to show what treatment they had received previously.'

Wendy Bailey, University Hospital South Manchester Trust



Benefits of the Treatment Summary for healthcare professionals

- As the Treatment Summary is a structured template or letter, it prompts healthcare professionals to share key information to an agreed level of detail and clarity and encourages a more patient-centred approach.
- It informs the GP what to look out for in terms of recurrence and consequences of treatment, enabling them to discuss treatments more confidently. This can lead to more effective care being provided by the GP, reducing unnecessary and inappropriate hospital re-admissions.
- Receipt of the Treatment Summary can support consistent patient records by using the appropriate Read Code (see Appendix 4) thus helping to ensure information is up to date.
- It can also be used to provide structure for the Cancer Care Review.
- If completed electronically, some aspects of the Treatment Summary can be accessed through Summary Care Record enabling out-of-hours professionals to see important treatment information.

'One of our patients had lost faith in his GP; he had not been in touch with him throughout his cancer journey. The patient felt he should have been. However his GP was prompted by our Treatment Summary to contact his patient, helping to restore their relationship.'

Mel Barron, Southport and Formby District General Hospital

Treatment Summary formats and templates



Clinicians and administrative staff can choose the template that best suits their local practice. The options are:

- > a standard Treatment Summary template
- > a structured letter template, and
- > electronic templates.

The templates can be adapted to suit the local community or IT systems if the document follows the rationale in Appendix 5.

Treatment Summary templates and documents

In the Appendix at the back, you will see a list of templates with guidance on how to complete them:

- > **Appendix 1:** Macmillan Treatment Summary template.
- > **Appendix 2:** structured letter template.
- > **Appendix 3:** a completed example template.

Accompanying the templates there are documents designed to be used alongside a Treatment Summary:

- > **Appendix 4:** GP Read Codes to be sent with a Treatment Summary.
- > **Appendix 5:** A simple guide that shows which fields are essential and which are desirable (Note: this information is important if the form is going to be redesigned for local use).

Using an electronic template

An electronic template can be automatically populated from the Cancer Information Systems (CIS) such as those provided by the Somerset Cancer Register and InfoFlex CIMS Ltd. It can then be added to the electronic patient record (EPR), making it quicker and easier for a clinician to complete following treatment. The template can also be built into local systems. For further information, please contact your CIS provider or your local IT provider.



Neil, Macmillan GP

Tips from health professionals on implementing the Treatment Summary



Establish (or use an existing) working group to plan and scope the use of Treatment Summaries

This should include a wide range of healthcare professional roles and ideally a patient representative. The group can determine:

- > who will be completing the Treatment Summary
- > which treatments and tumour sites will first introduce the Treatment Summary, and how feedback can be obtained from patients and healthcare professionals
- > whether to use a standardised template or develop a new one
- > who will be responsible for sending it out to the patient and to GPs
- > how and who will be updating electronic records

If you're using an electronic system, you will need to include your IT team as part of your working group, so they are engaged and ready to help in overcoming potential technical barriers.

Involve administrative staff early on when implementing the Treatment Summary process and encourage them to suggest the best ways of embedding it locally.

You may already have existing structures that are in place for supporting process change that can be used to implement the Treatment Summary.



Engage with local practices

It is important to speak to the GPs within your area to understand what they would like to see in the Treatment Summary. Getting this right is crucial as the main audience will be patients and their GPs.



Develop or use existing templates

Information that the GP must read, including any actions, should be on the first page of the Treatment Summary.

Work with other health professionals to develop a template or letter with headings to provide structure. Alternatively use the Macmillan Treatment Summary Triplicate Pack; which is a format designed by GPs. The information on how to order a triplicate pack is found in page 35 under Resources.

If you use Somerset Cancer Register or InfoFlex, you can also use the Treatment Summary templates that are built into those systems. These will self-populate much of the information gathered from the multidisciplinary team meetings.

You should check the Treatment Summary template you use is designed to fit with other hospital documents. Consider using the data fields listed in Appendix 5, as the terminologies are commonly used.

If the Treatment Summary template is to be set up on a local system, it would be good to add common effects of treatment, signs and symptoms of recurrence and medications as drop-down menus auto select options.



Training healthcare professionals about Treatment Summaries

Conduct information or training sessions with key stakeholders, so that they understand the purpose of Treatment Summaries, and their benefits.

Develop clear written instructions on what key information should be included on a Treatment Summary and what should not. The Macmillan Treatment Summary template (Appendix 1) can be used as a guide of what to be included.

Make sure all members of the medical records department are familiar with the Treatment Summary and know where it should be filed in the medical records. This will prevent any Treatment Summaries from being filed in the wrong place or inappropriately removed from the medical records.

'To decrease the amount of time spent completing summaries and ensure all sections are completed, follow a standardised approach, be informative but concise and be accurate.'

Keeley Davies, Salford Royal NHS Foundation Trust



Sue, Sarah and Sue, Macmillan Breast Outreach Nurses



Testing and embedding Treatment Summaries as part of practice

Test the process with a few clinicians then review and amend if necessary before its full implementation. This includes reviewing with GPs to ensure they are satisfied with the information provided.

