Holistic Cancer Care Reviews in London – Mapping

Transforming Cancer Services Team for London

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1. Introduction

The average survival rate for people diagnosed with cancer in the 1970s was only 1 year, in the 1990s it has gone up to 2 years with 1.2 million living with beyond cancer. In 2015 average survival is 10 years with 2.5 million people who are living with beyond cancer. By 2030 average survival rate will continue to increase and it is predicted that 3.1 million people will be living with beyond cancer[1]. 70% of people with cancer also have another long-term condition. Almost 30% of people with cancer have 3 or more long term conditions as well as cancer, which amounts to 600,000 people in England.[2]

For cancer patients, living does not necessarily mean living well. Certain treatments can increase the risk of other long-term conditions such as chronic heart disease, high blood pressure or mental health problems. [3] These consequences are often long term. Many experience physical, emotional and financial consequences of cancer and its treatment and this can remain the case for many years after treatment has ended e.g. fatigue, mental health problems, sexual difficulties, pain, urinary and gastrointestinal problems.[4]

In 2015, the Transforming Cancer Services Team (TCST) launched the 4-point model to deliver holistic cancer care in primary care[5], the four key points of delivery were:

1. Improved coding for patients being added to the practice's cancer register (as per QOF CAN 001[6])
2. Appropriately timed appointments to support the holistic cancer care reviews (as per QOF CAN 003)
3. Holistic cancer care reviews at the end of a phase of treatment (where funding is available)
4. Include cancer patients as part of long-term conditions management service specifications (as per NICE Guidance NG56 on multi-morbidity management and care planning[7]).

A series of events were organised by TCST in the same year to engage clinicians and commissioners on the 4-point model[8].

In 2020, TCST conducted a stocktake to identify what progress has been made since the launch. The focus of this exercise was point 3 and 4 of the 4-point model, namely Holistic CCR at the end of a phase of treatment and include cancer patients as part of the long-term condition service review. However, one CCG also included point 1 (coding) in their local enhanced commissioning specification. This brief report sets out the provision of Holistic CCRs across London and examines commissioning arrangements where this detail was available.

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1 Estimates of prevalence are based on the method developed by *Maddams J, Utley M and Møller H. 2012. Projections of cancer prevalence in the United Kingdom, 2010–2040. British Journal of Cancer. 2012; 107: 1195-1202.*

2 Macmillan Cancer Support. The burden of cancer and other long-term conditions. April 2015 www.macmillan.org.uk/Documents/Press/Cancerandotherlong-termconditions.pdf.

3 Macmillan Cancer Support. The burden of cancer and other long-term conditions. April 2015 www.macmillan.org.uk/Documents/Press/Cancerandotherlong-termconditions.pdf.

4 Macmillan Cancer Support (2013) *Cured – but at what cost? Long-term consequences of cancer and its treatment.*

5 https://www.healthylondon.org/wp-content/uploads/2017/12/Four-point-model-for-holistic-cancer-care-reviews-cancer-as-a-long-term-condition.pdf

6 https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/general-practice-data-hub/quality-outcomes-framework-qof

7 https://www.nice.org.uk/guidance/ng56

8 https://www.healthylondon.org/wp-content/uploads/2017/11/Transforming-primary-care-for-people-living-with-and-beyond-cancer-events-Oct-2017.pdf

The aim of this document is to provide a summary of:

- The picture of commissioning and delivering holistic cancer care review, including the model/approach and protocol, at the time of the stocktake.
- The key successes in delivering holistic cancer care reviews
- The key challenges faced by delivering holistic cancer care reviews.

This report acknowledges that services consistently evolve and change. The information contained in this report was correct as of December 2019.

2. Methodology

A stocktake exercise was undertaken to understand the provision of holistic cancer care review in primary care across London.

A semi structured survey was developed and a member of the TCST team approached and interviewed key stakeholders who have developed holistic cancer care reviews in their locality. In some cases, commissioners completed the semi-structured survey and sent it back to TCST via email.

