Covid-19: Personalised Cancer Care in Primary Care

A framework for improvement in primary care for people affected by cancer

Introduction

The purpose of this document is to provide a framework of improvement principles, the rationale behind those principles and a repository of resources for primary care teams.

This document is focused on supporting people affected by cancer and managing cancer as a long term condition.

The document has been developed in partnership between the Transforming Cancer Services Team and Macmillan Cancer Support in London in response to the COVID pandemic.

It is intended for use by:

- Primary care networks and practices
- CCG/STP GP Cancer leads
- Training hubs
- GPN forums
- Cancer Alliance primary care groups
- Macmillan GPs and Macmillan professionals working with primary care.

Acknowledgements

This document has been drawn together from clinical and strategic experts in long term condition management of cancer by primary care teams. It has been led and coordinated by the Transforming Cancer Services Team (TCST) for London, part of the Healthy London Partnership and Macmillan Cancer Support. It has been supported by the pan London STP GP Cancer Leads clinical working group.

With thanks to the following who co-produced the document:

- Tania Anastasiadis - GP Associate Macmillan Cancer Support and Cancer Clinical Lead Tower Hamlets CCG
- Anthony Cunliffe - GP Advisor, Macmillan Cancer Support and Joint Clinical Chair, South East London Cancer Alliance
- Sandra Dyer – Primary Care Nurse Lead (Cancer), South West London CCG
- Liz Price - Associate Director (Personalised Cancer Care) TCST
- Emma Tingley - Strategic Partnership Manager, Macmillan Cancer Support (London region)
- Jason Tong - Senior Implementation Lead, TCST

Background

With improved outcomes for people diagnosed with cancer and the increased numbers of those living with and beyond cancer, there is an increased need for new models of care that best meets the needs of those who are surviving.

Cancer is increasingly seen as a long-term condition and the role of healthcare services outside of hospital is developing. The numbers of people living with cancer continues to grow with a life time risk of cancer of 1 in 2.

Additionally, 70% of people with cancer have another long-term condition. Living with another long-term condition reduces survival rates and adds complexity to care provision. The numbers of those with one long term condition or more is also expected to continue to rise.

In summer 2020, NICE consulted on the Quality Outcomes Framework indicator for cancer care reviews. This suggests national recognition that delivery of cancer care reviews need to change, for example with regards to timing and having a structured conversation.

NHS England’s Directly Enhanced Service for Primary Care Networks will be launched in October 2020, which includes a specification for early diagnosis of cancer. In 2021/22, it is anticipated that the personalised care specification will also be included within the DES. Long term management of cancer is part of personalised care.

NHS England’s 10-point plan for General Practice Nursing (2017) provides a strategic plan to improve recruitment as well as providing a robust career pathway for primary care nursing. Considering the role of primary care nurses in managing cancer as a long term condition will support the ambitions of the 10-point plan. This includes nursing leadership and continuing professional development for nurses in the long term condition management of cancer. The benefits of doing so will contribute improving the long-term retention of GPNs and making general practice an attractive career choice for nurses. Similar consideration to AHPs within primary care will also support recruitment and retention.

Priority areas

Two high priority areas for improvement in primary care that are included in this document are:

1. **Improve the accuracy of cancer registers -** so that patients can be safety netted and supported pro-actively, particularly in considering the risk of subsequent cancers and consequences of cancer treatment.

2. **Prioritise good quality cancer care reviews for those people who have been diagnosed with cancer recently and those who have been shielding as a result of COVID –** so that primary care teams can assess individual levels of need, signpost/refer to other services as necessary and provide personalised care.

Framework principles

The following principles provide a rationale for initiating or continuing service improvements in primary care for people affected by cancer.

1. **Deliver personalised cancer care education for primary care teams.**

    1.1. The pandemic has provided impetus to use technology more than ever. With this in mind, educators are delivering education and training virtually. Our workforce (both registered and unregistered staff) may have more flexibility to participate in virtual training, either delivered live or pre-recorded.

    1.2. Training needs analyses from London shows that GPs, Practice Nurses and other workforce within the health and care system are not confident in supporting people with their cancer as a long term condition.

