Living with and Beyond Cancer

CCG information Pack 2016

East Sussex locality

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Executive Summary

Cancer survival is at its highest ever, with significant improvements made over the last 15 years. The number of people living with cancer in the UK has risen by 400,000 in the last five years - taking the total number of people living with cancer in the UK to 2.5 million. More than half of people receiving a cancer diagnosis will now live ten years or more. This progress has been driven by improvements in our knowledge of how to treat and control cancer, combined with the commitment of NHS staff to deliver transformative care. We need to make sure that we don’t just help more people to live following a cancer diagnosis, but to live well.

Achieving World-class Cancer Outcomes, A Strategy for England 2015-2020, (Independent Cancer Taskforce, July 2015) emphasises the importance of taking a whole person, whole pathway approach to the commissioning and provision of cancer services, and highlights the need to improve quality of life for people living with and beyond cancer as a key component of that. This was reiterated by the Secretary of State in September 2015 in his statement of support for the new strategy, in which he committed to ensuring that every cancer patient receives the interventions known as the ‘Recovery Package’.

(NHS England, April 2016)

About this document…

The following document is an update for CCGs, based on the 2015 South East Coast, Cancer SCN audit and reports (Hugason-Briem, May 2015) and assumes that the aim of all NHS organisations is to achieve full roll out of the Recovery Package by 2020, as stated in the Taskforce Strategy (Independent Cancer Taskforce, July 2015) and supported by NHS England (NHS England, April 2016).

The document will address 3 things:

1) An update of what is currently happening in individual areas of the South East
2) What needs to be done to achieve full implementation of the Recovery Package
3) The wider aspects of Living with and beyond cancer as directed by the National documents stated above ie Stratified pathways of care.

This document is one of a series, covering the following geographical areas:

- Brighton and Hove
- West Sussex
- East Sussex
- Surrey
- North Kent
- West Kent
- East Kent

Please note: Although the SE CN spoke to all of the organisations based in this area it was not possible to do a full audit with the East Sussex CCGs or BSUH. However, as information becomes available in these areas the document will be updated accordingly.
Introduction

In Oct 2014 NHS England published its Five Year Forward View. As part of this document there was specific mention of Cancer and in particular reference to the Cancer Recovery Package.

We will also 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. 

(NHS England, Oct 2014)


ACHIEVING WORLD-CLASS CANCER OUTCOMES
A STRATEGY FOR ENGLAND 2015-2020

7.3 COMMISSIONING SERVICES FOR PEOPLE LIVING WITH AND BEYOND CANCER

Better support for people after treatment can deliver significant benefits in terms of improved quality of life. It can also encourage behaviours that are more likely to prevent recurrence or acute presentations back to the health service with late consequences of treatment. For example, there is strong evidence that patients who are encouraged to undertake a programme of physical activity post-treatment suffer from reduced levels of fatigue and have overall higher quality of life, across a range of cancer types. However, most patients are not given advice on exercise, and they need to be supported to make lifestyle changes.

Some progress has been made in developing interventions to support people living with and beyond cancer. But much more needs to be done. The National Cancer Survivorship Initiative (NCSI), which ran from 2008 to 2013, developed a case for change and identified priority areas for focus. The Living With and Beyond Cancer Programme (a two year programme of work) has taken this forward, seeking to embed these priority areas into commissioning and practice. We now need to accelerate the pace of change across the health and social care system, by strengthening national and local leadership, setting national service specifications and rolling out tested solutions.

The Recovery Package is a combination of different interventions, which when delivered together, can greatly improve the outcomes and coordination of care, including better and earlier identification of consequences of treatment. It has been developed and tested through the NCSI to assist people living with a diagnosis of cancer to prepare for the future, identify their individual needs and support them to live well after treatment.

Recommendation 65: 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. In addition, NHS England should work with NICE to develop a guideline, by mid 2016, for a minimum
service specification, building on the Recovery Package, thereafter to be commissioned locally for all patients, together with a suite of metrics to monitor performance. This specification would be expected to evolve over time, as resources permit.

Initially this specification could include the following elements:

- A holistic needs assessment and a written individualised care and support plan at key points across the pathway. The patient should agreed with and own this plan which should be shared with their GP or other designated local healthcare professional. It should take in to account social circumstances, mental health needs, and any co-morbidities.
- Information on likely side-effects of treatment and how best to manage these, including those that might appear after some months/years.
- Potential markers of recurrence/secondary cancers and information on what to do in these circumstances.
- Key contact point for rapid re-entry if recurrence markers are experienced or if serious side effects become apparent.
- A cancer care review to discuss ongoing needs and completed by the patient’s GP or practice nurse.
- A treatment summary completed at the end of every phase of acute treatment, sent to the patient and their GP.
- Access to a patient education and support event, such as a Health and Wellbeing Clinic, to prepare the person for the transition to supported self-management, including advice on healthy lifestyle and physical activity.
- Signposting to rehabilitation, work and financial support services.

Children, teenagers and young adults have specific post-treatment requirements which overlap with but may be different to adults. These need to be appropriately commissioned and delivered. Transition points are often particularly poorly managed, not least as treatment can often be delivered a long way from home. Age-specific support will need to be determined for these patients, and some specific psychosocial and/or keyworker services maybe provided by specialist charities, for example, Clic Sargent or Teenage Cancer Trust. NHS England should ask the CTYA CRG to feed into the NICE guideline living with and beyond service requirements for the CTYA populations.

(Independent Cancer Taskforce, July 2015)
Since then there have been a number of responses to the Cancer Taskforce Report by NHS England. Included in this, in addition to the recovery package, is stratified pathways – a different approach to traditional follow up of patients by supporting self-management, where appropriate.

**NHS England, April 2016, Implementing the cancer taskforce recommendations: commissioning person centred care for people affected by cancer** which states that its purpose is to “support commissioners and strategic clinical networks to ensure every person affected by cancer will have access to the Recovery Package and stratified follow-up pathways (specifically breast, colorectal and prostate) by 2020, as set out in the cancer strategy.”

And furthermore a commitment to transform the approach to living with and beyond cancer and the promise of a measurement, which can be used to assess this and this will be done through the newly formed Cancer Alliances.

**NHS England, May 2016, Achieving World-Class Cancer Outcomes: Taking the strategy forward**

Clinical leaders and patients will drive improvements in care and support for people living with and beyond cancer through Cancer Alliances.

We know that risk stratified follow-up pathways for breast cancer patients can not only improve care for patients after treatment, but create more efficient pathways in the NHS that can, for example, reduce unnecessary outpatient appointments. Through Cancer Alliances, we will support the spread of these pathways throughout the NHS and assess the role of commissioning incentives to drive implementation.