Test the Treatment Summary with patients, to ensure that they fully understand the diagnosis and treatment information listed on it.

Once initial testing has concluded, your working group should obtain feedback from those who tested. This will help you understand the challenges that may have occurred and agree measures to improve practice or the templates.

Share experiences with colleagues to encourage more people to use the Treatment Summary. Developing case studies from those who were part of the early phase of using Treatment Summaries, may encourage others to implement in their practice.

Consider creating a separate list of signs and symptoms and key contacts for complex tumour groups which you can cut and paste from.

Think about providing a list of prompts for clinicians to use as they dictate the content of the Treatment Summary in clinic.

Attach the paper template or list of prompts to the front of the case notes before a person is seen in the clinic to help encourage its completion. Pre-populate the template/s where possible use bullet points eg with the common signs and symptoms of recurrence and treatment toxicities. Remember that different tumour groups may require different pre-populated entries.

Include the standard GP Read Codes attachment to whichever Treatment Summary format has been used or issued to GP practices separately.



For more in depth information on implementing Treatment Summaries, please refer to 'Innovation implementation: Stratified pathways of care of people living with or beyond cancer A 'How to guide''.
www.macmillan.org.uk/ncsi-rp-guide

'We met and discussed with each clinical team (often multiple times) so they could determine what information they wanted as standard. A number of templates per tumour sites have been developed (eg radiotherapy sites, different chemo regimes, different operations, radio-iodine etc). At the start of dictation, a clinician can choose the specific template most relevant.

We are continuing to look at ways to improve our TS quality. We have a TS working group, coordinated across the local Trusts by the Macmillan Recovery Package and Rehabilitation lead, which includes the Lead Cancer Nurse, CCG cancer lead GP, a breast surgeon with input from other oncologists and radiographers. GPs have made suggestions around TS wording, being clear about who is responsible for requesting blood tests for example, who is responsible for acting on results.'

Ruth Hendy, University Hospital Bristol



Emma and Liz, Radiotherapy Late Effects Team

Overcoming barriers

Issues	Potential solution
'We don't have an electronic provider to use Treatment Summaries with'	Have you considered completing Treatment Summaries on paper by using the Macmillan Treatment Summary triplicate pack? Paper templates can be a useful starting point to establish processes and procedures in practice before adopting an electronic solution.
'Whose responsibility is it to send it to primary care?' 'How is this done?'	Develop a working group (or use existing forums), to determine the Treatment Summary process that works best for your Trust, including who's responsible for completion and how it will be sent to primary care. A working group can consist of a wide range of healthcare professionals from oncologists to administrators.
'When is the Treatment Summary completed? Is it at the end of each treatment phase?'	<p>The working group can determine the Treatment Summary processes that works best for your Trust.</p> <p>Review each cancer site and treatment modality pathway with the clinical team, they should determine who (which professional group) and when (in the pathway) each Treatment Summary will be completed. Be very specific. For example, post chemotherapy Treatment Summary, to be dictated by Oncologist in first clinic appointment post-chemo. Post prostate brachytherapy Treatment Summary, to be completed by Consultant Radiographer immediately post procedure, following patient discharge. Post-surgery Treatment Summary to be dictated by surgeon in first post-operation outpatient clinic review.</p> <p>Enable each clinical team to determine the process that will work best for their speciality. One size doesn't fit all.</p> <p>Trial different ways of completing Treatment Summaries and determine what works best for each team and for your trust.</p> <p>Ensure that each person knows what activity they are responsible for.</p>

Issues	Potential solution
<p>'It's just another form that we need to complete'</p> <p>'Will anyone read this form if I complete it?'</p>	<p>This information is crucial to GPs as it may draw their attention to potential consequences of a patient's treatment.</p> <p>It is also of benefit to patients as they will have a record of their treatment, rather than what they were treated with, which they can use for travel insurance purposes.</p> <p>Consider completing 10 Treatment Summaries at your trust and then collate feedback from the GPs and patients on how they found using them.</p> <p>According to NCSI research, 80% of GPs found Treatment Summaries useful or very useful with 50% saying it would make a difference to the way they managed patients.⁸</p>
<p>'My trust currently completes a consultant letter (or discharge summary) at the end of each treatment so we don't feel the need to complete a treatment summary'</p>	<p>The Macmillan Treatment Summary was designed by GPs, with patient engagement.</p> <p>The Treatment Summary is written in a patient friendly way and relates to each treatment whilst the consultant letter is written once the patient is discharged. Therefore, the information provided on the letter is different to what is provided in the Treatment Summary (see Appendix 4).</p> <p>It may be possible to combine the two documents. Where possible, enhance the discharge letter with areas covered within the Treatment Summary.</p>
<p>'It will take too long to complete'</p>	<p>Try out different ways of completing the Treatment Summary, for example, will different people need to complete each section or can you take turns with other members of your trust to complete Treatment Summaries.</p>

