Cancer Survivorship Best Practice Review

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Commissioning Strategy and Planning Support
Commissioning Delivery
Making Change Happen
Operations Support
**Purpose:** This report has been written for the members of the Bristol Clinical Commissioning Group Cancer Steering group. It is intended that this report is used for reference to help inform a cancer survivorship patient pathway. The information presented in this paper is to inform debate, assist in decision-making and signpost to examples of best practice.

**Aim:** The aim of this report is to enable readers to consider the available information around Best Practice in cancer survivorship to help support future decision making around cancer pathways.

**Methodology:** Information included in this report has come from an on-line search of Healthcare databases (through NHS Athens and Google Scholar) and searches of specific websites (including NHS Evidence, NHS Networks,). This report focusses on answering three key research questions:

1. What is meant by cancer survivorship patient pathways and why is it needed?
2. What does Best Practice in cancer survivorship look like?
3. What do cancer survivorship pathways look like in other regions/countries?
4. What are the key sources for analysis information on cancer survivorship?

Some text included in this report has been directly lifted from the original primary text. References to the primary information sources have been provided for more detailed reading.
1. **What is meant by cancer survivorship patient pathways and why is it needed?**

**Background context**

The National Cancer Survivorship Initiative (NCSI) was introduced in 2007 the main focus was diagnosing and treating cancers. However one of the underlying aims of the initiative was to enable cancer survivors to live a long and healthy life as possible. Improvements in cancer screening, detection, treatment and care have resulted in increased 5-10-year survival rates, with many cancers now considered chronic diseases (Franklin 2007). Cancer survival rates are increasing; current research has focused on the effect of diagnosis and treatment on individuals’ quality of life after completion of treatment and its ongoing consequences. In the UK there is a limited knowledge of the needs of cancer survivors and whether there is the infrastructure in place to meet these needs.

A common criticism of traditional models is that they are ‘disease focused’ – that is, intent on detecting disease recurrence rather than providing a patient-centred approach to care. If we continue to deliver a ‘business as usual’ service we will likely fail to meet the needs of survivors and this will prevent us from meeting the outcomes that are central to the government’s focus for the NHS and social care. Armes et al (2009) found that 30% of patients had five or more unmet needs at the end of their cancer treatment, the most frequently reported being fear of recurrence and psychological needs, and 20% continued to have more than five unmet needs after six months. Patients report specific concerns about fear of recurrence and death (Ziner et al 2012), altered social support (Sammarco 2001), emotional difficulties (Sherman et al 2012), work and financial difficulties (Shewbridge et al 2012) and altered relationships with healthcare professionals (Corner et al 2013).

Bristol CCG needs to consider commissioning and providing the right support based on need in order to continue to improve the rate of survivorship as well as quality of life and patient experience. The process of physical and psychological recovery can be lengthy and require tailored support. Cancer rehabilitation is now becoming recognised as a critical part of survivor care plans. There is a ‘disconnect’ between cancer survivorship and rehabilitation whereby community-based rehabilitation programmes lack oncology focus and oncologists in tertiary centres are not exposed to comprehensive rehabilitation services (Alfano et al. 2012).

**Rehabilitation**

As more and more people survive cancer and a greater percentage of people now live with cancer, there is a greater recognition for the need for rehabilitation to either deal with the late effects of treatment or the physical effects of the disease. Early intervention with rehabilitation can minimise the level of disability and the effects of cancer treatment, and continued access to rehabilitation throughout the cancer pathway supports the patients as they undergo treatment.
As the complexity of treatments increases, many patients report ongoing side effects and concerns after treatment is completed; some also report a lack of self-confidence. If supportive care is provided to people with cancer and their carers it should be throughout the patient pathway, from pre-diagnosis onwards and it should be given equal priority with other aspects of care and be fully integrated with diagnosis and treatment.

- **Key Recommendation 1:** Access - a timely and responsive service with agreed assessment triggers for referral, including provision of equipment.

- **Key Recommendation 2:** Planning - patients receiving an active and planned approach to rehabilitation that involves assessment, goal setting, care planning and evaluation.

- **Key Recommendation 3:** Responsive - prompt referral for those patients who might benefit from rehabilitation specialists.

- **Key Recommendation 4:** Integrated - a seamless service with good planning processes and systems delivered in an appropriate setting, but aligned with generalist service with links to community support groups.

