

Transforming Cancer Services for London The Recovery Package

# A commissioning guide for London

November 2015

# Transforming London's health and care together

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# **Document History**

Date	Version	Author/s	Summary
01.04.15	0.1	Liz Price	Executive Summary, Health & Wellbeing Events, Glossary, References.
17.06.15	0.2	Liz Price	Amendments following feedback from LWBC Board.
18.08.15	0.3	Liz Price	New text re Holistic Needs Assessment, Treatment Summaries and Cancer Care Reviews
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### **Executive Summary**

#### Purpose

The purpose of this commissioning guide is to provide the context, useful resources and recommendations to London Clinical Commissioning Groups (CCGs) and Strategic Planning Groups (SPGs). This is to assist in commissioning and performance management of their local providers on the recovery package as part of the living with and beyond cancer programme.

#### Background

Currently there are two million people living with or beyond cancer England. When we talk about people living with and beyond cancer (LWBC), we are referring to the phase of the cancer pathway extending from the point of diagnosis through treatment to cure or living with indolent or advanced disease. This part of the cancer pathway also includes people who are living with the consequences of their treatment, whether they are palliative or not. The LWBC agenda does not extend into end of life care (people are considered to be approaching the end of life when they are likely to die within the next 12 months, although this isn't always possible to predict).

It is estimated that the number of people living with cancer will rise to four million by 2030. Increasing incidence is due to:

- an aging population, and subsequent higher rates of diagnosis in older people
- earlier diagnosis and better treatment, which means that people are living longer with and beyond cancer

As a result, the national and regional LWBC programme aims are to support people to <u>self-manage</u> and for CCGs to regard cancer as a long term condition. Good outcomes means not only that people survive their cancer, but that they have the best quality of life possible for as long as possible. The National Cancer Survivorship Initiative (NCSI) and the new Cancer Taskforce Strategy outlines the national strategy for LWBC. Recommendation 65 in the Cancer Taskforce Strategy states that "every person with cancer has access to the elements of the recovery package by 2020".

#### London CCGs

For London and West Essex in 2010, there were 186,600 people living with and beyond cancer (who were diagnosed in the last twenty years). This is enough to fill Wembley Stadium twice. CCG level information is available from the <u>Macmillan NCIN toolkit</u>. Each CCG has a different local approach to cancer. Some CCGs have Board members who are dedicated primary care cancer leads, while others will have this role within an Integrated Care remit. Most CCGs also have a primary care cancer lead funded by the CCG and/or charity partners eg Macmillan and Cancer Research UK.

Most CCGs also have a local cancer strategy – this may be at borough level, or it may be a collaborative of CCGs working together. NHS England (London) would like all Strategic Planning Groups (SPGs) to have a sub-regional strategy for cancer, as it is a priority nationally and regionally. Commissioning Intentions for cancer are developed each year by the Transforming Cancer Services Team (TCST) in consultation with CCG leads. They are endorsed by London's Cancer Commissioning Board (which includes directors from London Cancer and London Cancer Alliance) and via the Office of London CCGs before formal circulation to providers by local commissioners.

#### **Recovery Package**

The <u>Recovery Package</u> is a series of different interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer. The interventions are:

- Holistic Needs Assessment (HNA)
- <u>Treatment Summary</u> (TS)
- <u>Health and Wellbeing Events</u> (HWBE)
- Cancer Care Review (CCR) in primary care

These elements (see Figure 1) are part of an overall support of self-management which also includes <u>physical</u> <u>activity</u>, managing the physical and psychological consequences of treatment, <u>financial support</u> and <u>vocational rehabilitation</u>.



#### Stratified Follow-up

<u>Stratified follow-up</u> is a model of aftercare that addresses the specific clinical and personal needs of the individual

Figure 1 – Macmillan Recovery Package

living after a cancer diagnosis and also empowers individuals to self-manage their health. It also has a focus on supported self-management – providing patients with essential information about lifestyle changes that will reduce their risk of recurrence and symptoms to report to their clinical team or GP if their wellbeing changes. Currently there are three pathways where evidence is available for stratification: breast, colorectal and prostate. London Cancer and London Cancer Alliance have produced clinical pathway guidelines that incorporate stratification.

