Table of Contents

Table of Contents ............................................................................................................. 1

Executive Summary ......................................................................................................... 3

Introduction ....................................................................................................................... 1
  Operational Planning 2017-19 ....................................................................................... 3
  The Cancer Recovery Package ......................................................................................... 5
  Stratified Pathways ......................................................................................................... 7
  Financial and non-financial levers and incentives .......................................................... 9
  National Cancer Dashboard ............................................................................................ 10
  Cancer Alliances ............................................................................................................. 10

.......................................................................................................................................... 11

My Area ............................................................................................................................ 11
  Your local Trust Contact details: .................................................................................. 12
  Your named CCG Contacts: ......................................................................................... 12
  Local Third Sector Support ............................................................................................. 13
  Prevalence of Cancer in our area and prediction of future needs .................................. 14

Commissioning the Cancer Recovery Package ................................................................ 16
  Awareness of the Recovery package ............................................................................. 16
  An example of a commissioning plan: London Cancer Alliance .................................. 17

Primary Care ...................................................................................................................... 19
  Cancer Care Review ....................................................................................................... 19

Acute Trust ......................................................................................................................... 22
  Awareness of the Recovery package ............................................................................. 22
  Holistic Needs Assessment and care planning ............................................................... 25
  eHNA ............................................................................................................................... 26
  Care Planning .................................................................................................................. 27
  Treatment Summary ....................................................................................................... 28
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
- East Kent
- North Kent
- West Kent
## Introduction

In Oct 2014 NHS England published it’s 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.

(Independant 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>
</tr>
</thead>
<tbody>
<tr>
<td>Ensure all parts of the Recovery Package are available to all patients including:</td>
</tr>
<tr>
<td>A. Ensure all patients have a holistic needs assessment and care plan at the point of diagnosis and at the end of treatment</td>
</tr>
<tr>
<td>B. Ensure that a treatment summary is sent to the patient’s GP at the end of treatment</td>
</tr>
<tr>
<td>C. Ensure that a cancer care review is completed by the GP within six months of a cancer diagnosis</td>
</tr>
<tr>
<td>2018/19</td>
</tr>
<tr>
<td>Ensure all parts of the Recovery Package are available to all patients including:</td>
</tr>
<tr>
<td>A. Ensure all patients have a holistic needs assessment and care plan at the point of diagnosis and at the end of treatment</td>
</tr>
<tr>
<td>B. Ensure that a treatment summary is sent to the patient’s GP at the end of treatment</td>
</tr>
<tr>
<td>C. Ensure that a cancer care review is completed by the GP within six months of a cancer diagnosis</td>
</tr>
<tr>
<td>Metrics</td>
</tr>
<tr>
<td>Local data collection</td>
</tr>
<tr>
<td>Currently piloting collection of HNA data using COSD (PHE)</td>
</tr>
<tr>
<td>Developing national quality of life metric</td>
</tr>
<tr>
<td>Local data collection</td>
</tr>
<tr>
<td>Exploring how data may be collected nationally</td>
</tr>
<tr>
<td>Developing national quality of life metric</td>
</tr>
<tr>
<td>CNS question in CPES (Q17 Cancer Patient Experience Survey, annual, NHS England Statistics)</td>
</tr>
</tbody>
</table>
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.

![Figure 1: Macmillan RP diagram](image)

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 surgical procedure as treatment (ie not just cancer). 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 (Indepedant 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 Error! Bookmark not defined.):

- 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 Type</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Prostate</th>
<th>Lung</th>
</tr>
</thead>
<tbody>
<tr>
<td>Included at Staff induction</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care Planning</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>eHNA/HNA</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Treatment Summaries</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Shared records between primary and secondary care</td>
<td></td>
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</tbody>
</table>

### Supported Self Management

<table>
<thead>
<tr>
<th>Service</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Prostate</th>
<th>Lung</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timely re-access</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Annual Mammography until screening programme</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CEA, CT Scans colonoscopy per local protocol</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>PSA Monitoring</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remote monitoring</td>
<td>X</td>
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</table>

### Professional Led Follow up

<table>
<thead>
<tr>
<th>Service</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Prostate</th>
<th>Lung</th>
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</thead>
<tbody>
<tr>
<td>Consultant Led</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Consultant Led (respiratory Oncology, thoracic)</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Clinical Nurse Specialist Led</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Telephone Led</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Nurse specialist Led</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

### Supportive and Palliative Care

<table>
<thead>
<tr>
<th>Service</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Prostate</th>
<th>Lung</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone led</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Specialist palliative Care led</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Primary Care/community palliative Care Led</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Hospice Led</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Primary Care Led</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

### Transition to End of Life

<table>
<thead>
<tr>
<th>Service</th>
<th>Breast</th>
<th>Colorectal</th>
<th>Prostate</th>
<th>Lung</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Continence/Stoma</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Continence</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Menopause Clinics</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Physiotherapy/occupational therapy</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Physiotherapy/Breathlessness Clinics</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Diet and Nutrition</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>District Nursing</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Sexuality/Body Image</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping/Psychological</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Erectile Dysfunction/sexuality</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational/Wheelchair Services</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Home Oxygen Services</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Lymphodema</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Self Management Programmes</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Information Days</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information prescriptions</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Local Authority community or privately Led Exercise Schemes</td>
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<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Trust Led Exercise Programmes</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Reablement/social Care</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Finance and benefits</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Vocational Rehab</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complimentary Therapies</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Voluntary sector /Support Groups</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Legal Advice</td>
<td>X</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

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Living with and beyond cancer, CCG info Pack
North Kent locality
Financial modelling references you might find interesting:


- London Transforming Cancer Services Team have commissioned an economic analysis for Prostrate 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.

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.

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
Your local Trust Contact details:

<table>
<thead>
<tr>
<th>Trust</th>
<th>Contact Details</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dartford and Gravesham NHS Trust</td>
<td>Pippa Miles Cancer Manager</td>
<td><a href="mailto:pippamiles@nhs.net">pippamiles@nhs.net</a></td>
</tr>
<tr>
<td>Medway NHS Trust</td>
<td>Denise Hodges Clinical Nurse Specialist (Lung)</td>
<td><a href="mailto:Denise.Hodges@medway.nhs.uk">Denise.Hodges@medway.nhs.uk</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</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swale CCG</td>
<td>Debbie Pyart</td>
<td><a href="mailto:debbiepyart@nhs.net">debbiepyart@nhs.net</a></td>
</tr>
<tr>
<td>Medway CCG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dartford, Gravesham and Swanley CCG</td>
<td>Michelle Jee</td>
<td><a href="mailto:michellejee@nhs.net">michellejee@nhs.net</a></td>
</tr>
</tbody>
</table>
Other Important contacts

<table>
<thead>
<tr>
<th>Macmillan GP</th>
<th>Dr Amit Kumar</th>
<th><a href="mailto:amit.kumar2@nhs.net">amit.kumar2@nhs.net</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>Kent Community Health NHS Foundation Trust</td>
<td>Jeanette Holland-Cowles Community Cancer Nurse Specialist</td>
<td><a href="mailto:J.HollandCowles@nhs.net">J.HollandCowles@nhs.net</a></td>
</tr>
<tr>
<td>Macmillan GP</td>
<td>Dr Bana Haddad</td>
<td><a href="mailto:b.haddad@nhs.net">b.haddad@nhs.net</a></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.

