



Cancer as a long term condition

Cancer Care Reviews and a proposed model for London

Produced by Cancer as a Long Term Condition Task & Finish Group
Part of the London living with and beyond cancer board

Transforming Cancer Services Team for London

December 2015



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This report has been split into two sections:

Section 1 is the Evidence based review of Cancer Care Review and proposed model for London

Section 2 is the evaluation of the consultation event that took place on 29th October 2015.

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Foreword



Care for patients presenting with symptoms of a potential cancer, their diagnosis and treatment, their subsequent support and follow up and end of life care are all prime examples of the need for patients, their families and carers, general practice teams, community services, secondary care and specialist services, and many others across the professions to work together and communicate effectively.

In the vast majority of cases, such care is delivered well and general practice can be rightly proud of the part it plays in ensuring the best for patients

We can always do better however, and a particular area where gaps have been identified is the time following on from discharge from treatment in secondary/specialist care – the “black hole” of living with cancer.

This review offers a way to address this need and general practices will rightly want to ensure that we rise to this challenge.

Londonwide LMCs (as the representative of GPs as providers in 27 boroughs in London) strongly endorses this initiative and calls upon CCGs to deliver the recommendations of this review, with particular emphasis on addressing the resource implications for practices in delivering this valued and valuable service.

We look forward to feeding into the proposed pilots and their evaluation and encouraging practices to participate.

A handwritten signature in black ink that reads "Tony Grewal".

Dr Tony Grewal

**Medical Director
Londonwide LMCs**

Foreword - a patient perspective



I have been offering my views and reflecting my experience of cancer care from the perspective of someone who has been affected by cancer, both in relation to my own personal experience and that of my husband. Since 2009 I have been providing those perspectives into the development of the Case for Change and the Model of Care for Cancer in London.

The launch last year of the 5 year Strategy for transforming London's cancer services was an enormous landmark and I was proud to have played some small part in its development.

There is however still work to be done in the area that was of particular concern to me, that of survivorship or living with and beyond cancer.

This was due to the experience that I had (or hadn't) and that I knew others were having (or not having) from primary care following discharge after our main course of treatment.

With the acknowledged increase in the numbers of people living with and beyond cancer that is now well known - a more integrated approach to supporting survivors was necessary.

So what was driving me to want to improve the experience of people living with and beyond cancer?

- Because of the feeling of isolation that I felt after discharge
- In my case, there was a primary care service that didn't seem to care
- I was living with the feeling that I had fallen in to a big black hole.

This was how I felt. Even though I had a relatively easy journey with no major after effects or consequences of my treatment, I still felt that because I had no support from primary care (probably magnified because my cancer was diagnosed through the screening programme) that they didn't care. No cancer care review was offered either to me or my husband - in fact we had no contact from primary care whatsoever.

I soon became aware that I was not alone. There are many others affected by cancer, particularly those who were suffering the consequences of treatment, who were experiencing the same lack of support or feeling that there was a lack of support.

I am working with my local CCG trying to raise the issue of survivorship and the part that primary care can play for patients. Talking to people affected by cancer locally we heard similar stories:

- "I have to remind my GP about my cancer drug therapy."
- "Do GPs read the hospital notes?"
- "I never see the same GP".
- "Could we have a cancer follow-up clinic at the GP surgery?"

And I still continue to hear comments about the lack of support after treatment.

There have been a number of reports and studies outlining the support needs of survivors including those suffering from late effects and the consequences of treatment which led to development of the National Cancer Survivorship Initiative's recommendations for a recovery package. The 5 year strategy for London supported the Recovery Package which includes the provision of a Cancer Care Review in primary care.

Data indicate that across London CCGs there's a 79.4% achievement of undertaking a CCR but I'm pretty sure that if you asked patients whether they were aware of having had a CCR at their GP practice you wouldn't get the same result.

As I've already mentioned, I heard nothing from my practice at any time through my cancer journey from diagnosis to treatment, from discharge and into survivorship. Even just an acknowledgement would have been nice.

I do acknowledge that many GPs and practices do offer and give fantastic support to their patients with cancer - but sadly it's not universal.

As a member of the Task and Finish Group that has worked on this 4-Point proposal for the Cancer Care Review, I'm confident that if all the elements described in this document work in an integrated and timely way, the practice and person affected by cancer should have a timely, comprehensive and collaborative CCR.

This will lead in turn to the development of a supported self-management plan, where appropriate, and a more confident and reassured person living with and beyond cancer.

A handwritten signature in black ink, appearing to read 'Bonnie D. Green', written in a cursive style.

Bonnie Green

**Co-Chair, TCST pan London Cancer User Partnership
and member of the Living with and beyond cancer Board**

Executive summary - a GP perspective

Dr Afsana Safa, Associate GP lead with Transforming Cancer Services for London



We have already begun the shift in thinking of cancer from purely an acute condition to that as a longer term condition with specific consequences and needs. In this report we intend to take that thinking one step further, particularly in the primary care arena. We have created an evidence based proposal for the cancer patient journey in primary care which fits in with current thinking around long term conditions. We would like patients, clinicians and commissioners to read this report, take note of the enhancements made to current practice and consider the recommendations going forward.

We would like patients, clinicians and commissioners to read this report, take note of the enhancements made to current practice and consider the recommendations going forward.

In the UK, cancer remains the leading cause of mortality and is a top priority nationally and in London. And the number of people affected is not insignificant. In 2010, 186,600 Londoners were living with and beyond cancer. With the incidence of cancer rising to 1 in 2 people, this number is set to rise significantly. Patients with a recent diagnosis of cancer present in primary and secondary care with increased physical and psychological needs. The Nuffield Trust have produced evidence showing fifteen months after diagnosis these patients have 60% more A&E attendances, 97% more emergency admissions and 50% more contact with their GPs than a comparable group. Macmillan have also produced evidence to show that 70% of people with cancer have at least one other long term condition.

The management of the unmet needs of cancer patients during and post-acute treatment has been captured by the National Cancer Survivorship Initiative in its Recovery Package. This comprises holistic needs assessments (HNA), health and wellbeing events (HWBE), treatment summaries (TS) and finally the Cancer Care Review (CCR) in primary care.

QOF covers the CCR in the form of an unspecified review to be done within 6 months of diagnosis. For QOF purposes there is no further guideline around the quality of this review or how it is done. A number of studies have shown patient and GP dissatisfaction with many aspects of current practice including the mode of consultation, time allocated, knowledge base and poor communication back from secondary care. With rapidly increasing workloads and many competing priorities, GPs would like to see a more structured pathway, and one which includes secondary and community care. Patients would like primary care to offer a service that caters for their long term needs and reduce the sense of being alone with their cancer after primary treatment ends.

There have been a number of projects across the UK where further guidance for the CCR has been proposed and in some cases incentivised. In this report, these have been reviewed and compared; the best practice from all taken forward into the creation of the proposed review.

Proposed 4 point model

The aim of the holistic CCR: Cancer Care Reviews are to be co-produced between the primary care clinician (GP, practice nurse or allied health professional) and the patient at the end of primary treatment. The CCR should be holistic, covering psycho-social needs, physical needs, needs of carers and support patients towards self-management. More generally, cancer can therefore be integrated within a long term conditions management approach at practice or network/federation level. Furthermore the model would complement the current QOF process. Example trigger points for CCR model for London:

- At notification from hospital confirming a new diagnosis (via 2ww, routine outpatient, screening, A&E, other primary care routes, previous diagnosis/recurrence)
- Newly registered patients with cancer diagnosis in last 5 years
- On receipt of Treatment Summary Record and /or transfer of care / discharge to community

Point 1: Patient added to cancer register (QOF CAN001 or local incentive scheme)

The purpose of a register in QOF is to define a cohort of patients with a particular condition or risk factor. In some cases, this register then informs other indicators in that disease area.

QOF registers must not be used as the sole input for the purposes of individual patient care and clinical audit i.e. call and recall of patients for check-ups, treatments etc. There are patients for whom a particular treatment or activity is clinically appropriate but they may not meet the criteria as defined by the QOF register and therefore would not be picked up by a search based solely on the QOF register. As such, although QOF registers can be used to supplement clinical audit, they should be supported by appropriate clinical judgement to define which patients should be reviewed, invited for consultation etc. to ensure patients do not miss out on appropriate and sometimes critical care¹.

Point 2: 1st intervention: First contact after diagnosis (QOF CAN003 or local incentive scheme)

- Telephone call and/or letter to patient regarding recent diagnosis with invitation for the patient to attend the practice for a (holistic) chat and to offer a holistic appointment at the end of treatment. This could be completed by GP or practice nurse.
- Template letter for primary care to send to patients who have just received a cancer diagnosis. The letter is to be tailored with the GP name, oncologist name, name of their key worker (if known), treating hospital; the type of cancer diagnosed and includes an outline of the recovery package that they should be receiving along with the Macmillan Top Ten Tips.
- Information for patient on what to expect as part of a Recovery Package with a prompt to request a key worker and HNA from secondary care if not provided by the CCR appointment. Pan London HNA to be included for reflection and reviewed at subsequent CCR. Signposting to local support groups will also be included.

¹ <http://www.nhsemployers.org/your-workforce/primary-care-contacts/general-medical-services/faqs-and-queries/qof-faqs>

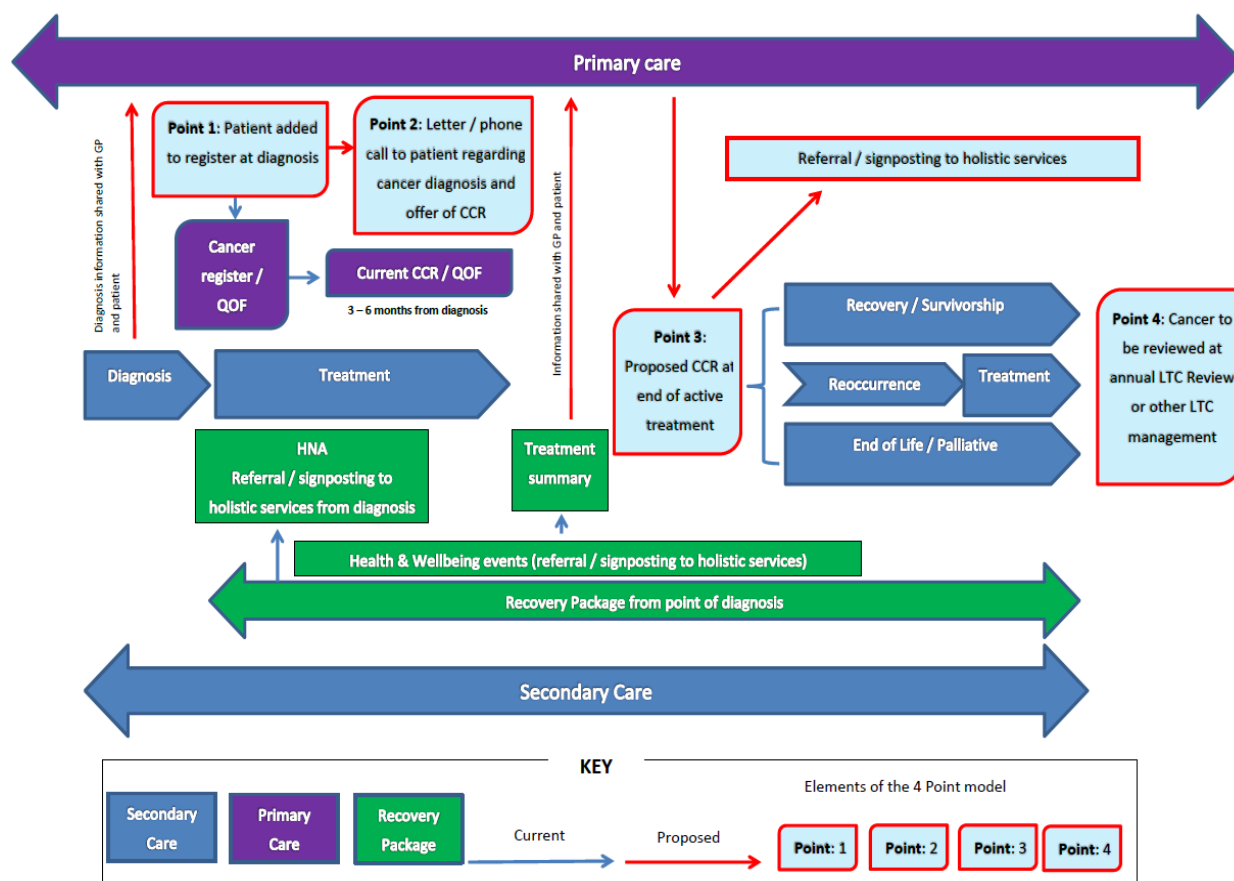
Point 3: 2nd intervention: Holistic cancer care review at the end of primary treatment
(local incentive scheme)