The full survey questions are provided in Appendix A. In summary, the survey asked commissioners and clinical leads to identify:

- Name of commissioner/clinical lead, their role and the organisation they represent
- Whether they have a Local Enhanced Service (LES) in place for holistic cancer care reviews and to share the specifications where possible
- Any other models developed
- Duration of the LES covered
- Degree of uptake of the LES in terms of number of practices and number of Holistic CCRs completed
- Elements that constitute good Holistic CCRs and the stage within the patient's cancer pathway (e.g. post diagnosis or post treatment) required to deliver within.
- Training and support provided by the CCGs prior and during implementation phase
- KPIs/outcome measures
- Governance and performance monitoring
- Whether reviews are incorporated into multimorbidity long term condition management and how
- Case studies or good practice
- Evaluations that have been carried out

A call to interview was launched in Autumn of 2019, the following CCGs were identified to have implemented Holistic CCRs and were interviewed. Note that no CCGs were identified for North Central London STP.

STPs	**CCGs**
South East London	Bexley
	Lewisham
South West London	Richmond
	Wandsworth
North East London	City and Hackney

	Newham
	Tower Hamlets
North West London	Central London (Westminster)

3. Key findings:

3.1. Approaches to improve Holistic CCRs

The stocktake identified two broad approaches.

The First approach was based on the traditional commissioning model where commissioners engaged with primary care (usually with the GP Federation and the Local Medical Committee (LMC)) and developed and agreed on a Local Enhanced Service (LES) or Local Incentive Scheme (LIS) contract. This contract normally specifies:

- The overall rational, aims and objectives of the intervention.
- The key delivery requirements.
- The eligibility criteria and exclusions.
- Workforce requirement.
- Performance indicators and methodology of validation or evaluation.
- Applicable standards of good practice.
- Payment and claims process.

The second approach was based on a quality improvement (QI) model and methodology. CCGs or practices may have used QI methodology to identify improvement opportunities in CCRs. This normally includes:

- Data collection of performance (perspective and/or retrospective).
- Reflection of how Holistic CCRs are currently delivered, gaps and issues identified.
- Identify and agree appropriate actions to improve performance.
- Evaluate performance and identify improvement.

This improvement cycle can start again if required.

3.2. Commissioning Model Approach

3.2.1 City and Hackney CCG

City and Hackney CCG has been commissioning Holistic CCRs since 2017, the contract was delivered through City and Hackney GP confederation. The key driver for this initiative was based on the 4-point model. GPs were under pressure to deliver CCR and agreed with the CCG that further funding was required to deliver a quality Holistic CCR.

Key details included:

Number of practices participated	42 in 2017 (2 have now closed)
Number of cancer patient registered	5271 in 2018/19
Number of CCRs completed	1028 CCR completed in 2018/19
Eligibility criteria	30 mins of Holistic CCR completed by the GP/nurse
Payment	£80 per consultation
Training provided	Online and face to face training
Evaluation	Pan Hackney cancer audit showed that there is an improvement in clinical coding.

3.2.2 Wandsworth CCG

Wandsworth CCG has been commissioning Holistic CCR since 2015, the contract was delivered through Wandsworth GP Federation and was reviewed by the Local Delivery Unit (LDU) steering group. The key drivers for developing this model were the feedback from cancer patient survey and recognising the quality of CCR was poor.

Key details included:

Number of practices participated	37 out of 39 GP practices have participated (2018/19)
Number of CCRs completed	1081 in 2018/19
Eligibility criteria	20 mins of Holistic CCR completed by the GP/nurse. Holistic CCR carried out 9 to 12 months after diagnosis.
Payment	£20 if completed by GPs and £15 if completed by a nurse. Telephone consultation also accepted.
Training provided	Training was carried out in an event at the start of the project. Macmillan GP will check its compliance when attends practice visit and offer further training if required.
Evaluation	Evaluation has been set up as part of the project. However, as the evaluation was not mandatory, the return rate had been very low.
Integration with long term condition review	A template has been developed based on the Planning All Care Together (PACT) project which included other long-term conditions such as frailty, dementia, diabetes, mental health etc. The cancer section of the template highlighted the psychological support and the Macmillan Move More project. It included many other issues such as clinical consequences of treatment, stages, other medical conditions, carer's concerns and issues, social care issues such as disability allowance. The template linked to Wandsworth Council website so local community and social care assets can be identified.

3.2.3 Richmond CCG

Richmond CCG has been commissioning Holistic CCR since 2016, the contract was delivered by the local primary care commissioners. There had been two local commissioned services launched, the first one was launched in 2016 and a second one was launched in 2019. The key drivers for developing this model were feedback from patient survey and initiatives developed by Macmillan on cancer care reviews.