Issues	Potential solution
<p>'Consultants at my trust won't complete the Treatment Summary'</p>	<p>Develop a Treatment Summary with pre-populated fields (a dictation template). You will need more than one for the different tumour types/different treatments. For example, prostate brachytherapy, thyroid radio-iodine, thoracic VATS lobectomy.</p> <p>Consider involving the medical secretary right from the beginning. Secretaries may find the structure useful as it is fixed and easy to follow as they're being dictated to.</p>
<p>'Patient has complex pathway that requires treatment at multiple hospitals'</p>	<p>This is why it is important to complete a Treatment Summary after each treatment, so the patient and their GP understands the effects and alert symptoms of each treatment. The risk of relying on the discharge summary only is that it may not capture all the treatments and effects of each treatment.</p>



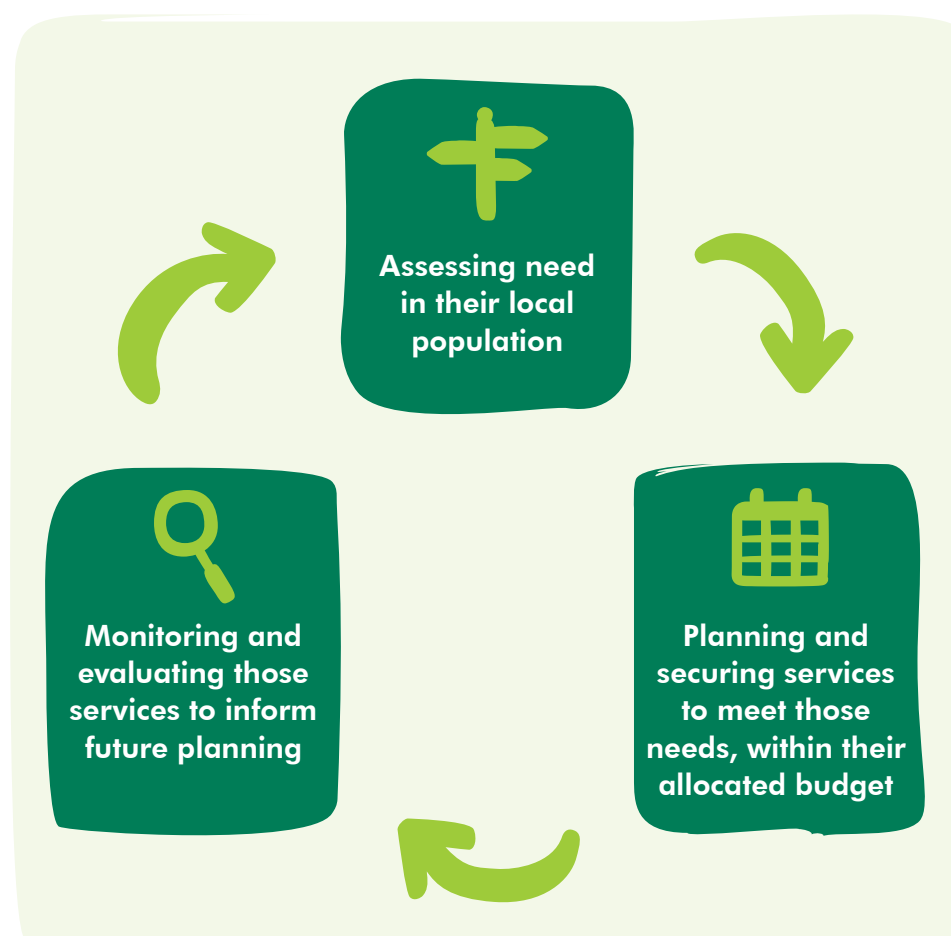
Susanne, Macmillan Nurse

Engaging with commissioners/ service planners



When designing your cancer service, it's important to think about how you could engage with and involve organisations within the wider health and social care landscape. Stakeholder mapping can help to understand the most appropriate people to engage with and how – from sending them updates and evaluations through to inviting them to join a local steering group. By doing this you will ensure that your work fits in with wider strategic plans and decisions, eg the Sustainability and Transformation Partnerships (STPs) in England.

Working with commissioners/service planners in local services can help you drive your priorities forward. The 'commissioning cycle' describes the work of commissioners, an ongoing process of:



Commissioners can use the mechanisms within the commissioning cycle to promote, encourage, incentivise, and facilitate implementation of the Recovery Package (RP).

The type of mechanisms used can include:

- > conducting a cancer needs assessment;
- > reviewing and revising contracts;
- > encouraging and directing providers through regular performance conversations;
- > using financial incentives such as CQUINs; and
- > supporting training opportunities.

Finding out about the mechanisms and tools available to the different commissioners/service planners can help you to align your work, and any evaluation you carry out, with them, ahead of any redesign discussions you may want to have. For example, find out what data would be useful to include in a cancer needs assessment.

For example, commissioners/service planners can support their provision by establishing a baseline of current activity; including a requirement for Treatment Summaries to be completed in contracts, service specifications and their associated quality measures; and by exploring other incentives and local tariffs.