- **Key Recommendation 5:** Workforce - teams made up of the right mixture of specialist and general staff (MDT) with clear support/training structures and professional standards to deliver service interventions at the right levels (1-4).

- **Key Recommendation 6:** Quality - delivering evidence based care using clearly defined patient pathways that are tumour specific, with clear intervention routes, alignment to clinical/national pathways and appropriate entry points for patients (recognition of trigger factors). These ought to be compliant with the Improving Outcomes Guidance.

- **Key Recommendation 7:** Patient Focused - focus on prevention of long term effects, better patient experience where all patients have their needs for rehabilitation services assessed throughout the patient pathway.

- **Key Recommendation 8:** Communication - good communication with readily available access to patient information at all stages.
Rehabilitation is an essential component of the cancer journey and aims to optimise dignity and reduce the extent to which cancer affects the patients physical, psychological and economic functioning.

- **Key Recommendation 9:** Fundamental to the rehabilitation package is: (NICE, 2004)
  - An early assessment of need
  - Co-ordination of ongoing assessment
  - A co-ordinated multi-disciplinary approach to care
  - Care provided by a competent, trained workforce

Building the case for change is essential if commissioners are to comply with NICE Supportive and Palliative Care guidance that states that people with cancer should be "offered a comprehensive care and rehabilitation package as outlined above at the time of diagnosis. This should include information on prognosis and treatment; rehabilitation and nutrition. The provision of psychological/spiritual/emotional support should also be covered. The package should be reviewed at regular intervals, but especially at the completion of treatment.

**Key Recommendations on taking action: promoting recovery:** (DH, et al, 2013)

- **Key Recommendation 10:** Patients’ wellbeing will be greater and their demand for services lower if they get the support that is relevant to their particular needs, and which promotes healthy lifestyles and independence.

- **Key Recommendation 11:** The ‘recovery package’: a combination of assessment and care planning, Treatment Summary, and a patient education and support event (Health and Wellbeing Clinic) is potentially the most important building block for achieving good outcomes. Providers and commissioners who wish to achieve good patient outcomes will want to implement these measures.

- **Key Recommendation 12:** These interventions can deliver immediate benefits to patients as well as supporting improvements in care further down the survivorship pathway.

- **Key Recommendation 13:** Re-allocate any cost efficiencies, achieved through follow-up, to other areas of the survivorship pathway, such as assessment and care planning, or community support.
2. What does Best Practice in cancer survivorship look like?

In terms of the timeframe for a future survivorship pathway, there seems to be a differing of opinion with many authors indicating a period of ‘5 years from the date of initial diagnosis’ was considered important, while two clinicians believed survivorship could be defined by the individual patient,(Pearson, 2013). For this project it will therefore be important to consider how long it is felt that support can be effectively offered.

The NCSI vision to enable survivors to lead long and healthy lives after treatment, proposed that by 2012 all cancer survivors should have (DH et al 2010):

- A personalised assessment and care plan
- Support to self-manage their condition
- Information on long-term effects
- Access to specialist medical care

In terms of the pathway, Griffith et al (2010) names four essential components of survivorship care:

1) Preventive measures to reduce the risk of recurrence, new cancers, and late effects of treatment;
2) Surveillance for cancer progression, recurrence, new cancers, and late effects;
3) Intervention to address medical and psychosocial effects of cancer therapy;
4) Coordination among cancer specialists and primary care providers (PCPs), including physicians, nurses, and other health care professionals.

Building on the above DH et al, (2013) stated that ensuring holistic assessment and care planning are a routine part of every patient’s pathway is important and in particular that all patients are offered a Treatment Summary. The Treatment Summary should include the READ codes that inform the GP IT systems that the patient had cancer, their treatment and whether they are at risk of developing other conditions, such as cardiac disease, osteoporosis and diabetes. As well as the option to access Health and Wellbeing Clinics and other patient and education events as a way of raising awareness of the support available and enabling patients to engage with these services. Finally, Holistic Needs Assessments should take place at or near diagnosis, and at the end of treatment. The cost of this proactive care planning will be offset by reduced unplanned contact, as it ensures that patients have appropriate information and a clear management plan.

3. What should be included in the pathway?

This section considers some of the key elements which the literature highlights would be best practice for inclusion within a pathway. Below is further detail of each:
Rehabilitation and supported care
Whilst general support, education, financial assistance or advocacy during or after treatment may benefit some people. For individuals with more complex needs individual rehabilitation has been found to be effective (Fitch, 2000). Different rehabilitation services are required at different times and intensities to address the range of impairments following cancer treatment (Thorsen et al. 2011).