- Appointment triggered by a date entered into the Cancer Register and/or receipt of Treatment Summary / transfer to primary care.
- Extended consultation conducted by GP or nurse depending on complexity of patients' needs (eg double or triple appointments).
- Use of a clinical template for holistic CCR that captures whether the patient had an HNA in secondary care and their information needs. Using Treatment Summaries or discharge letters, discuss consequence of treatment and further advice on physical activity, signs and symptoms to be aware of regarding recurrence carer's needs.
- Healthcare professional to use available screening tools to conduct a psychological assessment.
- Collection of minimum data for audit
- Professionals to undertake training modules
- Patient and professional experience survey
- Primary care MDT meeting to discuss patients on register outlining care planning actions and review any Significant Event Audits (SEAs)

Point 4: 3rd intervention: Cancer incorporated and reviewed at an annual LTC Review
(QOF or generic Long term conditions local incentive scheme)

- Annual review may be for a period of time, for example up to five years, or it may be indefinite. It may also only apply to groups patients who have specific needs e.g. multi-morbidities, social risk factors, part of a local integrated care framework. Figure 4 below outlines the proportion and number of people with cancer living with other long-term health conditions
- The LTC review should include a conversation regarding the person's psycho-social and physical needs re cancer (e.g. preventing recurrence and detecting and/or managing any consequences of treatment) as well as any other long term conditions that the person may have.

Proposed Cancer Care Review Pathway



Recommendations

Recommendation for TCST

- To develop a Training and Education package for Cancer as a Long Term Condition
- Support commissioners with the delivery of the Recovery Package in particular the Treatment Summaries
- Support Strategic Planning Groups and CCGs to deliver the Cancer as a Long Term Condition agenda
- Continue to provide input in to Healthy London Partnership programmes such as Primary Care Transformation and Workforce
- Development of tools to support audit and evaluation
- Through the Cancer as Long Term Condition T&F consult with stakeholders on developments in 2016/17

Recommendations for CCGs and SPG cancer programmes

- Define cancer as a long term condition within integrated care frameworks
- Commissioning primary care to deliver high quality and holistic Cancer Care Reviews through QOF or local incentive schemes as per the 4 Point Model
- Support the delivery of education and training in primary care of cancer as a Long Term Condition
- Contribute to building the evidence based for managing Cancer as a Long Term Condition e.g. through local evaluations and other data

Recommendations under the Quality Outcomes Framework

- Accuracy data collected and maintained as part of the Cancer Register (CAN001)
- First contact with patient after notification of cancer diagnosis to offer a holistic conversation via a telephone or face to face appointment (CAN003)
- Primary care providers to use the Macmillan Cancer Care Review Template covering physical, psychological, social and financial aspects of patient and carer needs.
- Minimum 30 minute e-learning module for GPs and primary care nurses (who conducts CCRs) such as BMJ Learning and RCGP modules

Recommendations under the incentive scheme

- A named Cancer GP and named Cancer Nurse per practice (under a local incentive scheme) or per Network / Federation (under a Networked or Federated schemes)
- Primary care commissioners (NHS England and/or CCGs through co-commissioning or through a federated approach) to adopt a local incentive scheme for provision of holistic cancer care reviews at the end of primary treatment
- Long Term Conditions incentive schemes to include people affected by cancer who have specific needs e.g. multi-morbidities, social risk factors or part of the local integrated care framework
- The provision of and access to social prescribing services, Improving Access to Psychological Therapies (IAPT) and local directories of a wide range of support services etc. to be made available
- Feedback from patients should be obtained and used to develop local service delivery of Cancer as a Long Term Condition

Requirements from secondary care

- A part of the London Commissioning Intentions, copies of HNA to primary care, standardised Treatment Summaries with explicit consequences of treatment clearly outlined
- Recovery package 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).

Section 1: Evidence based review of Cancer Care Review

Introduction

There are 186,000 Londoners (including West Essex) who are living with and beyond cancer diagnosed within the last 20 years, and this number is increasing as survival rates of cancer increase². The number of people living more than 5 years from initial diagnosis is predicted to more than double between 2010 and 2030. Currently 70%³ of people who have a diagnosis of cancer have at least one other long term condition. This has led to a shift in thinking of cancer as an acute illness to a chronic one.

The National Cancer Survivorship Initiative² has highlighted the immediate and long term physical and psychological impact that cancer can have on those who have recovered. It states that many cancer survivors have unmet needs, particularly at the end of primary treatment whilst others are struggling with the consequences of treatment. The recommended 'Recovery package' model comprises four aspects: holistic needs assessments (HNA), health and wellbeing events (HWBE), Treatment Summaries (TS) and finally the cancer care review (CCR) in primary care. See 1 figure below.

Figure 1



Commissioning the Recovery Package for London

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 receive a package of care without variation.

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Methodology

The Transforming Cancer Service Team for London (TCST) developed a vision for cancer as a long term condition which was endorsed by the London Cancer Clinical Leaders Advisory Group and London Cancer Commissioning Board. The TCST is part of the Healthy London Partnership and this work stream has been designed with NHS England's (London) Primary Care Transformation strategy in mind. In February 2015, a Task & Finish (T&F) Group was established with a membership of patients, 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 work stream was project managed by the TCST.

² Macmillan NCSI Toolkit

³ <http://www.ncsi.org.uk/what-we-are-doing/the-recovery-package>

The T&F Group conducted a literature search in order to collate evidence of good practice for managing cancer as a long term condition and as a starting point reviewed known CCR models that are outlined on page 20. Together with collating patient and professional views of the quality outcomes of the current CCR, the objective of the work stream was to review current CCR practice and recommend a good practice model and guidance for primary care professionals. In addition, outputs include a recommended CCR model for London, a package of resource 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 consult on the proposed model was held in October 2015 with a call for CCGs to test the tools and incentive scheme as part of a full evaluation.

This document, produced by the LWBC Board’s Task & Finish Group seeks to bring the evidence together for comparison and using the evidence available, propose a best practice model and guidance for London.

Current Cancer Care Review

The national Cancer Care Review process is governed by the Quality and Outcomes Framework (QOF) and requires GPs to carry out a one-off cancer care review at a maximum of 6 months post cancer diagnosis. Practices can claim a maximum of 11 QOF points against two indicators for cancer outlined in Table1. The value of a QOF point for 15/16 is £160.15⁴ and payments are weighted by list size (the Contractor Population Index (CPI)) and in the clinical domain by disease prevalence.

Table1: QOF indicators for cancer

Cancer (CAN)	Indicator	2015/2016 points	2015/2016 achievement threshold
CAN001	The contractor establishes and maintains a register of all cancer patients defined as a ‘register of patients with a diagnosis of cancer excluding non-melanotic skin cancers diagnosed on or after 1 April 2003’	5	-
CAN003	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	6	50-90%

Source: Health and Social Care Information Centre

The *achievement thresholds* outlined in the last column of Table 1 is the percentage in which practices are assessed on the points achieved. The minimum percentage presents the start of the scale (i.e. for cancer, anything 50% or under will have a value of zero points); and the maximum points will be awarded to practices that achieve over 90% of the achievement threshold. If a practice achieved a percentage score that is between the minimum and the maximum set for the indicator, the practice will achieve a proportion of the points available in relation to that indicator⁵

As part of the QOF scheme, practices are required to record that a patient review has occurred within six months of diagnosis in order to achieve this indicator. However, given the importance of primary care practitioners making early contact with patients who have been diagnosed with cancer, good practice would suggest that a review should occur between three to six months of diagnosis.⁶

⁴ <http://www.nhsemployers.org/your-workforce/primary-care-contacts/general-medical-services/faqs-and-queries/QOF-faqs#1>

⁵ <https://www.gov.uk/government/publications/nhs-primary-medical-services-directions-2013>

⁶ [2015/16 General Medical Services \(GMS\) contract Quality and Outcomes Framework \(QOF\)](#)

A review of Cancer Care Reviews in Practice

An opportunistic survey of a handful of GPs that attended an unrelated training session was asked about how they currently conduct CCRs, their understanding of the Review, its purpose and how CCRs can be improved. The results ($n=15$) outlined that the majority of the responses indicated that the CCRs are conducted with a GP, face to face or via the telephone. Length of appointment times varied, from a five minute telephone call to twenty minute face to face in the surgery. Crucially, the survey outlined a need for a “structured” templates and clarity on the purpose of the CCR.

The survey also showed that there are no set clinical or patient experience standards and the current CCR review can be completed with varying quality – from a tick box exercise possibly without the patient’s knowledge, to an extended consultation using a holistic approach that included carer needs.

The opportunistic survey prompted a wider investigation on the how primary care professionals currently conduct cancer care reviews in practice. A survey was sent out to all known Cancer Lead GPs and Macmillan Leads to disseminate across their respective CCG area.

55 responses were received with a large majority of responses from GPs (48 GPs, 1 GP Registrar and 1 Clinical Director). Other responses were from primary care nurses ($n=4$) and Allied Health Professionals ($n=1$).

82% of the respondents who were all GPs said that they conduct cancer care reviews in practice. Of these:

- 74% use the QOF CCR template
- 14% use the Macmillan CCR template
- 12% didn’t know what template they used
- 53% conducted review face to face with the patient
- 41% had a mixture of face to face and telephone consultations
- 6% conducted the cancer care reviews without the patient
- 60% of the respondents said they receive a Treatment Summary from secondary care. 24% didn’t and 16% of the GPs didn’t know if they received the summary
- 33% felt their consultations catered to their holistic needs
- 37% were not holistic in their nature and 30% were not sure
- CCR appointment lengths varied greatly from 2 – 40 minutes with an average of 10-20 minutes depending on the complexity of the cases.