Key details included:

Number of practices participated	15 out of 27 practices between 2016 and 2018 and 26 out of 27 practices in 2019
Number of CCRs completed	340 CCRs completed in 2017/18 but only 181 completed in 18/19. The reduction has been identified as a result of lack of communication to practice about this initiative.
Eligibility criteria	30 mins of Holistic CCR by GP/nurse.
Payment	£20 per 1000 patients (practice population) for a search and invitation of patients on the cancer register appropriate for a holistic cancer care review (between 6-24 months post diagnosis) £50 for every holistic CCR completed (this was increased to £60 for the 2019 LCS).

Training provided	Training was provided for GPN and half day cancer education event to raise awareness of the local commissioned service (LCS) Three patient focus group has been carried out
Evaluation	Improved in coding practices– based on the coding 389H (holistic needs assessment)

3.2.4 Newham CCG

Newham CCG commissioned Holistic CCR for 2 years, between 2017 and 2019. The contract was commissioned and delivered by the local primary care commissioners. The key driver of this local enhanced service was to incentivise practices to deliver CCRs in the aim that it will be business as usual. This contract was additional to the QOF payment with the recognition that QOF did not specify CCRs templates and the commissioners intention to standardise the approach within GP practices and the benefit of having this carried out face to face.

Number of practices participated	All practices in Newham CCG participated.
Number of CCRs completed	3,037 invited between 2017-2019 1,667 completed (674 -2017/18 and 993 – 2018/19)
Eligibility criteria	All newly diagnosed patients to be seen for 20mins with a GP and at 6 months after diagnosis patients to be seen for 15 mins. Patient to be sent holistic needs assessment prior to CCR.
Payment	£36.67 each for 20 mins initial appointment and £7.50 each for CCR
Training provided	The primary care commissioner and the clinical lead provided one to one and cluster training to GPs and practice nurses.
Key Performance Indicator	In the first year there were no KPIs. In the Second year the KPI was based on the number of care plan per GP practice. Care plans should be completed in 50% of the CCRs carried out. Practices also required to submit randomised sample of their Cancer Care plans (10% of all care plans or up to a maximum of 5 per practice undertaken)

3.3 Quality Improvement Model Approach

3.3.1 Lewisham CCG

Lewisham CCG commissioned a primary care nurse which was hosted by Lewisham GP Federation. The role of the primary care nurse was to liaise with GP practices to identify and code any newly diagnosed cancer patients, and GP practices to contact the patient for a face-to-face appointment via send a letter or a call. They were responsible to complete CCRs and have an educate role in teaching other primary care nurses to complete CCRs. They were also responsible to coordinate cancer patients who have been diagnosed for over a year to complete a long-term condition review. An evaluation was originally planned to carry out to identify its effectiveness, however, due to Covid this did not happen. Funding of the project started in November 2019 and it is only a one-year funding.

3.3.2 Bexley CCG

Bexley CCG offered a range of quality improvement initiatives in cancer care, part of the Referral Management Optimisation Scheme (ReMOS). The timeline of this initiative is between January 2019 and March 2020. This included the requirement for practices to:

- Attend quarterly cancer and palliative care round table meetings
- Organise, facilitate and participate in at least two in-house MDT meetings to discuss cancer patients and review their care plans, including when the practice is informed of an emergency attendance or admission of a cancer patient

- Bring in patients who have been diagnosed in the last 3 months to carry out a Cancer Care Review. This review will be based on a Macmillan template and where appropriate to include a Crisis/Medical Intervention Plan.
- Submit two half year audit reports to the 2ww referrals by speciality

3.3.3 Central London CCG

A comprehensive quality improvement was carried out in one General Practice in Westminster. This project was led by the Central London Macmillan GP in their own practice. The key aim of this approach was to follow the 4-point model set out by TCST, this unfunded project included:

- All correspondences about diagnosis, discharge and end of treatment sent to the cancer lead to be reviewed.
- The healthcare assistant was responsible for coding patients who has a cancer diagnosis and are reviewed by the cancer lead.
- CCRs were carried out at 6 months by the lead GP.
- Long term condition reviews were carried out on an ad hoc basis where required.
- Medicine reviews were completed by the pharmacist.
- Patients were referred to Social prescribing when required.