Needs assessment /review for holistic needs and functionality
Purposive screening for needs is as important as medical reviews with the oncologist focusing on disease surveillance not function, functional problems are not generally documented or recognised by oncologists, this issue was raised by survivors (Pearson et al, 2013).

Locations of services
There is evidence that community based programmes combining exercise and psychological education have been successful. This calls into question if this project should consider commissioning services outside of the acute hospital environment.

As cancer survivors are living longer they are spending more time in the community and requiring more support from their GP. Primary care has an important role to play in meeting the needs of people living with and beyond cancer. This might include providing ongoing treatment. For example, men on ongoing hormone therapy for prostate cancer often receive their treatment at their local GP practice. The Quality and Outcomes framework for primary care includes incentives for GP’s to invite patients for a review appointment within six months of diagnosis of cancer. This cancer care review enables GPs to understand the need of cancer survivors and carers and provide information and support. In the future GP’s will play a pivotal role in cancer survivorship and will need to be able to identify signs of reoccurrence or the consequences of treatment and refer and support patients and carers appropriately. However it is also important to recognise that GP’s are unlikely to have experience in assessment or managing the side effects of a wide variety of treatments.

Involvement of social care
A range of care and support is provided by local authorities for cancer survivors. Research for Macmillan cancer support has described the social care needs of people with cancer and their carers, which can include help with daily chores during treatment, formal domiciliary care, formal respite care, home adaptions and benefits assessment. The voluntary sector also provide services to support.

Friends, Family and Carers (Miller, 2014)
As part of the survivorship pathway one paper recommends also considering the needs and feelings of the patient’s family. Moreover cancer affects the patients and patient’s family. A patient’s partner, for example, tends to experience as much distress and uncertainty as the patient him/herself. Because patients and partners are often interdependent in their adjustment to cancer, the partner’s well-being can greatly affect the patient’s well-being.
Health and social care
Social care funding has been cut by up to 40% in some areas and the NHS is facing a £30 billion overspend by 2020. It is already apparent the effect this is having with decreased care packages to support people in the final stages of illness to stay at home. When asked approximately 80% of people say they would like to die at home, yet only just over 20% do so. We know that people must make End of Life care plans, only 10% die in hospital. However, there is an increasing recognition that people with cancer may have a range of broader social care needs, including help with activities of daily living (Macmillan Cancer Support, 2010). These needs may encompass a variety of services and may be both short-term (for example a home adaptation to assist with daily living) and long-term (for example admission to long-term residential or nursing care).

The Compassionate Cities is all about developing community capacity and resilience at the end of life. A public health community development approach increases the capacity of communities to care for the dying themselves and reduces burden on professional services. The challenges to this for communities supporting people at the end of life into bereavement have similarities with supporting people with ill health, but different in that the effort that is needed is time limited. This can make it easier for people to give commitment to support. In addition there is a significant role in using the expertise of those people who have been a carer and have become bereaved, as a guide and support to those who become patients and carers.

Uncertainty in pathway/process
For many individuals, managing information is used as a means of coping with illness-related uncertainty. In-depth interviews with 60 cancer patients were conducted. Many of the participants in this study reported feeling uncertain about the challenge awaiting them in cancer survivorship and reported experiencing various information behaviours and challenges relates to their uncertainty management. Long term cancer survivors and their partners may experience uncertainty relating to reoccurrence, physical changes, financial burdens and newfound relational challenges. One way individuals can cope with this uncertainty is by managing illness-related information. This supports the idea of supported self-management and providing a detailed cancer care review or holistic needs assessment.