#### Consequences of treatment pathways

Cancer treatment can have both short and longer term consequences, some of which may arise years after treatment was administered. These <u>consequences of treatment</u> include physical and psychological effects, such as chronic fatigue, sexual difficulties, mental health problems, pain, urinary and gastrointestinal dysfunction and lymphoedema. Failure to identify and manage these significant late effects can impact on recovery and quality of life for the person with cancer and their carers.

#### Cancer Care Reviews in Primary Care

A holistic <u>Cancer Care Review</u> (CCR) should be carried out by the GP practice (ideally within a number of weeks after the end of active treatment). The purpose of a CCR is to support self-management and ensure an individual's holistic needs are addressed in the post-treatment phase of the pathway. It is recommended that the cancer care review provides tailored information (for example prescription exemptions, possible late effects of the disease and treatment including physical and psycho-<u>social</u> needs) and signposting and onward referrals to relevant local services. The person may benefit from annual follow up in primary care as part of a holistic, multi-morbidity review - particularly as 70% of people with cancer have at least one other long term condition.

For further information, please contact the Transforming Cancer Services TeamTel: 020 30494331Email: <a href="mailto:secsu.tcstlondon@nhs.net">secsu.tcstlondon@nhs.net</a>

### Commissioning the recovery package

The national cancer taskforce strategy (2015-2020) expects all people with cancer to have access to all of the recovery package interventions by 2020.

As per the NCSI recommendations and London's cancer commissioning strategy, the recovery package interventions have been included in London's acute commissioning intentions every year since 2012/13. Acute providers are expected to implement all interventions that relate to their services (HNA, TS, HWBE) in parallel so that patients do indeed receive a package of care. In practice, the majority of acute trusts started with implementing holistic needs assessments.

Data should be returned to London Cancer (North Central and East London trusts) and London Cancer Alliance (West and South London trusts) no later than 25 working days after month end, and using the data return templates provided by London Cancer (LC) and London Cancer Alliance (LCA).

To date, no additional investment has been provided by London CCGs for delivering the recovery package or other aspects of the Living With and Beyond Cancer programme (stratified pathways and consequences of treatment). National guidance from NCSI outlines that the recovery package and stratified pathways should be cost neutral to providers and commissioners. This is because capacity released from implementing stratified follow up pathways can be utilised for holistic needs assessment clinics, end of treatment clinics, remote surveillance and health & wellbeing events.

This guidance for London, and immiment guidance from NHS England LWBC Programme, does not contain any costings for the recovery package. Instead, Macmillan Cancer Support have commissioned an economic analysis and a report is due in December 2015.

Local commissioners may wish to work with their trusts and NHS Improvement (previously Monitor) to set a financial envelope in which to determine locally agreed tariffs for a LWBC package of care, including the recovery package and stratified follow up pathways.

Commissioners of primary care services currently pay for a cancer care review through the Quality Outcomes Framework (QOF) for primary care. Generally six QOF points are allocated to a CCR and five QOF points for including patients on the cancer register. There is no set quality standards for conducting a CCR. Instead, primary care commissioners (NHS England and/or CCGs through co-commissioning) may wish to develop a local incentive scheme for provision of holistic cancer care reviews. More information is provided later in this guidance.

#### Holistic Needs Assessment

#### Background

Effective assessment and care planning with people who have been diagnosed with cancer will help to identify their concerns and needs. Understanding the importance of addressing psychological, social, spiritual and financial support alongside physical and medical issues was first published in NICE guidance (2004)<sup>1</sup>.

When conducted at key points, holistic needs assessment (HNA) leads to early recognition and management of the consequences of treatment, improved communication between professionals within different parts of the NHS and social care, as well as providing better equity of care and patient experience.

Integral to the HNA is the care plan, which describes the agreed plan made as a result of the conversation held to address the identified concerns. This plan could include support, information, signposting and referrals to other services if required) and will support people to self manage where possible. This should minimise the risk of a crisis which can lead to emergency or unplanned care.

HNA helps healthcare professionals to move away from a "one sized fits all" approach to patient care and towards personalised care planning, which in turn facilitates supported self management and shared care.

There has been a peer review measure for the implementation of HNA since 2011. The measure states that MDTs should have an agreed list of responsibilities for each of the core CNS of the team. These responsibilities include:

- Contributing to the MDT discussion and assessment/care planning decision.
- Leading on patient and carer communication issues and coordination of the care pathway for
  patients referred to the team acting as the key worker or responsible for nominating the key
  worker for the patient.
- Ensuring that the person's wishes and needs, possibly identified through the HNA, are taken into account in the decision making process.