Consider connecting with people in other parts of the UK to find out how they have gone about working with commissioners/service planners to implement the Recovery Package. Macmillan can help facilitate this for you.

Please find below resources and tools that will provide more information about the role of commissioners:

- > You can find them by going to www.macmillan.org.uk/about-us/working-with-us/health-social-care-commissioners
- > For more information about NHS structures around commissioning go to www.nhs.uk/NHSEngland/thenhs/about/Pages/nhsstructure.aspx
- > The British Medical Association guide to commissioning can be found at www.bma.org.uk/advice/employment/commissioning and go to Commissioning.
- > The guide to commissioning by the Royal College of Nursing contains useful guidance on how to engage with commissioners. Go to www.rcn.org.uk/professional-development/publications/pub-003853
- > For more information on the commissioning cycle go to commissioning.libraryservices.nhs.uk/commissioning-cycle

Case studies



Kate Cooper – Macmillan Specialist Radiographer, Musgrove Park Hospital

‘Prior to implementing Treatment Summaries, patients were given a business card with contact details for a therapy review radiographer, who they could contact if any problems arose. They were effectively left to manage on their own after treatment and there was no established line of communication between the treatment team and primary care.’

‘We’ve developed a standardised set of discharge summary letters, based on the Macmillan template and adapted for different tumour types. We developed these in collaboration with our local Macmillan GP, to ensure that the content and format was as useful as possible to primary care teams.

‘We’ve also produced team guidelines on Treatment Summaries and run training sessions so that all the radiographers know how to complete them and are using a consistent approach.

‘The summary is always signed off by the specialist review radiographer, who provides the GP with extra information regarding details of any medications prescribed during treatment, requesting that these are placed on a repeat prescription if necessary. The summaries are then stored in the EPR.

‘A key benefit we’ve observed is how receiving a Treatment Summary can alleviate people’s concerns about their side effects. Radiotherapy can cause a number of acute side effects, including skin reactions and these are very worrying for patients in the weeks after treatment. The summary lets them know what is a normal side effect and therefore what might be a cause for concern. This has reduced the amount of calls that the radiotherapy team receive relating to common problems and allows more time to deal with other queries. Treatment summaries have been able to bridge a communication gap from the Oncology unit to primary care – enhancing patient and carer experience.

‘Since using Treatment Summaries we have noticed better overall engagement with primary care teams. They open a channel of communication and have encouraged a more multidisciplinary approach to care. In addition to Treatment Summaries, where necessary we are also able to provide a care plan, particularly for complex needs patients – for example, if a severe skin reaction requires wound care support, a care plan is written for the practice nurses, to ensure continuity of care and that appropriate dressings are utilised.

‘An added benefit to implementing this process has been a significant increase in the whole team’s knowledge about the effects of treatment and how to manage them.’

Kate Cooper is a Macmillan specialist radiographer at the Beacon Centre at Musgrove Hospital in Taunton



Dr Lucy Thompson – Macmillan GP Adviser

‘Some months ago, a 50-year-old woman attended my surgery. She was a patient I knew quite well and had been receiving treatment for breast cancer diagnosed approximately six months earlier. I had seen her shortly after her initial surgery, but latterly not seen much of her.

‘I knew she had been up and down to the hospital (a 20-mile round trip), often daily, for both adjuvant radiotherapy and chemotherapy. I had received a letter outlining the planned treatment at one point, but knew very little of what the treatment fully entailed or how she had got on with it. She started by telling me she had finished her treatment, but instead of seeming relieved that it was all over, I was surprised to find her upset and distressed. She told me that following this very intensive treatment, with frequent, regular contact with the hospital team, one of the doctors at her last treatment had said to her, “You are all done now. We’ll send you an appointment for a follow-up in about six months”. I remember vividly her description of how that felt to her.

“‘I have felt so closely held throughout my treatment but now I feel as if I have just been dropped. I’m scared”. We spent some time talking through her concerns. Her treatment had left her very tired. She didn’t feel ready to return to work but was worried about the financial impact on her family. She was feeling pain near the radiotherapy site and wasn’t sure whether this was normal following treatment or a cause for concern.

‘To many GPs, this will be a familiar scenario. Although we know many of our patients well, primary treatment for cancer is often intensive, and during this period we may not see our patient at all. The information we receive may be incomplete or delayed. We know, however, that there are certain key facts that are useful to us to provide good care for our patients when they finish initial treatment. To have these facts on a single sheet, easily extractable, so that we can see quickly what has been going on and record them in the patient’s notes, allows us to be much better able to provide good care for our patients at this time.

‘The Treatment Summary provides exactly that. The Macmillan GP Advisers who helped develop it all have a particular interest in cancer, but are also working GPs and knew what information would be useful. Letters during treatment or after clinic visits may typically provide some, but not all, of this information. For example, an oncologist may know immediately from looking at a chemotherapy regime what the likely treatment toxicities may be, but many GPs won’t. The oncologist may not think it necessary to document these in a clinic letter but when our patient returns to the surgery with symptoms, we need this information to understand their significance.