Risk stratified care
The NCSI suggest that the transformed pathway of care for cancer survivors should be based on a model of care for people with long term conditions. A stratification process should be used to help to identify which care pathway is most suitable for each patient. This should be done the clinical team and the person living with cancer making a decision about the best form of aftercare based on their knowledge of the disease (the type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short and long term) and the person (whether they have other illnesses or conditions, and how much support they feel they need). Supporting patients to self-manage their own health and wellbeing can meet unmet needs and reduce demand on services, where appropriate.
They go onto suggest that this can be done in the following ways:

- Stratifying patients to an appropriate pathway based on clinical and individual needs.
- Organising needs assessments and care plan reviews at key points in the pathway – for example, at the end of treatment or when problems arise.
- Providing a treatment summary that is a succinct record of diagnosis, treatments, potential side effects of treatment, contact details and other key information.
- Improving access to clinical and non-clinical support services.
- Offering advice on health and wellbeing, and signposting to local support services – for example, walking groups, support groups, stop smoking groups, etc.
- Ensuring that, for those suitable for a self-management pathway at the end of treatment, surveillance tests will continue to be scheduled and monitored by the specialist team and, according to NICE standards, remote monitoring systems continue to be used with results sent by post without the need for face-to-face follow-up appointments.

Fig 1: The three forms of aftercare the risk stratification model
Based on fig 1, below is a greater explanation of the three forms of aftercare models:

1. **Self-care support with open access**
   This should be for the vast majority of patients where they access supported self-management. This is when patients are given information about self-management support programmes or other types of available support, clinical signs and symptoms to look out for and whom to contact if they notice any, scheduled tests they may need (such as annual mammograms), and how to contact relevant professionals if they have any concerns.

2. **Shared care (Evaluation of Macmillan’s cancer care review template)**
   Shared care – when patients continue to have face-to-face, phone or email contact with professionals as part of continuing follow-up. This can be part of a cancer care review (CCR) which is initiated by the GP, it acts as a review of the patients and a holistic needs assessment combined. The CCR needs to be a holistic broad-based discussion, taking into account co-morbidities and the social, psychological and practical aspects of disease, rather than just the medical and physical. The cancer care review can also be seen as a platform to trigger further discussions, eg supporting secondary prevention through advice about healthy lifestyle and physical activity.

3. **Complex ongoing care in hospital**
   For some patients with complex requirements complex case management will be required. In these cases patients are given intensive support to manage their cancer and/or other conditions.

   By commissioning services in this way it argued that there will be a resulting release of resources by moving away from the traditional follow up approach for everyone. This allows those with complex needs to have more contact with their specialist team and those experiencing problems to re-access help more quickly. This change in approach has been broadly welcomed by clinicians and patient groups alike who are enthusiastic in taking the initiative forward and developing similar pathways for other types of cancer.

The following recommendations (14-17) were made by Dorothy Goddard (Clinical lead of the South West Cancer Clinical Network) at an event on Best Practice in Cancer Pathways.

- **Key Recommendation 14:** Support through primary treatment from diagnosis

- **Key Recommendation 15:** Promote recovery, tailored package of care – end of treatment summary replace discharge letter clues look for etc (holistic needs assessment). If survivors exercise 3 times a week, changes of cancer reoccuring decrease by 50%.
- **Key Recommendation 16:** Sustain reduce burden of long term consequences of treatment – open access back to specialist service. Replace routine follow up clinic with self-supported management, with remote monitoring/PSA/blood monitoring. With this it is important to have an effective IT system.

- **Key Recommendation 17:** Support patient with acute advance metastatic disease. MDT decides which part of model you start in.

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**Fig 2:** A diagram representing Macmillan’s recovery package, each part of the Recovery Package is designed to work together to inform the overall care pathway.
The Recovery Package Explained
The recovery package includes:

**Holistic Needs Assessment (NCAT 2010)**
Holistic Needs Assessment: It is a means of ensuring that the person’s concerns or problems are in the first place identified so that attempts can be made to address them. It supports the broader aim of ensuring personalised care that reflects an individual’s health and care needs. An assessment is not a ‘one-off’ process and should continue through the patient journey into survivorship or end of life care pathways. There will be a requirement, incorporated into the peer review measures, to provide evidence that holistic needs assessment is being undertaken.

The recommendation is that this is carried out at two key points in the care pathway, firstly at or near diagnosis and then at the end of treatment and again whenever health and social needs change, resulting in a written Care Plan outlining the actions to be taken to address identified needs. The assessment identifies the individual needs of the person affected by cancer and contributes to a consultation. The consultation can then be focused on the needs identified, a care plan can be developed and an appropriate referral can be made to services that support patients, such as lymphoedema, psychological and services dealing with the consequences of treatment. This ensures that care is proactive and support services are planned and accessed appropriately. The assessment can be used to inform the treatment summary. The patient receives a copy of the care plan to enable self-management; further copies are stored in the medical records and can be sent to the GP.