<table>
<thead>
<tr>
<th>Harmony Trust</th>
<th>Charity</th>
<th>Alternative Therapies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Macmillan Exercise Support referrals</td>
<td>Charity</td>
<td></td>
</tr>
<tr>
<td>Macmillan Welfare Support</td>
<td>Charity</td>
<td></td>
</tr>
</tbody>
</table>
Prevalence of Cancer in our area and prediction of future needs.

<table>
<thead>
<tr>
<th></th>
<th>Swale CCG</th>
<th>Medway CCG</th>
<th>Dartford, Gravesham and Swanley CCG</th>
<th>Combined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of People in your CCG at the end of 2010 who were living with and beyond cancer up to 20 years after diagnosis.</td>
<td>2,800</td>
<td>6,500</td>
<td>6,600</td>
<td>15,900</td>
</tr>
<tr>
<td>Estimated Number this could rise to by 2030 (based on current 20-year prevalence and indicative future estimates).</td>
<td>5,400</td>
<td>12,600</td>
<td>12,900</td>
<td>30,900</td>
</tr>
</tbody>
</table>

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/
Living with and beyond cancer, CCG info Pack
North Kent locality
Commissioning the Cancer Recovery Package

Currently there are no national indicators or targets for the Recovery Package beyond the high level aspiration that it should be fully implemented by 2020 (NHS England, May 2016) (Independant Cancer Taskforce, July 2015) (NHS England, April 2016) (NHS England, Oct 2014), 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. Dartford Gravesham and Swanley CCG, Medway CCG and Swale 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. The 3 commissioners in this area work together ensuring that they share responsibility to gather and disseminate information between them. They are also aware of the National documents that have been published recently.

Awareness of the Recovery package

In 2015 only one CCG in this area said they were aware of the recovery package and for all 3 CCG’s there were no services commissioned or development of plans.

However in 2016 things have changed considerably. There is now greater awareness of the Recovery package and stratified pathways.

Local commissioning

DGS CCG has a commissioning project manager and their main role is cancer work, the commissioner is working in collaboration with the Macmillan GP and the Community Cancer Nurse to

DGS CCG has been involved in the development of their STP and Operational Plans and LW&BC and The Recovery Package have been included.

DGS CCG know who their contact is within the Trust and regularly have communication and have additionally established a Local Implementation Group.
Medway CCG has a commissioner who spends approximately 50% of her time in cancer, although they would like it to be more. They did know who their contact was within the Acute Trust, however, they have recently left and someone new has taken over. Medway CCG have been involved with the development of their Sustainability and Transformational Plans and have LW&BC in their operational plan (see CCR). The biggest barrier has been getting enough time for the commissioner to pull all the relevant documentation together.

Last year (2015) Medway CCG referred to The NHS Medway ‘Living With and Beyond Cancer’ (LWBC) project which commenced in September 2008 as collaboration between NHS Medway, Kent and Medway Cancer Network, Macmillan Cancer Support, Medway NHS Foundation Trust and Medway cancer patients. This project worked with patients to understand what felt they needed in terms of support systems from a psychological, psychosocial and practical perspective. The project looked at the development of a Community Cancer Nurse Role to support patients on discharge, signpost to other agencies. But PCTs then reconfigured and became CCGs and project unable to move to next stage in community.

A report relating to this project can be found in Appendix C

Swale CCG has a planned care and cancer lead whose time is split between roles. With the development of the Cancer workstream there is an increasing amount to do within this role. Plans are being developed for Living with and beyond cancer and this will be enhanced by the arrival of a new Macmillan GP (working jointly with Medway Foundation trust).

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>• A Holistic Needs Assessment and care plan.</td>
<td></td>
</tr>
<tr>
<td>• Attendance at a health and well-being event</td>
<td></td>
</tr>
<tr>
<td>• A treatment summary</td>
<td></td>
</tr>
</tbody>
</table>
The alliance target does not include the Cancer Care Reviews, 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.
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.

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

---

<table>
<thead>
<tr>
<th>Local Practice has been reviewed</th>
<th>Dartford Gravesham and Swanley CCG</th>
<th>Medway CCG</th>
<th>Swale CCG</th>
</tr>
</thead>
<tbody>
<tr>
<td>Plans in place to review</td>
<td>In Development</td>
<td>In Development</td>
<td>No</td>
</tr>
<tr>
<td>QOF Measure April 13 – March 14. CAN 002 *</td>
<td>76.21%</td>
<td>75.74%</td>
<td>67.53%</td>
</tr>
<tr>
<td>QOF Measure April 14 – March 15. CAN 003 *</td>
<td>83.48% ↑</td>
<td>79.09% ↑</td>
<td>76.77% ↑</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)
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.

**Local Implementation of CCR**

**DGS CCG** – The Macmillan GP is currently reviewing the CCR and is raising the profile by educating at the CCG PLT and with individual practice visits.

**DGS CCG** are also aware of the Macmillan practice nurse courses and are in discussion at the moment about whether this is something they would like to consider. In the meantime the Macmillan GP and the Community Cancer Nurse have provided some CCG education sessions to practice nurses.

In 2016 **Medway CCG** had been working with the Macmillan GP to recruit a Macmillan Practice Nurse Facilitator to support the provision of the Macmillan Practice Nurse Course. Funding for the course has been secured and this will commence in early 2017. The course aims to provide practice nurse with the skills to support patients living with cancer and to educate them to the services available to signpost patients to.

In **Swale CCG** there is now a new Macmillan GP who is working jointly with Medway Foundation Trust, taking responsibility for the Recovery Package. This includes Holistic Needs Assessment, treatment Summaries and Cancer Care reviews. There are education sessions planned for next year.

**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

Local primary care and community Support (for professionals)

In DGS area there is a community cancer nurse employed by Virgin Health Care. Her role is to bridge the gap between primary and secondary care for cancer including End of life, and is involved in the MDT’s. Going forward the CCG are keen to utilise the Community Cancer Nurse for the implementation of The Recovery Package.

DGS have also just recruited a Macmillan GP who’s role it will be to raise the profile of Cancer locally including supporting non specialist GPs.
Acute Trust

The Trusts in this area are: Dartford and Gravesham NHS Trust and Medway 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.

Details of resources available can be found on page Error! Bookmark not defined. of this document.

<table>
<thead>
<tr>
<th></th>
<th>Dartford and Gravesham NHS Trust</th>
<th>Medway NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness recovery package</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Awareness of Clinical Network LW&amp;BC</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Programme</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Implementing the Recovery Package

Medway Maritime Hospital are aware of the Recovery Package and are keen to move ahead with implementation however there are some technical issues that need resolving ie in the use of Infoflex which is a county wide IT product.