The offering of HNA is monitored through the national Cancer Patient Experience Survey (CPES) and through London's commissioning intentions. In the most recent CPES, almost 80% of people said that they did not receive an HNA and a written care plan.

In 2015/16, the pan London cancer commissioning intentions include a KPI for 70% of cancer patients to receive an HNA. Through local negotiations during the contracting round, this threshold may be lower for some providers, and may be included within the Quality Requirements Schedule or the Service Development Improvement Schedule of the NHS contract. The national Cancer Taskforce Strategy outlines that by 2020, all people diagnosed with cancer should receive an HNA.

#### What is included in an HNA?

The HNA tools help to identify needs and levels of distress. They might cover the following:

<sup>&</sup>lt;sup>1</sup> National Institute for Clinical Excellence (2004), *Guidance on cancer services: Improving supportive and palliative care for adults with cancer.* 

- Discussion and advice on any physical, practical, emotional, spiritual, social or lifestyle concerns raised in the assessment
- Signposting to either local or national support groups
- Information about Health and Wellbeing Clinics, education events or self management courses as available in the local area
- Referral to allied healthcare professionals for support if required
- Advice related to lifestyle eg stop smoking services
- Information or referral to an appropriate physical activity programme
- Information or referral for advice on diet and nutrition
- Referral for counselling or psychological support
- Support related to work and finance concerns
- Support for spiritual needs

The needs of carers may also be taken into account during this discussion.

This conversation will help to screen for particular areas of concern for the patient. Further discussion, onward referral and/or full assessment of the identified concerns will be necessary. However, the clinician conducting the assessment is not expected to solve all the problems identified. Concerns should be acknowledged and then either managed or signposted/referred to other services as appropriate.

London has an HNA tool which can be conducted either on paper or electronically. It is also being utilised by the hospital sites in London who are pilot sites for the national Macmillan eHNA pilot project. The HNA template includes:

- a distress thermometer,
- a concerns checklist which allows patients to identify specific concerns that they may have had in the last week and whether they wish to discuss them with a health professional
- a care plan template. This enables clinicians to record the main concerns identified with a brief summary for each one, as well as the actions required to follow up on these concerns. Both the patient and the health professional are expected to sign the care plan as a joint record.

Patients should always receive a copy of their HNA, unless they specifically ask not to. A copy should be shared with their GP (subject to obtaining patient consent). It should be included as part of the hand over whenever the key worker role is handed on. Information contained in the HNA should be summarised and provided at the end of each treatment period (please see next chapter for further information).

The London HNA tool can be downloaded from the London Cancer and London Cancer Alliance websites. Please see resources section below.

#### When should an HNA be offered?

Hospital clinicians, usually a Cancer clinical nurse specialists (CNS), normally conduct an HNA with a patient within 31 days of the patient being diagnosed with cancer. This may take place within an HNA clinic. However, there is increasing practice across the UK of HNA being conducted in the community, by clinicians and non-clinicians alike. It is often necessary to repeat the HNA (either a structured or unstructured conversation) and update the person's written care plan at key stages in the patient pathway after the point of diagnosis, including:

- Commencement of treatment
- Completion of active treatment
- Each new episode of disease recurrence

- Recognition of incurability
- Beginning of end of life
- Point at which dying is diagnosed
- Any time at the patient's request.

It is necessary to review and update the HNA, as some case studies have shown that people's needs change as they move along they treatment pathway - they often have more needs and higher levels of distress as their treatment progresses. The majority of needs were identified at the end of treatment.

HNA can be offered to people in a variety of ways: in clinics with a qualified health care professional carrying out the resultant conversation and care plan, by the clinic staff (doctors, nurses, AHPs), with by a volunteer who assists the person to complete an HNA template prior to the conversation with a health care professional, or, by someone in a community service (eg a Macmillan support worker, social worker or community oncology CNS). Paper versions may be completed at home and returned at the next appointment to provide the basis for the care-planning conversation. The care planning discussion may happen at the same time as the HNA, or it may take place in the next appointment. Alternatively it may be completed over the telephone after the appointment when the HNA was completed.