    - In 2016, Transforming Cancer Services Team's Training Needs Analysis showed that 48% of nurses and 36% of GPs surveyed felt they were *sometimes* clear about their role in providing on going care to patients of common cancers. Only 8% of GP and 9% of nurses stated that they were *almost always clear*. 12% of GP and 17% of nurses stated they were *rarely clear* about their role[1].

    - In 2018, 80% of South West London General Practice Nurses (GPNs) said that patients asked them questions relating to cancer at least once a month and 58% of them reported that they were asked questions on a daily or weekly basis. However, only 11% of nurses completed CCRs in their roles. 73% noted that GPs in their practice, or other nurse colleagues were completing these. Only 13% were unaware of them. Over 70% of nurses were not confident completing a CCR (13% strongly disagree, 41% disagree, 17% unsure)[2].

    - A second TNA of South West London GPNs demonstrated that a short intervention of one hour increased nurse's confidence in discussing a cancer diagnosis and consequences of treatments with patients.

    - In 2019, Tower Hamlets conducted a Training Needs Assessment of health and care workers in the borough. This included both registered and unregistered staff. Findings showed that just 13.6% of respondents (n=67) had received any training specific to supporting people living with and beyond cancer/cancer as a long term condition in the past three years, with only 7.6% receiving training relating to the early diagnosis of cancer. 53% of respondents (n=65) reported a score of 6 or above (on a ten point scale) to express their confidence in developing a personalised plan of care to support someone with cancer's needs with only 28.6% reporting a score of 6 or above in terms of their confidence in supporting with the late effects of cancer or its treatment.

---

[1] https://www.healthylondon.org/resource/primary-care-cancer-educational-toolkit/training-needs-assessments-tna/

[2] https://www.swlondon.nhs.uk/training-needs-analysis-reports/

1.3. Macmillan professionals and Training Hubs have access to a range of training and education resources to share with local primary care teams on managing cancer as a long term condition.

1.4. There are significant benefits in delivering inter-professional learning. These include an increased MDT approach to care outside of the hospital with potential for improved care and patient experience. Case based education might be particularly helpful in managing cancer as a long term condition - participants will be able to explore the value of other professionals' input into care and move towards a holistic approach to long term management.

1.5. Consider how you provide training on cancer as a long term condition for locums working in your area.

2. Use innovative methods to understand cancer patient experience in your area.

2.1. The national cancer patient experience survey (NCPES) tells us that people don't always feel supported by primary care during their cancer treatment. There are also ongoing issues for people who may have been diagnosed some time ago, for example consequences of treatment that may arise years after treatment.

2.2. Analysis of patient experience of their care out of hospital reveals many gaps. The NCPES 2019 identifies that nationally only 57% of people feel they had some support from primary care during their cancer treatment, and only 21% felt that once their cancer treatment finished, they were given enough care and support from health or social services. Historically, London performs worse than the national average in these questions.

2.3. Discussions with a wide range of staff in your practice or network may generate innovative ideas to understand patient experience more locally. You may have also used innovative methods for other groups of patients that could be adapted for your registered cancer population.

2.4. Some examples include text based surveys, recording people's stories who have been diagnosed with cancer, patient & public involvement 'deep dive' discussions about challenges and opportunities.

3. Improve the accuracy of cancer registers so that patients can be safety netted and supported pro-actively.

3.1. Accurate cancer registers are necessary for managing the risk of subsequent cancers, multi-morbidity management, accurate shielding lists during COVID surges etc.

3.2. Analysis conducted by Public Health England and the Transforming Cancer Services team shows that more than 110,000 people were not recorded on practice cancer registers in England, when compared to the national cancer registry. In London, this figure was over 18,000 people.

3.3. With the shift from READ code to SNOMED codes, it is not yet clear whether practice registers are more or less accurate than the national cancer registry. There is an urgent need to ensure SNOMED codes generated by CCR templates are correct. If a practice notices errors, these should be reported immediately so they can be resolved.

3.4. A quality improvement project conducted by Tower Hamlets CCG, the Clinical Effectiveness Group and the primary care networks showed that many patients coded with a cancer diagnosis did not map correctly to practice cancer registers.

4. Prioritise good quality cancer care reviews for those people who have been diagnosed with cancer recently and those who have been shielding as a result of COVID.

