

**WE ARE
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CANCER SUPPORT**

TREATMENT SUMMARY

**A tool to improve communication between
cancer services and primary care.**

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In 2010, a group of Macmillan GP advisers identified key information that would be helpful to them at the end of a patient’s initial cancer treatment. The GPs had been receiving multiple forms of communication from colleagues in secondary care and lacked a simple summary of a patient’s cancer diagnosis, treatment and an ongoing management plan.

To improve this situation, the Treatment Summary template was designed by the National Cancer Survivorship Initiative (NCSI). The Treatment Summary is a document produced by secondary cancer care professionals at the end of treatment and sent to the patient’s GP. It provides important information for GPs, including possible treatment toxicities, information about side effects and/or consequences of treatment, signs and symptoms of a recurrence and any actions for the GP.

It aims to inform GPs and other primary care professionals of any actions they need take and who to contact with any questions or concerns. The patient also receives a copy to improve understanding of their condition and to provide a summary to share with other professionals and those of their choice, eg for travel insurance purposes. A copy of the Treatment Summary in the case notes is also useful for medical staff if the patient is admitted in an emergency after primary treatment is complete.

Testing

Treatment Summary was tested in 11 NHS test sites across four tumour groups, using a standard template. Testing was supported by NHS Improvement. Around 250 summaries were issued to GPs over a six-month period. Its use was evaluated by the NCSI through surveys, telephone interviews and face-to-face meetings with over 50 clinicians.

The Treatment Summary was positively received in both primary and secondary care. 80% of GPs found the summary ‘useful’ or ‘very useful’. Over 50% felt it would make a difference to the way they managed patients, and 90% wanted its use to continue. The majority of hospital clinicians recognised the value of recording what could be months of treatment and holistic care into a concise summary. One clinician commented that he felt, ‘it made us document and communicate better’, another thought it to be ‘excellent’.

An updated version of the Treatment Summary has been developed for wider use. It can be found together with a user guide at ncsi.org.uk It can be formatted to suit local community or IT systems, however the key headings, GP READ codes and NCSI acknowledgements should be maintained.

Cancer Care Review

The Treatment Summary informs the Cancer Care Review (CCR). This is a review that GPs are required to carry out with their patients six months after a diagnosis of cancer. A CCR template was also tested and evaluated by Macmillan during 2010. The evaluation looked specifically at how the templates are used by GPs, how they could be used more effectively, and how helpful the review is for patients. See page viii for more about CCR and the evaluation.

Treatment Summary template

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 is outlined below. The patient has a copy of this summary.

Diagnosis:	Date of diagnosis:	Organ/Staging Local/Distant
Summary of Treatment and relevant dates:		Treatment aim:
Possible treatment toxicities and / or late effects:		Advise entry on to primary care palliative or supportive care register Yes / No DS1500 application completed Yes/No Prescription Charge exemption arranged Yes/No
Alert Symptoms that require referral back to specialist team:		Contacts for referrals or queries: In Hours: Out of hours:
Secondary Care Ongoing Management Plan: (tests, appointments etc)		Other service referrals made: (delete as necessary) District Nurse AHP Social Worker Dietician Clinical Nurse Specialist Psychologist Benefits/Advice Service Other
Required GP actions in addition to GP Cancer Care Review (eg ongoing medication, osteoporosis and cardiac screening)		
Summary of information given to the patient about their cancer and future progress:		
Additional information including issues relating to lifestyle and support needs:		

Completing Doctor:

Signature:

Date:

For more information, please see our *Treatment summary and user guide* which can be ordered at <http://be.macmillan.org.uk/be/s-689-recovery-package.aspx>

This section of the article describes the use of the Treatment Summary from both a secondary and primary care perspective.

A secondary care perspective

Dr Alastair Smith

Cancer diagnosis, treatment and aftercare usually take place in secondary care, with primary care and community services looking after people who require palliative or end-of-life care. Although post-cancer aftercare is beginning to change, the majority of organisations continue to provide aftercare and follow-up in a very traditional way. People often attend specialist outpatient clinics simply to receive the results of any follow-up tests, a process repeated over many years until discharge. There is no systematic approach to addressing their other health needs. In effect, the clinics look more at the cancer’s presence or absence rather than the whole patient. Other healthcare professionals, especially GPs, are capable of looking for, identifying

or reporting concerns following cancer treatment, as are most patients provided they have the necessary information and are empowered to do so. The problem currently is that GPs and patients don’t receive appropriate information from secondary care in a structured, practical, easy-to-read format.