3.3.4 Tower Hamlets CCG

Tower Hamlets launched a specific quality improvement project on improving the quality of CCRs in April 2019 as part of their Primary Care Network Enablers. This was a funded piece of work.

The purpose was to improve the Quality of Cancer Care reviews conducted in Tower Hamlets through a process of reflection and quality improvement at practice level.

Quality Cancer Care Reviews were defined as

- Identifying and exploring patients unmet needs
- Offering support to help meet those needs

Practices were asked to :

- Run a specific Cancer patients sample search in Q1 identifying random historical cancer patients, import their patients results into a Reflection Tool and complete the tool (tool aspects included demographics, whether CCR completed within 6 months, type of appointment, conducted by whom, needs explored, unmet needs identified, support offered)
- Reflect as a practice on the results and review the CCR Resources & Recommendations that were distributed to all practices (including guidance on CCRs, reminder of the Tower Hamlets Long term conditions CCR template page, suggested patient invitation letters and the Macmillan CCR Checklist that could be sent to patients prior to their CCR appointment)
- The practice plans to improve the quality of their CCRs were submitted via a proforma along with their anonymised Q1 search results
- At the end of Q4 each practice was asked to run a second random sample search identifying recent cancer patients, complete the tool for these patients and reflect on whether their quality improvement plans had been effective in improving the quality of the CCRs undertaken and submit both the search results and completed proforma.

(All 36 practices submitted their initial proformas of reflections and proposals for improving the quality of their CCRs but due to COVID the end of year submissions were suspended).

Tower Hamlets has kindly shared a number of resources they used during this pilot. See appendix for details.

4. Conclusion

Overall, the stocktake identified eight out of 31 CCGs (see section 2 for summary) across London who initiated a local enhanced services or quality improvement approach to completing CCRs between 2015 and 2019. Most of the CCGs interviewed either did not have evaluation included as part of their initiative or the evaluation was not completed at the time of the stocktake.

However, the key themes of the barriers and challenges include:

- Quality Outcomes Framework (QOF) specified that CCRs must be complete within six months of diagnosis - the general views from health care professionals and commissioners are that this is unhelpful timing, as many cancer patients are still receiving acute treatment at six months after diagnosis and therefore receiving support from their hospital team.
- Commissioners and lead clinicians generally agree that CCRs should be delivered face to face. However, no matter what the delivery method is, all initiatives in the stocktake focused on improving the quality of CCRs.
- Coding accuracy and consistency was identified as a concern.
- All initiatives have considered the use of the TCST 4-point model. However, most of the initiatives found it difficult to deliver fully and have implemented a simplified model. It is due to local commissioning decisions such as limited funding or decision about focusing on one aspect of the model. Where we found a comprehensive model being carried out, it is small scale delivered in 1 GP practice (e.g., Central London CCG).
- The majority of the CCRs were conducted with limited information from secondary care. Many CCRs were conducted without a treatment summary or discharge summary in place.
- As a result, clinicians often found it difficult to formulate a holistic care plan with their patients.
- Many of the initiatives used the Macmillan CCR template - many clinicians found it helpful in guiding their conversations with their patients.

The key success includes:

- The commissioning model approach is arguably more successful when measure it in terms of the number of General Practice participated in the scheme and the scope of the specification. It is also where most of the quantitative evaluation has taken place.
- Where General Practices used the quality improvement model approach, there was a real drive to test out non-traditional models such as nurse led CCRs or the comprehensive holistic CCR approaches.
- All initiatives were led by strong clinical leadership, mostly from Macmillan GPs and some are from CCG cancer leads. This demonstrated the importance of clinical leadership in delivering measurable transformation in primary care.

5.Recommendation

Cancer alliances and primary care teams within Integrated Care Systems should learn from the key barriers and challenges highlighted in section 4 when designing and developing future approaches to holistic cancer care reviews.

Appendix 1:

Tower Hamlets Quality Cancer Care Review Enabler 2019-2020 Guide (published with permission from TH CCG)

TOWER HAMLETS QUALITY CANCER CARE REVIEW ENABLER 2019-2020 GUIDE

The purpose of this enabler is to improve the **Quality of Cancer Care reviews** conducted in Tower Hamlets through a process of reflection and quality improvement at practice level.