There also needs some CCG and senior engagement to ensure that the work is driven forwards.

**Medway Foundation Trust** now have a joint Macmillan GP who will in future be working with the CCG on implementing the Recovery Package.

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...

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
At Dartford and Gravesham NHS Trust all CNS use the HNA template on Infoflex. Patients’ holistic needs are discussed and referrals are made to outside agencies according to the patient’s needs e.g. palliative care, falls, OT. To simplify the process the team have negotiated with outside agencies to accept the HNA as a referral to their services. The assessment is also shared with the GP.

However, the Infoflex template does not produce a written care plan. The patient discusses their needs and a care plan is agreed verbally, but there is no written plan.

The HNA is discussed at various points in the pathway and always at diagnosis and end of treatment. During the pathway it can be repeated depending on patient need, CNS and AHP. Infoflex is live and always updated. The Trust feel that the CNSs should have the advanced communication skills to be able to have the conversation at diagnosis without asking traumatic questions.

The breast pathway is more structured than others and there are three points in the pathway where HNA is undertaken. HNA is always reviewed before chemo and surgery.
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

Dartford Gravesham and Swanley and Medway CCG were aware of the HNA but were not aware of any specific work being done.

All Trusts use Holistic Needs Assessment or Care Planning in some form. Only Dartford and Gravesham reported consistent use of the HNA with a standard template across all tumour groups, the Community Cancer Nurse has been supporting the Trust in delivering the HNA to patients in their home.

<table>
<thead>
<tr>
<th>HNA/eHNA</th>
<th>Dartford and Gravesham NHS Trust</th>
<th>Medway NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standardised HNA and CP</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>for all tumour groups?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial use of HNA and CP</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>in some tumour groups</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Last Year some CNS in Medway had incorporated HA into initial patient paper documentation assessment but this was not consistent practice across all tumour sites and they were planning for eHNA training in April 2015.

However, the use of the Macmillan paper based system did not go to plan and the system was not a success associated with the administration of the paperwork. The Trust would like to go over to an electronic based HNA which would make it much easier to transfer paperwork to GPs via email. In order to do this there needs to be a change to the Infoflex system, however, this is a database accessed by more than one site. A neighbouring hospital is hoping to come over soon to demonstrate other versions of doing the HNA.
At Dartford and Gravesham NHS Trust a weekly Supportive Care MDT has been established which is chaired by the Psychosocial Social Worker. This mandatory meeting is attended by the CNSs, chaplain, dietician, Trust Grade doctor for oncology, palliative care consultant, community cancer nurse who has good links to primary care and the Supportive Care MDT support worker. The focus is the patients’ holistic needs (social care needs, emotional support, benefits advice, counselling, referrals to support services) and a separate MDT is held for patients’ medical needs. This meeting has proven to be extremely valuable in ensuring that the patients’ needs are being met not just medically. The workforce which might have shied away from asking difficult questions are getting more adept at meeting patients’ needs and questioning their own abilities. The teams have learned a lot since these meetings were launched and this has been facilitated by peer support.

At Dartford and Gravesham NHS Trust the breast pathway is more structured than others and there are three points in the pathway where HNA is undertaken. HNA is reviewed before chemo and surgery.

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. Medway were due to have eHNA training, however, this has not happened and they are not keen on taking up again if the Info flex system can be adapted to do the HNA as part of the internal system. This will require a multiagency approach to adapting the Infoflex system.

**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.
Treatment Summary

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.

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

In Medway the local Macmillan GP started to work on Treatment Summaries, however they were waiting for some changes to take place in the Acute Trust and this did not get implemented. There is now a new Macmillan GP who hopes to pick this up again.

Implementation of Treatment Summaries

In Medway Maritime Hospital there is no consultant lead for this piece of work and this means that there is uncertainty about who is responsible for them. At the moment the CNS are doing them with a degree of success, and they recognise the
importance of the T/S to GPs in the CCR, however, it was felt that much of the information would be much better coming from the medical staff.

Again, much like the HNA, there needs to be a technical solution via Infoflex to ensure consistency of the approach. With emphasis on other parts of the recovery Package T/S was unlikely to a priority within this year.

<table>
<thead>
<tr>
<th>Treatment Summaries</th>
<th>Dartford and Gravesham NHS Trust</th>
<th>Medway NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>Used for all Tumour Groups</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Used in Some tumour Groups</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Planned</td>
<td></td>
<td>No</td>
</tr>
</tbody>
</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

DGS CCG – There is currently no formal Health and Wellbeing programme over and above that covered in previous projects, however there are plans to address this. The greatest barrier to this is funding. DGS were keen to talk to other CCGs where this has been implemented to find out how it works and where he finding comes from.
**Medway CCG** – There is currently no formal Health and Wellbeing programme. There used to be as per 2008 plan, however, these stopped (see appendix).

<table>
<thead>
<tr>
<th>Health and Wellbeing Events</th>
<th>Dartford and Gravesesham NHS Trust</th>
<th>Medway 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>

**Secondary Care H&W Events :**

At Medway NHS Trust they are keen to look at health and Wellbeing events however there is a lack of financial input and there is not staffing capacity to organise it. They would be interested in working with their CCG to hold a joint event.

**D&G** - At Queen Mary’s hospital in Sidcup the gastroenterology and breast CNSs run a ‘Health & Wellbeing Session’ for patients post treatment. The patients are given advice, exercise leaflets and their next appointments. This pilot will be evaluated in 6 months.

**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 Engagement – Kent and Medway Cancer Collaborative supports the CCG and Trusts across Kent and Medway to facilitate the Cancer Action Groups. The Cancer Action Group is a partnership between patients and carers who want to use their experience of cancer services to work alongside professionals from the Trusts, CCG and voluntary sector to contribute to future services. The Cancer Action Group will be key when implementing The Recovery Package.

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

Medway Trust have not implemented any specific work on stratified pathways.

Swale CCG have recently written a plan to implement stratified pathways. This will be developed over time.

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 Error! Bookmark not defined.

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/](http://www.ncsi.org.uk/)

Recovery Package.

Website: [www.ncsi.org.uk/what-we-are-doing/the-recovery-package/](http://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:

Recovery Package


**NHS England**
Website: [www.england.nhs.uk/ourwork/cancer/](http://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
Bibliography


NHS Improvement. (June 2013). *Innovation to implementation: Stratified pathways of care for people living with or beyond cancer- A “how to guide”*

NHS Innovation - Cancer. (March 2012). *Stratified pathways of care...from concept to innovation*.