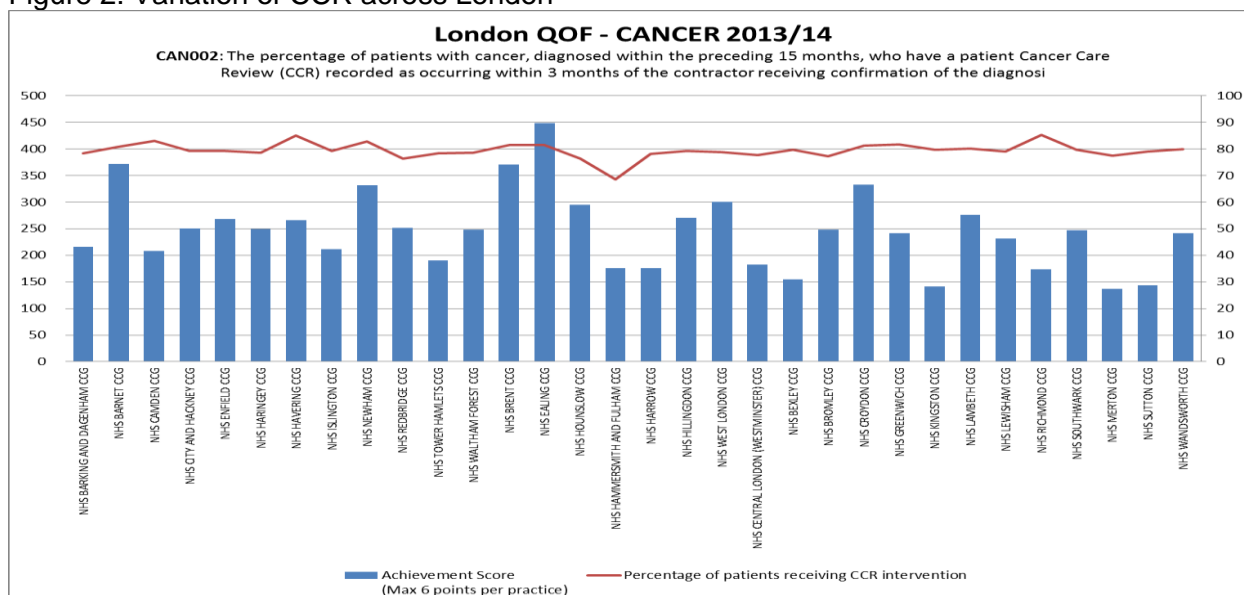
Free text questions around the purpose of the cancer care reviews showed that a large majority of the respondents (regardless if they conducted the CCRs) understood that the reviews were to highlight the needs of patients diagnosed with cancer. Interestingly as only 33% felt that their consultations were holistic, this leaves an assumption that the “needs” of the patients were more medical in nature.

Finally, when asked how the cancer care review can be improved, an over whelming majority of respondents called for a more standardized template that is not too prescriptive that can be at a multidisciplinary level. Other popular comments were around standardizing consultation so that the CCR is not “rushed”. Better quality of information from secondary care was also highlighted with comments that suggested a two-way dialogue with secondary care regarding any advice on issues raised at the CCR.

The finding of the two surveys of London-based primary care professionals show that not only is the quality of the current CCR provision under QOF variable, but so is the actual provision of the review itself. The graph in Figure 2 below shows the wide variation in completion of these reviews for patients across CCGs in London. This may be due to time and appointment

constraints, but also due to the lack of clarity of the aims of the review and what it needs to cover.

Figure 2: Variation of CCR across London



Data source: CQRS and GPES database - 2013/14 data as at end of June 2014

Case for change

Consequences of Treatment may start immediately after treatment, or years after primary treatment has finished. These consequences, such as lymphoedema, bladder, bowel and sexual dysfunction, psychological and emotional problems, cancer related fatigue can be treated very effectively (clinically and economically) if they are diagnosed early. All of these issues can be supported by primary care and the earlier they are picked up, the better outcomes for patients.

- In the UK, cancer remains the leading cause of mortality (NHS England). It is a top priority nationally and in London.
- 1 in 2 people will get cancer sometime in their life (CRUK).
- There are over 2 million people living with and beyond cancer in the UK and that this number is set to double by 2030 (Macmillan).
- In London, we expect there to be around 387,000 people by 2030 (Macmillan).
- In 2010, there were 186,600 Londoners who were living with or beyond cancer - diagnosed in the last 20 years (Macmillan).
- 70% of people who have cancer, have at least one other long term condition (NCSI).

Independent Cancer Taskforce

The Independent Cancer Taskforce in its document “*ACHIEVING WORLD-CLASS CANCER OUTCOMES: A STRATEGY FOR ENGLAND 2015-2020*” outlined in Recommendation 65.⁷

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

⁷ https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

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 agree 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 comorbidities.
- 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 on-going 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.

It is estimated that GPs have an average of eight or nine 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 long term management.⁸

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. A refined CCR represents an opportunity to address patients' holistic needs and on-going support and information requirements.

Numerous research papers show that people with cancer see an important role for primary care with regards to their diagnosis and treatment. This is particularly relevant at the point of end of initial treatment, often labelled the 'black hole syndrome'⁹ as frequent contact with secondary care reduces. But there are barriers to GP involvement. This can include time restrictions, access, lack of expertise and poor communication between secondary and primary care.

Traditional follow-up frequently fails to identify or adequately address many survivors' concerns. Aftercare needs to be planned to enable better outcomes for survivors, while using scarce health-care resources efficiently¹⁰.

⁸ <http://www.nice.org.uk>

⁹ Carolyn Preston, Francine Cheater, Richard Baker, Hilary Hearnshaw "Left in limbo: patients' views on care across the primary/secondary interface" *Quality in Health Care* 1999;8:16–21

¹⁰ Jefford M, Rowland J, Grunfeld E, Richards M, Maher J, Glaser A. Implementing improved post-treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA. *British Journal of Cancer*. 2013;108(1):14-20. doi:10.1038/bjc.2012.554.

A comprehensive assessment and treatment summary on discharge is a vital element of the Recovery Package:

- ▶ The end of Treatment Summary is worth the investment in time and when shared with GP and the person, along with any HNA. These should form the basis of an individualised, holistic self-management plan.
- ▶ This puts the person at the centre of the process and gives them the support and confidence to manage their well-being but with contingency to deal with crisis should it occur.

The T&F Group and the Living with and Cancer Board believe that the Recovery Package will go a long way to dispelling the 'black hole' and the 'cliff edge' in primary care that many people living with and beyond cancer experience. However, the information from the Recovery Package must be shared with both the patient and the GP.

The Nuffield Trust

To further support the case for change, The Nuffield Trust studied the use of primary and secondary health care and social care services of a sample size of 8,072 people with a first diagnosis of cancer from two areas of England, for a year before diagnosis and up to 18 months after, excluding activity that occurred around the time of death. They found that unplanned hospital activity peaked for most cancers in the period leading up to diagnosis, while elective admissions and outpatient attendances generally were at their highest in the three months after diagnosis.

The results show that fifteen months after diagnosis, people with cancer have:

- 60 per cent more accident and emergency (A&E) attendances
- 97 per cent more emergency admissions
- four times as many outpatient attendances
- nearly six times more elective admissions than expected

A similar pattern is seen for GP visits, with cancer survivors having 50 per cent more contact with their GPs than expected 15 months after diagnosis¹¹.

The National Cancer Patient Experience Survey (CPES)

The 2014 Cancer Patient Experience Survey showed the some of the lowest scored questions were related to support to patients with cancer and their families after discharge, provision of information about financial support, coordinated care between hospital and community services and the opportunity for patients to discuss fears and worries. London based CCGs fall considerably short of the best in England and lag behind England's average, see Table 2.

There is, however, clear evidence that patients and carers would welcome a formal cancer care review and feel it legitimises raising their concerns about their cancer and the consequences of any treatment¹².

The need for a structured consultation was highlighted in the evaluation of the Macmillan cancer care review template which showed 71% of patients surveyed reported being 'very satisfied' when GPs use the Macmillan template¹³.

¹¹http://www.nuffieldtrust.org.uk/sites/files/nuffield/140602_social_care_for_cancer_survivors_full_report.pdf

¹² Kendall, Marilyn et al. "Proactive Cancer Care in Primary Care: A Mixed-Methods Study." *Family Practice* 30.3 (2013): 302–312. *PMC*. Web. 4 Nov. 2015

¹³ <http://be.macmillan.org.uk/be/p-20187-evaluation-of-macmillans-cancer-care-review-template.aspx>

Table 2

SPG	CCG	Patient's rating of care excellent/ very good (Q70)	Satisfaction with support from GPs and practice nurses (Q64)	Satisfaction with support from health and social services post discharge (Q56)
Best in England	-	96.9%	83.3%	85.3%
England average	All England CCGs	88.5%	66.6%	58.3%
London average	All London CCGs	84.7%	60.3%	48.1%
London lowest	All London CCGs	63%	47%	23%

Source: The National Cancer Experience Survey, 2014

A comprehensive and holistic cancer care review is an important part of the cancer pathway where information, reassurance and detail of the on-going care plan is provided. Patients need to have confidence in primary care services to manage physical and psychological consequences of their cancer and treatment¹⁴ so Cancer Care Review training is very important.

Limitations of Quality Outcomes Framework (QOF)

Routine cancer care review consultations in primary care focus on the medical agenda set by QOF where the practitioner is the expert, and the patient agenda unheard. Patient needs outside the narrow protocol of the QOF review are made invisible by the process of the review except in extreme cases such as anticipating death and bereavement¹⁵.

As outlined in the *review of Cancer Care Reviews* on page 13 of this report, the quality and provision of cancer care reviews across London is highly variable. As suggested by those that conduct the reviews, a standardised more holistic template could help structure the consultation within the restricted time and resources limitations faced by primary care professionals.

There seems to be a growing national view that the value of QOF as it stands is in doubt with CCGs across the country discussing plans to replace QOF with local incentive schemes. An investigation by *Pulse* found that 150 plans from CCGs for co-commissioning of primary care, submitted last year, found that CCGs were actively looking to replace the QOF targets with incentives to offer longer appointments to patients with certain long-term conditions¹⁶ such as cancer.

¹⁴ Pascoe SW, Neal RD, Allgar VL, Selby PJ and Wright EP. Psychosocial care for cancer patients in primary care? Recognition of opportunities for cancer care. *Family Practice* 2004; 21: 437–442

¹⁵ Chew-Graham et al. How QOF is shaping primary care review consultations: a longitudinal qualitative study. *BMC Family Practice* 2013, 14:103

¹⁶ <http://www.pulsetoday.co.uk/your-practice/qof/local-scheme-to-replace-the-qof-a-success/20009612.fullarticle>

Summary of current CCR models and templates

The T&F Group took forward the TCST vision for cancer as a long term condition and collated and reviewed a number of known CCR models that try to provide more structure to this assessment in primary care. These models are outlined below and the compare and contrast of these models are presented in Table 3.

Macmillan Cancer Care Review, 2010

Following on from the QOF requirement of GPs conducting a one off 'cancer care review' within 6 months of diagnosis, Macmillan sought to clarify what this review should cover and create a template incorporated into GP IT systems. The template was the first of its kind to be designed for cancer and specifically similar to those for other chronic disease templates.

As well as details of the cancer diagnosis, this template is a holistic approach to health and covers psychosocial aspects also. It has been rolled out nationally and extensively evaluated, however the limitations include low level use by non-cancer or indeed non-Macmillan GPs.