The psychological effects of a cancer diagnosis are often felt long after treatment has finished. Many of these issues are identified too late to prevent costly interventions and unnecessary use of health services. With timely, effective support many psychological problems can be dealt with in a more cost effective manner or avoided altogether (Macmillan 2011).

**The Treatment Summary**
The treatment plan and summary templates were developed to help improve documentation and coordination of cancer treatment and survivorship care. They are intended to facilitate provider-to-provider and provider-to-patient communication - the templates may be distributed to patients or providers as records of the care planned and received. Importantly, the treatment plan and summary are not intended to replace detailed chart documentation, including complete patient histories.

This should be developed by the multidisciplinary team to inform the patient and the GP of the care and treatment received (NCSI 2012). The summary includes possible treatment toxicities and /or late effects, alert symptoms that require referral back to a specialist team, an ongoing management plan, and a summary of information given to the patient about their cancer and future progress and any required GP actions to support the patient. Late effects are caused by the damage that cancer treatment does to healthy cells in the body. Most late effects are caused by chemotherapy or radiation. Major surgery can also lead to late effects.
The Treatment Summary should be able to inform the GP database as well as being used to inform the Cancer Care Review. The patient should receive a copy to share with other family members and health care providers. Further copies should be stored in the medical records and inform emergency/unplanned admissions.

**Cancer Care Review (CCR)**
The Quality and Outcomes Framework (QOF) requires all patients diagnosed with cancer to receive a CCR by their GP within **six months** of the GP practice being notified that the person has a cancer diagnosis (Macmillan 2012). A CCR is about the GP having a conversation with the patient to get a sense of their understanding of their diagnosis, answer any queries and assess support needs. The review should include post-treatment support, financial impact of cancer, patient awareness of prescription exemptions, possible late effects of cancer and cancer treatment and the information needs to enable self-management.

**Health and Wellbeing clinics**
The clinics are designed to be education events to give the person affected by cancer all the information they need to enable rehabilitation and self-management. This may include the opportunity for advice about work or finance, physical activity and local services that offer help and support for people living with a long term condition.

4. **What do cancer survivorship pathways look like in other regions/countries?**
Building on the last 3 sections of this document, this section seeks to consider what is already happening across the world around survivorship pathways to help in the development of the local pathway for Bristol CCG.

**UK - End of treatment clinic- Breast Cancer**
In 2009 staff in cancer services at Guy’s and St Thomas' NHS Foundation Trust (GSTT) initiated a number of projects to develop an alternative model of care. This study evaluated the development and delivery of a nurse-led end of treatment consultation clinic for women who have completed treatment for early breast cancer. The consultation focuses on ongoing physical and psychosocial concerns and plans for follow-up care and surveillance, lifestyle advice and optional survivorship programmes. It was to be held once a week at a time when no other clinics were running to ensure that nurses did not have competing demands. The clinic is staffed by the nurse consultant and advanced nurse practitioners – experienced breast cancer nurses who have completed advanced assessment and communication skills training. As the project developed it became clear that there are core topics that need to be addressed with women at this time. These include ongoing physical and psychological concerns, plans for follow-up and imaging, and discussion of risk of recurrence and signs and symptoms to report to the clinical team. Advice on health promotion and lifestyle issues is provided where relevant, and these cover areas such as smoking, diet, exercise, weight management.
The clinic included the following:

- A 45-minute consultation with an experienced cancer nurse.
- Holistic needs assessment – this was requested to be completed before their appointment.
- A care plan is developed that is shared with the patient and their GP.
- A dedicated telephone advice service called “Surviving Cancer-Living Life” – this which provided information and ongoing support to patients who had completed treatment for breast and prostate cancer.

One development of the project at Guys and St Thomas was the HNA becoming digitalised on an Ipad, this worked very well it ensured that the information was already entered when they arrive at the clinic; saving time.