‘Treatment Summaries are not prescriptive – secondary care teams can adapt it in style and format, producing it as a hard copy or electronically. From my own experience, I have found it can really improve communication between cancer services and primary care and, equally as important, be a useful summary of information for the patient themselves.’

Dr Lucy Thompson is a GP in Wiltshire and a member of the Macmillan GP Adviser group

Appendix 1: Treatment Summary template

Treatment Summary

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

Please complete this form using BLOCK CAPITALS and black ink.

Patient's name:

GP contact details:

Date of birth:

Record number:

Address:

Hospital trust:

Your patient has had the following diagnosis and treatment for cancer and received a summary and ongoing management plan as outlined below. They have/have not received a copy of this summary. (Delete as applicable)

Diagnosis:	Date of diagnosis:	Staging:
Summary of treatment and relevant dates:		Treatment aim:
Possible treatment toxicities and/or late effects:		Advise entry onto primary care palliative/supportive care register: Yes /No/Not yet recommended DS 1500 application completed Yes/No/Not yet recommended Prescription charge exemption agreed: Yes/No/Not yet recommended
Alert symptoms that require referral back to specialist team:		Contacts for re referrals or queries: In hours: Out of hours:
Secondary care ongoing management plan: (tests, appointments etc)		Other service referrals made: (delete or add) District nurse AHP Social worker Dietician Clinical Nurse Specialist Psychologist Benefits/advice Service Other
Recommended GP actions in addition to GP Cancer Care Review:		
Summary of information given to the patient about their cancer and future progress:	Additional information including issues relating to lifestyle and support needs:	

Completing Clinician:

Signature:

Date:

You can order Treatment Summary triplicate pack through be.macmillan.org.uk

Appendix 2: Suggested structured letter template (refer to rationale in appendix 5)

Date: <insert date>

Dear Dr <insert GP's name>

Re: <insert patient's name>

Your patient has had the following diagnosis and treatment for cancer and received a summary and ongoing management plan as outlined below. They have been offered/received a copy of this summary.

Diagnosis:

Date of diagnosis:

Staging:

Summary of treatment and relevant dates:

Treatment aim:

Possible treatment toxicities and/or late effects:

Alert symptoms that require referral back to specialist team:

Secondary care ongoing management plan: (tests, appointments)

Recommended GP actions: (e.g. medication, osteoporosis/cardiac screening)

Summary of information given to the person living with cancer:

Additional information including issues related to lifestyle, physical activity and support:

Advise entry onto primary care palliative or supportive care register: (Yes/No)

DS1500 application completed: (Yes/No/N/A)

Prescription charge exemption arranged: (Yes/No)

Contact for re-referral or any queries:

In hours:

Out of hours:

Yours sincerely
<insert clinician's signature>
<Insert clinician's name> CC:
<Insert patient name>

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

Appendix 3: Completed Treatment Summary example

Treatment Summary

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

Please complete this form using BLOCK CAPITALS and black ink.

Patient's name:	John Smith	GP contact details:	Dr Jones
Date of birth:	10.10.10	Record number:	
Address:	3 Park Road	Hospital trust:	
	Doncaster DN4 5EF		

Your patient has had the following diagnosis and treatment for cancer and received a summary and ongoing management plan as outlined below. They have/have not received a copy of this summary. (Delete as applicable)

Diagnosis: Colorectal cancer	Date of diagnosis: 10.02.10	Staging: Dukes T2
Summary of treatment and relevant dates: Surgery – Resection (March 10) and reversal of stoma (Sept 10) Radiotherapy – May–June 2010 Possible treatment toxicities and/or late effects: Diarrhoea following pelvic radiotherapy		Treatment aim: Curative
Possible treatment toxicities and/or late effects: Surgery – Resection (March 10) and reversal of stoma (Sept 10) Radiotherapy – May–June 2010 Possible treatment toxicities and/or late effects: Diarrhoea following pelvic radiotherapy		Advise entry onto primary care palliative/supportive care register: No DS 1500 application completed No Prescription charge exemption agreed: Yes
Alert symptoms that require referral back to specialist team: Diarrhoea for more than two weeks not relieved by loperamide/ codeine Blood or mucus per rectum Further change in bowel function Abdominal pain that persists for longer than four weeks and does not respond to simple analgesia		Contacts for re referrals or queries: In hours: 01234 567890 (CNS team) Out of hours: 01234 987654 (oncology ward)
Secondary care ongoing management plan: (tests, appointments etc) Next OP Review – Jan 2011 CEA next due in Jan 2011 then annually until 2015 CT scan (abdo and chest) next due Sept 2011 Colonoscopy repeat next due Sept 2015		Other service referrals made: (delete or add) Dietician Benefits/advice Service
Recommended GP actions in addition to GP Cancer Care Review: Please review dose of XXXXX in two months if symptoms of XXXX resolved reduce to 4mg daily		
Summary of information given to the patient about their cancer and future progress: John Smith and his wife have been informed that the cancer in his colon was non-invasive and that he has received surgery and radiotherapy with curative intent. He is aware however that it may recur in the future and we have briefly discussed the further treatment available should this be required. He is fully aware of the symptoms of recurrence and what to do should any occur.	Additional information including issues relating to lifestyle and support needs: I have advised him to quit smoking and referred to smoking cessation clinic. He is keen to join local colorectal support group and plans to attend next session in November.	