#### What are the main concerns that people have?

During 2014 and 2015, Macmillan has been piloting an electronic HNA (eHNA) tool across the UK, of which there are twelve London Trusts participating. National data published by Macmillan shows that the top ten concerns for people are:

- 1. Worry, fear or anxiety
- 2. Tiredness / exhaustion or fatigue
- 3. Sleep problems / nightmares
- 4. Pain
- 5. Eating or appetite
- 6. Anger or frustration
- 7. Getting around (walking)
- 8. Memory or concentration
- 9. Hot flushes / sweating
- 10. Sore or dry mouth

Earlier in 2015, TCST and the London Mental Health Strategic Clinical Network (SCN) produced guidance for commissioners on psychological support for people living with cancer. This guidance includes a number of recommendations that support the emotional and psychological needs of people with cancer – including holistic needs assessments for every person with cancer, as well as advanced communication skills for all key workers (CNS and AHPs). The TCST has agreed to establish a task and finish group with key stakeholders to focus on delivery against the recommendations.

From late 2015, the TCST will be leading a project to produce guidance for commissioners on the physical consequences of treatment which will support a regional response to the concerns identified by patients. An interim Rehabilitation Clinical Lead was appointed in September 2015 and planning has commenced to scope commissioning for lymphedema. More information will be available for commissioners during 2016.

#### Information, Support, Signposting and Onward Referrals

We know from the national CPES that people do not always feel that they have the right information for their needs. NHS Choices' Information Prescriptions Service provides information on all aspects of different cancers and many other conditions.

Cancer Patient Information Services are also present on all London hospital sites, although they do vary in opening hours. These are often staffed by a trained Macmillan Information lead and may also have volunteers. There are other holistic support services available in London, for example the Macmillan Cancer Centre at UCLH, the Mulberry Centre at West Middlesex Hospital and the Maggie Centre at Charing Cross. The TCST & MH SCN commissioning guidance includes a list of information centres across London.

Professionals who conduct HNA with patients benefit from access to a local directory of services that includes contact details for relevant services for onward referral or signposting and signposting to services. These should include services physical, psychological, social, spiritual and financial support. These services are will be currently provided by an array of providers in the NHS, councils, third sector and other organisations.

From April 2015 under the Care Act (2014), local councils must have good information to help people choose the right care and support. Councils must give information and advice to everyone who wants it, not just people who have their care and support paid for by the council. In response to this, councils have service directories online that service users and health professionals can access for signposting and onward referral. A list of the London borough websites is provided in Appendix A.

#### Resources

- NCSI guidance <u>http://www.ncsi.org.uk/what-we-are-doing/assessment-care-planning/holistic-needs-assessment/</u>
- London HNA tool <u>http://www.londoncancer.org/media/79850/London-Holistic-Needs-Assessment\_print-version\_v2.2\_HW.pdf</u>
- NHS Choices information prescriptions <u>http://www.nhs.uk/IPG/Pages/IPStart.aspx#</u>
- London Cancer directory of services <u>http://www.londoncancer.org/cancerprofessionals/directory-of-services/</u>
- London Cancer provide HNA training events for CNSs and AHPs who act as key workers for people with cancer in North Central and East London
- London Cancer Alliance HNA Fact Sheet
- Macmillan's sharing good practice guide -<u>http://be.macmillan.org.uk/Downloads/CancerInformation/SGPwinter2012hna.pdf</u>
- Macmillan information regarding eHNA - <a href="http://www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogram">http://www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogram</a> <u>mesandservices/RecoveryPackage/ElectronicHollisticNeedsAssessment.aspx</u>
- TCST & MH SCN commissioning guidance on psychological support for cancer patients
   <u>http://www.londonscn.nhs.uk/publication/psychological-support-for-people-living-with-cancer</u>

#### Treatment Summaries

#### Background

The Treatment Summary (TS) is completed at the end of primary treatment (either active or palliative treatment) by the hospital and sent to the patient's GP Practice with a copy offered to the patient. It was developed to support improved communication between acute cancer services and primary care during a time of transition for patients.

Primary care clinicians (GPs, practice nurses, allied health professionals) will use the TS to inform individual Cancer Care Reviews (CCRs) with their patients. Patients will use the TS so that they can take a more active role in the management of their own health. The TS will also be useful for other clinicians particularly in Emergency Departments, for unplanned emergency admissions, hospices, day centres and care homes.

The TS is not intended to be, and should not be considered, a substitute for other written (eg a discharge summary) or verbal communication, physical examination and history, or review of the complete medical record.