**Internationally tiered model of care**

![The Tiered Model of Supportive Care](image)


Fig 2: A model adapted from Fitch, 2000
http://www.supportivecancercarevictoria.org/PublicPages/SupCareModel.html)

A model for cancer supportive care that has informed recent policy in Victoria, Australia was developed by Fitch in 2000. It recognises that people with a cancer diagnosis have differing needs and while ‘all’ require information, only a ‘few’ need highly specialised interventions. Cancer has a powerful emotional impact on patients and their families throughout the continuum of diagnosis, treatment and survival, and palliative care. Cancer care should not be a ‘one size fits all’ service – matching resources and services to the needs of patients and families makes for effective use of resources and is likely to promote optimal adjustment of patients and their families. The tiered model of care provides a link between evidence based clinical guidelines and actual clinical practice, and between community and acute care settings. (care forum 2006)
4. **What are the key sources for analysis information on cancer survivorship?**

The amount of literature available on cancer survivorship is vast with a huge array of disease specific papers. Many of those reviewed for this document, tended to focus on the changing of secondary care interventions but this may be due to the lag in time between making changes and research being published.

Below is a list of the sources used to inform this document. Should there be a desire to look at any other papers in greater detail then additional literature searches can be done from this paper.

One area which has already been identified for a separate paper is methodologies of evaluation for the pathway and work is underway to develop this paper to help inform the business case which is due in May 2015.
List of Sources


Improving Supportive and Palliative Care for Adults with Cancer. (n.d.).

Macmillan, Evaluations of Macmillans Cancer Review Template.


Shewbridge A, Wiseman T, Richardson A (2012) Working while receiving chemotherapy: a survey of patients’ experiences and factors that influence these. European Journal of Cancer Care. 21, 1, 117-123.


**Summary and Recommendations**

The National Cancer Survivorship Initiative (NCSI) was introduced in 2007 the main focus was diagnosing and treating cancers. However one of the underlying aims of the initiative was to enable cancer survivors to live a long and healthy life as possible. Cancer survival rates are increasing; current research has focused on the effect of diagnosis and treatment on individuals’ quality of life after completion of treatment and its ongoing consequences. In the UK there is a limited knowledge of the needs of cancer survivors and whether there is the infrastructure in place to meet these needs. Bristol CCG needs to consider commissioning and providing the right support based on need in order to continue to improve the rate of survivorship as well as quality of life and patient experience.

This paper would like to highlight the following points and recommendations to Bristol CCG.

- Early intervention with rehabilitation can minimise the level of disability and the effects of cancer treatment and continued access to rehabilitation throughout the cancer pathway supports the patients as they undergo treatment.

- NICE guidelines (2004) state that the following is fundamental to the rehabilitation package:
  - An early assessment of need
  - Co-ordination of ongoing assessment
  - A co-ordinated multi-disciplinary approach to care
  - Care provided by a competent, trained workforce

- The NCSI vision to enable survivors to lead long and healthy lives after treatment, proposed that by 2012 all cancer survivors should have (DH et al 2010):
  - A personalised assessment and care plan
  - Support to self-manage their condition
  - Information on long-term effects
  - Access to specialist medical care

- In terms of the pathway, Griffith et al (2010) names four essential components of survivorship care:
  1) Preventive measures to reduce the risk of recurrence, new cancers, and late effects of treatment;
  2) Surveillance for cancer progression, recurrence, new cancers, and late effects;
3) Intervention to address medical and psychosocial effects of cancer therapy;
4) Coordination among cancer specialists and primary care providers (PCPs), including physicians, nurses, and other health care professionals

**Recommended elements to incorporate into the pathway**

**Holistic Needs Assessment (NCAT 2010)**
Holistic Needs Assessment: It is a means of ensuring that the person’s concerns or problems are in the first place identified so that attempts can be made to address them. It supports the broader aim of ensuring personalised care that reflects an individual’s health and care needs. An assessment is not a ‘one-off’ process and should continue through the patient journey into survivorship or end of life care pathways. There will be a requirement, incorporated into the peer review measures, to provide evidence that holistic needs assessment is being undertaken. The recommendation is that this is carried out at two key points in the care pathway, firstly at or near diagnosis and then at the end of treatment and again whenever health and social needs change, resulting in a written Care Plan outlining the actions to be taken to address identified needs. The assessment identifies the individual needs of the person affected by cancer and contributes to a consultation.

**The Treatment Summary**
The treatment plan and summary templates were developed to help improve documentation and coordination of cancer treatment and survivorship care. They are intended to facilitate provider-to-provider and provider-to-patient communication - the templates may be distributed to patients or providers as records of the care planned and received. Importantly, the treatment plan and summary are not intended to replace detailed chart documentation, including complete patient histories. This should be developed by the multidisciplinary team to inform the patient and the GP of the care and treatment received (NCSI 2012).