Completing Clinician: Charles Goodenough

Signature: _____

Date: 30.10.10

You can order Treatment Summary triplicate pack through [be.macmillan.org.uk](#)

For more examples of Treatment Summary templates, please go to our Recovery Package LearnZone page at [www.learnzone.org.uk/recoverypackage](#) and go to Treatment Summary. Here you will find a selection of templates and examples.

Appendix 4: GP Read Codes for common cancers (For GP use only)

Please include with the Treatment Summary to the GP. Note: This is an aide memoir for common cancer related codes, not all will apply to this patient. Other GP Read Codes are available if required. (Note: the codes are case and symbol sensitive so always ensure codes are transcribed exactly as below)

Systemone	(5 digit codes)	All other systems	Version 3 five byte codes
Treatment		Treatment	
Palliative radiotherapy	5149.	Radiotherapy tumour palliation	5149.
Curative radiotherapy	XalpH	Radiotherapy	7M371
Chemotherapy	x71bL	Chemotherapy	8BAD.
Radiotherapy	Xa8S1		
Treatment aim		Treatment aim	
Curative procedure	Xallm	Curative treatment	8BJ0.
Palliative procedure	XaiL3	Palliative treatment	8BJ1.
Actions recommended to the GP		Actions recommended to 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.
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.	Carers details	9180.

Appendix 5: Rationale for data fields included in the Treatment Summary

Field	Why include this?	Essential (E) or Desirable (D)
Diagnosis	<ul style="list-style-type: none">Important for the GP and patient to know the type and location of cancer and the likely source of secondary recurrence.	E
Organ staging/local or distant spread (grade)	<ul style="list-style-type: none">Information about staging and spread provides insight into prognosis and risk of recurrence.	D
Date of diagnosis	<ul style="list-style-type: none">Shows how long the person has known their diagnosis.Shows the time period between referral from primary care and diagnosis – helps identify where delays can be minimised in future.Important data for monitoring treatment outcomes in relation to survivorship.Helps plan the date of a GP Cancer Care Review.	E
Summary of treatment and relevant dates	<ul style="list-style-type: none">To understand the range and order of treatment/s and the likely sequence of treatment effects.Essential to inform future treatment choice if further disease occurs.Important information for people wishing to take out insurance or a mortgage.	E
Treatment aim	<ul style="list-style-type: none">Shows whether treatment intended is curative, palliative or for symptom relief – helping the GP understand the aims of treatment and to refer back to secondary care or other services appropriately.Supports the GP to anticipate future care needs.	E

Field	Why include this?	Essential (E) or Desirable (D)
Possible treatment toxicities and/or late effects of treatment	<ul style="list-style-type: none">People undergoing some cancer treatments may be more prone to toxicity and late effects of treatment such as osteoporosis or heart disease. Including risks here will help ensure the patient is entered onto appropriate ongoing surveillance programmes by the GP practice (see Quality Outcome Framework (QOF)).Signs and symptoms addressed earlier may improve quality of life and treatment outcomes from side effects or late consequences of treatment.Suggested or preferred treatment associated with toxicities and late effects can be initiated without the patient needing to be referred back to the specialist.Raises awareness of common late effects and reduces delays to further investigation and treatment. This may also impact on survival rates as symptoms are picked up sooner.	E
Advise entry onto palliative or supportive care register	<ul style="list-style-type: none">Including the patient on the palliative care register ensures that the out of hours (OOH) teams are made aware that a patient is nearing end of life, and they and their carers may need more support.The register is shared with all relevant OOH doctors, as well as staff from the ambulance service, community district nursing teams, Macmillan support team, social care and hospice, as appropriate. Patients can then receive the support, information and benefits they need.	E
Key contact in hours for advice and re-access	<ul style="list-style-type: none">To ensure the person living with a cancer diagnosis, GPs and primary care team know who and when to contact should they have queries or concerns.The contact should be able to triage enquiries and initiate action.	E