Key learning points from the Macmillan Cancer Care Review template evaluation:

- Overall positive response from GPs and patients
- There is more of a psychological element than for other long term disease reviews
- Template can function during the consultation but most GPs prefer to use as an aide-memoire
- GP should be encouraged to mention all topics in the template
- Scheduling a specific appointment for the CCR is ideal
- Lack of timely and accurate information from secondary care is obstructive to this process
- The CCR needs to be a flexible process
- Needs to be integrated into current IT systems

Cancer On-going Review Document (CORD), 2013

In Edinburgh, a group of primary care researchers used a mixed methods study to assess the feasibility of using a structured template to provide holistic follow up of patients in primary care. An electronic template was created – CORD, which incorporated both physical and psychological aspects of care.

Key learning from the CORD study:

- Integration into IT systems is required
- Template also used as an aide memoire and patients not always aware that a formal CCR was taking place. This was thought to be appropriate in some circumstances.
- Funding was not sufficient to change practice (shows importance of consultation time and IT integration to the process)
- Suggests good evidence for incorporating into long term disease reviews going forward.
- Suggests carrying out reviews at set intervals rather than to be a one off process

Wandsworth PACT Holistic Cancer Care Review, 2014

Following on from the Macmillan template evaluation, Wandsworth CCG offered GPs to provide similar detailed cancer care reviews at yearly intervals up to five years post diagnosis. The template created is more detailed than the Macmillan model – particularly in respect to the long term effects of cancer and cancer treatment. The template is populated with electronic links for further clinical

information, and local services for signposting. Within the specification, a core payment of £67 per patient per year was provided relating to 50 minutes of GP clinical time. Patient questionnaires were also provided.

Time to talk for cancer patients via extended practice consultations, City & Hackney CCG, 2015

This model extends the QOF requirement into a 30 minute GP consultation for the cancer care review, and identifying a named GP to provide continuity of care to the patient. Although a formal template has not been created, GPs are provided with a list of key points that closely align with the Macmillan model. It also highlights Health and Wellbeing events as part of the recovery package.

Enhanced prostate cancer primary care-led follow-up, Croydon CCG, 2013-Dec 2015

In line with the National Survivorship Initiative Stratified Pathways (2012) and NICE Prostate Cancer: CG175 2014, Croydon CCG piloted a primary care-led follow-up of stable prostate cancer patients who are identified as suitable by secondary care.

The model requires a prostate cancer care review to be conducted at end of active treatment for patients stable at 2 years post treatment and the mandatory maintenance of a prostate cancer register. A holistic care plan is jointly produced between patients and primary care professions such as a primary care nurse which is to be reviewed at subsequent follow-up appointments. Payment to practices consists of a one-off £50 payment for a 30 minute appointment for newly transferred patients where a holistic care plan is co-produced. A recurrent payment of £43 per patient per follow-up appointment (20 minutes) is also included. The pilot was funded by Prostate Cancer UK in 2015/16 and Croydon CCG has continued the funding for this incentive scheme.

London Cancer / Macmillan: Supporting GP Practices to conduct Cancer Care Reviews, 2015

The aim of this quality improvement project is to improve patient experience and outcomes by supporting primary care to deliver high quality cancer care reviews in East London (WELC): Waltham Forest, Tower Hamlets, Newham and City and Hackney CCGs.

The project will work with the healthcare clinician (GP or practice nurse) in a maximum of 15 surgeries to deliver high quality cancer care reviews for patients who have been newly diagnosed with a cancer diagnosis. A key aspect of this work will be to review each surgery's current knowledge base and processes involved with conducting cancer care reviews with their patients and exploring the potential of practice nurses to conduct the CCRs. Cancer care review guidance and a GP IT system compatible template will be developed and the Practice Nurse Improvement Lead will support practices to individualise and implement. This project does not incentivise the CCR outside of the QOF.

It was noted that none of the models outlined above specifically link to the management of other long term conditions in primary care.

None of the evaluations have been able to assess whether the time invested has translated into a reduction in GP appointments, outpatient contacts or emergency presentations throughout the patient pathway.

Table 3: Comparison of know CCR models:

	Macmillan model	CORD	Wandsworth	City & Hackney	Croydon Prostate	LC /Macmillan
Trigger for review	As for QOF	On receipt of cancer diagnosis from hospital	Not specified	On receipt of cancer diagnosis from hospital	Patient identified by Consultant or GP	On receipt of cancer diagnosis from hospital
Frequency of review	After diagnosis one off review in keeping with QOF	After diagnosis, and then according to patient need	After diagnosis then yearly for 5 years	After diagnosis One off	After active treatment / transfer to primary care. 6 monthly	One off review in keeping with QOF
Consultation time	Not specified	Not specified	Not specified	Up to 30 mins	30 minute initial, 20 minute thereafter	Not specified
Clinician carrying out review	Not specified – GP	GP	GP	GP	GP/PN	GP/PN
Mode of delivery	F2F	F2F	F2F	F2F	F2F	F2F
Template available	Yes	Guidelines	Awaiting information	List	Yes	Yes
IT integration?	Yes	No	Unknown	Unknown	Yes	Yes
Training provided	Online resources	Yes	Not specified	Not specified	Yes. Accredited modules	Yes
Patient information	No	No	Not specified	Not specified	Yes	No
Incentive, governance provided?	QOF	No	Yes - £67 per patient per year. Part of PACT contract	Yes - £35 per patient	£50 for initial 30min consultation, £43.26 thereafter	QOF
Covers psychosocial and lifestyle needs	Yes via clinical template only	Yes via clinical template only	Yes via clinical template only	Yes but delivery unknown	Yes via clinical template and prostate cancer holistic care plan	Yes via clinical template and proposed holistic care plan
Patient feedback/outcomes measured	Yes	Yes	Unknown	No	Yes	Yes
Link to LTC management?	No	No direct link but signposts	No	No	No	No
Other areas of note	Rolled out nationally, incorporated into IT systems	Mixed-methods study			Supports Stratified pathways at end of active treatment	
Evaluation	Yes. National evaluation	Yes	No. Evaluation tbc	No. Evaluation	Evaluation Dec 2015	No Evaluation tbc

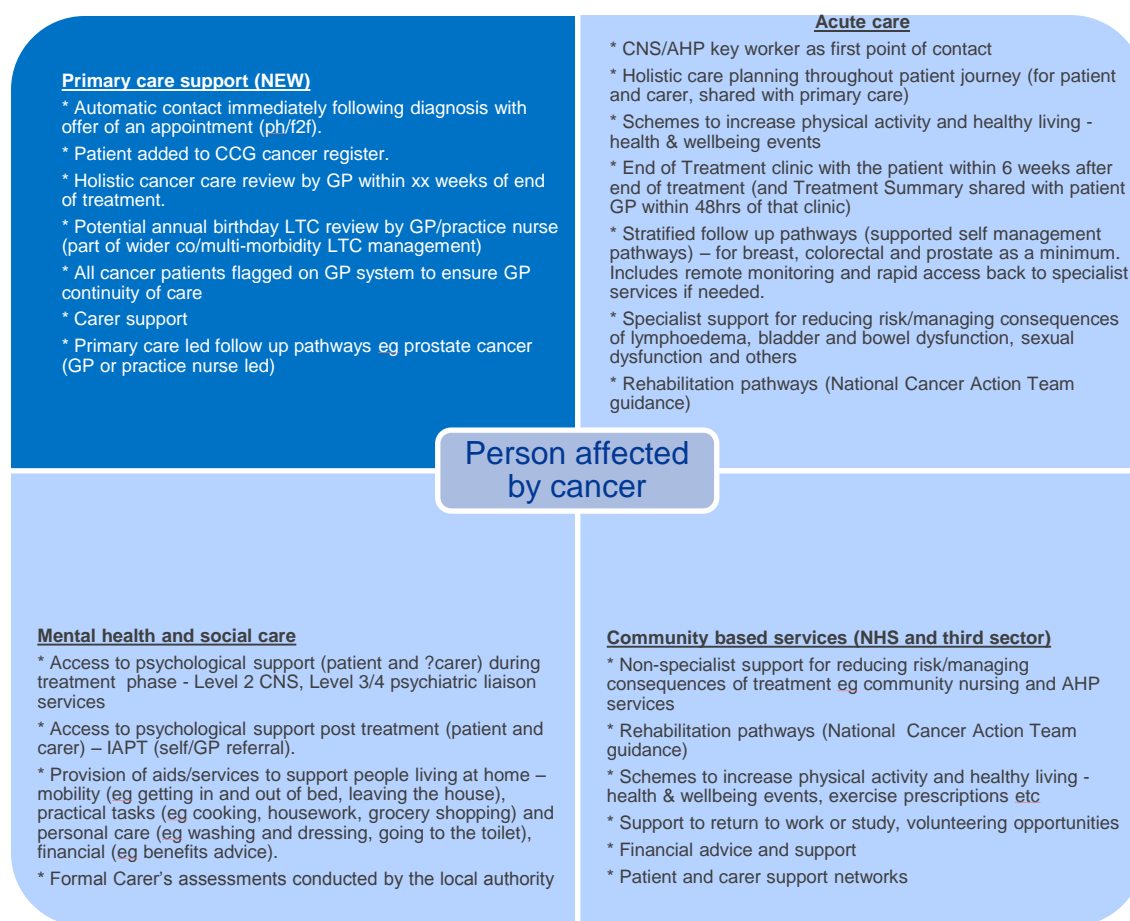
Proposed Cancer Care Review Model for London

Some patients have said that they would like proactive contact from the practice soon after diagnosis which supports the need for a CCR to be offered and conducted at the start of the patient's cancer pathway. An increasing number of patient-facing research shows that most patients felt the optimal time for this was at completion of initial treatment¹⁷. It is also recommended that patients and healthcare providers should carefully evaluate the various domains around quality of life and monitor the patterns of change within each domain after active treatment has ended¹⁸. They voiced concerns that the individualised and personalised aspects of the cancer care review in primary care should not be lost¹⁹.

After reviewing the models available, the Transforming Cancer Services Team has proposed a model that draws on the models that are available across the sector, and indeed nationally, see Figure 3 below. The model is based **around** the person affected by cancer where their personal needs are taken into account. The needs of carers are also a fundamental part of this model

Furthermore the model would complement the current QOF process and support patient centred care.

Figure 3: TCST holistic and personalised model of care for people who are living with and beyond cancer.



¹⁷ Kendall, Marilyn et al. "Proactive Cancer Care in Primary Care: A Mixed-Methods Study." *Family Practice* 30.3 (2013): 302–312. *PMC*. Web. 4 Nov. 2015

¹⁸ John P. Garofalo, PhD, Sheela Choppala, PhD, Heidi A. Hamann, PhD, and Jill Gjerde, MS: "Uncertainty During the Transition From Cancer Patient to Survivor" *Cancer Nurs.* 2009

¹⁹ Adams E, Boulton M, Rose P, et al. Views of cancer care reviews in primary care: a qualitative study. *The British Journal of General Practice.* 2011;61(585):e173-e182. doi:10.3399/bjgp11X567108.

Proposed 4 point model

Aim of the holistic Cancer Care Review: CCRs are to be co-produced between the primary care clinician (GP, practice nurse or allied health professional) and the patient at the end of active treatment. The CCR should be holistic, covering psycho-social needs, physical needs, needs of carers and support patients towards self-management. More generally, cancer *can* therefore be integrated within a long term conditions management approach at practice or network/federation level.

Trigger points:

- At notification from hospital confirming a new diagnosis (via 2ww, routine outpatient, screening, A&E, other primary care routes, previous diagnosis/recurrence)
- Newly registered patients with cancer diagnosis in last 5 years
- On receipt of Treatment Summary Record and /or transfer of care / discharge to community

Point 1: Patient added to cancer register (QOF CAN001 or local incentive scheme)

The purpose of a register in QOF is to define a cohort of patients with a particular condition or risk factor. In some cases, this register then informs other indicators in that disease area.