Quality, N. I. (Sept 2013). *Stratified cancer pathways: redesigning services for those living with or beyond cancer*. 
SE Clinical Senate. (June 16). *Re-designing community based pathways to improve care and reduce the unnecessary use of Acute hospitals (Interim Report).*

**Glossary**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
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<tbody>
<tr>
<td>CCG</td>
<td>Clinical Commissioning Group</td>
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<tr>
<td>CCR</td>
<td>Cancer Care Review</td>
</tr>
<tr>
<td>CNS</td>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td>H&amp;WB</td>
<td>Health and Well Being</td>
</tr>
<tr>
<td>HNA / CP</td>
<td>Holistic Needs Assessment &amp; Care Planning</td>
</tr>
<tr>
<td>KSS</td>
<td>Kent, Surrey and Sussex</td>
</tr>
<tr>
<td>LTC</td>
<td>Long Term Condition</td>
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<tr>
<td>NCSI</td>
<td>National Cancer Survivorship Initiative</td>
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<td>RP</td>
<td>Recovery Package</td>
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<tr>
<td>CN</td>
<td>Clinical Network</td>
</tr>
<tr>
<td>TS</td>
<td>Treatment Summary</td>
</tr>
</tbody>
</table>
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, PN
- 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?
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
MEDWAY

‘LIVING WITH and BEYOND CANCER’

PROJECT.

Christina Belcher

Macmillan Cancer Information and Support Service Manager
Table of Contents

Introduction ............................................................................................................. 2

Task 1: Determine an appropriate ‘End of Treatment’ model to support individuals coming to the end of their cancer treatment ......................................................... 2/3

Task 2: Pilot Project .............................................................................................. 3/5

Task 3: Evaluation of the Pilot Project ................................................................. 5/11

Additional information ......................................................................................... 12

Appendices ........................................................................................................... 13/22
MEDWAY ‘LIVING WITH and BEYOND CANCER’ PROJECT.

Introduction

The NHS Medway ‘Living With and Beyond Cancer’ (LWBC) project commenced in September 2008 as collaboration between NHS Medway, Kent and Medway Cancer Network, Macmillan Cancer Support, Medway NHS Foundation Trust and Medway cancer patients.

From 2008-2010 a steering group developed the following initiatives:

- Supported the development of a patient led support service in the community, which was subsequently disbanded through lack of attendance.
- Worked with the Kent and Medway Cancer Network to pilot holistic needs assessment and care planning tools.
- Developed a cancer Welfare Benefit Service in partnership with NHS Medway, Medway Council and Macmillan.

In July 2010, through a funding bid to Macmillan, a cancer ‘Information Service’ was established with the intention of supporting the manager of this new service to further develop the LWBC project.

A ‘LWBC working group’ was reconstituted to meet 3 monthly whilst a smaller CORE group of members met more frequently (monthly) to take forward ideas and make decisions on behalf of the ‘working group’. Within this structure the following tasks were subsequently identified and implemented:

Task 1

To set up a service whereby individuals coming to the end of active treatment are offered an “end of treatment” interview and holistic assessment of their needs and signposting to appropriate individuals / services and information.

Activities

- Existing ‘end of treatment’ models operating nationally were researched. Two particular group models were identified for further consideration:
• The HOPE group coaching and support programme for cancer survivors (Applied Research Centre in Health & Lifestyle Interventions, Faculty of Health & Life Sciences, Coventry University). HOPE is a 6 week programme aimed at “increasing individuals’ ability to manage aspects of their health through improving goal motivation and planning”. This project was researched through communication with the Macmillan team responsible for training and implementation of the group programme.

• Ipswich ‘Moving On’ Project, a self management education and training programme. ‘Moving On’ is a 4 week group programme, which “activates and empowers individuals, promoting self management skills (goal setting, action planning), improves quality of life, coping behaviour, self efficacy and symptom management” (Living With and Beyond Cancer National Survivorship vision presentation). This project was researched through strong working links being forged with the Ipswich information manager (Louise Smith) responsible for developing and implementing this model. This included a presentation by Louise Smith to the Medway ‘LWBC working group’ and a visit by three Members of the working group to Ipswich to participate in a ‘Moving On’ group session.

Outcome

✓ The self management education and training model based upon the Ipswich programme was selected having demonstrated the following benefits:

• The 4 week group programme had received very positive evaluation from individuals attending and external sources such as NHS Improvement, which had led to plans to subsequently implement the programme throughout the whole of East Anglia.

• The model incorporates an end of treatment psycho-social (holistic) assessment as part of an on-going series of assessments throughout individuals’ cancer pathway (Kent & Medway Cancer Network initiative).

• The model makes use of a personal care plan (“Management and Support Plan”) – arising from assessment of disease, treatment and personal circumstances. The care plan is completed in collaboration with individuals as part of the group programme and a copy sent to their GP with their agreement. An ‘End of treatment’ Summary is also copied to the individual and their GP.

• The model provides a key point of contact, on-going individualised support and increases patient satisfaction.

• The group programme supports a change in follow up from routine follow ups to a 3 tier risk stratified approach. The National Cancer Survivorship Initiative (NCSI) estimate that this could result in a reduction of at least 50% in outpatient appointments and a 10% reduction in unplanned admissions, allowing services to be used more effectively.
• Supports the NCSI agenda.

• The model has sufficient flexibility to be able to be adapted to the needs of individuals.

Task 2

Based on the results of Task 1, a 4 week group entitled the ‘Living With and Beyond Cancer Group’ was piloted to a small group of individuals who had reached the end of their cancer treatment.

Activities

✓ A specific tumour site was identified from which Individuals at the end of their treatment would be selected for this pilot group.

Outcome

✓ Colorectal was selected based upon the understanding that the Colorectal CNS, a member of the ‘LWBC working group’ and therefore fully versed in the requirements of the project, was able to obtain the approval of the Colorectal MDT, which was crucial to the successful implementation of this new way of working.

A small group of 6 individuals was selected for this pilot group (3 men and 3 women) and consisted of individuals who remained anxious 2/3 years post treatment and individuals who had more recently ended treatment for Bowel/Rectal Cancer; 2 of the individuals had stomas.

Activities

✓ The ‘CORE’ Group was tasked with researching and selecting an appropriate ‘Holistic Assessment Tool’ for use, not only with this pilot group but for cancer services generally as this had been on the Kent and Medway Cancer Network Agenda for some time. The following assessment tools were identified and circulated to the ‘LWBC working Group’ and all cancer services professionals for feedback:

• ‘Patient Concerns Checklist’ – provides a brief bio-physical-social-spiritual (holistic) assessment of individuals at any stage through their treatment or once cancer treatment has ended and encourages identification of services and resources that may help to
resolve the individual’s concerns (by Dr Elaine Johnstone, Psychosocial Lead, Kent and Medway Cancer Network, February 2010).

- SPARC – A screening tool designed to improve access to palliative care (The University of Sheffield, August 2007).

- Pepsi Cola Aide Memoir – An holistic common assessment of supportive and palliative care needs for adults with cancer (Prof Alison Richardson, March 2007; NICE – Supportive & Palliative Care Improving Outcomes Guidance, 2004)

Outcome

✓ The ‘Patient Concerns Checklist’ (Appendix A) was selected as the most appropriate tool for this Project as its use could be implemented generally throughout individuals’ cancer pathway, the recommendation being at critical points i.e. at the beginning, middle and end of treatment. A second consideration was that the tool had been successfully trialled by the breast care CNS’s who had reported it to be helpful in identifying individuals’ concerns.