A key point for the person with cancer is when planned treatment (surgery,

‘For many cancer types, occasional follow-up is wholly ineffective at picking up relapse, thus ‘follow-up’ isn’t achieving what it’s thought to achieve’

chemotherapy or radiotherapy – or combination of these) has been completed. A clinical outcome has been achieved and no further treatment may be planned

(depending on the cancer type, its stage and biology) or ongoing maintenance or hormonal treatment may be required. The patient will perhaps be cured, at variable risk of relapse, or have achieved a partial response with an anticipated period of disease stability thereafter. There may be specific prescribing requirements, for example, hormonal treatments in breast or prostate cancer, or long-term Imatinib (Glivec®) in chronic myeloid leukaemia. For a minority of patients, the outcome of initial treatment will be poor with a limited prognosis, and referral to palliative and supportive care is appropriate.

These aspects of care need to be identified and recorded. This has traditionally been done in the clinic letters that follow the patient’s review in secondary care. A critical review of a random selection of secondary care clinic letters following treatment of cancer is likely to show the majority to be not ‘fit for purpose’.



About the author

Alastair has over 28 years experience as a consultant haematologist, with an emphasis on management of myeloma, leukaemia, and related haematological cancers. He led the production of UK guidelines for myeloma care between 1998 and 2006. He developed a specialist myeloma clinic in Southampton as well as an outreach clinic in the New Forest to manage chronic blood conditions.

During the past 10 years he has championed the use of active triage and written advice to help colleagues manage increasing numbers of general haematology referrals from primary care, thus reducing the number of unnecessary clinic appointments and actively managing clinic capacity.

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Assessment

A process of gathering and discussing information with the patient and/or carer/supporter to understand what the person living with and beyond cancer knows, understands and needs. This holistic assessment is focused on the whole person. Their entire well-being is discussed. The process culminates when the assessment results are used to inform a care plan.^[1]

The care plan

A plan based on the diagnosis and holistic assessment of the patient. The essential components will include identification of issues related to the diagnosis. It will need to prioritise the patient’s issues and include a statement on the specific actions and approaches to address them, and recognise issues that may not be readily resolved.^[1]

¹National Cancer Survivorship Initiative. *Assessment and care planning definitions*. www.ncsi.org.uk/assessment-care-planning/assessment-care-planning-definitions (accessed 11 August 2011).

There is as yet, limited uptake of a formal ‘post-treatment’ summary letter that is practical and useful for both the GP and the patient. In some cases, the content may be good, but the letter written in such a way that it’s difficult to readily identify the relevant information. Others are simply inadequate, containing too much unnecessary technical information and incomprehensible acronyms. In reality, the clinic letters are not truly directed at the GP – they represent a combination of a printed account of the consultation for hospital records and are effectively directed at the next secondary care specialist seeing the patient.

The Treatment Summary pilot work stems from this context and is an attempt to improve communication and facilitate the exchange of key information about care and follow-up. The aim is to improve the engagement of patients and primary care clinicians in post-cancer treatment survival. The outcomes of the Treatment Summary can be summarised as follows:

- The patient has undergone a process of ‘formal’ post-treatment assessment from an appropriately-trained professional, such as a specialist doctor or nurse.
- It records that the patient has received information and support to take a more active role in the management of their own

- health, including deciding when to have a test and when to contact a specialist.
- It recognises the need for specific, long-term follow-up for the consequences of cancer, eg osteoporosis following endocrine treatment. It provides information and guidance about appropriate surveillance and management.
- It encourages the primary care and secondary care teams to see themselves as one team looking after the patient.
- A key component is also to record what the patient has been told in respect of outcome and prognosis including, where appropriate, issues relating to end-of-life care.

Feedback from the project has been encouraging. There are those in secondary care who say they are ‘too busy’ to complete the Treatment Summary and some uncertainty has been expressed as to whether it is instead of, or additional to the traditional clinic letter. Given there is a greater amount of positive comment, the challenge now is to take this further and achieve a substantial cultural change in secondary care that has the potential to enhance and catalyse major changes in dealing with cancer survivorship.

An alternative way of looking at the Treatment Summary is to see it as simplifying the process of communication. With regular use and suitable adaptation for the specific cancer group or type treated, it should actually save clinician time. It's based on a series of headings and topics directing the secondary care clinician to identify information that is relevant and practical for both the GP and the patient.