Quality Cancer Care Reviews:

- Identify and explore patients unmet needs
- Offer of support to help meet these needs

REASON FOR ENABLER:

- Many patients will survive their cancer but may live with long term consequences of their cancer or treatment – cancer is a LTC for many
- 72% of people with cancer will also have another long term condition
- For cancer patients living does not necessarily mean living well
- The consequences of treatment may include physical and psychological effects e.g. fatigue, mental health problems, sexual difficulties, pain, urinary and gastrointestinal problems. These consequences are often long term
- Certain treatments can increase the risks of other long term conditions such as heart disease, a second cancer or osteoporosis.
- Many patients face significant financial & social problems post their diagnosis and treatments
- The National Cancer Patient Experience Survey (2017) TH Q53: Practice staff definitely did everything they could to support patient – we scored 55%
- We know primary care can contribute in many ways not only to improved outcomes but also to patient experience following a cancer diagnosis

We are asking practices to:

1) Run the Cancer patients sample 1 search in Q1, import the patients into the Reflection Tool and complete it
2) Reflect as a practice on the results and review the Resources & Recommendations (within this document)
3) Submit by end of Q1 the practice plans to improve the Quality of cancer care reviews for patients at your practice using the proforma & submit the anonymised spread sheet of sample 1 patients
4) Q2 and Q3 work on the improvements you have decided on (no submissions)
5) End of Q4: each practice to run the second sample search, export patients, complete the Quality Cancer Care Reflection tool again
6) Reflect on the practice results from the second sample of cancer patients
7) Resubmit the original proforma with Q4 area reflection completed: demonstrating improvements in Cancer Care reviews & submit with the second anonymised spread sheet

RESOURCES & RECOMMENDATIONS:

RCGP/Macmillan Consequences of cancer Toolkit:

https://www.rcgp.org.uk/coc?utm_source=The%20King%27s%20Fund%20newsletters&utm_medium=email&utm_campaign=6482260_HMP%202015-12-01&dm_i=21A8,3UXQS,I1JDCR,DXYY1,1

Carrying at an effective CCR – Tips sheet

https://www.macmillan.org.uk/_images/carrying-out-an-effective-ccr_tcm9-297613.pdf

Macmillan: Support for primary care

https://www.macmillan.org.uk/about-us/health-professionals/resources/resources-for-gps.html

Cancer as a long term condition: Healthy London Partnership

https://www.healthylondon.org/resource/cancer-long-term-condition/

Appendix 2:

Tower Hamlet Quality CCR submission document 2019/20 (published with permission from TH CCG)

Quality Cancer Care Review Enabler submission document 2019/2020:

End Q1 and end Q4

DATE	
Network	
Practice	
Cancer lead for practice (name and email)	
Person (name, role, email) completing submission if not practice cancer lead	
Confirm resources on Cancer Care Reviews reviewed at practice level Any comments?	
To be completed end Q1: What are you going to do differently? Reflections / plans on improving the quality of CCR that can be made at practice level Please specify exactly what / why / how / and how practice team were involved (if minimal detail forms will be returned)	
Reminder send anonmyised spreadsheet of CCR reflections from sample group 1 with this form by end Q1	
To be completed end Q4: Have the quality of the CCRs improved after implementing your plans? How?	

Reflections & evidence demonstrating planned changes to delivering quality CCR in Q1 have occurred (e.g., please attach as evidence any revised or new practice policies, pathways, letters for patients, feedback from CCR patients if applicable) Demonstrate your improvements.	
Reminder send anonymised spreadsheet of CCR reflections from sample group 2 with this form by end Q4	

Appendix 3:

Sample patient letter to invite them to CCR (published with permission from TH CCG)

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'd be glad to discuss with you your diagnosis, treatment or any other concerns you have and help get you any support you may need.

We have enclosed a check list that some patients find helpful to go through and bring in to their appointment, it helps patients think about what they may need support and help with at the moment.

If you need anything from us at the moment please make an appointment to come in or if easier we can arrange a telephone appointment to touch base.

You're welcome to bring a family member or friend with you to the appointment.

Please feel free to book in with the doctor of your choice.

Yours sincerely

Dr….