We will work with Macmillan Cancer Support to agree an approach by March 2017 for collecting data on long-term quality of life so that it can be included in the Cancer Dashboard, with the aim that this will start conversations locally through Cancer Alliances about their performance and focus activity on better structuring pathways and services with patients to support their wider needs. Patient input into this work will be crucial.

**Operational Planning 2017-19**

In September 2016, as part of routine CCG planning, NHS England and NHS Improvement published the 2017-2019 NHS Operating Planning and Contracting Guidance. As well as other priority work streams the document also outlines requirements relating to the delivery of the recovery package and stratified pathways as a “must do”.

The following table is extracted from that document.
Cancer services transformation planning requirements

<table>
<thead>
<tr>
<th>2017/18</th>
<th>2018/19</th>
<th>Metrics</th>
</tr>
</thead>
</table>
| Ensure all parts of the Recovery Package are available to all patients including: A. Ensure all patients have a holistic needs assessment and care plan at the point of diagnosis and at the end of treatment
B. Ensure that a treatment summary is sent to the patient’s GP at the end of treatment
C. Ensure that a cancer care review is completed by the GP within six months of a cancer diagnosis | Ensure all parts of the Recovery Package are available to all patients including: A. Ensure all patients have a holistic needs assessment and care plan at the point of diagnosis and at the end of treatment
B. Ensure that a treatment summary is sent to the patient’s GP at the end of treatment
C. Ensure that a cancer care review is completed by the GP within six months of a cancer diagnosis | Local data collection
Currently piloting collection of HNA data using COSD (PHE)
Developing national quality of life metric |
| Ensure all breast cancer patients have access to stratified follow up pathways of care and prepare to roll out for prostate and colorectal cancer patients | Ensure all breast, prostate and colorectal cancer patients have access to stratified follow up pathways of care | Local data collection
Exploring how data may be collected nationally
Developing national quality of life metric |
| Ensure all patients have access to a clinical nurse specialist or other key worker | Ensure all patients have access to a clinical nurse specialist or other key worker | CNS question in CPES (Q17 Cancer Patient Experience Survey, annual, NHS England Statistics) |
The Cancer Recovery Package

The Recovery Package (RP) has been developed and tested by the National Cancer Survivorship Initiative (NCSI) to assist people living with a diagnosis of cancer to prepare for the future, identify their individual needs and support rehabilitation to enable people to return to work and or a near normal lifestyle. The RP is a combination of different interventions, which when delivered together, have been shown to improve the outcomes and coordination of care for people living with and beyond cancer. The four elements are:

- **A Holistic Needs Assessment** at key points in the pathway including near diagnosis and at the end of treatment resulting in a written Care Plan outlining the actions to be taken to address identified needs which the patient.

- **A Treatment Summary** from the Hospital Team should inform the patient and GP about the care and treatment received possible treatment toxicities and/or late effects, and the ongoing management plan and any required actions to support the patient.

- **A Cancer Care Review** should be carried out by the patient’s GP practice six months after a diagnosis of cancer (previously three months post diagnosis). This should include post-treatment support and information to enable self-management.

- **A patient education and support event**, such as a Health and Wellbeing Clinic, to prepare the person for the transition to supported self-management, which will include advice on healthy lifestyle and physical activity.

The main benefits of the RP were defined by Macmillan in *The Recovery Package, Sharing Good Practice*, Summer 2014 as:

- A more systematic and proactive approach to cancer care and rehabilitation to aid recovery. This will improve outcomes for cancer survivors, reduce inappropriate use of hospitals and enable people to live a health and active life.

- More emphasis on empowering people to manage their own care by giving them the appropriate information and support to do so.

- A shift in focus from a standard ‘one size fits all’ approach to one where follow-up care is truly patient-centred and where clinical, psychosocial and...
practical needs are assessed and managed effectively. This proactive approach will help improve patient experience, avoid unnecessary appointments and avoid unplanned admissions. Achieving this balance between quality and cost is a key consideration for both commissioners and providers.

- A more integrated model of care, through a better coordinated approach to shared documentation and improved information-giving between secondary, primary and community care and the person with cancer.

(Macmillan Cancer Support, 2015)

**Please note** the Recovery Package is not directly linked to the Enhanced Recovery Programme.

The enhanced recovery programme improves patient outcomes and speeds up a patient's recovery after surgery. - See more at: http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/enhanced_recovery_programme.html#sthash.lXwPxpKW.dpuf

Although, in cancer, the two can be related and could overlap and it would be easy to mistake their titles, however, they are two very different programmes. For example the enhancing recovery programme can be used in all disease groups that have a
The “Macmillan Recovery Package” is the name given to a combination of different interventions, which when delivered together, will greatly improve the outcomes and coordination of care for people [specifically] living with and beyond cancer.
Stratified Pathways

Stratified follow-up pathways comprise needs assessment, support for patients to self-manage, remote monitoring and re-entry pathways. This can offer a more effective approach to after-care than traditional medical models of follow-up. More tailored care in this phase has the potential to reduce costs through reducing recurrences, better managing side-effects, improving patient satisfaction and supporting people to live well. All pathways are suitable for stratification; however the National Cancer Strategy (Independent Cancer Taskforce, July 2015) suggests a primary focus on breast, colorectal and prostate.

In general, individuals deemed at low risk of recurrence and late effects (physical and psychosocial), should be encouraged towards supported self-management, those at medium risk may receive planned coordinated care and those at high risk should receive complex care from specialist services. A system must be developed for rapid re-entry to the specialist cancer service as required.

(NHS England, April 2016)

The three forms of aftercare are:

- Supported Self Management – where patients are given the information about self management support programmes or other types of available support, the signs and symptoms to look out for and who to contact if they notice any, what scheduled tests they may need such as annual mammograms, and how they get in touch with professionals if they have any concerns.
- Shared Care – where patients continue to have face to face, phone or email contact with professionals as part of continuing follow up.
- Complex Case Management – where patients are given intensive support to manage their cancer and/or other conditions.

The diagram right illustrates the stratification process. Cancer patients will be treated according to which approach is most suitable, and the level of professional care (illustrated down the left hand side of the triangle) will vary accordingly.

Cancer survivors may move between these different options according to how their cancer and its treatment progresses and whether they are more able to manage their disease, or whether they need more help. The proportion of people in each option will vary depending on the tumour type.