The TS template includes:

- details of diagnosis including READ codes for both diagnosis and treatment so that the GP can update their patient database and cancer register.
- indication on whether the patient should be added to the primary care palliative or supportive care register
- possible short-term treatment toxicities and side effects, including when urgent review is indicated
- information about the consequences /side effects of treatment
- alert symptoms that require referral back to specialist team: i.e.
- signs and symptoms of recurrence
- any required GP actions to monitor/support the individual for the GP
- summary of information given to the patient about their cancer and future progress:

The National Cancer Survivorship Initiative (NCSI) produced a TS template and user guide to support implementation. Both London Cancer and London Cancer Alliance have recommended that their partners/members utilise the NCSI template. It is available electronically on the two main cancer information systems in London: Somerset Cancer Register and InfoFlex Cancer Information Management System.

The TS template was thoroughly tested and positively evaluated by both GPs and oncology clinicians through the NCSI programme in 2010. Results showed that 80% of GPs found the template useful or very useful and 90% wanted its use continued. It can replace or be sent alongside the standard clinic letter. It may also be used when there is a referral from secondary care to palliative care for symptom control.

In 2015/16, the pan London cancer commissioning intentions include a KPI for 70% of cancer patients to have a Treatment Summary which is sent to their GP. Through local negotiations during the contracting round, this threshold may be lower for some providers, and may be included within the Quality Requirements Schedule or the Service Development Improvement Schedule of the NHS contract. In 2016/17, we expect Treatment Summaries to be shared with GP practices and patients within 48 hours of completion, preferably electronically. The national Cancer Taskforce Strategy outlines that by 2020, all people diagnosed with cancer should receive a treatment summary at the end of primary treatment.

#### What constitutes the "end of primary treatment"?

In Macmillan's (2015) *Treatment Summary: Sharing Good practice guide*, the end of primary treatment for an individual patient is when:

- The planned treatment for their cancer (surgery, chemotherapy, radiotherapy or a combination of these) has been completed, AND
- A clinical outcome has been achieved and no further treatment is planned (this will depend on cancer type, its stage and biology), OR
- Ongoing maintenance or hormonal treatment may be required

Clinical outcomes include whether the patient may be: cured, at variable risk of relapse, or have achieved a partial response with an anticipated period of disease stability thereafter. There may be specific ongoing prescribing requirements. For some patients, the outcome of initial treatment will be poor with a limited prognosis and referral to palliative and supportive care is appropriate.

#### Completing a TS

The patient should have undergone a process of "formal" post-treatment assessment from a clinician, such as a nurse or specialist doctor, usually provided during an end of treatment clinic. As cancer patients may be treated in more than one hospital, the TS should be completed by the hospital team where the primary course of treatment was given. Some sections of the TS will be appropriate for the nurse to complete, others will need to be completed by a doctor.

There are three styles that may be used – a standard template, or a structured letter or an electronic solution. Some information can be automatically populated from Somerset and Infoflex and then once fully completed, the TS can be added to the patient's electronic record (Somerset –<u>CancerReg@SomersetHIS.nhs.uk</u>, InfoFlex - <u>http://www.infoflex-cims.co.uk/cims/contact/</u>).

#### Sharing the TS with GP practices

NCSI's (2011) *Treatment Summary revised user guide* outlines a number of standards. One of these is that the TS should be completed promptly and sent to both patient and GP practice within six weeks of the end of primary treatment. The NCSI also suggests that the end of treatment clinic should be within four weeks following the end of active treatment.

Upon receipt of the TS, GP practices should ensure that the patient's details are entered onto appropriate monitoring and review surveillance systems. Relevant information should also be uploaded to primary care IT systems using appropriate READ codes.

#### Resources

- NCSI guidance <u>http://www.ncsi.org.uk/wp-content/uploads/NCSI-treatment-summary-2.pdf</u>
- NCSI user guide including recommended practice (p3) <u>http://www.ncsi.org.uk/wp-content/uploads/Treatment-Summary-User-Guide2.pdf</u>
- NCSI project evaluation <u>http://www.ncsi.org.uk/wp-content/uploads/TS-Summary-</u> <u>Review.pdf</u>
- Macmillan's sharing good practice guide <u>http://www.ncsi.org.uk/wp-</u> content/uploads/Treatment-Summary-Sharing-Good-Practice.pdf

#### Health and Wellbeing Events

#### Background

Health and Wellbeing Events (HWBE) or Clinics are education and information events to support and enable people living with cancer and their families to take control and participate in their recovery, giving them necessary information, and promoting positive lifestyle change such as nutritional advice and encouragement to increase physical exercise. Health and Wellbeing Events are designed to help people get support that improves the quality of their lives, making these as long, healthy and active as possible.