QOF registers must not be used as the sole input for the purposes of individual patient care and clinical audit i.e. call and recall of patients for check-ups, treatments etc. There are patients for whom a particular treatment or activity is clinically appropriate but they may not meet the criteria as defined by the QOF register and therefore would not be picked up by a search based solely on the QOF register. As such, although QOF registers can be used to supplement clinical audit, they should be supported by appropriate clinical judgement to define which patients should be reviewed, invited for consultation etc. to ensure patients do not miss out on appropriate and sometimes critical care²⁰.

Point 2: 1st intervention: First contact after diagnosis (QOF CAN003 or local incentive scheme)

- Telephone call and/or letter to patient regarding recent diagnosis with invitation for the patient to attend the practice for a (holistic) chat and to offer a holistic appointment at the end of treatment. This could be completed by GP or practice nurse.
- Template letter for primary care to send to patients who have just received a cancer diagnosis. The letter is to be tailored with the GP name, oncologist name, name of their key worker (if known), treating hospital; the type of cancer diagnosed and includes an outline of the recovery package that they should be receiving along with the Macmillan Top Ten Tips. See Appendix 1 for sample letters to patients.
- Information for patient on what to expect as part of a Recovery Package with a prompt to request a key worker and HNA from secondary care if not provided by the CCR appointment. Pan London HNA to be included for reflection and reviewed at subsequent CCR. Signposting to local support groups will also be included.

²⁰ <http://www.nhsemployers.org/your-workforce/primary-care-contacts/general-medical-services/faqs-and-queries/qof-faqs>

Point 3: 2nd intervention: Holistic cancer care review at the end of primary treatment
(local incentive scheme)

- Appointment triggered by a date entered into the Cancer Register and/or receipt of Treatment Summary / transfer to primary care.
- Extended consultation conducted by GP or nurse depending on complexity of patients' needs (e.g. double or triple appointments).
- Use of a clinical template for holistic CCR that captures whether the patient had an HNA in secondary care and their information needs. Using Treatment Summaries or discharge letters, discuss consequence of treatment and further advice on physical activity, signs and symptoms to be aware of regarding recurrence carer's needs.
- Healthcare professional to use available screening tools to conduct a psychological assessment.
- Collection of minimum data for audit
- Professionals to undertake training modules
- Patient and professional experience survey
- Primary care MDT meeting to discuss patients on register outlining care planning actions and review any Significant Event Audits (SEAs)

Point 4: 3rd intervention: Cancer incorporated and reviewed at an annual LTC Review
(QOF or generic Long term conditions local incentive scheme).

- Annual review may be for a period of time, for example up to five years, or it may be indefinite. It may also only apply to groups patients who have specific needs e.g. multi-morbidities, social risk factors, part of a local integrated care framework.

Figure 4 below outlines the proportion and number of people with cancer living with other long-term health conditions in the UK.

- The LTC review should include a conversation regarding the person's psycho-social and physical needs regarding their cancer (e.g. preventing recurrence and detecting and/or managing any consequences of treatment) as well as any other long term conditions that the person may have.

Figure 4

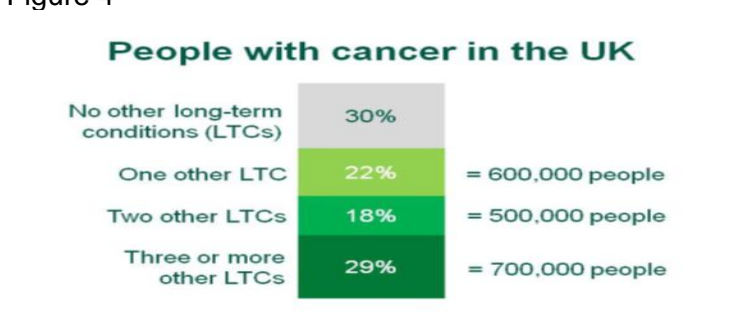
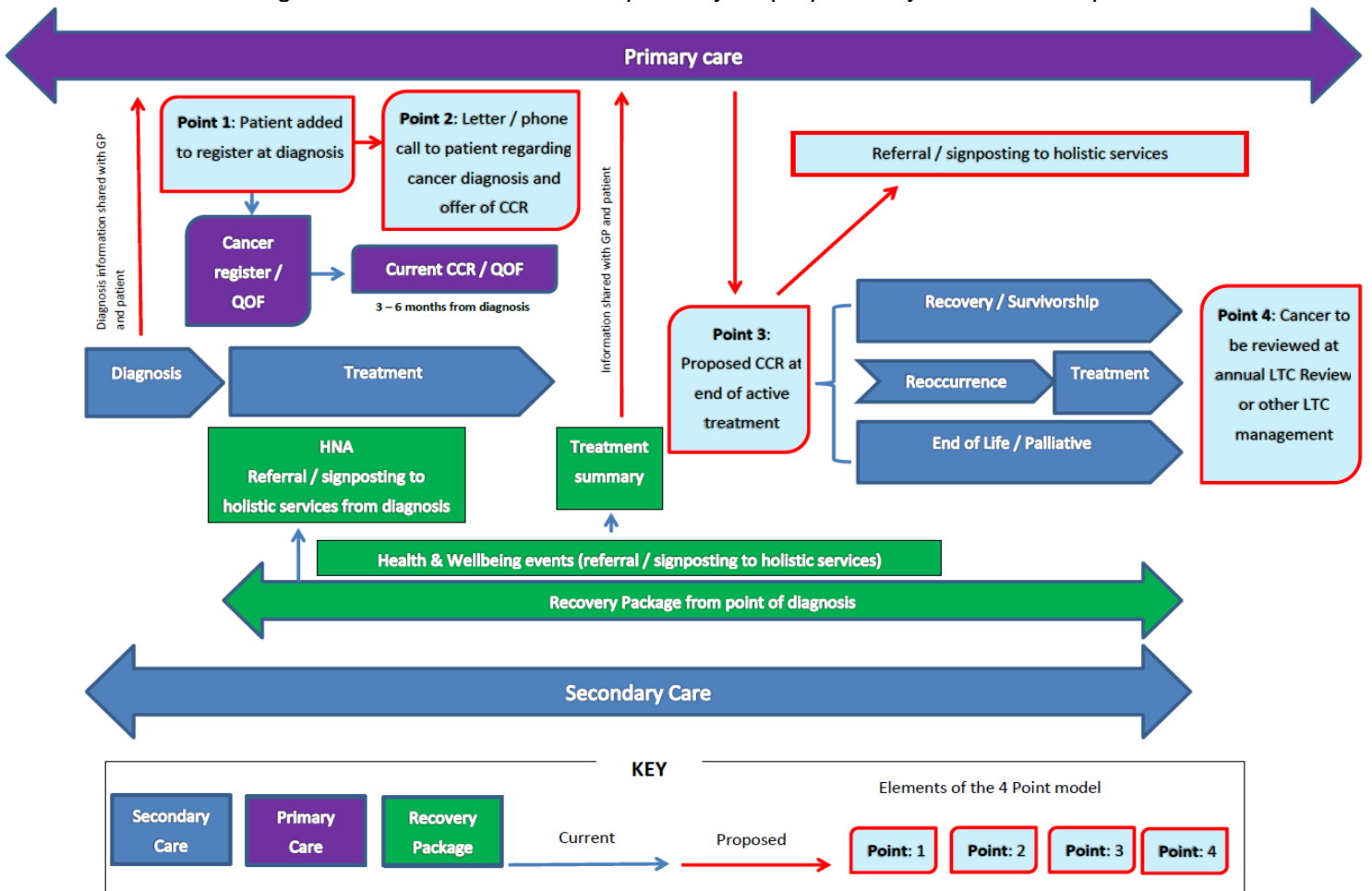


Figure 4 from Macmillan outlines the proportion and number of people with cancer living with other long-term health conditions.

This further supports the notion of cancer as a long term condition.

Figure 5: Cancer Care Review pathway as proposed by the T&F Group.



Consultation with stakeholders

The proposed 4 Point model was presented at a consultation event on the 29th October 2015 to an audience of NHS healthcare managers, Charity partners, commissioners, primary care clinicians and patients. The purpose of the event was to give delegates the opportunity to feedback on the proposed model presented above.

The agenda was split between scene setting to ensure the audience received an update on the direction of travel for the Living with and Beyond Cancer work stream and the position for London in terms of meeting the objectives set out by NHS England. This was supported by a patient guest speaker who outlined the gaps he experienced regarding the support needed whilst undergoing cancer treatment. The proposed Cancer Care Review 4 Point model was introduced by the co-Chair of the pan London Cancer User Partnership Group and presented by the TCST Associate GP and Chair of the cancer as a long term condition Task & Finish Group.

The presentations were followed by a Question & Answer session that included the four speakers and joined by the Medical Director of the Londonwide Local Medical Council. Finally, delegates were arranged into geographically-assigned discussion tables and tasked with answering three specific questions which aimed to further inform the final Cancer Care Review proposal that will be sent to the London Cancer Commissioning Board and the Cancer Clinical Leads Advisory Board.

The following 3 questions were posed and delegates had 45 minutes to discuss before feeding back to the wider group:

Q1. How would you improve the 4 point model?

Q2. What are the barriers to implementation of this?

Q3. How would the model / notion of a holistic cancer care review impact you as a patient, GP, primary care nurse or a Commissioner and what else could we be doing in primary care for patients after treatment of cancer?

Highlights of the consultation event:

- The proposed 4 Point model was well received and supported by all delegates
- More information needed on how the model will be/should be commissioned
- Guidance needed on managing patient expectations
- Need for templates and education to support primary care professionals on structuring CCR consultations
- Development of tools that can be used in primary care to screen for psychological effects of treatment
- Training modules/sessions for primary care professionals

Two immediate positive outcomes of the event:

- A commitment from Anthony Cunliffe, Macmillan GPA to work with all Macmillan GPs in London to prioritise delivering a training session on Living with and Beyond Cancer and the CCR. The TCST will work with the Primary Care Education Group to develop a package/presentation that could be run in CCGs as a priority.
- Four CCG areas have firmly expressed interest in piloting the proposed 4 point model (or a locally adapted version). The TCST will be working with these CCGs on implementation.

Please see Section 2 for evaluation report of the consultation event.

Proposed levers and incentives

Sharing of vital information

The following examples of levers and incentives could be used by commissioners to promote person centred care for people affected by cancer and to ensure flow of relevant information from secondary to primary care.

For example, in areas where a Commissioning for Quality and Innovation (**CQUINs**) payments framework encourages care providers to share and continually improve how cancer care is delivered states: 'Every patient with a cancer diagnosis will have at a minimum, a holistic needs assessment and care plan around the time of diagnosis and on completion of treatment and that a treatment summary record will be completed. These key documents will be shared with the patient's GP'.

QOF

Value of a QOF point for 15/16 is £160.15²¹ and payments are weighted by list size (the Contractor Population Index (CPI) and in the clinical domain by disease prevalence. The T&F recommend that CAN001 and CAN003 QOF incentives should continue and would form the basic level of incentives at practice level.

Local Incentive Scheme tariffs

Incentivised model based on LMC costs for GP and Practice Nurse Appointments.