(National Cancer Survivorship Initiative)

Resources you might find useful (links can be found on page 35):

- Innovation to implementation: Stratified pathways of care for people living with or beyond cancer- A “how to guide”
- Stratified pathways of care...from concept to innovation, NHS Improvement – Cancer, March 2012
Below are a list of suggested services for each of the pathways. Adapted from *Stratified pathways of care...from concept to innovation (NHS Innovation - Cancer, March 2012)*

<table>
<thead>
<tr>
<th>Service</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Prostate</th>
<th>Lung</th>
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<tbody>
<tr>
<td>Included at Staff induction</td>
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<tr>
<td>Care Planning</td>
<td></td>
<td>X</td>
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<tr>
<td>eHNA/HNA</td>
<td>X</td>
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<tr>
<td>Treatment Summaries</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Shared records between primary and secondary care</td>
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<tr>
<td>Supported Self Management</td>
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<tr>
<td>Timely re-access</td>
<td>X</td>
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<td>Annual Mammography until screening programme</td>
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<td>CEA, CT Scans colonoscopy per local protocol</td>
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<td>PSA Monitoring</td>
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<tr>
<td>Remote monitoring</td>
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<tr>
<td>Professional Led Follow up</td>
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<tr>
<td>Consultant Led (respiratory Oncology, thoracic)</td>
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<tr>
<td>Clinical Nurse Specialist Led</td>
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<tr>
<td>Telephone Led</td>
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<tr>
<td>Nurse specialist Led</td>
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<tr>
<td>Supportive and palliative Care</td>
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<tr>
<td>Telephone led</td>
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<tr>
<td>Specialist palliative Care led</td>
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<tr>
<td>Primary Care/community palliative Care led</td>
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<tr>
<td>Hospice Led</td>
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<td>Primary Care Led</td>
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<tr>
<td>Transition to End of Life</td>
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<tr>
<td>Psychological</td>
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<td>Continence/Stoma</td>
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<tr>
<td>Continence</td>
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<tr>
<td>Menopause Clinics</td>
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<td>Physiotherapy/occupational therapy</td>
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<tr>
<td>Physiotherapy/Breathlessness Clinics</td>
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<tr>
<td>Diet and Nutrition</td>
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<td>District Nursing</td>
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<tr>
<td>Sexuality/Body Image</td>
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<tr>
<td>Coping/Psychological</td>
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<tr>
<td>Erectile Dysfunction/sexuality</td>
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<tr>
<td>Occupational/Wheelchair Services</td>
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<td>Home Oxygen Services</td>
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<td>Lymphodema</td>
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<td>Education and Information</td>
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<tr>
<td>Self Management Programmes</td>
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<tr>
<td>Information Days</td>
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<tr>
<td>Information prescriptions</td>
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<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Physical Activity</td>
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<tr>
<td>Local Authority community or privately Led Exercise Schemes</td>
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<tr>
<td>Trust Led Exercise Programmes</td>
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<tr>
<td>Other Support Services</td>
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<tr>
<td>Reablement/social Care</td>
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<td>Finance and benefits</td>
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<tr>
<td>Vocational Rehab</td>
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<tr>
<td>Complimentary Therapies</td>
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<td>Voluntary sector /Support Groups</td>
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<tr>
<td>Legal Advice</td>
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</table>
Financial and non-financial levers and incentives

Finance remains one of the most tricky aspects of implementing post treatment care with resources being allocated according to competing priority. Consensus of opinion says that changes in the system from regular consultant follow-up which has a definite conclusion, to more nurse and self-led support is cost neutral or saves money whilst providing a better quality of support over an undetermined length of time.

Financial modelling references you might find interesting:


- London Transforming Cancer Services Team have commissioned an economic analysis for Prostate Cancer Follow up Services. This can be found here: [https://www.myhealth.london.nhs.uk/healthy-london/cancer/resources](https://www.myhealth.london.nhs.uk/healthy-london/cancer/resources) along with other commissioning documents that you might find interesting.

The following list adapted from NHS England gives a list of suggestions on financing options and incentives, although it is left to the individual organisation to the justification of priority for the workstream.

**Financial:**
- Using the contract to manage quality (NHS England Standard Contract 15/16);
- Quality premium
- Commissioning for Quality and Innovation (CQUIN)
- Quality Outcome Framework (QOF)
- Best practice tariffs (BPT)
- National and local enhanced service schemes.

**Non-financial:**
- CCG outcomes indicator set
- Commissioning for value / pathways on a page

Abbreviated from (NHS England, April 2016)

The CN will continue to share examples, via the CAG, of innovative commissioning, contracting financing and justification of these schemes.
National Cancer Dashboard

Public Health England and NHS England have been developing a National Cancer dashboard which can be accessed by all, without registration. This dashboard will eventually contain a Quality of Life marker, which is in development.

You can find the dashboard here:
https://www.cancerdata.nhs.uk/dashboard/#?tab=Overview

Sustainability and Transformation Plan (STP)

In December 2015, the NHS outlined a new approach to help ensure that health and care services are built around the needs of local populations. To do this, every health and care system in England will produce a multi-year Sustainability and Transformation Plan (STP), showing how local services will evolve and become sustainable over the next five years – ultimately delivering the Five Year Forward View vision of better health, better patient care and improved NHS efficiency. (NHS England, 2016).

Feeding into this STP will be the work of Cancer Alliances.

Cancer Alliances

Cancer pathways are often complex and fall between CCG and NHS England specialised commissioning, which can result in shared ownership and uncertainty.

In order to simplify these pathways NHS England are committed to the development of cancer alliances which will become a vehicle for delivering high quality cancer care.

As this document is being written the exact shape and function of these Alliances is not determined, but there is anticipation that they will be in place in 2017.
Local Information
My Area

Your local Trust Contact details:

<table>
<thead>
<tr>
<th>Authority</th>
<th>Contact Details</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>East Sussex Healthcare NHS Trust</td>
<td>Mark Collins ESHT Macmillan Lead Cancer Nurse</td>
<td><a href="mailto:markcollins@nhs.net">markcollins@nhs.net</a></td>
</tr>
<tr>
<td>Brighton and Sussex University Hospitals NHS Trust</td>
<td>Sarah Randall Team Leader: Cancer CNSs</td>
<td><a href="mailto:Sarah.j.randall@bsuh.nhs.uk">Sarah.j.randall@bsuh.nhs.uk</a>, <a href="mailto:Sarah.randall1@nhs.net">Sarah.randall1@nhs.net</a></td>
</tr>
</tbody>
</table>

The Trust is aware of the Recovery Package.

Your named CCG Contacts:

<table>
<thead>
<tr>
<th>CCG</th>
<th>Contact Details</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hastings and Rother and Eastbourne, Hailsham and Seaford CCG</td>
<td>Lisa Elliott Senior Delivery Manager</td>
<td><a href="mailto:lisaelliott1@nhs.net">lisaelliott1@nhs.net</a></td>
</tr>
<tr>
<td>Highweald Lewes Havens CCG</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Local Third Sector Support

The following information is supplied to give a picture of third sector organisations that are available in your area. The Clinical Network does not endorse or support any organisation listed below.

|   |   |   |   |
## Prevalence of Cancer in our area and prediction of future needs.