Ideally the event would be an event covering a wide range of topics where volunteers and professionals will play key roles; running the clinics, providing information and sign posting to local services, financial advice and expert medical care. People making the shift from treatment to life after cancer can talk to a broad range of individuals, including their peers, a range of NHS clinicians (such as clinical nurse specialists, oncologists, allied health professionals etc), complementary therapists, benefits advisers and volunteers. The events should include information about healthy lifestyles (dietary advice, exercise, smoking cessation and alcohol consumption).

In 2015/16, the pan London cancer commissioning intentions include a KPI for 70% of cancer patients to attend a HWBE. Through local negotiations during the contracting round, this threshold may be lower for some providers, and may be included within the Quality Requirements Schedule or the Service Development Improvement Schedule of the NHS contract. The national Cancer Taskforce Strategy outlines that by 2020, all people diagnosed with cancer will attend a HWBE.

#### How should HWBEs be delivered?

This commissioning guide does not recommend any particular model. There are a range of models that commissioners can choose from and this list is not exhaustive. Events could be generic for all long term conditions, generic for all cancers, tumour specific, or a combination of these:

Internal NHS	External providers
One to one clinic appointment - with CNS or AHP (this would be different from an end of treatment consultation that is used to complete HNAs and Treatment Summaries, unless the appointment covers the 'core content' of an HWBE (as outlined in LC/LCA guidelines).	<i>Macmillan</i> - HOPE course
Hospital led event - led by local Information Nurse/ CNS/ AHP for example. These may be small, medium or large events.	<i>Penny Brohn</i> - Living Well with Cancer course
<i>Community led event</i> - generic long term conditions + cancer module which is delivered by the local acute team. These may be small, medium or large events.	Breast Cancer Care – Moving Forward course

Commissioners should discuss with their local providers and service user representatives to decide whether HWBEs should take place in the community or in the acute setting. Some CCGs/Local authorities already commission similar events for long term conditions and may wish to invite people with cancer into these generic sessions. If this is the case, it is recommended that CCGs invite the local acute Trust to provide specific, additional cancer

module/s so that they include short/long term consequences of treatment, signs and symptoms of recurrence etc.

Commissioners may also want a variety of models delivered in the local area. The benefits of this would be in offering choice in style to patients and their carers. Some people prefer the one-to-one support whilst some like to meet other people with similar experiences. Some people may not be able to attend multiple sessions and would prefer a "one-off" event. People should also have choice as to when they attend the event – for example it may not be a good time to go in the immediate future, but attending an event in a months' time would be preferable for them.

#### How should HWBEs be funded?

Across London, CCGs generally do not provide additional funding for HWBEs. HWBEs may attract costs for things like project management support, venue hire, catering, information materials etc. There is a range of options for funding them, including (but not limited to):

- Within the provider's existing resources
- Grant from local hospital charity
- Grant from a third sector partner
- Joint funding between local CCG and Public Health
- CCG funding (additional to the current contract value)

#### Resources

- NCSI has more information about health and wellbeing events <u>http://www.ncsi.org.uk/what-we-are-doing/health-and-wellbeing-clinics-draft/</u>
- LC HWBE guidelines were published in January 2015 and provides more detail about what to consider when designing a health and wellbeing event. <u>http://www.londoncancer.org/media/104131/Health-and-Wellbeing-Events-Specification-Jan-2014.-FINAL-version.pdf</u>
- LCA HWBE guidelines were published in June 2015. <u>http://www.londoncanceralliance.nhs.uk/media/100126/lca-guidance-on-health-and-well-being-events-may-2015.pdf</u>
- Macmillan has produced a "sharing good practice" report which can be purchased from their website. This includes the evidence base and case studies. <u>http://be.macmillan.org.uk/be/p-22337-health-and-wellbeing-clinics-and-events-sharinggood-practice.aspx</u>
- Penny Brohn have conducted an evaluation of their "Living Well with the impact of cancer" course

http://www.pennybrohncancercare.org/living-well-evaluation-summary/

 Breast Cancer Care conducts four-week courses in partnership with local hospitals. These courses are fully funded by BCC for breast cancer patients. <u>https://www.breastcancercare.org.uk/breast-cancer-services/information-and-support-sessions/improving-wellbeing/moving-forward-programme</u>

#### **Cancer Care Review**

#### Background

This section will be populated following publication of the TCST's Cancer As a Long Term Condition task and finish group report on holistic cancer care reviews in primary care. This is due for discussion at London's Cancer Commissioning Board in December 2015.