Activities

✓ Copies of supporting paperwork (care plan and end of treatment summary) used in the Ipswich Survivorship Project was circulated to the ‘LWBC working group and all cancer services professionals for feedback and selection for this pilot project.

Outcome

✓ A Medway ‘Management and Support’ Plan was developed in response to feedback and to meet the requirements of Medway patients (Appendix B). The suggested format and content of a ‘Treatment Report Summary’ developed by GP Macmillan Advisors was also selected for use with this pilot project (Appendix C).

Activities

✓ A range of professionals were invited to develop a 4 week group programme based upon the Ipswich group model.

Outcome
The agreed group programme was facilitated throughout the 4 week period by the Macmillan information manager with ‘guest speakers’ presenting individual sessions. A leaflet was produced to illustrate the programme (Appendix D) and sent to the selected group members.

Activities

Available locations and possible timings for the pilot group were researched.

Outcome

The group was held on Thursday evenings throughout June from 4.45 – 7.15pm in Medway Maritime Hospital’s Postgraduate Centre, Common Room. This decision was based on the following factors:

- The Postgraduate Centre was accessible to both guest speakers and group members, could be booked in advance for evening meetings and had no cost implications. Furthermore parking was easily accessible at this time and free car parking authorisation could be obtained from Security for group members.

Task 3

The ‘Living With and Beyond Cancer’ Pilot Group outlined in Task 2 was evaluated by building in a space for verbal feedback on each of the sessions and by completion of evaluation forms (5/6 group members completed all questionnaires). Guest speakers were also invited to provide written/verbal feedback.

Activities

The evaluation forms invited feedback on the following issues:

- The venue and timing of the group sessions.
- Individuals aims and expectations and if this had been achieved.
- Relevance of the topics covered and feedback on individual sessions.
- Whether partners should be included in the sessions (all/one/none).
- How helpful peer experience and support had been.
- The most / least helpful aspect of the group programme and how it could be improved.
- What difference the group programme had made to individuals.
- How confident individuals felt that they now knew who to contact if they had any questions or symptoms.
- How confident individuals felt to manage or resolve any issues/problems/symptoms in the future on a scale of 0 – 10.
- How helpful individuals assessed the group programme to have been overall on a scale of 0 – 4.
- Additional comments invited.

**Feedback on venue and timing.**

The venue and timing of this pilot project had been largely determined by practical issues and constraints as outlined previously. However the feedback from group members demonstrated that a pleasant and informal venue distanced from clinical practice had been welcomed.

- Venue and timing were good and fitted comfortably into my routine.
- The venue was fine. I feel the meetings could have run for an extra 30 minutes to cover things more fully.
- Venue was fine, excellent really - timing was perfect and around the right time after our cancer journey with bowel cancer.
- Venue was fine. I loved being in the conservatory as it felt more relaxing less formal.
- Subjects covered were adequate but lesson time to be extended on some subjects.

However, important questions were raised from both group members and guest speakers concerning issues around timing. These have been summarised below along with the options suggested to address them:

1. Firstly, the issue was one of timing in the treatment pathway. Group members had repeatedly voiced how helpful such a group would have been earlier in their treatment and it was therefore questioned whether the group was correctly placed at the end of treatment.

**Recommendation**

As this project was specifically designed to provide information and support for individuals coming to the end of active treatment it was felt that the group programme was appropriately placed.
However, the need for further support at an earlier stage of their treatment expressed by group members may in the future appropriately be addressed by the introduction of a Medway Colorectal support group. This is a facility provided by many of the main tumour sites and open to patients and their partners at various stages of their treatment. Whilst Medway patients have access to such a support group (The Semi-Colon Club) at Maidstone, many find the distance too great.

2. Secondly, on many occasions throughout the programme guest speakers ran out of time to present everything they had planned within their allotted time slot. The question therefore arose as to whether the content should be limited or the number of weeks/sessions extended. This issue is likely to be further exacerbated in future as it is anticipated that, to meet demand for this service, the number of members invited to each group rise from 6 (pilot group) to 10. Whilst this will offer a greater variety of experiences/perspectives into the group it may not be welcomed by members:

- “Would not work so well if more than 6”.

**Recommendation**

In terms of limiting the content, group members’ response indicated that they benefited from the broad range of information provided:

- “Helpful as I learnt so much/ No need to improve the programme.
- Information I did not know about gave me a feeling of being able to manage with problems if and when they arise.
- Programme hit all the right buttons and pitched just right.
- Would have been beneficial to have a Stoma Nurse involved.
- Would have been helpful to have information about hernias but not necessary.

Therefore it would seem that the most beneficial way of addressing the shortage of time would be to extend the sessions by 30 minutes. Taking account of the needs of guest speakers, who will regularly be required to give their time, this could be more easily accommodated by planning future group sessions during the working day. As the Postgraduate Centre is only available to the group during the evening a suitable venue external to the Trust e.g. Health Living Centre would need to be researched.

---

1 Whilst some group members expressed a wish to also include information tailored to their individual needs this would make the programme unmanageable and can more appropriately be managed through signposting to appropriate services or identified and addressed during the individual’s holistic needs assessments prior to the start of the Group.
To meet the needs of those individuals who have returned to work, a limited number of evening groups could also be added to the programme throughout the year or one day events, offering a variety of workshops, could be built into the yearly programme. The latter is also an alternative means of information and support for those individuals who feel unable to join a group.

**Feedback on Aims and Expectations.**

It is envisaged that this 4 week group programme will run on a rolling programme throughout the year enabling individuals to select a time, after the end of their treatment that is suitable for them. It therefore felt important that we ascertain the range of aims and expectations individuals might bring to the group, depending upon their stage on the post treatment pathway and whether the group programme was able to meet them. Pilot group members ranged in age from 27 – late 60’s and from 3 months – 3 years post treatment; their response to this question is outlined below:

- **To gain information about my condition and the changes in my body e.g. stoma/hernia, to enable me to feel more confident to manage any difficulties in the future and know what to do about them. Also see how others were coping.** – Achieved that plus an awareness of others in the same boat.

- **More support.** – I did not know about some of the services available. I have been anxious of late and being able to talk and listen to others and gain information from professionals has been useful.

- **To meet others who have had similar experiences.** – Helped me so much in lots of different ways.

- **Confidence – Information obtained from the programme has boosted my confidence in achieving a full recovery ultimately.**

- **Hoped to gain ideas to speed up my recovery.** – Made no difference to me as I am already a very positive person.

Whilst some group members found it helpful to meet with others at different stages:

- “Speaking to other people that are further down the line was interesting. Nice to think where I might be in a year or so”

One member responded to how we might improve the programme by suggesting that:
“All candidates to be at the same stage / recovery of their treatment if possible”.