Evidence supports incentives to practices (for double appoint)²² it's well known that most of the improvements in care associated with the introduction of QOF had occurred by 2004 – after that improvements largely plateaued.²³

2014 LMC tariff:

- GP cost 20 minute appointment £43.26
- Practice Nurse cost 20 minute £15.87

Recovery Package

No additional investment has been provided by 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.

Local commissioners may wish to work with their trusts and 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.

Recommendations

Recommendation for TCST

- To develop a Training and Education package for Cancer as a Long Term Condition
- Support commissioners with the delivery of the Recovery Package in particular the Treatment Summaries
- Support Strategic Planning Groups and CCGs to deliver the Cancer as a Long Term Condition agenda
- Continue to provide input in to Healthy London Partnership programmes such as Primary Care Transformation and Workforce

²¹ <http://www.nhsemployers.org/your-workforce/primary-care-contacts/general-medical-services/faqs-and-queries/QOF-faqs#1>

²² Mark J Harrison, Mark Dusheiko, Matt Sutton, Hugh Gravelle, Tim Doran, Martin Roland Effect of a national primary care pay for performance scheme on emergency hospital admissions for ambulatory care sensitive conditions: controlled longitudinal study. *BMJ* 2014;349:g6423 doi: 10.1136/bmj.g6423

²³ Stephen M. Campbell, David Reeves, Evangelos Kontopantelis, Bonnie Sibbald, Martin Roland, D.M. Effects of Pay for Performance on the Quality of Primary Care in England. *N Engl J Med* 2009; 361:368-378 July 23, 2009 DOI: 10.1056/NEJMsa0807651

- Development of tools to support audit and evaluation
- Through the Cancer as Long Term Condition T&F consult with stakeholders on developments in 2016/17

Recommendations for CCGs and SPG cancer programmes

- Define cancer as a long term condition within integrated care frameworks
- Commissioning primary care to deliver high quality and holistic Cancer Care Reviews through QOF or local incentive schemes as per the 4 Point Model
- Support the delivery of education and training in primary care of cancer as a Long Term Condition
- Contribute to building the evidence based for managing Cancer as a Long Term Condition e.g. through local evaluations and other data

Recommendations under the Quality Outcomes Framework

- Accuracy data collected and maintained as part of the Cancer Register (CAN001)
- First contact with patient after notification of cancer diagnosis to offer a holistic conversation via a telephone or face to face appointment (CAN003)
- Primary care providers to use the Macmillan Cancer Care Review Template covering physical, psychological, social and financial aspects of patient and carer needs.
- Minimum 30 minute e-learning module for GPs and primary care nurses (who conducts CCRs) such as BMJ Learning and RCGP modules

Recommendations under the incentive scheme

- A named Cancer GP and named Cancer Nurse per practice (under a local incentive scheme) or per Network / Federation (under a Networked or Federated schemes)
- Primary care commissioners (NHS England and/or CCGs through co-commissioning or through a federated approach) to adopt a local incentive scheme for provision of holistic cancer care reviews at the end of primary treatment
- Long Term Conditions incentive schemes to include people affected by cancer who have specific needs e.g. multi-morbidities, social risk factors or part of the local integrated care framework
- The provision of and access to social prescribing services, Improving Access to Psychological Therapies (IAPT) and local directories of a wide range of support services etc. to be made available
- Feedback from patients should be obtained and used to develop local service delivery of Cancer as a Long Term Condition

Requirements from secondary care

- A part of the London Commissioning Intentions, copies of HNA to primary care, standardised Treatment Summaries with explicit consequences of treatment clearly outlined
- Recovery package 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).

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Appendix 1: Sample patient letters

LW&BC Cancer Care Review - Primary Care letters

1. Template letter following diagnosis

Dear

I am sorry to hear you have been diagnosed with cancer and expect that this may be a worrying time for you. If you wish, I'll be happy to discuss with you your diagnosis, proposed treatment or any other concerns. If so, please make an appointment and you're welcome to bring a family member or friend with you.

Towards the end of your main course of treatment I will be inviting you to make an appointment to discuss any needs or concerns that you might have as well as agreeing together a plan for future care. This is called a Cancer Care Review. We can discuss any on-going treatment you may have had and what side-effects you could have from your treatment and talk through any concerns that you, or those that are close to you, may have. We will be able to identify what support can be provided.

You may have met your Cancer Nurse Specialist or key worker at the hospital already. They should be offering you a Holistic Needs Assessment and an invitation to a Health and Wellbeing Event - if these haven't been offered, I would suggest you request them. The needs assessment is a checklist of common concerns that people may have when diagnosed with a serious illness and it helps to identify what support can be offered to meet their needs. Some information about this is enclosed. The Health and Wellbeing event, which should happen towards the end of your treatment, will give you an opportunity to get further support and information.

You may find the enclosed Macmillan Cancer Support leaflet helpful along with the list of local support and information centres.

Your hospital will keep me informed of your care. You can ask to receive copies of their letters if you wish. When your main course of treatment has finished, you and I will receive a copy of your Treatment Summary from the hospital. This will include details of your treatment, any side effects of your treatment to look out for, medication that has been prescribed, follow-up care, the holistic needs assessment report etc. This Treatment Summary will form the basis of the Cancer Care Review mentioned above.

In the meantime, please contact me if you have any concerns.

Yours sincerely

xxxxxxxxxxxxxx

Encs: HNA Patient Information Leaflet
Macmillan What to expect Leaflet
List of local support organisations

Sample patient letter

LW&BC Cancer Care Review - Primary Care letters

Template letter 2: When main course of treatment has finished/Treatment Summary Received

Dear

You may remember I wrote to you when you received your diagnosis of cancer and I'd now like to invite you to make an appointment for your Cancer Care Review. This review is to help you with your recovery and will be aminute appointment with a doctor or practice nurse.

You should have received a Treatment Summary from the hospital but in case you have not, a copy is enclosed. This will help with our discussions and together we can make a plan for your care or support. You may also be offered a Holistic Needs Assessment similar to that undertaken by your hospital during your treatment. A family member or friend is welcome to come with you to the appointment as they may also have concerns or may need some support.

I have included some information from Macmillan Cancer Support about what to look out for after treatment which you may find useful.

Please contact the surgery to make an appointment and please mention that this is for a Cancer Care Review.

With best wishes/Yours sincerely

GP name

Enc: Macmillan 10 Top Tips
Treatment Summary Record

Sample patient letter

Section 2:

Evaluation of Cancer Care Review consultation event held on 29th October 2015

Evaluation of Cancer Care Review consultation event held on 29th October 2015

Acknowledgements

The Transforming Cancer Services Team and the Pan London Living with and Beyond Cancer Board are grateful to all the event speakers, Q&A Panel members, scribes and facilitators who gave us their time, expertise, support and contributed to the effective running of the event. A special note of thanks goes to Chris Lewis and Bonnie Green for their thought-provoking testimonies that provided the backdrop to cancer patient experiences. Thanks and appreciation to Dr Tony Grewal from the Londonwide LMC for his contribution to the Q&A panel. We would also like to thank Tyah Pinnock and Barbara Gallagher whose organisational and hosting skills ensured the event ran smoothly.

Finally, huge thanks go to the 51 delegates who not only attended and actively participated in the discussions but provided valuable and honest input to the table discussions.

1. Overview

More and more people are surviving cancer but London continues to have the poorest outcomes in the UK. The 2014 Cancer Patient Experience Survey showed the some of the lowest scored questions in London were related to support to patients with cancer and their families *after* discharge. The Nuffield Trust (2014) has reported that:

- 15 months after diagnosis, people with cancer have 60% more accident and emergency (A&E) attendances
- 97 per cent more emergency admissions
- 4 times as many outpatient attendances and nearly six times more elective admissions than expected
- A similar pattern is seen for GP visits, with cancer survivors having 50% more contact with their GPs than expected 15 months after diagnosis.

Furthermore, the QOF data for completion of Cancer Care Reviews (CAN003) shows variable achievement across London. Current data does not give us information on the quality of reviews conducted either.

In response to this, the Transforming Cancer Services Team has developed a vision of cancer as a long term condition that supports the pan London primary care transformation framework and the Five Year Forward View to enhance quality of life for people with long term conditions. A pragmatic 4 Point model for the delivery of Cancer Care Reviews at the end of active treatment was presented on the 29th October 2015 to an audience of GPs, cancer leads, primary care nurses, patients and commissioning managers. Delegates were given the opportunity to provide feedback on the proposed model for the attention of the London Cancer Commissioning Board. Please see *Appendix A* for the 4 Point Model.

2. Delegate recruitment and attendance

In order to have an open discussion regarding cancer as a long term condition and appropriately support patient in primary care, attendance was sought and gained from the geographical remit of the Transforming Cancer Services Team:

- Outer North London (Barking, Redbridge and Havering)
- North Central London
- Waltham Forest and East London and City
- South East London
- South West London
- North West London
- Pan London (for delegates that were not assigned to any particular area of London or represented two or more geographical areas)

Invitations for the event were sent out to all known cancer managers, Macmillan GPs, Cancer Lead GPs, primary care nurses and patient groups from across the Capital. On this occasion representation from West Essex was not achieved but a separate consultation will take place in this locality.

A breakdown of the 51 delegates is outlined in Chart 1 below.

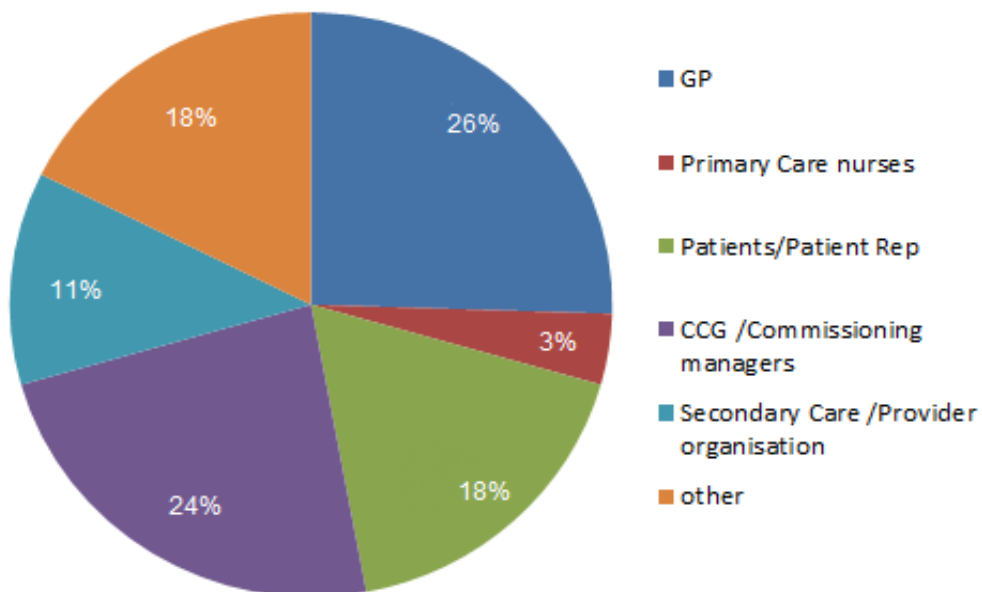
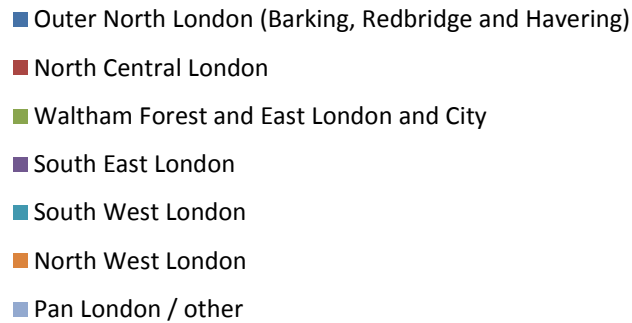


Chart 2 below outline the geographical areas represented at the event.