The TCST developed a vision for cancer as long term condition which was endorsed by the London Cancer Clinical Leaders Advisory Group and London Cancer Commissioning Board in early 2015. The vision is framed the within NHS England (London) Primary Care Transformation Programme (2015), the NCSI and integrated, long term conditions frameworks. The vision supports a long term condition management approach for cancer, with a holistic cancer care review conducted at the end of a person's active treatment phase.

In February 2015, a Task & Finish (T&F) Group was established with a membership of patients and primary and secondary health care professionals from the pan London Living with and Beyond Cancer Board to take the cancer as a long term condition work stream forward.

The T&F Group has conducted a literature scan to collate evidence of good practice for managing cancer as a long term condition and as a starting point, reviewed known CCR models. Together with collating patient and professional views of the quality outcomes of the current CCR, the objective of the work stream is to review current CCR practice and recommend a good practice model and guidance for primary care commissioners. In addition, outputs include a recommended CCR model for London, a model local incentive scheme with a range of financial options for commissioners, a package of resources for practices which include training resources, standardised patient letters, and specific guidance on conducting a *holistic* CCR and a tiered financial model for London's primary care commissioners.

A stakeholder event to launch the proposed model is scheduled for 29 October with a call for CCGs and service users to test the tools and incentive scheme as part of a full evaluation. The final report, produced by the LWBC Board's Cancer as a Long Term Condition T&F Group will bring together the evidence for comparison and using the evidence available, propose a best practice model and guidance for London. This report is due in Winter 2015/16.

#### Resources

• Evaluation of the Macmillan CCR template - <u>http://be.macmillan.org.uk/be/p-20187-</u> evaluation-of-macmillans-cancer-care-review-template.aspx

### Glossary

AHP	Allied Health Professional
CCG	Clinical Commissioning Group
CCR	Cancer Care Review
CNS	Clinical Nurse Specialist (cancer)
HNA	Holistic Needs Assessment
HWBE	Health and Wellbeing Event (or clinic)
KPI	Key Performance Indicator
LC	London Cancer (North and East)
LCA	London Cancer Alliance (West and South)
LTC	Long term condition
LWBC	Living with and beyond cancer
NCIN	National Cancer Intelligence Network
NCSI	National Cancer Survivorship Initiative
SCN	Strategic Clinical Network
SPG	Strategic Planning Group
T&F	Task and Finish group
TCST	Transforming Cancer Services Team for London

TS Treatment Summary

### **Further References**

Carers UK http://www.carersuk.org/

- Independent Cancer Taskforce (2015), "Achieving World Class Cancer Outcomes: A strategy for England 2015-2020"
- King's Fund (2013), "Delivering better services for people with long-term conditions: Building the house of care"
- King's Fund (2014), "Commissioning and contracting for integrated care"
- London Health Commission (2014), "Better Health for London"
- Lymphoedema Support Network http://www.lymphoedema.org/
- Macmillan side effects and symptoms of treatment <u>http://www.macmillan.org.uk/information-and-support/coping/side-effects-and-symptoms</u>
- Macmillan (?2011), "Cancer as a Long Term Condition: Practice Nurse Pilot Evaluation"
- Macmillan (2012), "Evaluation of Macmillan's cancer care review template"
- Macmillan (2013), "Throwing Light on the consequences of cancer and its treatment"
- Macmillan (2015), "Hidden at home: the social care needs of people with cancer"
- Macmillan (2015), "The Rich Picture: People with Cancer"
- National Cancer Survivorship Initiative (2014), "Living with and beyond cancer: taking action to improve outcomes"
- NHS England (2014), "Next steps towards primary care co-commissioning"
- NHS England (2014), "NHS Five Year Forward View"
- NHS England (2014), "The Forward View into Action: Planning for 2015/16"
- NHS England et al (2015), "Quality of life of colorectal cancer survivors in England"
- NHS England & Coalition for Collaborative Care (2015), "Guidance on delivering personalised care and support planning: the journey to person centred care (supplementary information for commissioners)"
- NHS England & London CCGs (2015), "Strategic Commissioning Framework for Primary Care Transformation in London: Better Health for London – a new deal for general practice"
- Nuffield Trust (2014), "Use of health and social care by people with cancer"
- Pelvic Radiation Disease Association <u>http://www.prda.org.uk</u>
- Sexual Advice Association (formerly the Sexual Dysfunction Association) http://www.sda.uk.net/