<table>
<thead>
<tr>
<th></th>
<th>Hastings and Rother CCG</th>
<th>Eastbourne, Hailsham and Seaford CCG</th>
<th>Highweald Lewes Havens CCG</th>
<th>Combined</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Number of People in your CCG at the end of 2010 who were living with and beyond cancer up to 20 years after diagnosis.</strong></td>
<td>5,400</td>
<td>6,100</td>
<td>5,100</td>
<td>16,600</td>
</tr>
<tr>
<td><strong>Estimated Number this could rise to by 2030 (based on current 20-year prevalence and indicative future estimates).</strong></td>
<td>10,600</td>
<td>11,900</td>
<td>10,000</td>
<td>32,500</td>
</tr>
</tbody>
</table>

Assumption: People will continue to get and survive cancer at increasing rates in line with recent trends (except for prostate cancer), and the general population will continue to grow and age.

Source: [http://lci.cancertoolkit.co.uk/](http://lci.cancertoolkit.co.uk/)
Commissioning the Cancer Recovery Package

Currently there are no national targets for the Recovery Package, however the National Cancer dashboard which is in development has a Quality of Life indicator, which is thought to contain a score related to patient experience and living with and beyond cancer services.

There has been consideration of a regional target for recovery package implementation but this is still in development.

The SE CN has a “Living with and Beyond Cancer” programme which looks at post cancer diagnosis patient care. West Sussex CCG are regularly attending South East Clinical Network (SE CN) meetings and events and are aware of the resources, local packs and bulletins that have been produced. They are also aware of the National documents that have been published recently.


Awareness of the Recovery package

In 2015 knowledge of living with and beyond cancer was poor within CCGs, however, things have changed considerably since then.

The SE CN has a “Living with and Beyond Cancer” programme which looks at post cancer diagnosis patient care. East Sussex CCG are occasionally attending South East Clinical Network (SE CN) meetings and events and are aware of the resources, local packs and bulletins that have been produced. They are also aware of the National documents that have been published recently.

Local commissioning

Unfortunately the position for the East Sussex CCGs has varied little since last year. There is no specific work being undertaken regarding Living with and Beyond Cancer.

<table>
<thead>
<tr>
<th></th>
<th>Hastings and Rother CCG</th>
<th>Eastbourne, Hailsham and Seaford CCG</th>
<th>Highweald Lewes Havens CCG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aware of the RP</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Currently Commissioned?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commissioning Intentions</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Recovery Package Recommendations

- Awareness of the Recovery Package has improved, however, there needs to be a general increased awareness of the Macmillan branded Recovery Package and its elements.
- There needs to be awareness of the NHS England response to the taskforce strategy which is recommending that the Recovery Package and Stratified Pathways should be implemented by 2020. (NHS England, May 2016), the NHS England Business Case 16/17 (NHS England, 2016) which commits to rolling out recovery package and self-managed pathways and the Operational Planning Guidance 2017-19 (NHS England and NHS Improvement, Sept 2016) which makes implementation of the recovery package and some stratified pathways a “must do”.

The SE CN are aware that some Trusts use similar non branded products, due to matters of Trust identity. If these are quality products and deliver good patient care then this isn’t a problem. The important thing is that there should be provision within each of the 4 main elements and aspiration for the additional elements around healthy lifestyle, finance and work support, and managing the consequences of treatment.

An example of a commissioning plan: London Cancer Alliance

As a best practice example, The London Cancer Alliance have developed a commissioning plan which sets a goal for delivery of the Recovery package by March 16.

<table>
<thead>
<tr>
<th>All cancer services will be commissioned to deliver the recovery package as described in the NCSI</th>
<th>70% of all new patients will have a completed recovery package by March 2016 consisting of:-</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• A Holistic Needs Assessment and care plan.</td>
</tr>
<tr>
<td></td>
<td>• Attendance at a health and well-being event</td>
</tr>
<tr>
<td></td>
<td>• A treatment summary</td>
</tr>
</tbody>
</table>

The alliance target does not include the Cancer Care Reviews (CCR), which are part of the QOF contract with NHS England. The quality of CCRs is the responsibility of the Quality Nursing Teams within the CCGs.

Example 2 : Wessex

In the Wessex Clinical Network Area they have suggested a 75% target, which is now included in service contracts.
Primary Care

Cancer Care Review

A Cancer Care Review should be carried out by the patient’s GP practice six months after a diagnosis of cancer (previously three months post diagnosis). This should include post-treatment support and information to enable self-

<table>
<thead>
<tr>
<th></th>
<th>Hastings and Rother CCG</th>
<th>Eastbourne, Hailsham and Seaford CCG</th>
<th>Highweald Lewes Havens CCG</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCG aware of Cancer Care Reviews</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer Care Review as part of local CCG plans</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>QOF Measure April 13 – March 14, CAN 002 *</td>
<td>83.74%</td>
<td>80.72%</td>
<td>79.53%</td>
</tr>
<tr>
<td>QOF Measure April 14 – March 15, CAN 003 *</td>
<td>82.6%</td>
<td>80.17%</td>
<td>77.53%</td>
</tr>
</tbody>
</table>

*CAN 003- 6 points - The percentage of patients with cancer, diagnosed within the preceding 15 months, who have a patient review recorded as occurring within 6 months of the date of diagnosis, NICE 2012 menu ID: NM62, NICE 2012 menu ID: NM62 (please note the wording has changed from last year)

Informed by the Treatment Summary, the cancer care review is completed by a GP or practice nurse in order to discuss the person’s needs. It is carried out within six months of a cancer diagnosis and covers post-treatment support, financial impact of cancer, patient awareness of prescription exemptions, possible late effects of cancer and cancer treatment and information needs to enable self-management. Some commissioners in England have local incentive schemes to improve quality, timing and/or frequency of the CCR. The cancer care review is also eligible for Quality Outcomes Framework (QOF) points.

(NHS England, April 2016)

An excerpt from the NICE guidance can be found in Appendix B.

Cancer Care reviews are the only part of the Recovery package delivered in primary care. They are delivered as part of the Quality Outcomes Framework which measures the number of Cancer Care Reviews done. As such there is no doubt about the number of CCRs carried out, but the quality which is anecdotally variable.

It is generally believed that GPs are the best person to carry out the CCR, however, with many cancer patients also having co-morbidities there are increasing suggestions that practice nurses can be trained to carry out the CCR, by encompassing Cancer as a Long Term condition and treating the patient holistically. There are currently courses are running in the area by Macmillan which some of the
practice nurses have participated, however this is not prevalent across all the CCGs. (Bamdad, June 2016)

The Macmillan GPs across the South East have declared that improving CCR quality will be their priority for 16/17. The SECN, along with Macmillan, will pick up this workstream and work with CCGs and GPs to raise awareness of this.