Places were limited but achieved good clinical and commissioning decision makers from each sector across London. The mix of delegate provides sound representation of the cancer community that is needed for a consultation of this kind.

3. Event programme

The event took place over the course of an afternoon. The agenda (see *Appendix B*) was split between scene setting to ensure the audience received an update on the direction of travel for the Living with and Beyond Cancer work stream and the position for London in terms of meeting the objectives set out by NHS England. This was supported by a patient guest speaker who outlined the gaps he experienced regarding the support needed whilst undergoing cancer treatment. The proposed Cancer Care Review 4 Point model was introduced by the co-Chair of the pan London Cancer User Partnership Group and presented by the TCST GP, Chair of the Cancer as a Long Term Conditions group.

The presentations were followed by a Question & Answer session that included the four speakers and joined by the Medical Director of the Londonwide Local Medical Council. Finally, after a short refreshment break, delegates were arranged into geographically-assigned discussion tables and tasked with answering three specific questions which aimed to further inform the final Cancer Care Review proposal that will be sent to the London Cancer Commissioning Board and the Cancer Clinical Leads Advisory Board.

4. Q&A for the panel

The Q&A was a lively session, initially for 15 minutes but overran due to the engagement of the delegates. Questions posed to the panel were largely related to the proposed 4 Point model, the practicality of implementation and the need to link with primary care co-commissioning, CCGs and NHS England. A comment was made favouring a pan London approach to a commissioning scheme. It was suggested CCG areas could pilot the model and track unplanned attendance to evaluate financial savings as well as increase the quality of reviews carried out.

Other comments included links to public health, social care, health & well-being boards that also have elements of keeping patients out of hospital.

5. Breakout session

The breakout session was arranged by placing delegates from the same geographical areas together and ensuring a good mix of healthcare managers, commissioners, clinicians and patients at each table too. A pan London table was available for those delegates that represented more than one area or were from a pan London organisation.

Each table was asked to delegate a Facilitator and a Scribe. Ground rules for discussion were provided to help Facilitators to: ensure each person has an equal say, keep the group on time and focussed on the topic and to summarise each question in order to check the understanding of participants' comments. Scribes were to capture the salient points raised in the table discussion for inclusion into the final Report. This was to ensure the consultation was collected as accurately as possible.

The following 3 questions were posed and delegates had 45minutes to discuss before feeding back to the wider group:

Q1. How would you improve the 4 point model?

Q2. What are the barriers to implementation of this?

Q3. How would the model / notion of a holistic cancer care review impact you as a patient, GP, primary care nurse or a Commissioner and what else could we be doing in primary care for patients after treatment of cancer?

Three copies of Resource Packs were available on each table to aid discussions. These packs contained:

- Copies of the presentations from the previous sessions
- The 4 point model and the proposed CCR pathways (*Appendix A*)
- Sample Treatment Summary
- Sample of the London-wide Holistic Needs Assessment (HNA)
- Samples of letters that could be sent to patients that was ratified by the pan London Cancer User Partnership Group (a user group that advises on patient issues at a strategic level). The first letter for when the cancer diagnosis has been received and second once when a Treatment Summary has been received together. The letters are supported by information from Macmillan Cancer Support that outlines ten tips of dealing with cancer treatment.

Main themes from the Breakout session included:

- The proposed 4 Point model was well received and supported by all delegates
- More information needed on how the model will be/should be commissioned
- Guidance needed on managing patient expectations
- Need for templates and education to support primary care professionals on structuring CCR consultations
- Tools that can be used in primary care to screen for psychological effects of treatment
- Training for primary care professionals

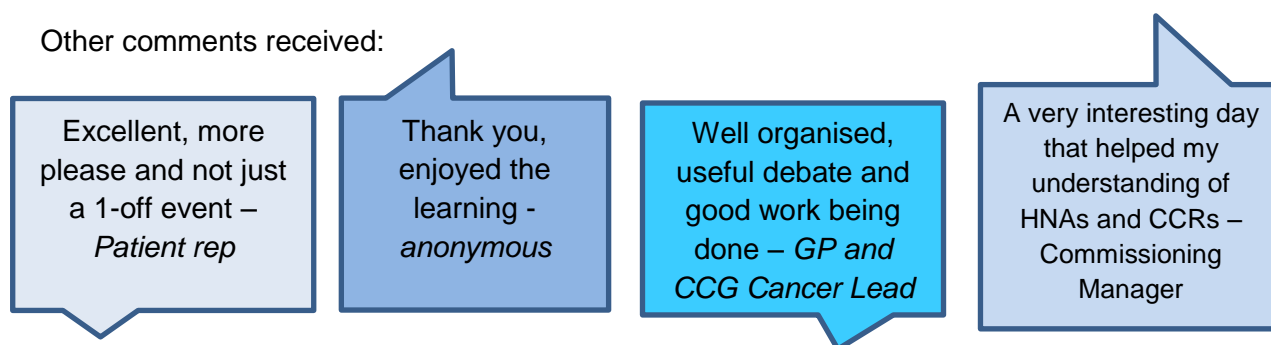
A full write up of the notes submitted by the Scribes are included in *Appendix C*.

6. Headline summary of delegate feedback

A total of 20 completed evaluation forms were collated after the event. Questions were focused particularly around the speakers, the content and the subject matter. A summary of the findings are below:

- 100% of delegates thought the content of the event was either “excellent” or “good”
- 100% thought the quality of the speakers was either “excellent” or “good”
- 100% of the delegates reported that the event was relevant to them with 85% of them outlining the presentations and the table discussions were the most useful. The remaining 15 % said that the whole event was useful.
- None of the delegates reported a least useful aspect of the event or its content.
- When asked about what delegates would have liked to have heard more about, 75% stated nothing or didn't provide an answer. The remaining 25% (5 respondents) outlined required more information on the timescales the TCST are working towards, a sample draft Local Incentive Scheme, links to Local Authority organisations, what support the TCST needed from CCGs and a breakdown of delegates that were in attendance at the event.

Other comments received:



The TCST are pleased to announce two immediate positive outcomes of the event:

- A commitment from Anthony Cunliffe, Macmillan GPA to work with all Macmillan GPs in London to prioritise delivering a training session on Living with and Beyond Cancer and the CCR. The TCST will work with the Primary Care Education Group to develop a package/presentation that could be run in the majority of CCGs as a priority.
- Four CCG areas have firm expressed interest in piloting the proposed 4 point model (or a locally adapted version). The TCST will be working with these CCGs on implementation.

7. Next Steps

A key aim of the event was to collect feedback on the proposed 4 Point model for Cancer Care Reviews across London and to highlight the barriers and limitations on implementing the model and the case for change. With this view, the draft report will be sent to all delegates that attended the event for comment before the final report is sent to the pan London Cancer Commissioning Board and the Cancer Clinical Leads Advisory Board.

The proposed timescales are outlined below:

TCST Lead - who	Feed back to pan London Boards	Month
Sarita Yaganti	CCR event delegates and members of the Living with and Beyond Cancer Board	11 th November 2015 (1 st draft report for consultation)
Dr Afsana Safa, Associate Lead GP	Living with & Beyond Board	17 th November 2015 (1 st draft report to be discussed and comments to be submitted at Board meeting)
Liz Price, Senior Strategy Lead	Cancer Programme Executive	24 th November 2015 (final draft report)
Liz Price, Senior Strategy Lead	Cancer Commissioning Board	15th December 2015 (final report for endorsement)
Sarita Yaganti, Implementation Lead	Primary Care Education Group	12th January 2016 (final report for endorsement)
Liz Price / Afsana Safa	Cancer Clinical Leads Advisory Group	19th January 2016 (final report for endorsement)
Sarita Yaganti	Pan London Cancer User Partnership Group	27th January 2016 (final report for endorsement)

If the proposal is accepted by the relevant Boards outlined above, the TCST Team will be present to provide support to CCGs regarding local implementation. The TCST will be recommending:

- Primary care commissioners (NHS England and/or CCGs through co-commissioning or through a federated approach) to adopt a local incentive scheme for provision of holistic cancer care reviews at end of active treatment. More detail will be provided in this guidance.
- A call for CCGs to test the tools and incentive scheme as part of a full evaluation.
- The provision of and access to social prescribing services, Improving Access to Psychological Therapies (IAPT) and local directories of support services etc. to be made available. Training and development to primary care workforce especially practice nurses and AHPs to conduct CCRs.

4 Point Model

Proposed 4 point model

The aim of the holistic CCR: Cancer Care Reviews are to be co-produced between the primary care clinician (GP, practice nurse or allied health professional) and the patient at the end of primary treatment. The CCR should be holistic, covering psycho-social needs, physical needs, needs of carers and support patients towards self-management. More generally, cancer can therefore be integrated within a long term conditions management approach at practice or network/federation level. Furthermore the model would complement the current QOF process.

Example trigger points for CCR model for London:

- At notification from hospital confirming a new diagnosis (via 2ww, routine outpatient, screening, A&E, other primary care routes, previous diagnosis/recurrence)
- Newly registered patients with cancer diagnosis in last 5 years
- On receipt of Treatment Summary Record and /or transfer of care / discharge to community

Point 1: Patient added to cancer register (QOF CAN001 or local incentive scheme)

The purpose of a register in QOF is to define a cohort of patients with a particular condition or risk factor. In some cases, this register then informs other indicators in that disease area.

QOF registers must not be used as the sole input for the purposes of individual patient care and clinical audit i.e. call and recall of patients for check-ups, treatments etc. There are patients for whom a particular treatment or activity is clinically appropriate but they may not meet the criteria as defined by the QOF register and therefore would not be picked up by a search based solely on the QOF register. As such, although QOF registers can be used to supplement clinical audit, they should be supported by appropriate clinical judgement to define which patients should be reviewed, invited for consultation etc. to ensure patients do not miss out on appropriate and sometimes critical care²⁴.

Point 2: 1st intervention: First contact after diagnosis (QOF CAN003 or local incentive scheme)

- Telephone call and/or letter to patient regarding recent diagnosis with invitation for the patient to attend the practice for a (holistic) chat and to offer a holistic appointment at the end of treatment. This could be completed by GP or practice nurse.
- Template letter for primary care to send to patients who have just received a cancer diagnosis. The letter is to be tailored with the GP name, oncologist name, name of their key worker (if known), treating hospital; the type of cancer diagnosed and includes an outline of the recovery package that they should be receiving along with the Macmillan Top Ten Tips.
- Information for patient on what to expect as part of a Recovery Package with a prompt to request a key worker and HNA from secondary care if not provided by the CCR appointment. Pan London HNA to be included for reflection and reviewed at subsequent CCR. Signposting to local support groups will also be included.