### Appendix A London borough council advice and information websites

-	West Essex	https://www.essex.gov.uk/Health-Social-Care/Pages/Health-and-Social-Care.aspx
BHR	Barking &	http://careandsupport.lbbd.gov.uk/kb5/barkingdagenham/asch/home.page
	Dagenham	
	Havering	https://www.havering.gov.uk/Pages/Category/Adult-care.aspx
	Redbridge	http://www2.redbridge.gov.uk/cms/care_and_health/adult_social_services/advice_and_information.aspx
WELC	City of London	https://www.cityoflondon.gov.uk/services/adult-social-care/Pages/default.aspx
	Hackney	http://www.hackney.gov.uk/GoogleSearch/Hackney/results.asp?cx=013470174590691097405%3A3fbhqwd9fes&
		cof=FORID%3A11&q=Information+and+advice
	Newham	http://adultsocialcare.newham.gov.uk/Pages/I-need-help-with.aspx
	Tower Hamlets	http://www.towerhamlets.gov.uk/search.aspx?cx=008280465879053608327:251xeiiz6ey&cof=FORID:11;NB:1&ie
		=UTF-8&q=Information%20and%20advice
	Waltham Forest	http://www.walthamforest.gov.uk/az-older-people Site currently being updated
SEL	Bexley	http://www.bexley.gov.uk/index.aspx?articleid=4133
	Bromley	http://www.bromley.gov.uk/info/200050/help for adults/117/adult social care support/2
	Greenwich	http://www.royalgreenwich.gov.uk/info/100010/health_and_social_care
	Lambeth	http://www.lambeth.gov.uk/social-support-and-health
	Lewisham	http://www.lewisham.gov.uk/myservices/socialcare/adult/howitworks/Pages/default.aspx?t=4
	Southwark	http://www.southwark.gov.uk/info/200407/my_support_choices
SWL	Croydon	https://www.croydon.gov.uk/healthsocial/adult-care/asc-assessing/advice
	Kingston	http://www.kingston.gov.uk/info/200182/get_support_to_stay_independent/137/can_we_help_you
	Merton	http://www.merton.gov.uk/health-social-care/adult-social-care.htm
	Richmond	http://www.richmond.gov.uk/acs_information_and_advice_strategy_2015-2018.pdf
	Sutton	https://www.sutton.gov.uk/info/200333/adult_health_and_social_care
	Wandsworth	http://www.wandsworth.gov.uk/acis
NWL	Brent	https://www.brent.gov.uk/services-for-residents/health-and-social-care/adult-social-services/how-do-adult-social-
		services-work-in-brent/
	Ealing	http://www.ealing.gov.uk/info/100010/social_care
	Hammersmith &	http://www.lbhf.gov.uk/Directory/Health_and_Social_Care/Health_and_disabilities/Leaflets_A_to_Z/15434_Adult_s
	Fulham	ocial_care_leaflets.asp
	Harrow	http://www.harrow.gov.uk/info/200050/help_for_adults
	Hillingdon	http://www.hillingdon.gov.uk/socialcare
	Hounslow	http://www.hounslow.gov.uk/index/health_and_social_care/adult_social_care.htm
	Kensington &	http://www.peoplefirstinfo.org.uk/
	Chelsea	

Westminster	https://www.westminster.gov.uk/social-care
Barnet	https://www.barnet.gov.uk/citizen-home/adult-social-care/advice-and-support.html
Camden	https://www.camden.gov.uk/ccm/navigation/social-care-and-health/adult-social-
	care/;jsessionid=F2362092C3C261BA5EEB3C3DE749A412
Enfield	http://www.enfield.gov.uk/info/1000000550/adult_social_care
Haringey	http://www.haringey.gov.uk/social-care-and-health/accessing-services/contact-us
Islington	http://www.islington.gov.uk/services/social-care-health/arrange-care/Pages/Assessing-your-needsaspx

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