Recommendation

The evidence seemed to suggest that overall the group programme had managed to meet most of the individual members aims and expectations and this was further clarified by responses to the following question (5/6 questionnaires completed):

### Overall how helpful did you find the Living With & Beyond Cancer Group programme?

<table>
<thead>
<tr>
<th>Number of Group Members</th>
<th>Series1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very helpful</td>
<td>1</td>
</tr>
<tr>
<td>Helpful</td>
<td>4</td>
</tr>
<tr>
<td>Not Sure</td>
<td>1</td>
</tr>
<tr>
<td>Not Helpful</td>
<td>0</td>
</tr>
</tbody>
</table>

On a scale of 1 - 4. 1 being least helpful and 4 being most helpful.

1. Do you feel confident that you know who to contact if you have any questions or symptoms?

<table>
<thead>
<tr>
<th>No of Respondents</th>
<th>Series1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>6</td>
</tr>
<tr>
<td>No</td>
<td>0</td>
</tr>
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</table>

From the project’s perspective the overall aims and expectations of this group programme had been to provide information and support that would enable individuals to feel confident that they could take control of their lives at the end of their treatment. These aims were embedded in 2 specific questions and the positive responses outlined below suggest that these aims were also met:
It is interesting to note that the lowest rating was made by an individual who presented themselves at the start of the group programme as “extremely anxious and negative” and who often needed lengthy telephone conversations with her Cancer Nurse Specialist.

“I cannot express how much more positive I think”.

Living with and beyond cancer, CCG info Pack
North Kent locality
As the questions suggest, a sense of control comes from feeling that you have the tools to manage difficulties that arise and know who to contact if you need help to manage. Further evidence of the effectiveness of this group programme was therefore demonstrated by the way in which specific sessions helped group members to identify personal issues and know which services they could access to help manage them:

Example 1 – The opening session, ‘Sharing experiences‘ identified difficult feelings for one lady:

 “Talking about things brought out feelings I hadn’t realised I had or had hidden – I did not know about counselling – seriously thinking of seeing”.

Example 2 – The session ‘Where are we now? – Symptoms and side effects’ identified ongoing difficulties for one lady who is now in contact with her CNS to discuss a referral to a specialist clinic for Post Radiation Bowel Dysfunction.

Example 3 – Whilst the session ‘Sexuality and relationships’ was identified by one member as perhaps being too intimate for a group:

 “More intimate discussions should be private”

It did however prompt the same gentleman to take his concerns to the group facilitator, subsequently access further support concerning erectile dysfunction and record this observation on his evaluation form:

 (2 years post treatment) “I honestly thought it (the group) wouldn’t be any use to me, I have been proved completely wrong”.

Example 4 – The session ‘The importance of exercise, building strength & stamina & tackling fatigue’ in itself proved to be very important to a gentleman who reconsidered his decision to give up his allotment, which he loved, due to fatigue:
“Of great benefit and I learned a lot – Advice given e.g. pacing yourself, include planned relaxation periods, not to overdo things on a good day, I found extremely helpful and I will implement”.

Example 5 – ‘Managing anxiety, worries fears & stress’ enabled one young lady to share concerns relating to her employment and access support:

“I walked away from this session feeling a 1,000 times happier and confident”.

(Feedback on individual sessions not mentioned above is noted at the end of this report).

Summary

Overall the evidence highlighted in this evaluation has indicated that the basic structure of this group programme had been very beneficial to group members and successful in providing relevant information, identifying issues and concerns, signposting to other services and promoting confidence to move forward.

As a pilot it would not have done its job if it had not also raised questions and issues that need to be addressed to adapt and improve the group programme. This has been discussed throughout this evaluation and the recommendations summarised below:

1. The 4 week group programme should be made available to individuals at the end of their treatment. A rolling group programme throughout the year will allow individuals to choose the right time for them.

2. The timing of each group meeting should be extended to 3 hours to be held during daytime hours at a venue external to the hospital site.

Further comments and suggestions not included in the body of this report are noted at the end.
3. A limited number of evening group programmes offered throughout the year would enable those individuals with work commitments to attend.

4. In addition ‘Information Days’ throughout the year could be held to increase capacity and provide information to those who choose not to participate in the group programme.

5. The development of a colorectal support group to support patients and their families throughout their treatment could be considered.

Recommendations made by guest speakers and group members

1. Include volunteers that have been through the group programme and can offer another dimension of support to group members.

2. Involve more external agencies to help with the moving on process rather than reference to Health professions.

3. Consider having two main facilitators and reducing the number of guest speakers.

Feedback on sessions not mentioned in the main body of the report.

“What do we mean by ‘Living With and Beyond Cancer’:

“Handout article by the doctor in Leeds was very interesting and personally summed up my ‘post treatment’ experience and seems a good basis on which to build”.
“Management and Support Plans & Treatment Summaries”:

- Very encouraging to learn that ‘post treatment’ support, or rather the absence of it has been identified and is being acted upon”.

“Getting back to work, hobbies & activities, confidence building etc”:

- “Hobbies, activities, confidence building, I feel are the engine of the whole process – getting back on one’s feet!”

“Review of support and resources available from external agencies”:

**Macmillan Welfare Benefit Service**

- “Very interesting and know that if benefits are available if I should need them”.

**Health and Lifestyle Team**

- “Gratifying that there is more support available & easily accessible”.

**Harmony Therapy Trust**

- “I realise relaxing is a great help to recovery, so will use these methods”.

Appendix A
Patient Concerns Checklist

Using the thermometer, please circle a number that best describes how much distress you have felt in the past week, including today.

### Practical / Social Concerns:
- Child Care
- Housing
- Insurance / Finances
- Getting to places
- Work / College / School issues
- Feeling isolated
- Housework / Shopping
- Washing / Dressing
- Walking / Getting around
- Preparing meals / Drinks
- Sexual functioning

### Physical Concerns:
- Nose dry/congested
- Breathing difficulties / Coughing
- Mouth sores / Oral Health
- Eating / Drinking (swallowing)
- Nausea / Vomiting
- Indigestion
- Changes in bowel / Constipation or Diarrhoea
- Changes in urination
- Fatigue / Tiredness
- Fevers / Temperature changes
- Swelling
- Tingling in hands/feet
- Changes to skin/hair/nails
- Pain / Changes in sensation
- Poor sleep
- Memory / Concentration
- Body image
- Genital / Gynaecological
- Fertility
- Weakness
- Weight Loss
- Wound Care
- Balance
- Hearing
- Seeing
- Speech

### Emotional Concerns:
- Depression
- Foams / Worry
- Sadness / Grief
- Anger
- Panicky
- Restlessness / Unable to relax
- Nervousness
- Confusion / Understanding
- Unable to make plans
- Loss of interest in usual activities
- Too much / little information
- Conflicting / confusing information

### Family / Relationship Concerns:
- Children
- Partner
- People close to you
- Looking after parents
- Intimacy

### Spiritual / Religious Concerns:
- Loss of faith
- Loss of meaning / purpose in life
- Relating to God
- Why me?

Next, please tick any of the following concerns that have been a cause of distress for you in the past week, including today.
## Management and Support Plan

### Patient Details

**GP**

### Carer Contact Details

This Assessment was completed, in conjunction with (who helped to complete form)

<table>
<thead>
<tr>
<th>Name:</th>
<th>Title:</th>
<th>Contact Details:</th>
</tr>
</thead>
</table>

*This Management and Support Plan provides a summary of the information about your diagnosis, treatment and your ongoing follow up and supportive care requirements. The plan also provides information on the symptoms you should be aware of and act upon as well as steps that you can take to stay healthy.*
You should show this plan to the doctors, nurses and other professionals involved in your care so that they are aware of the care you are receiving or require and can update the information with your agreement if necessary.