Field	Why include this?	Essential (E) or Desirable (D)
DS 1500 status (benefit that a patient can claim at the last six months of life)	<ul style="list-style-type: none">If a DS 1500 hasn't already been completed, this will prompt the GP to arrange this.	
Prescription exemption	<ul style="list-style-type: none">If a prescription exemption hasn't been completed, this will prompt the GP to arrange one. All cancer patients are entitled to have their prescription charges waived for any cancer treatment or drug they need.	E
Alert symptoms that require referral back to specialist team	<ul style="list-style-type: none">This should only include the symptoms where immediate re-referral to a secondary care specialist is required (eg acute breathlessness requiring a pleural tap) not the expected side effects of treatment that can be managed by the GP or community team.People living with cancer will have a better understanding of the symptoms that they should be concerned about and that should prompt them to contact the specialist team.	E
Contact for re-referrals or queries in and out of hours	<ul style="list-style-type: none">Confirms contact details for the patient or GP for advice on care or treatment or to arrange an urgent review. The OOH contact could be a ward, the acute oncology team or the relevant on call team.	E
Secondary care ongoing management plan	<ul style="list-style-type: none">Include any planned outpatient reviews and surveillance tests dates (or approximate timescales) – this provides a framework for GPs. If indicated here, further tests can be scheduled before the outpatient visits.People living with cancer will be better informed about follow up plans and what to expect.It is reassuring for people living with cancer to see the planned care, surveillance and support – then they know what to expect and when.	E

Field	Why include this?	Essential (E) or Desirable (D)
Referrals to other services	<ul style="list-style-type: none">Helps avoid duplication of referral if the patient visits the GP between appointments and is unsure of who is involved in their care.Particularly useful with social care referrals and when the person is known to other agencies.Can help to reinforce the importance of attending appointments with other agencies.Useful to also include details related to third sector support and centres such as a Maggie's Cancer Caring Centre, if available.	D
Recommended GP actions including medication etc	<ul style="list-style-type: none">To provide clarity about expectations in terms of the person's ongoing care and how they can support them.Provides prompts, to add the patient to routine screening programmes to help mitigate late effects of treatment.The person living with cancer will be more empowered to approach the GP if they need further advice and support.A specific request can be given to the GP to ensure continuity of care and avoid ambiguity.Provides the GP with guidance and advice on which drugs, if any, need stopping and when. Also whether any adjustment is needed between follow up appointments or following discharge.May avoid inappropriate prescriptions, overdose or misuse. Particularly important if the GP is going to continue to prescribe long term, ie endocrine manipulation.People living with cancer will also know what to expect from their GP.	E
Cancer Care Register	<ul style="list-style-type: none">This reminder helps ensure the patient is entered onto the register and that they are formally reviewed by the GP within six months of diagnosis. This is a requirement for the QOF for all general practices.	E

Field	Why include this?	Essential (E) or Desirable (D)
Summary of information provided to patient on diagnosis and prognosis	<ul style="list-style-type: none">Sharing information on what has been discussed with the patient and their carer, and any written information provided, improves the quality and openness of the discussion that the GP can have with people living with cancer.	E
Additional information to people living with cancer	<ul style="list-style-type: none">Confirms which lifestyle information and advice has been given or signposted to, including details of local support groups and psychosocial support, complementary therapies, returning to work advice etc.	D
Read Codes	<ul style="list-style-type: none">It is the GP's responsibility to assign the appropriate codes and enter them on their systems. GP Read Codes are similar to hospital HRG codes and are used to identify diagnosis, tests and treatments. Both are complex systems and must be input manually.Including the Read Codes in the TS prompts and encourages GPs to accurately code patients. This helps improve safety in terms of surveillance, disease tracking and audit.Please note: Codes may differ depending on the GP IT system used.	D

Rationale supplied by the Macmillan General Practitioner Advisers

Useful resources for the Recovery Package

Resources for professionals



Treatment Summary Triplicate pack
Contains 50 Treatment Summaries allows secondary care professionals to complete a Treatment Summary, storing a copy in the patient notes and issuing carbon copies to patients and GPs respectively.

be.macmillan.org.uk
Order code MAC15576



Recovery Package online toolkit
This will give users detailed information about each of the elements of the Recovery Package including information on the benefits of each and challenges of implementing. Includes links to resources and access to short clips explaining each resource.

www.learnzone.org.uk/recoverypackage



Holistic Needs Assessment, Care and Support Planning
This guide covers all areas of the HNA: key benefits, eight core principles and advice on suitable environments and how to best prepare for an HNA.

be.macmillan.org.uk
Order code MAC16266



Holistic Needs Assessment, Care and Support plan folder
This pack contains two triplicate pads for the assessment and the care plan. This enables the user to give a copy to the patient, a copy to the GP or audit, and place a copy in the medical records.

be.macmillan.org.uk
Order code: MAC13689

Resources for professionals



Electronic Holistic Needs Assessment
Allows for the patient to complete the eHNA electronically such as a touch screen tablet, smart phone or laptop.

Information is then sent via a secure link to enable the key worker and health professional to complete a care plan.

macmillan.org.uk/ehna



Health and wellbeing events how to guide
Advice on setting up health and wellbeing clinics, evaluating them and understanding their key benefits.

be.macmillan.org.uk
Order code MAC16500

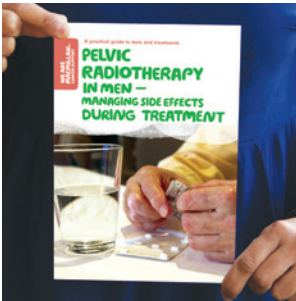


The Recovery Package – sharing good practice
The Recovery Package is a series of key interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer. This document outlines the interventions, the evidence and how it improves care.

be.macmillan.org.uk
Order code: MAC15514

Resources for people affected by cancer

We have a wealth of resources for consequences of cancer and its treatment. Go to www.macmillan.org.uk/cot and scroll down to 'For people affected by cancer'. Here you will be able to link to a large variety of resources.