Overall, the awareness of Cancer Care Reviews and their role within the cancer pathway has been raised since last year, however, there is still a lot of work to be done and measuring both quality and improvement will remain difficult.

**Implementation of CCR**
The position of CCGs in East Sussex has varied little from last year with no current plans for Living with and Beyond Cancer.

**Trust involvement of CCR**
East Sussex healthcare Trust are an integrated Trust ie they have contracts for both secondary and community care services. This means that they are often still involved with patients at 6 months post diagnosis (the time at which a CCR should be done). The Trust would therefore like to have multidisciplinary involvement in the formation of the cancer care review.

**CCR Recommendations:**

- A good quality CCR is part of the patient experience and gives a good milestone in their care to connect with primary care after a period of secondary care and can be the link with more holistic patient needs.
- Treatment Summaries to be used within the Cancer Care reviews
- Cancer Care Reviews to consider signposting to other community and third sector services ie support groups and exercise classes
- Seeing Cancer as a Long term condition using the “Every conversation Counts” philosophy can ensure that patients are treated holistically.
- Although the evidence to support the use of CCR’s is minimal CCGs can encourage the use of CCR’s (including discussions and education around their benefit, the content and use of templates) and promote the practice nurse courses that are held by Macmillan.
- The use and quality of CCR’s can be promoted through the primary care education process and the CCG newsletters and bulletins.
- An audit of Cancer Care Reviews can be undertaken. The following questions could be used :
  - Who undertakes the CCR? Is it the GP or a practice nurse?
  - In what form is it delivered?
  - Are the Macmillan Templates used?
- Cancer Care Reviews could also be added to the local peer review.
Acute Trust

The commissioned Trusts in this area are: East Sussex Healthcare NHS Trust and Brighton and Sussex University Hospitals NHS Trust

Awareness of the Recovery package

All Trusts across Kent, Surrey and Sussex are aware of the Recovery Package regardless of whether they are implementing it.

A resources page can be found on page 35 of this document.

<table>
<thead>
<tr>
<th></th>
<th>East Sussex Healthcare NHS Trust</th>
<th>Brighton and Sussex University Hospitals NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness recovery package</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>Awareness of Clinical Network LW&amp;BC Programme</td>
<td>Yes</td>
<td></td>
</tr>
</tbody>
</table>

Good practice Example.

The St Luke’s Alliance which is an organisation which works across 4 hospital sites in Surrey, have just completed a project to roll out the Recovery Package. A report which covers the project including an appendix filled with proforma templates can be found on the SECN website (as above). Copies of some of the proformas can be obtained by contacting the CN.

Recovery Package Recommendations:

- Awareness of the Recovery Package has improved, however, there needs to be a general increased awareness of the Macmillan branded Recovery Package and its elements.
- There needs to be awareness of the NHS England response to the taskforce strategy which is recommending that the Recovery Package and Stratified Pathways should be implemented by 2020. (NHS England, May 2016), the NHS England Business Case 16/17 (NHS England, 2016) which commits to rolling out recovery package and self-managed pathways and the Operational Planning Guidance 2017-19 (NHS England and NHS Improvement, Sept 2016) which makes implementation of the recovery package and some stratified pathways a “must do”.

The SE CN are aware that some Trusts use similar non branded products, due to matters of Trust identity. If these are quality products and deliver good patient care then this isn’t a problem. The important thing is that there should be provision within each of the 4 main elements and aspiration for the additional elements around
healthy lifestyle, finance and work support, and managing the consequences of treatment
Holistic Needs Assessment and care planning

A Holistic Needs Assessment at key points in the pathway including near diagnosis and at the end of treatment resulting in a written Care Plan outlining the actions to be taken to address identified needs which the patient.

Everyone with cancer should be offered an HNA and care plan. Effective assessment and care planning can lead to early interventions, diagnosis of consequences of treatment, improved communication and better equity of care.

The HNA and care plan ensure that people’s physical, emotional and social needs are met in a timely and appropriate way, and that resources are targeted to those who need them most. It should take place around diagnosis, at end of treatment, whenever the patient’s needs change or at any other time at the patient’s request.

An HNA may require input from a range of doctors, nurses and allied health professionals (e.g. dietitians, physiotherapists, occupational therapists, and speech and language therapists) to improve a person’s management and care. This creates a shared understanding between patient and healthcare professionals about what to expect during recovery, and identifies any needs to be addressed.

(NHS England, April 2016)

Local Commissioning of HNA

The position of CCGs in East Sussex has varied little from last year with no current plans for Living with and Beyond Cancer.

Implementation of HNA

East Sussex healthcare Trust use paper based HNAs and these are usually done within 2 weeks of diagnosis, however, there is no uniform template used.

<table>
<thead>
<tr>
<th>HNA/eHNA</th>
<th>East Sussex Healthcare NHS Trust</th>
<th>Brighton and Sussex University Hospitals NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standardised HNA and CP for all tumour groups?</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Partial use of HNA and CP in some tumour groups</td>
<td>Yes (Macmillan, Distress Thermometer, Own template)</td>
<td></td>
</tr>
</tbody>
</table>

HNA Recommendations:

- There is some discussion about the timing of the HNA within the pathway, with consideration always being the psychological wellbeing of the patient. This may not be appropriate at the time of the doctor disclosing diagnosis and not all patients are ready at the end of their treatment to discuss their ongoing needs.
There is a consensus that there should be some variation in the HNA between tumour groups, with some flexibility allowed.

There is a need for CNS’s to have Advanced Communication Skills Training.

HNAs should always be discussed and agreed with the patient.

HNA’s should be shared as part of a Multidisciplinary approach and should be revisited and updated regularly.

Consideration should seriously be made to using the Macmillan electronic HNA (eHNA). Macmillan will back this with a grant, technical and information support.

A service specification for an HNA should include the following:

- Physical concerns.
- Practical concerns
- Family / relationship concerns
- Emotional concerns
- Lifestyle, work or information needs

(NHS England, April 2016)

**eHNA**

Holistic Needs assessments have recently taken a step into the electronic age with the eHNA. There are currently pilots of this system being run across the country, including some sites in the South East, however, there are differing views on the suitability of collecting this patient data electronically.

East Sussex healthcare Trust are not currently using eHNA based on the technical complications associated with using the web based product and the fact it does not work automatically with hospital based systems.

**eHNA Recommendations**

- eHNA is a paperless system that patients can do from any internet based system either with or without supervision.
- eHNA can support easy development of the patients care plan
- Top scoring needs can be used to plan Health and Wellbeing agenda

Data analysis is possible, including audit

**Care Planning**

A Care Plan should be developed as part of this process. This enables appropriate interventions, including support and information, and signposting or referral to other services if required. The process prevents concerns from escalating and supports self-management.