A specific format has been tested – it shouldn't be taken as in any way fixed or final, there is no one-size-fits-all post-treatment summary. The learning from this work is that the principles embedded represent the direction that survivorship care needs to take. For example – focusing communication to address issues such as symptoms that would raise concern about recurrence, post-treatment side effects, and access to specialist advice.

Pressures on the healthcare system will increase as demand increases and funding does not. Separate from health-related politics, our approach as secondary care clinicians has to change.

For too long we have continued with an over-medicalised, paternalistic approach to post-cancer management. For many cancer types, occasional follow-up is wholly ineffective

at picking up relapse, thus 'follow-up' isn't achieving what it's thought to achieve and clinic capacity is compromised with patients who don't need or wish to be there for the most part.

Cancer outcomes and management have changed over the last 10 years, but available services haven't adapted accordingly to recognise and manage survivorship. To meet the needs of our patients in the coming decades, when the numbers of cancer survivors will increase substantially, medical specialists need to be at the forefront, leading the change to new models of care and follow-up for people with cancer.

Adoption of the Treatment Summary with structured, practical information, including a clear plan for necessary 'clinical surveillance' is long overdue. Primary care practitioners have welcomed it, based on experience from the pilot, and primary and secondary care should be working together to support patients. Working to a Treatment Summary that is relevant to the cancer type and the patient represents a logical direction of travel, and a challenge that we need positively to adopt. It has the potential to make life a great deal easier for all and underpin the long overdue change to follow-up care.

A primary care perspective

Dr Lucy Thompson

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 on a daily basis, 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 consultation 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.



Further information

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About the author

Lucy is a GP in Wiltshire and a member of the Macmillan GP Adviser group. She was first funded as a Macmillan GP Facilitator 15 years ago. Initially this role saw her concentrate on developing good communication between GP colleagues to cover out-of-hours care and educational initiatives, and tools to improve primary care palliative care. She then became more involved in earlier stages of the cancer pathway, working closely with secondary care colleagues providing a general practice view, for example when developing referral guidelines for suspected cancer.

She has been involved in national projects including the National Awareness and Early Diagnosis Initiative (NAEDI) and the NCSI being part of the supported self-management work stream). She works as a GP three days a week.



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 patient when they finish initial treatment. To have all of 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 might 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.

Through the NCSI, we were able to work with our secondary care colleagues to produce a template for a summary of key information. The test sites and evaluation have shown that it’s feasible for secondary care clinicians to produce, and that it’s useful in both secondary care and primary care settings. It’s not proscriptive – secondary care teams can adapt it in style and format, producing it as a hard copy or electronically. It can really improve communication between cancer services and primary care, as well as being a useful summary of information for the patient themselves.

Cancer Care Review

The Cancer Care Review (CCR) was introduced as a quality marker as part of the Quality and Outcomes Framework (QOF) in 2002. It states that a GP should review a patient within six months of a new diagnosis of cancer.

A GP will only see a relatively small number of people with a new cancer each year compared with a multitude of other conditions. Without a formal structure and framework, it can be difficult for a GP to know what form this review should take. Research has shown that many patients don’t even realise they have had a CCR when they have seen or spoken with their GP at this time. GPs may well focus on physical symptoms and treatment when in fact, a patient may be concerned with loss of income, getting back to work, psychosocial issues or body image.

Macmillan and the NCSI recognised how important these aspects are to people affected by cancer. Macmillan has supported the development and evaluation of structured templates for the CCR within GP software systems (INPS and EMIS). Use of these can help to inform the review and encourage a more holistic assessment. Early results from this initiative show that 81% of GPs surveyed find the CCR template user friendly and 71% of patients found the process very satisfactory.

It’s important that the CCR doesn’t become a ‘tick box’ exercise, but is seen as a series of prompts allowing the GP and patient to discuss a whole range of issues. The GP may wish to use a general opening question and prompts to make it clear they are happy to discuss a whole range of issues, not just the medical aspects of having cancer.

Areas on the template covering work and benefits remind GPs that these are very important to the person affected by cancer, and have as much impact on life as physical symptoms and treatment. Similarly, other parts of the template provide prompts to explore the patient’s understanding of their disease and the intent of treatment.

‘Early results from this initiative show that 81% of GPs surveyed find the CCR template user friendly and 71% of patients found the process very satisfactory’

Currently, GPs are asked to complete this review within six months of diagnosis. This may coincide with the time when primary treatment finishes, when patients traditionally return to their GP. It’s easy to see how a comprehensive but succinct Treatment Summary, coupled with a holistic CCR with the GP, can provide a person affected by cancer with good care and support at the time of finishing their initial treatment.