4.1. The Cancer Care Review should promote personalised support for people affected by cancer. The review should be tailored to the individual’s needs. One way to ensure this is to ensure the person understands what the review is and is invited to consider in advance what they may want to discuss. Concerns checklists are available to help people to do this and can be sent out in advance.

4.2. The review itself should be a good quality conversation that focuses on the individual’s needs and helps them identify ways to meet those needs either by direct help/support from the GP/GPN, by provision of appropriate supportive information or by signposting to other individuals or services that might be useful. Patients should also know who their key point of contact is within the practice/primary care network.

4.3. Clinical templates should be used to have a structured, holistic conversation. National standardised CCR templates have already been developed by Macmillan and made available in EMIS Web, TPP SystmOne and INPS Vision. These templates encompass a holistic approach and have been widely welcomed by the primary care community as a framework to guide conversations. Use of the Macmillan CCR template has encouraged patients to be more open about discussing their needs and in doing so, play an active role in shaping the delivery of their care. The impact of the templates is reflected in successive evaluations showing that:

- 71% of patients reported being ‘very satisfied’ with the process[3].
- the number of GPs who reported using the Macmillan CCR Template after completing the toolkit containing the CCR increased from 11.3% to 65.7%.
- 97% of GPs practices felt better equipped to support people as they go through treatment and are recovering from cancer (87% to a moderate or large extent).

---

[3] Macmillan Cancer Support, *Evaluation of Macmillan’s Cancer Care Review Template*, available in PDF.

- Benefits cited by GPs included that it enabled a higher quality CCR and it has made the cancer review more holistic, more structured and allows betted identification of the patients’ main problems and needs”[4].

4.4. A Multi-disciplinary team approach is beneficial for people living with and beyond cancer. It is important to remember that the responsibility to help is not just on the GP/GPN carrying out the review but that the whole Primary Care Team can be helpful in supporting the patient, such as AHPs, Pharmacists and Social Prescribers within the primary care network.

4.5. Primary care networks and practices may wish to consider the benefits of providing holistic, structured cancer care reviews innovatively.

- Some options include providing CCRs at a network level or in group consultations. There is growing evidence in support of these for other long term conditions.

- Patients and primary/community care MDTs should be involved in these discussions regarding where and how CCRs should be provided.

5. When you have contact with a patient on your cancer register, update their care plan and use quick interventions to identify health and wellbeing issues

5.1. People affected by cancer are at risk of developing a subsequent cancer (either a recurrence or a new primary cancer) and at risk of consequences of treatment such as heart disease, osteoporosis, lymphoedema, anxiety & depression, bladder and bowel dysfunction. They may also experience social isolation and financial difficulties as a result of not being able to study or work for a long period of time.

5.2. Consider referral to social prescribing services as part of care planning. The Cancer Wellbeing London website will help to find and promote health and wellbeing support offers in London. The Cancer Care Map is an online directory that helps people find cancer care and support services in their local area anywhere in the UK.

5.3. Ensure you safety net for any suspicion of a subsequent cancer and/or consequences of treatment to facilitate early diagnosis and treatment.

5.4. Consider a brief intervention approach to promoting exercise as there are clear benefits to reduce recurrence and managing consequences of treatment – signpost to local exercise specialist/rehabilitation services.

6. Identify actions to reduce inequalities, or prevent widening inequalities, in all improvement actions.

---

[4] Macmillan, Pilot Outcomes related to Cancer Care Reviews 2020
https://www.macmillan.org.uk/_images/ccr-template-primary-care-evaluation_tcm9-358497.pdf

6.1. COVID-19 has provided a strong reminder of how certain characteristics contribute to health inequalities and the need for a population based approach to primary health care.

6.2. Proactive searches for patients who are less likely to access healthcare interventions due to social, cultural, language barriers and offering a CCR and personalised care plan will support those who are most vulnerable. Work jointly with local community based services and groups in care planning and support.

6.3. Accessibility to information and estates is key for improving outcomes- consider language, mobility and appropriateness of communication medium taking into consideration language, cultural, cognitive needs

6.4. In order to meet the patients identified needs, the patient may need support beyond the practice team. This may be by identifying support within their own circles or communities or by ensuring awareness of the support from voluntary sector organisations within the community.