(NHS England, April 2016)
Care Planning usually occurs as part of the HNA process however, there is discussion about what constitutes a “good“ careplan with some emphasis be put on what the patient can do for themselves.

**Care Planning Recommendations**

- There needs to be agreement on what constitutes a “good“ careplan with some emphasis be put on what the patient can do for themselves.
Developed to support improved communication between cancer services and primary care, the TS is produced by secondary cancer care professionals at the end of primary treatment (the end of first treatment or treatments given) and sent to the patient’s GP and other primary care professionals to inform them of any actions they need to 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.

Treatment Summaries may also be used at other points in the journey, for example following treatment for recurrence or referral from secondary care to palliative care. It is used to inform the GP cancer care review, which is also part of the Recovery Package. A copy of the TS in the case notes is also useful for medical staff if the patient is admitted in an emergency after primary treatment is complete.

The TS provides important information for GPs, including possible treatment toxicities, information about side effects and/or consequences of treatment, signs and symptoms of a recurrence, whether they are at risk of developing other conditions such as cardiac disease, osteoporosis and diabetes and any actions for the GP. The form also includes the READ codes for the diagnosis and treatment so that the GP can update their patient database.

Thoroughly tested and positively evaluated by both GPs and oncology clinicians, the TS is now available electronically on the two main cancer information systems: Somerset Cancer Register and InfoFlex Cancer Information Management System.

(NHS England, April 2016)

There still appears to be some confusion nationally about when a treatment summary (TS) is produced in the pathway. Some centres believe that the term “end of treatment summary” implies that the document should be produced at discharge, which sometimes makes the timing of the summary difficult if the patient goes on to have subsequent treatment.

**Local Commissioning of Treatment Summaries:**
The position of CCGs in East Sussex has varied little from last year with no current plans for Living with and Beyond Cancer.

**Implementation of Treatment Summaries:**
East Sussex healthcare Trust patients are regularly copied into the letters written between professionals, however, in a recent patient survey the Trust were not looked on favourably for this approach. The Trust are aware of this and are working through the options.
Living with and beyond cancer, CCG info Pack  
East Sussex locality

<table>
<thead>
<tr>
<th>Treatment Summaries</th>
<th>Used for all Tumour Groups</th>
<th>No</th>
<th>Used in Some tumour Groups</th>
<th>No</th>
<th>Planned</th>
<th>No</th>
</tr>
</thead>
</table>

**Treatment Summary Recommendations:**

- Agreement should be reached within secondary care about the timing and purpose of the treatment summary.
- Treatment Summary to be used within the Cancer Care review.
- A good treatment summary can give primary care information about treatment and care given in secondary care.
- Regardless of when the Treatment Summary is written it should be seen as a communication aid between professionals and the patient and should be used as the basis of the Cancer care review.
- Routinely the patient should always receive copies of the Treatment Summary.
- Good practice is considered to be, writing the document as if to the patient and copy in the professionals. This way the language used is appropriate for the whole audience.
Health and Wellbeing (Patient Education)

A patient education and support event, such as a Health and Wellbeing Clinic, to prepare the person for the transition to supported self-management, which will include advice on healthy lifestyle and physical activity.

Health and wellbeing events provide an opportunity to inform and educate patients about the clinical and holistic aspects and ongoing management of their health. They also serve to impart information about local facilities, supportive care and opportunities that are available to individuals and their families. Every individual with cancer should be offered the opportunity to attend a health and wellbeing event at the end of treatment to support them to self-manage their condition.

(NHS England, April 2016)

During the course of this audit it has become clear that Health and wellbeing Events can take a variety of forms. Some are small specialised events for patients who have specialist needs or may not wish to access generic events, some are generic large annual events of more than 100 people some are more regular smaller less formal events of 30 – 40 people and then finally there are patient information centers which are open whenever patients wish to access them. From a lay-mans viewpoint there are pros and cons which each and it appears different patients prefer different models depending on their requirements. What is apparent is that those patients who attend seem to get a great deal of enjoyment from them.

There are 2 issues that seem to be predominant though.

1) Most formal events are funded by third sector grants (Macmillan). Although these are available and there is no sign that funding will stop, there is a great sense that this is not sustainable.

2) The evidence that patients benefit from these events can only be found by evaluating their needs before and after attending and establishing, almost hypothetically, whether these events have reduced the need for patients to attend expensive formal clinical support.

It is fair to say that the implementation of health and wellbeing is now gathering pace, however, with each event the thought process is evolving and in future they may well look very different.

Local Commissioning of H&W Events

The position of CCGs in East Sussex has varied little from last year with no current plans for Living with and Beyond Cancer.
Secondary Care H&W Events:

In East Sussex healthcare Trust it is the Breast Care Team that have been leading on health and wellbeing events. These have been multiagency events and patients have found them extremely beneficial and they have been well attended.

There have been no generic Health and wellbeing events/clinics. There is however, an awareness of the needs of patients post treatment and in the prostate pathway patients are often referred to physical activities groups.

The Trust have recently revamped their cancer user group and this will be a future topic of discussion.

<table>
<thead>
<tr>
<th>Health and Wellbeing Events</th>
<th>East Sussex Healthcare NHS Trust</th>
<th>Brighton and Sussex University Hospitals NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coordinated approach to H &amp;W events in place</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Pilots Completed</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>CCG and Secondary Care planning H/W together</td>
<td></td>
<td>No</td>
</tr>
</tbody>
</table>

Health and Wellbeing Recommendation:

- Health and Wellbeing Clinics should be considered across all tumour groups to give patients advice and support in preparation for self-management.
- Consideration should be made about whether the health and wellbeing events are tumour specific or generic. The more generic events are less resource intensive as a rule of thumb but still require a large amount of organising.
- A good model for Health and Wellbeing Events is to include primary care/CCG during the planning stages.
- Care should be taken around timing of events with consideration being made to providing information at other times either in written format, face to face or via the internet.

A health and wellbeing event should include:

- Expert advice on health
- Support to ensure that individuals have the confidence and skills to manage their condition
- Information about complementary therapies
- Advice on adjusting to life after treatment
Patient engagement

Although there is no specific requirement within the implementation of the Recovery Package relating to patient engagement, it is clearly referenced in the NHS England document Achieving World Class Cancer Outcomes: Taking the Strategy Forward (NHS England, May 2016) and will be part of a Long Term Quality of Life indicator coming in during the next year. It is therefore important that commissioners are aware of the Patient Experience Survey and its outcomes for their provider organisations.

We did not specifically ask about patient engagement as part of the audit but some organisations included in the discussions that were had with them.