It’s hoped that the use of both will become widespread over time, and that their combined use may revolutionise follow-up. The aim is to move away from the current model to one where people are empowered to self-manage with good primary care support and ready access to secondary care if and when necessary.

Policy

As part of the coalition government’s information revolution, it wishes to see greater collection and sharing of data and information. It wants to empower patients so that they can make more informed choices about their health, treatment and care.

England
Liberating the NHS:
an information revolution

After several delays, the coalition government is expected to respond to the consultation on its information strategy later in the year.

The strategy promotes personalised care planning discussions that focus on the needs and wants of those with long-term conditions. It says that people need, ‘information and support that enables them to understand clearly both their own situation and the options open to them’. The aim is for people to take more personal responsibility and fully participate in decision-making.

The strategy also continues to promote patients’ access to their health records. In fact, the government has begun to write to patients in England about the introduction of the Summary Care Record (SCR), which will give patients access to their records. For more information, visit dh.gov.uk

Improving outcomes: a strategy for cancer

The new strategy for cancer stresses the need to improve the care and support given to cancer survivors. In particular, the coalition government wants to see improvements in the outcomes for people living with and beyond cancer.

The strategy suggests that following cancer treatment, people should be offered, ‘a personalised, risk stratified pathway of care, following assessment and care planning. The assessment will include needs associated with the individual, the disease and the treatment. The pathway will include an end of treatment record summary shared between

the cancer centre and primary care team, and the care plan will be coordinated so that it addresses the full range of needs of those with co-morbidities’. For more information, visit dh.gov.uk

The National Cancer Survivorship Initiative (NCSI)

This initiative was a partnership between the Department of Health and Macmillan, and was supported by NHS Improvement. The aim of the NCSI was, by 2012, to have taken the necessary steps to ensure that people living with cancer get the care and support they need, to lead as healthy and active a life as possible, for as long as possible. The NCSI Vision document provides an update on the first year of the NCSI and describes its emerging vision for improved care and support for people living with and beyond cancer. To download the document, visit ncsi.org.uk/wp-content/uploads/NCSI-Vision-Document.pdf

National Cancer Patient Experience Survey

The last National Cancer Patient Experience Survey (2010) included questions directly related to the ability of those in general practice to care for patients during treatment, as well as the information given to GPs about the patient’s condition and treatment.

Only 61% of patients said different people (ie GPs, hospital doctors/nurses, specialists and community nurses) treating and caring for them always worked well together to give them the best possible care. However, 93% of patients said their GP was given enough

information about their condition and hospital treatment. The survey is likely to be repeated again in the near future. For more information, visit quality-health.co.uk/cancer-survey-materials

Scotland
Better Cancer Care

The Scottish Government’s action plan for cancer services includes a chapter dedicated to survivorship. It sets out details of a working group looking at how NHS Scotland can better support people living with and beyond cancer. For more information, visit scotland.gov.uk/publications

Northern Ireland
Services Framework for Cancer Prevention, Treatment and Care

The Northern Ireland Executive’s Service Framework sets out explicit standards for health and social care, helping health and social care organisations to plan and deliver services. The standards state that all patients should receive a holistic assessment at the end of each treatment episode and should be actively involved in decision making with regards to their aftercare arrangements. They should receive a permanent record of the agreed plan. For more information, visit dhsspsni.gov.uk

Wales
Chronic Conditions Management Demonstrators Programme

The Welsh Assembly Government (WAG) has been testing service models for chronic conditions. The WAG has published the findings of this programme in its Year 2 report. To download the report, visit ccmdemonstrators.com/article.aspx?CMSPageID=637

Promoting Treatment Summary
Macmillan and the NCSI have produced a supplement about the Treatment Summary for the Health Services Journal. They are planning to now concentrate on promoting the tool through various publications. Other plans include applying for Treatment Summary to become a Peer Review Measure and promoting the tool to patients.

When you have cancer, you don't just worry about what will happen to your body, you worry about what will happen to your life. Whether it's concerns about who you can talk to, planning for the extra costs or what to do about work, at Macmillan we understand how a cancer diagnosis can affect everything.

No one should face cancer alone. So when you need someone to turn to, we're here. Right from the moment you're diagnosed, through your treatment and beyond, we're a constant source of support, giving you the energy and inspiration to help you take back control of your life.

For support, information or if you just want to chat, call us free on **0808 808 00 00**
(Monday to Friday, 9am–8pm)
or visit **macmillan.org.uk**

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