**Cancer Care Review (CCR)**
The Quality and Outcomes Framework (QOF) requires all patients diagnosed with cancer to receive a CCR by their GP within **six months** of the GP practice being notified that the person has a cancer diagnosis (Macmillan 2012). A CCR is about the GP having a conversation with the patient to get a sense of their understanding of their diagnosis, answer any queries and assess support needs. The review should include post-treatment support financial impact of cancer, patient awareness of prescription exemptions, possible late effects of cancer and cancer treatment and the information needs to enable self-management.
**End of treatment clinic- Breast Cancer**

This study evaluated the development and delivery of a nurse-led end of treatment consultation clinic for women who have completed treatment for early breast cancer.

The clinic included the following:

- A 45-minute consultation with an experienced cancer nurse.
- Holistic needs assessment – this was requested to be completed before their appointment.
- A care plan is developed that is shared with the patient and their GP.
- A dedicated telephone advice service called “Surviving Cancer-Living Life” – this which provided information and ongoing support to patients who had completed treatment for breast and prostate cancer.
Appendix

Appendix 1: Key recommendations from NICE Guidance on Cancer Services
Improving Supportive and Palliative Care for Adults with Cancer. The Manual (2004)

- Communicating significant news should normally be undertaken by a senior clinician who has received advanced level training and is assessed as being an effective communicator. As this is not always practical, all staff should be able to respond appropriately to patients’ and carers’ questions in the first instance before referring to a senior colleague.

- The outcome of consultations in which key information is discussed should be recorded in patients’ notes and communicated to other professionals involved in their care. Patients should be offered a permanent record of important points relating to the consultation.

- Commissioners and provider organisations should ensure that patients and carers have easy access to a range of high quality information materials about cancer and cancer services. These materials should be free at the point of delivery and patients should be offered appropriate help to understand them within the context of their own circumstances.

- Policies should be developed at local (Cancer Network/provider organisation/team) level detailing the information materials to be routinely offered at different stages to patients with particular concerns. These policies should be based on mapping exercises involving service users.

- Mechanisms need to be implemented within each locality to ensure that medical and nursing services are available for patients with advanced cancer on a 24-hour, seven days a week basis, and that equipment can be provided without undue delay. Those providing generalist medical and nursing services should have access to specialist advice at all times.

- Primary care teams should institute mechanisms to ensure that the needs of patients with advanced cancer are assessed, and that the information is communicated within the team and with other professionals as appropriate. The Gold Standards Framework provides one mechanism for achieving this.

- In all locations, the particular needs of patients who are dying from cancer should be identified and addressed. The Liverpool Care Pathway for the Dying Patient provides one mechanism for achieving this.
Commissioners and providers, working through Cancer Networks, should ensure they have an appropriate range and volume of specialist palliative care services to meet the needs of the local population, based on local calculations. These services should, as a minimum, include specialist palliative care in-patient facilities and hospital and community teams. Specialist palliative care advice should be available on a 24 hour, seven days a week basis. Community teams should be able to provide support to patients in their own homes, community hospitals and care homes.

Provider organisations should nominate a lead person to oversee the development and implementation of services that specifically focus on the needs of families and carers during the patient’s life and in bereavement, and which reflect cultural sensitivities.

Cancer Networks should work closely with Workforce Development Confederations (the Workforce Development Steering Group in Wales) to determine and meet workforce requirements and to ensure education and training programmes are available.

Provider organisations should identify staff who may benefit from training and should facilitate their participation in training and ongoing development. Individual practitioners should ensure they have the knowledge and skills required for the roles they undertake.

Assessment and discussion of patients’ needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as at diagnosis; at commencement, during, and at the end of treatment; at relapse; and when death is approaching). Cancer Networks should ensure that a unified approach to assessing and recording patients’ needs is adopted, and that professionals carry out assessments in partnership with patients and carers.

Each multidisciplinary team or service should implement processes to ensure effective inter-professional communication within teams and between them and other service providers with whom the patient has contact. Mechanisms should be developed to promote continuity of care, which might include the nomination of a person to take on the role of ‘key worker’ for individual patients.

Mechanisms should be in place to ensure the views of patients and carers are taken into account in developing and evaluating cancer and palliative care services. Cancer Partnership Groups provide one potential mechanism. Systems should be devised to support patients and carers to participate in
their own care, featuring a range of informal support opportunities such as self-help activities and peer support schemes within community settings.