Patient Experience Recommendation:

- There should be awareness of the Cancer Patient Experience Survey and its outcomes
- Patient experience is likely to be the main measure of success for living with and beyond cancer.
- Good practice suggests that no service delivery change should be implemented without some discussion and consultation with local patients and/or the general public.

Stratified Pathways

Implementation in Secondary Care

East Sussex healthcare Trust is providing a traditional post cancer service, however, there is a current business case being considered for a “post treatment effects” service which will be at 4 – 6 weeks post treatment. The primary purpose of this service is to access patients post treatment to establish any long lasting effects that might be contributable to the treatment itself, in order to address them early, improve quality of life and prevent longer term complications.

This would be a multidisciplinary service looking at encouraging patients to self manage and will include dietary advice amongst other things.

At BSUH the breast cancer pathway has a forward thinking clinician who has already implemented stratified pathways into his work. All but a few patients are discharged from treatment with regular mammography (and a safe recall system) but without regular medical follow up.
Thought has been given to incorporating Recovery Package into day to day clinics. Clinic letters are written to the patient based on the clinic conversation and there is avoidance of technical jargon in the text. However, a text box of technical jargon is included at the top of correspondence. Formal Treatment Summaries are kept on Somerset with copies sent to the GP and updated routinely. Thought is being given to how clinicians who don’t currently provide a Treatment Summary can write a similar style report without using the Somerset template.

Patients are offered access to a “moving on “ programme and health and wellbeing advice provided by an external provider. There is a help line telephone number given to all patients which goes through to the CNS’s.

The use of technology ie apps, is used to give information and support. The first patient appointment can be recorded so that the patient can replay information later in the comfort of their own home.

For those patients who are followed up in clinic a holistic approach to welfare is adopted ie discussion covers a diverse range of topics, including sexual dysfunction, sleep disturbance and psychological support. This discussion is initiated by the patient filling in an HNA prior to the appointment.

This appears to be a really good model of care, although further thought should be given to how community support is offered and additional information is shared, with patients who do not receive follow up in clinic.

**Stratified Pathways Recommendations**

The Recovery Package should not be considered in isolation but as part of a pathway of care for patients, post treatment.

Each element of the Recovery package should link together as part of a multidisciplinary/cross organisational approach to patient care.

The SE Clinical network, along with its partner organisations, are exploring a new model of post treatment care, incorporating stratified pathways. A number of events and promotions will be put together, as part of this work through the Living with and beyond cancer Clinical Advisory Group.

Please contact the SE Clinical Network for more information.
Drivers

National

The National Independent Cancer Taskforce published its recommendation “Achieving World-class Cancer Outcomes” in July 15. There is a specific recommendation regarding the Recovery Package. As part of these recommendations it is suggested that NICE develop a minimum service specification and performance monitor

NHS England Implementing the cancer taskforce recommendations: commissioning person centred care for people affected by cancer intended to support commissioners and strategic clinical networks to ensure every person affected by cancer will have access to the Recovery Package and stratified follow-up pathways by 2020, as set out in the cancer strategy.

NHS England Achieving World-Class Cancer Outcomes: Taking the strategy forward


Summary of Recommendations

- To raise the profile and priority of the Recovery package and stratified pathways as part of the Living with and Beyond Cancer agenda within CCG’s.
- There should be widespread promotion of the elements of the recovery package and knowledge of its content, for professionals. This will probably include professional education events.
- To develop strategic and operation plans to implement Recovery package and stratified pathways in line with the Taskforce Report (Independent Cancer Taskforce, July 2015) and Operational Planning Guidance (NHS England and NHS Improvement, Sept 2016) and other associated documents.

Resources can be found on page 35

Recovery Package Recommendations (General)

- Awareness of the Recovery Package has improved, however, there needs to be a general increased awareness of the Macmillan branded Recovery Package and its elements.
- There needs to be awareness of the NHS England response to the taskforce strategy which is recommending that the Recovery Package and Stratified Pathways should be implemented by 2020. (NHS England, May 2016), the NHS England Business Case 16/17 (NHS England, 2016) which commits to rolling out recovery package and self-managed pathways and the Operational Planning Guidance 2017-19 (NHS England and NHS Improvement, Sept 2016) which makes implementation of the recovery package and some stratified pathways a “must do”.

CCR Recommendations (primary care):

- A good quality CCR is part of the patient experience and gives a good milestone in their care to connect with primary care after a period of secondary care and can be the link with more holistic patient needs.
- Treatment Summaries to be used within the Cancer Care reviews
- Cancer Care Reviews to consider signposting to other community and third sector services ie support groups and exercise classes
- Seeing Cancer as a Long term condition using the “Every conversation Counts” philosophy can ensure that patients are treated holistically.
- Although the evidence to support the use of CCR’s is minimal CCGs can encourage the use of CCR’s (including discussions and education around their benefit, the content and use of templates) and promote the practice nurse courses that are held by Macmillan.
- The use and quality of CCR’s can be promoted through the primary care education process and the CCG newsletters and bulletins.
- An audit of Cancer Care Reviews can be undertaken.
• Cancer Care Reviews could also be added to the local peer review.

**HNA Recommendations (secondary Care):**

• There is some discussion about the timing of the HNA within the pathway, with consideration always being the psychological wellbeing of the patient. This may not be appropriate at the time of the doctor disclosing diagnosis and not all patients are ready at the end of their treatment to discuss their ongoing needs.
• There is a consensus that there should be some variation in the HNA between tumour groups, with some flexibility allowed.
• There is a need for CNS’s to have Advanced Communication Skills Training.
• HNAs should always be discussed and agreed with the patient.
• HNA’s should be shared as part of a Multidisciplinary approach and should be revisited and updated regularly.
• Consideration should seriously be made to using the Macmillan electronic HNA (eHNA). Macmillan will back this with a grant, technical and information support.

**eHNA Recommendations (secondary care)**

• eHNA is a paperless system that patients can do from any internet based system either with or without supervision.
• eHNA can support easy development of the patients care plan
• Top scoring needs can be used to plan Health and Wellbeing agenda
• Data analysis is possible, including audit

**Care Planning Recommendations (secondary care)**

• There needs to be agreement on what constitutes a “good “careplan with some emphasis be put on what the patient can do for themselves.