Managing the effects of pelvic radiotherapy

Before and during treatment – to be used as appropriate at various points from consent to treatment through to post-treatment follow up (if no late effects are evident).

Booklets for those, or are going to have, radiotherapy to the pelvic area.



be.macmillan.org.uk
Men: Order code: MAC13943
Women: Order code: MAC13944

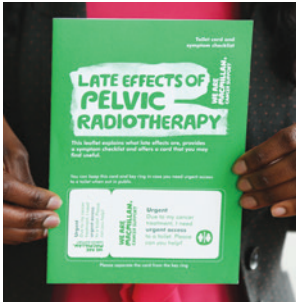


After treatment – intended for use if late effects are identified.
Booklet for those who are experiencing long term effects of pelvic radiotherapy treatment.

be.macmillan.org.uk
Men Order code: MAC13825
Women Order code: MAC13826



Resources for people affected by cancer (continued)



Toilet Card with symptom checklist

This leaflet includes trigger questions and a symptom checklist to highlight when matters should be raised with a professional. It also includes our toilet card.

be.macmillan.org.uk
Order code: MAC15193



Toilet Card

Cancer treatment can affect bowel and bladder function. Gain urgent access to a toilet with this toilet card and key ring.

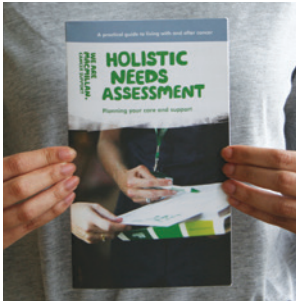
be.macmillan.org.uk
Order code: MAC15193_A5_0215



What to do after cancer treatment ends: 10 top tips

This leaflet helps patients get the support they need to lead as healthy and active a life as possible following cancer treatment.

be.macmillan.org.uk
Order code: MAC13615



Holistic Needs Assessment: Planning your care and support

This booklet for patients outlines the process of assessment and care planning, what to expect and what they can prepare for.

be.macmillan.org.uk
Order code: MAC12957



Physical activity and cancer treatment

This booklet is written for people living with or after cancer who want to know more about the benefits of being physically active. It includes practical advice and useful organisations.

be.macmillan.org.uk
Order code: MAC12515



Your follow-up care and support

A resource for people affected by cancer to introduce the concept of supported self-management as well as the components of the Recovery Package.

be.macmillan.org.uk
Order code: MAC16184



Macmillan Organiser

The Macmillan Organiser is designed for the patient to help them keep track of their treatment, make notes, and find the information and support they may need. It enables people to record useful information to help them self-manage and contains useful assessment tools such as the concerns checklist and mood and food diaries.

be.macmillan.org.uk
Order code: MAC15835

References

¹ Maddams J, Uitley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010 – 2040. Br J Cancer. 2012; 107: 1195-1202

² Macmillan Cancer Support. Throwing light on the consequences of cancer and its treatment. 2013. London

³ Macmillan Cancer Support. Cancer in the UK 2014: State of the Nation Report, 2014. [http:// www.macmillan.org.uk/Documents/AboutUs/WhatWeDo/CancerintheUK2014.pdf](http://www.macmillan.org.uk/Documents/AboutUs/WhatWeDo/CancerintheUK2014.pdf)

⁴ The Scottish Cancer Strategy’s Beating Cancer: Ambition and Action 2016 – A strategy for Scotland <http://www.gov.scot/Resource/0049/00496709.pdf>

⁵ NHS Five Year Forward View. NHS England, October 2014. [http://www.england.nhs.uk/ wp-content/uploads/2014/10/5yfv-web.pdf](http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf). [Accessed May 10, 2017]

⁶ http://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

⁷ Wales Cancer Delivery Plan for Wales 2016-2020 <http://gov.wales/topics/health/nhswales/plans/cancer-plan/?lang=en>

⁸ Tribal Evaluation: Treatment Summary, October 2010

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The group welcomes all comments and suggestions for future editions via the Macmillan Recovery Package Programme at **recoverypackage@macmillan.org.uk**

You'll know that cancer can affect everything. Health, relationships, finances, and more. At Macmillan, we've been helping to ease the practical and emotional consequences of cancer since 1911. Today you can call on us whenever you feel the people in your care would benefit from extra support.

As the UK's leading cancer support charity, we can provide a range of services to complement your vital work, giving you the resources you need to help people live as full a life as possible

Working with you, we can be there for people during treatment, help with job and money worries and will always make time to listen if someone needs to talk. Whatever's needed – be it help with benefit applications or emotional support for the whole family – we can work together to transform how people live life with cancer.

From diagnosis, for as long as we're needed, we're here to help you support the people in your care and their loved ones.

Visit **macmillan.org.uk/professionals** for more information about our services.