- Commissioners and providers of cancer services, working through Cancer Networks, should ensure that all patients undergo systematic psychological assessment at key points and have access to appropriate psychological support. A four-level model of professional psychological assessment and intervention is suggested to achieve this.

- Explicit partnership arrangements should be agreed between local health and social care services and the voluntary sector to ensure that the needs of patients with cancer and their carers are met in a timely fashion and that different components of social support are accessible from all locations.

- Patients and carers should have access to staff who are sensitive to their spiritual needs. Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual care givers who can act as a resource for patients, carers and staff. They should also be aware of local community resources for spiritual care.

- Commissioners and providers, working through Cancer Networks, should institute mechanisms to ensure that patients’ needs for rehabilitation are recognised and that comprehensive rehabilitation services and suitable equipment are available to patients in all care locations. A four-level model for rehabilitation services is the suggested model for achieving this.

- Commissioners and NHS and voluntary sector providers should work in partnership across a Cancer Network to decide how best to meet the needs of patients for complementary therapies where there is evidence to support their use. As a minimum, high quality information should be made available to patients about complementary 1213 therapies and services. Provider organisations should ensure that any practitioner delivering complementary therapies in NHS settings conforms to policies designed to ensure best practice agreed by the Cancer Network.

- Within each Cancer Network, commissioners and providers (statutory and voluntary) of cancer and palliative care services, working with service users, should oversee the development of services in line with the recommendations of this Guidance. Key personnel will need to be identified to take this forward.
Appendix 2 - A list of all the recommendations this paper makes to Bristol CCG.

- Key Recommendation 1: Access - a timely and responsive service with agreed assessment triggers for referral, including provision of equipment.

- Key Recommendation 2: Planning - patients receiving an active and planned approach to rehabilitation that involves assessment, goal setting, care planning and evaluation.

- Key Recommendation 3: Responsive - prompt referral for those patients who might benefit from rehabilitation specialists.

- Key Recommendation 4: Integrated - a seamless service with good planning processes and systems delivered in an appropriate setting, but aligned with generalist service with links to community support groups.

- Key Recommendation 5: Workforce - teams made up of the right mixture of specialist and general staff (MDT) with clear support/training structures and professional standards to deliver service interventions at the right levels (1-4).

- Key Recommendation 6: Quality - delivering evidence based care using clearly defined patient pathways that are tumour specific, with clear intervention routes, alignment to clinical/national pathways and appropriate entry points for patients (recognition of trigger factors). These ought to be compliant with the Improving Outcomes Guidance.

- Key Recommendation 7: Patient Focused - focus on prevention of long term effects, better patient experience where all patients have their needs for rehabilitation services assessed throughout the patient pathway.

- Key Recommendation 8: Communication - good communication with readily available access to patient information at all stages.

- Key Recommendation 9: Fundamental to the rehabilitation package is: (NICE, 2004)
  - An early assessment of need
  - Co-ordination of ongoing assessment
  - A co-ordinated multi-disciplinary approach to care
  - Care provided by a competent, trained workforce
Key Recommendation 10: Patients' wellbeing will be greater and their demand for services lower if they get the support that is relevant to their particular needs, and which promotes healthy lifestyles and independence.

Key Recommendation 11: The 'recovery package': a combination of assessment and care planning, Treatment Summary, and a patient education and support event (Health and Wellbeing Clinic) is potentially the most important building block for achieving good outcomes. Providers and commissioners who wish to achieve good patient outcomes will want to implement these measures.

Key Recommendation 12: These interventions can deliver immediate benefits to patients as well as supporting improvements in care further down the survivorship pathway.

Key Recommendation 13: Re-allocate any cost efficiencies, achieved through follow-up, to other areas of the survivorship pathway, such as assessment and care planning, or community support.

Key Recommendation 14: Support through primary treatment from diagnosis

Key Recommendation 15: Promote recovery, tailored package of care – end of treatment summary replace discharge letter clues look for etc (holistic needs assessment). If survivors exercise 3 times a week, changes of cancer reoccurring decrease by 50%.

Key Recommendation 16: Sustain reduce burden of long term consequences of treatment – open access back to specialist service. Replace routine follow up clinic with self-supported management, with remote monitoring/PSA/blood monitoring. With this it is important to have an effective IT system.

Key Recommendation 17: Support patient with acute advance metastatic disease. MDT decides which part of model you start in.