**Treatment Summary Recommendations (secondary care):**

• Agreement should be reached within secondary care about the timing and purpose of the treatment summary .
• Treatment Summary to be used within the Cancer Care review.
• A good treatment summary can give primary care information about treatment and care given in secondary care.
• Regardless of when the Treatment Summary is written it should be seen as a communication aid between professionals and the patient and should be used as the basis of the Cancer care review..
• Routinely the patient should always receive copies of the Treatment Summary.
• Good practice is considered to be, writing the document as if to the patient and copy in the professionals. This way the language used is appropriate for the whole audience.
Health and Wellbeing Recommendation (joint working):

- Health and Wellbeing Clinics should be considered across all tumour groups to give patients advice and support in preparation for self-management.
- Consideration should be made about whether the health and wellbeing events are tumour specific or generic. The more generic events are less resource intensive as a rule of thumb but still require a large amount of organising.
- A good model for Health and Wellbeing Events is to include primary care/CCG during the planning stages.
- Care should be taken around timing of events with consideration being made to providing information at other times either in written format, face to face or via the internet.

Stratified Pathways Recommendations (general):

- The Recovery Package should not be considered in isolation but as part of a pathway of care for patients, post treatment.
- Each element of the Recovery package should link together as part of a multidisciplinary/cross organisational approach to patient care.

Patient Experience Recommendation (general):

- There should be awareness of the Cancer Patient Experience Survey and its outcomes
- Patient experience is likely to be the main measure of success for living with and beyond cancer.
- Good practice suggests that no service delivery change should be implemented without some discussion and consultation with local patients and/or the general public.
Resources of Interest

National Cancer Survivorship Initiative
The NCSI was the birth place of the Cancer Living with and Beyond Cancer work Programme. Although it close in 2013 the website contains a wealth of information that can be used as a reference for all aspects of Living with and Beyond Cancer.

Website : www.ncsi.org.uk/
Recovery Package.
Website : www.ncsi.org.uk/what-we-are-doing/the-recovery-package/

Macmillan Cancer Support
You can also find information on Living with and Beyond cancer here : www.macmillan.org.uk/GetInvolved/Campaigns/Weareforceforchange/Survivorship/Livingwithorbeyondcancer.aspx
Recovery Package

NHS England
Website : www.england.nhs.uk/ourwork/cancer/

SE Clinical Network

Stratified Pathways
Innovation to implementation: Stratified pathways of care for people living with or beyond cancer- A “how to guide”

Stratified pathways of care...from concept to innovation, NHS Improvement – Cancer, March 2012
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**Glossary**

CCG - Clinical Commissioning Group
CCR - Cancer Care Review
CNS - Clinical Nurse Specialist
H&WB - Health and Well Being
HNA / CP - Holistic Needs Assessment & Care Planning
KSS - Kent, Surrey and Sussex
LTC - Long Term Condition
NCSI - National Cancer Survivorship Initiative
RP - Recovery Package
CN - Clinical Network
TS - Treatment Summary
Appendix A

Cancer Care Review – Proposed Peer Review Questions

This is split into three areas: how the CCR is organised, what happens in the review itself, how can the CCR be improved to make it meaningful and add value?

How the CCR is organised?
- Are patients called in to CCRs systematically or are they carried out opportunistically when a patient is there for another reason?
- Are carers invited?
- How are the reviews carried out – in person/ by telephone?
- Who carries out the review? GP, Practice Nurses
- Who attends the review? Patient alone or with carer?
- How does the review fit in the pathway?
- Are patients offered one review (QOF) or follow ups?
- How much time is allocated for a CCR appointment?

The review itself
- Is a template used and if so how? McMillan/ own, please provide details/ aide memoire/ tick box?
- If template is not used, what is discussed? Holistic approach (anxiety, psychological and physical well-being, medication review, information needs (signposting re benefits etc), healthy lifestyle..?
- Do you have all the info you need to respond to patient concerns? If not what else is required and from whom? E.g. Treatment Summary from trust at end of treatment.
- How is it recorded?

How can the CCR be improved – adding value?
- How can the review be improved to make it meaningful?
- Are there any education requirements?
- Is any support required – e.g. upload of MacMillan templates on the system?
- How does the CCR fit in cancer pathway?
- Design of local template/ prompts/ aide memoire?
- YOC style approach – patients given info (not results) to think about prior to appointment?
- What does/ should the CCR offer that is not already being done by the secondary care cancer team?
- Do you/ can you carry out the CCR as part of LTC annual reviews?
- Other?
Appendix B

QOF indicator guidance: cancer (August 2012)

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE
QUALITY AND OUTCOMES FRAMEWORK (QOF) INDICATOR DEVELOPMENT PROGRAMME

Indicator guidance

QOF indicator area: cancer
Output: Indicator guidance for QOF
Date: August 2012

Indicator for NICE menu (indicator ID: NM62)
The percentage of patients with cancer diagnosed within the preceding 15 months who have a review recorded as occurring within 3 months of the practice receiving confirmation of the diagnosis.

(please note this indicator has been updated. Wording now reads - The percentage of patients with cancer, diagnosed within the preceding 15 months, who have a patient review recorded as occurring within 6 months of the date of diagnosis.)

Indicator to be replaced
CANCER 3. The percentage of patients with cancer, diagnosed within the preceding 18 months, who have a patient review recorded as occurring within 6 months of the practice receiving confirmation of the diagnosis.

Rationale
A GP will have an average of 8 or 9 new cancer diagnoses per year and will be looking after 20 to 30 patients with cancer. The increasing number of cancer survivors has led to an increase in the number of people requiring follow-up care, monitoring and management.
Most practices will see patients with a new cancer diagnosis following assessment and management in a secondary or tertiary care setting. These patients quickly resume consultations in general practice at an increased rate to pre-diagnosis and treatment, therefore primary care has an important role in managing survivorship. This review represents an initial opportunity to address patients’ needs for individual assessment, care planning and ongoing support and information requirements.

A cancer review in primary care should include:

- The patient’s individual health and support needs, which will vary with, for example, the diagnosis, staging, age and pre-morbid health of the patient and their social support networks. In collaboration with the National Cancer Survivorship Initiative, Macmillan primary care community has produced a template which recommends that this could cover a discussion of the diagnosis and recording of cancer therapy, an offer of relevant information, medication review, benefits counselling and recording of a carer’s details.
- The coordination of care between sectors.

Further information on survivorship and the potential role for primary care can be found on the National Cancer Survivorship Initiative website.

While a review should be face to face in most cases, making contact with a patient over the telephone will qualify as a success for this indicator. Where contact is made over the phone, an offer should be made for a subsequent face to face review.

**Reporting and verification**

The practice reports the percentage of people with a new diagnosis of cancer in the preceding 15 months who have had a review performed within 3 months of the practice receiving confirmation of the diagnosis. QOF assessors may wish to review records where a review is claimed to confirm that both elements have been completed.

**Further information**
This is NICE indicator guidance for QOF, which is part of the NICE menu of indicators. This document does not represent formal NICE guidance. The NICE menu of indicators for QOF is available online at

www.nice.org.uk/aboutnice/qof/indicators.jsp