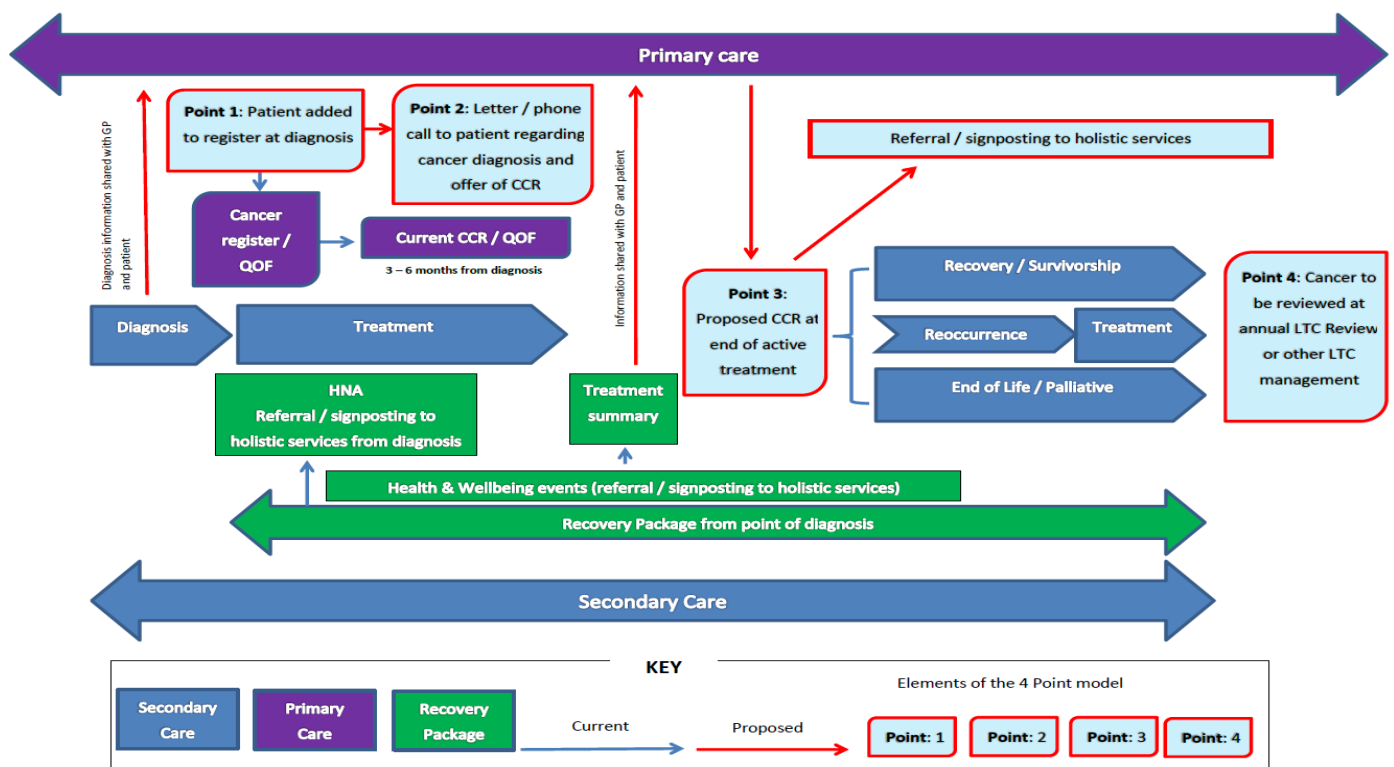
²⁴ <http://www.nhsemployers.org/your-workforce/primary-care-contacts/general-medical-services/faqs-and-queries/qof-faqs>

Point 3: 2nd intervention: Holistic cancer care review at the end of primary treatment (local incentive scheme)

- Appointment triggered by a date entered into the Cancer Register and/or receipt of Treatment Summary / transfer to primary care.
- Extended consultation conducted by GP or nurse depending on complexity of patients' needs (eg double or triple appointments).
- Use of a clinical template for holistic CCR that captures whether the patient had an HNA in secondary care and their information needs. Using Treatment Summaries or discharge letters, discuss consequence of treatment and further advice on physical activity, signs and symptoms to be aware of regarding recurrence carer's needs.
- Healthcare professional to use available screening tools to conduct a psychological assessment.
- Collection of minimum data for audit
- Professionals to undertake training modules
- Patient and professional experience survey
- Primary care MDT meeting to discuss patients on register outlining care planning actions and review any Significant Event Audits (SEAs)

Point 4: 3rd intervention: Cancer incorporated and reviewed at an annual LTC Review (QOF or generic Long term conditions local incentive scheme).

- Annual review may be for a period of time, for example up to five years, or it may be indefinite. It may also only apply to groups patients who have specific needs e.g. multi-morbidities, social risk factors, part of a local integrated care framework. Figure 4 below outlines the proportion and number of people with cancer living with other long-term health conditions
- The LTC review should include a conversation regarding the person's psycho-social and physical needs re cancer (e.g. preventing recurrence and detecting and/or managing any consequences of treatment) as well as any other long term conditions that the person may have.



Agenda



Transforming Cancer Services Team for London

Cancer Care Review: a proposal for London Event

Thursday 29th October 2015

Venue: The Connaught Rooms 61-65 Great Queen Street, London, England, WC2B 5DA

Time: 1300 – 17:15pm

13:00	Registration & Lunch
13:45	Welcome & Introduction <i>Teresa Moss, Director of Transforming Cancer Services Team for London</i>
13:55	Living with and Beyond Cancer: a patient perspective: Chris Lewis Cancer as a Long Term Condition: a model for London: Liz Price, Senior Strategy Lead for Living with and beyond cancer, Transforming Cancer Services Team for London
14:25	Proposed Cancer Care Review Model: Bonnie Green, co-Chair Pan London Cancer User Partnership Group and member of pan London Cancer Commissioning Board and Living with and beyond Cancer Board Dr Afsana Safa, Associate GP for Transforming Cancer Services Team for London and Macmillan Cancer Lead GP for Central London CCG
15:00	Q&A
15:15	Refreshments break
15:25	Table discussion <i>Consultation on CCR proposal</i>
16:25	Feedback from table discussion
17:00	Closing Remarks <i>Next steps and follow up</i>

Breakout session notes as submitted by Scribes

Geography	Q1 How would you improve the 4 Point model?
Waltham Forest and East London	<ul style="list-style-type: none"> Model presented is fine. No comments made.
North Central London	<ul style="list-style-type: none"> Include SEA – also for GP Appraisals Diagnosis letter from hospital to prompt patient to contact GP for CCR. Patient letters to be kept simpler and more reassuring. Macmillan Top Tips to be sent after discharge and given by hospital A sample Locally Commissioned Service is needed Need for screening tools for psychological referrals that can be used in primary care
South East London	<ul style="list-style-type: none"> QOF is not properly understood Automatically adding patients to the Register Need to improve the value of the register
South West London	<ul style="list-style-type: none"> QOF points to keep patient register Cancer / CCR related codes Should be assigned to a cancer lead or a champion in each practice so responsibility is recognised Need more guidance on best practice to maintain Registers Template letter is good for guidance but telephone call is seen as best practice either by GP or practice nurse if trained. Protocol to ensure main/referring GP is informed if GP is not available so they can follow up later
Pan London	<ul style="list-style-type: none"> Need template for GP to proper structure conversation Support patients to think what their concerns, expectation v desired outcomes beforehand (see PARAPET Project in Bristol) Patient concern – GP need to get to know their patient before hand Is there a gap in understanding between what GPs / primary care can offer and what patients expect? Guidance on managing patient expectations Sending prompts to patients may be counterproductive “questions you can ask your GP” Consider the timeliness of the communication going out
North West London	<ul style="list-style-type: none"> Practices to design calling/writing to patients individually Can other health care professionals conduct the cancer care review? E.g. radiotherapists

Geography	Q2. What are the barriers to implementation of this?
Waltham Forest and East London	<ul style="list-style-type: none"> GP not always clear if patient has been informed of cancer diagnosis. A letter to the GP needs to be explicit. Telephone call to patient is seen as being OK. Concerns around raising expectations of the patient when asking patient to come in and talk about treatment. GPs need information on treatment complications / consequences of treatment. Signposting information i.e. where patients go for support or who to call if problems arise from treatment such as chemotherapy.

	<ul style="list-style-type: none"> Local Authorities are meant to signpost to supportive services but GPs are not aware of this. Support services need to be easily accessible for GPs. In order to avoid the “come in for a holistic chat” GPs need concise information to structure the CCR consultation.
North Central London	<ul style="list-style-type: none"> Cancer commissioning needs input from NHS England NHS England LCS through Primary care commissioning Funding to support the LCS/extended consultations Practices are very busy Confidence levels in primary care regarding managing cancer patients. Confidence being a greater need than just education
South East London	<ul style="list-style-type: none"> Could lower standard of care Pot of money to Federations could lose funding for initiatives Integration
South West London	<ul style="list-style-type: none"> Funding Education Resources within practices – i.e. those that are appropriately trained GP awareness of issues faced by people living with and beyond cancer and what the role of primary care should be Implementing SEAs to capture adverse incidences for future learning Need an LCS or as part of core contract of co-commissioning Is the timing to be within 4 weeks of active treatment ending or later? Need patient’s input Worry that Cancer Care Reviews would get lost in holistic LTC Reviews as all other conditions get covered but cancer is left out. However Cancer should be discussed as part of an LTC Review
Pan London	<ul style="list-style-type: none"> Even if you phone patient to invite, that may not be enough to overcome barriers Treatment summaries are imperative Encourage hospital letters to be copied to patients which can support / trigger conversations and discussions Cultural change in in clinicians and patients needed. Letters need to be permissive to overcome the “Sorry to bother you doctor” attitude Letter need to be sensitively offered. Needs market research to identify the helpful bits Also needs MR to GP as presently 20% below capacity at the moment. Need to ask GPS if this is helpful Education for clinicians
North West London	<ul style="list-style-type: none"> Time available to clinicians Lack of urgency - as initial treatment is over Knowledge – lack of good quality information from treating hospitals

Geography	Q3. How would the model / notion of a holistic cancer care review impact you as a patient, GP, primary care nurse or a Commissioner and what else could we be doing in primary care for patients after treatment of cancer?
Waltham Forest and East London	<ul style="list-style-type: none"> • Ideal trigger for holistic review is the Treatment Summary from secondary care but this is not readily available. • Good communication needs to be maintained between primary and secondary care and the patient. • Create a model that isn't too rigid in order for local implementation
North Central London	<ul style="list-style-type: none"> • Template and HNA shared at event was suitable • Should expect/increased delays. GP to get in touch with patient's CNS for advice.
South East London	<ul style="list-style-type: none"> • Empowers the patient but having hand held notes • Model needs to be more patient centred • Needs to be web based • Holistic reviews seen as being a "comfort blanket"
South West London	<ul style="list-style-type: none"> • Time as resource...is there enough time? • Links to local resources are available to support patients and we need to ensure practices are aware of them • Ask patient to engage with CCG and that user input is valued • Has to be a part of CCG strategy / commissioning intentions • Show cost is low to moderate for CCG i.e. in Wandsworth £24k for 350,000 patients for a 40 minute apt
Pan London	<ul style="list-style-type: none"> • User Guide. Macmillan has tips on how to share Treatment Summaries and HNAs done in secondary care which must be shared with primary care • Sympathetic but structures letter to start. Generic 2nd page • GPs to see this not as a threat • Share data that has been collected • Need reporting anonymised audit that is built into the IT systems • Evaluation , Read codes, A&E attendances to see how they change
North West London	<ul style="list-style-type: none"> • Federations could provide cancer review centres or Macmillan nurses to do the reviews • Patient accessible websites to give local information about services. Allows more autonomy and promotes self-care

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Transforming Cancer Services Team for London

TCST is part of the Healthy London Partnership, a collaboration between all London CCGs and NHS England London region to support the delivery of better health in London



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