Remember if you are at all worried you can contact your GP/ or the Macmillan Cancer Information Centre on 01634 830000

If you require access to a professional for general queries, advice or support; you should contact:

If you require access to a member of the specialist team involved in your cancer care; you should contact:

<table>
<thead>
<tr>
<th>Normal working hours:</th>
<th>Out of Normal Working Hours:</th>
</tr>
</thead>
</table>

Initial Treatment and Management Plan Summary:

You have identified the following key concerns, care needs or goals that you would like to address, improve or achieve.
Your Follow Up / Monitoring Requirements:

<table>
<thead>
<tr>
<th>The medicines that you have been prescribed need to be reviewed by:</th>
<th>Within the following specified period or stated date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your Consultant:</td>
<td>Your GP:</td>
</tr>
</tbody>
</table>

Services you have been referred to if applicable:

Further Self Management Programmes that you have been advised to access to assist your recovery:
Healthy Lifestyle Advice that has been given to you

Included as part of the ‘Living With and Beyond Cancer’ Group Programme

- Physical symptoms/side effects/body changes.
- Exercise, building strength and stamina & managing fatigue
- Diet and healthy lifestyle.
- Getting back to work/activities/ confidence building.
- Anxiety and stress management.
- General information including travel and insurance.
- Relationships and sexuality
- Review of external support and resources including financial advice, complimentary therapies and the support of the Health & Lifestyle Team.

Signs and Symptoms to look out for and seek advice on:
It is important to remember that most people will not experience any of these symptoms and that even if you do it does not necessarily mean that the cancer has come back.

Information given to you

See ‘Living With and Beyond Cancer’ Folder

- ‘Eating well after cancer treatment’
- ‘Your feelings after cancer treatment’
- ‘Travel and Cancer’
- ‘Getting Travel Insurance’

Specific information given:

Would you like a copy of this plan to be sent to your GP /Other HealthCare Professional (Pls Specify)

Yes [ ] No [ ]
<table>
<thead>
<tr>
<th>Date of Next Review</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature of Patient/ Carer:</th>
<th>Signature of Professional:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Dear Dr X

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

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

<table>
<thead>
<tr>
<th>Diagnosis:</th>
<th>Date of Diagnosis:</th>
<th>Organ/Staging</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Local/Distant</td>
</tr>
</tbody>
</table>

**Summary of Treatment and relevant dates:**

<table>
<thead>
<tr>
<th>Treatment Aim:</th>
</tr>
</thead>
</table>

**Possible treatment toxicities and/or late effects:**

<table>
<thead>
<tr>
<th>Advise entry onto primary care palliative or supportive care register</th>
</tr>
</thead>
</table>

| Yes / No |

<table>
<thead>
<tr>
<th>DS 1500 application completed</th>
</tr>
</thead>
</table>

| Yes/No |

<table>
<thead>
<tr>
<th>Prescription Charge exemption arranged</th>
</tr>
</thead>
</table>

<p>| Yes/No |</p>
<table>
<thead>
<tr>
<th>Alert Symptoms that require referral back to specialist team:</th>
<th>Contacts for re referrals or queries:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>In Hours:</td>
</tr>
<tr>
<td></td>
<td>Out of hours:</td>
</tr>
<tr>
<td></td>
<td>Other service referrals made: (delete as nec)</td>
</tr>
<tr>
<td></td>
<td>District Nurse</td>
</tr>
<tr>
<td></td>
<td>AHP</td>
</tr>
<tr>
<td></td>
<td>Social Worker</td>
</tr>
<tr>
<td></td>
<td>Dietician</td>
</tr>
<tr>
<td></td>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td></td>
<td>Psychologist</td>
</tr>
<tr>
<td></td>
<td>Benefits/Advice Service</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Secondary Care Ongoing Management Plan: (tests, appointments etc)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Required GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Summary of information given to the patient about their cancer and future progress:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Additional information including issues relating to lifestyle and support needs:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Completing Doctor:</th>
<th>Signature:</th>
<th>Date:</th>
</tr>
</thead>
</table>

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

<table>
<thead>
<tr>
<th>System 1</th>
<th>All other systems</th>
<th>Version 3 five byte codes (October 2010 release)</th>
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</thead>
<tbody>
<tr>
<td><strong>Diagnosis:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lung Malignant Tumour</td>
<td>XaOKG</td>
<td>Malignant neoplasm of bronchus or lung</td>
</tr>
<tr>
<td>Carcinoma of Prostate</td>
<td>X78Y6</td>
<td>Malignant neoplasm of prostate</td>
</tr>
<tr>
<td>Malignant tumour of rectum</td>
<td>XE1vW</td>
<td>Malignant neoplasm of Rectum</td>
</tr>
<tr>
<td>Bowel Intestine</td>
<td>X78gK</td>
<td>Malignant neoplasm of Colon</td>
</tr>
<tr>
<td>Large Bowel</td>
<td>X78gN</td>
<td>Malignant neoplasm of female breast</td>
</tr>
<tr>
<td>Female Malignant Neoplasia</td>
<td>B34..</td>
<td>Malignant neoplasm of male breast</td>
</tr>
<tr>
<td>Male Malignant Neoplasia</td>
<td>B35..</td>
<td></td>
</tr>
<tr>
<td><strong>Histology/Staging/Grade:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tumour grade</td>
<td>X7A6m</td>
<td>Tumour staging</td>
</tr>
<tr>
<td>Dukes/Gleason tumour stage</td>
<td>XaOLF</td>
<td>Gleason grading of prostate Ca</td>
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<tr>
<td>Recurrent tumour</td>
<td>XaOR3</td>
<td>Recurrence of tumour</td>
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<tr>
<td>Local Tumour Spread</td>
<td>X7818</td>
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<td>Mets from 1°</td>
<td>XaFr.</td>
<td>Metastatic NOS</td>
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<td><strong>Treatment</strong></td>
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<td>Palliative Radiotherapy</td>
<td>5149.</td>
<td>Radiotherapy tumour palliation</td>
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<tr>
<td>Curative Radiotherapy</td>
<td>XalpH</td>
<td>Radiotherapy</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>x71bL</td>
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<td>Radiotherapy</td>
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<tr>
<td><strong>Treatment Aim:</strong></td>
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<td></td>
</tr>
<tr>
<td>Curative procedure</td>
<td>Xallm</td>
<td>Curative treatment</td>
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<tr>
<td>Palliative procedure</td>
<td>XaiL3</td>
<td>Palliative treatment</td>
</tr>
<tr>
<td><strong>Treatment toxicities/late effects:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Osteoporotic #</td>
<td>Xa1TO</td>
<td>At risk of osteoporosis</td>
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<tr>
<td>---------------</td>
<td>-------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>XaELC</td>
<td>Osteoporosis</td>
</tr>
<tr>
<td>Infection</td>
<td>Xa9ua</td>
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<tr>
<td><strong>Ongoing Management Plan</strong></td>
<td></td>
<td><strong>Ongoing Management Plan</strong></td>
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<tr>
<td>Follow up arranged (&lt;1yr)</td>
<td>8H8..</td>
<td>Follow up arranged</td>
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<tr>
<td>Follow up arranged (&gt;1yr)</td>
<td>XaL..</td>
<td></td>
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<tr>
<td>No FU</td>
<td>8HA1.</td>
<td>No follow up arranged</td>
</tr>
<tr>
<td>Referral PRN</td>
<td>8HAZ.</td>
<td></td>
</tr>
<tr>
<td><strong>Referrals made to other services:</strong></td>
<td></td>
<td><strong>Referrals made to other services:</strong></td>
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<tr>
<td>District Nurse</td>
<td>XaBsn</td>
<td>Refer to District Nurse</td>
</tr>
<tr>
<td>Social Worker</td>
<td>XaBsr</td>
<td>Refer to Social Worker</td>
</tr>
<tr>
<td>Nurse Specialist</td>
<td>XaAgq</td>
<td></td>
</tr>
<tr>
<td>SALT</td>
<td>XaBT6</td>
<td></td>
</tr>
<tr>
<td><strong>Actions required by the GP</strong></td>
<td></td>
<td><strong>Actions required by the GP</strong></td>
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<tr>
<td>Tumour marker monitoring</td>
<td>Xalqq</td>
<td>Tumour marker monitoring</td>
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<td>PSA</td>
<td>Xalqh</td>
<td>PSA</td>
</tr>
<tr>
<td>Osteoporosis monitoring</td>
<td>XalSd</td>
<td>Osteoporosis monitoring</td>
</tr>
<tr>
<td>Referral for specialist opinion</td>
<td>Xalst</td>
<td></td>
</tr>
<tr>
<td>Advised to apply for free prescriptions</td>
<td>9D05</td>
<td>Entitled to free prescription</td>
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<tr>
<td>Cancer Care Review</td>
<td>Xalyc</td>
<td>Cancer Care Review</td>
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<tr>
<td>Palliative Care Review</td>
<td>XalG1</td>
<td>Palliative Care Plan Review</td>
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<tr>
<td><strong>Medication:</strong></td>
<td></td>
<td><strong>Medication:</strong></td>
</tr>
<tr>
<td>New medication started by specialist</td>
<td>XEOhn</td>
<td>Medication given</td>
</tr>
<tr>
<td>Medication changed by specialist</td>
<td>8B316</td>
<td>Medication changed</td>
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<tr>
<td>Advice to GP to start medication</td>
<td>XaKbF</td>
<td></td>
</tr>
<tr>
<td>Advice to GP to stop medication</td>
<td>XaJC2</td>
<td></td>
</tr>
<tr>
<td><strong>Information to patient:</strong></td>
<td></td>
<td><strong>Information to patient:</strong></td>
</tr>
<tr>
<td>DS1500 form claim</td>
<td>XaCDx</td>
<td>DS1500 completed</td>
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<tr>
<td>Benefits counselling</td>
<td>6743.</td>
<td>Benefits counselling</td>
</tr>
<tr>
<td>Cancer information offered</td>
<td>XaImL</td>
<td>Cancer information offered</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Cancer diagnosis discussed</td>
<td>XalpL</td>
<td>Cancer diagnosis discussed</td>
</tr>
<tr>
<td>Aware of diagnosis</td>
<td>XaQly</td>
<td></td>
</tr>
<tr>
<td>Unaware of prognosis</td>
<td>XaVzE</td>
<td></td>
</tr>
<tr>
<td>Carer aware of diagnosis</td>
<td>XaVzA</td>
<td></td>
</tr>
<tr>
<td><strong>Miscellaneous:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>On GSF palliative care framework</td>
<td>XaJv2</td>
<td>On GSF Palliative Care Framework</td>
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<tr>
<td>GP OOH service notified</td>
<td>XaltP</td>
<td>GP OOH service notified</td>
</tr>
<tr>
<td>Carers details</td>
<td>9180.</td>
<td>Carer details</td>
</tr>
</tbody>
</table>
Car parking

There is parking available in the Main Car Park adjacent to the Postgraduate Centre. In the first group session you will be given a letter, which authorises you for free parking throughout the course times. At the end of each group session you should take your letter to the Security Desk in the Main Reception along with your parking ticket and free parking will be approved.

LIVING WITH and BEYOND CANCER

A 4 week programme for people who have completed treatment for cancer

Covers issues such as managing symptoms, anxieties, worries and fears; diet and exercise; relationships and sexuality and much more.

Come and learn about techniques that can aid the process of healing, both body & mind.

Programmes run from 4.45 – 7.15 pm in the Common Room, Postgraduate Centre, Medway Maritime Hospital (opposite entrance to A & E) refreshments provided. For further information please contact Christina, Information Manager 01634 830000 extension 5941.

We look forward to meeting You.
Programme dates and topics covered

Week 1 – Thursday 9th June 4.45 – 7.15 pm.

- Welcome and introductions – Christina, Information manager
- What do we mean by ‘Living With & Beyond Cancer?’ – Christina, Information manager
- Sharing experiences of cancer - All
- Break
- ‘Where are we now?’, symptoms and side effects / body changes – Catherine, Cancer Nurse Specialist / Frances, Counsellor

Week 2 – Thursday 16th June 4.45 – 7.15 pm.

- Welcome / feedback from previous week – Christina, Information Manager
- A healthy balanced diet – Caroline and Natalie Dieticians
- Break
- Getting back to work, hobbies & activities, confidence building etc. – Sara, Occupational Therapist
- Managing anxiety, worries, fears & stress – Chris, Social Worker / Sara, Occupational Therapist

Week 3 – Thursday 23rd June 4.45 – 7.15 pm.

- Welcome / feedback from previous week - Christina, Information Manager
- The importance of exercise, building strength & stamina & tackling fatigue – Claire, Physiotherapist
- Break
- Relationships and sexuality – Sarah, Senior Sister / Irina, Cancer Nurse Specialist.

Week 4 – Thursday 30th June 4.45 – 7.15 pm.

- Welcome / feedback from previous week and completed self assessments (Management & Support Plan)
  Review of support and resources available presented by:
  - Jo, Macmillan Welfare benefits Team.
  - Break
  - Julie, Health & Lifestyle Team
  - Dawn, Harmony Therapy Trust (Holistic Therapies)
  - Feedback and evaluation.