6.5. Referrals to social prescribing teams will help to reduce inequalities by providing tailored support to patients. Obtain support from community based organisations and work collaboratively to support your patients. Co-developing patient communication with community groups/voluntary sector can help to ensure cultural relevance for example. In addition, local services can be added to the Cancer Care Map very easily. The Cancer Care Map is an online directory that helps people find cancer care and support services in their local area. People with cancer, their friends and family can either search for a service or can browse the types of services available. It uses stories and videos to show how the services have benefited other people living with cancer and sign-posts services across the country whether they are charity funded, community based or NHS led.

7. Consider ways to improve communications within your primary care teams and across health and care services in all improvement actions

7.1. Primary care teams should receive copies of Holistic Needs Assessments (including care plans) and Treatment Summaries from secondary care. If you are not receiving these, please contact your referring hospitals to facilitate improvements to communications.

7.2. Consider how you share and receiving information with community based organisations in the voluntary sector as well as health and local authority.

7.3. Your primary care network may choose to coordinate the care of the registered cancer population at scale. If this is the case, consider how the referring practice is kept informed of care provided by other practices within the network and vice versa.

8. **Evaluate your improvement actions to know whether they improve or worsen experience and outcomes for your patients, your workforce and productivity.**

    8.1. Evaluation should be planned for at the start of any improvement. You will need to have some baseline data so that you can measure before and after.

    8.2. The “Plan, Do, Study, Act” cycle is a methodology for action research and can be easily used in service improvements. It is a rapid cycle methodology and allows you to check the impact of changes, make adjustments and check again.

Appendix 1 – Resources

Principles	Resources	
1. Education	**TCST**: Education Toolkit	TCST Education Toolkit provides a repository of online courses and resources for primary and community healthcare professionals, as well as information about local educational events taking place in London.
	Macmillan: MIMS Learning Course (personalised cancer care in primary care	This recorded webinar presentation (0.5 CPD hours) discusses how primary care clinicians can provide support for people living with cancer during and beyond the COVID-19 pandemic. Users will need to register to view the content (registration is free).
	Macmillan: Explore course	Macmillan Explore is an e-learning programme supported with telephone mentoring for Band 5/6 nurses wanting to develop further or looking for a speciality change, newly recruited Band 7 nurses and Allied Health Professionals across disciplines.
	Macmillan: Social prescribing	Training pack includes • A guide for primary care networks about social prescribing in Macmillan • Primary care resource pack • 10 top tips for social prescribing
2. Patient experience	**City & Hackney CCG**: Time to talk feedback text-based pilot PDF CCR T2T Cancer Patient Survey Resul	An evaluation report on Time to talk Cancer 2016/17

	Health Watch England: Public engagement in health: a literature review	Healthwatch England commissioned a review of literature and research relating to public engagement in both service improvement and service transformation, focussing particularly on the outcomes and effectiveness of engagement across the fields of health and social care.
	National Association for Patient Participation: Practices and patient engagement	This guide helps commissioners in engage in sustainable and useful ways with patient participation groups (PPGs)
	Macmillan: Finding Cancer stories in London using Ethnography	This report is intended to provide information and recommendations for anyone working in cancer services generally, and broadly in health and wellness in London. Its purpose is to enable greater inclusion of people affected by cancer (PABC) in these processes.
	Social prescribing patient feedback	
3. Accuracy of practice cancer registers	**Tower Hamlets CCG/TCST**: Guidance on clinical coding of cancer patient in primary care	The purpose of this guidance is to: • Share comparative analysis of prevalence data with stakeholders – data is sourced from the National Cancer Registration & Analysis Service (NCRAS) and primary care registers (from the Quality Outcomes Framework) between 2003 and 2015 • Share an example of how practice coding registers have been 'cleansed' in one CCG where all GP practices use the EMIS clinical system. • Share our learning with NHS England (regarding the national QOF review) and NHS Digital (re the implementation of SNOMED in primary care)
	TCST/PHE: Prevalence dashboard	The toolkit covers clinical, psycho-social and patient experience dimensions and provides recommendations for all organisations that plan, commission and deliver cancer care for Londoners.

4. Good quality cancer care reviews	**Macmillan:** Cancer Care Review	Recommendation from Macmillan on how to conduct a good quality Cancer Care Review
	Macmillan: Cancer Care Review Clinical Templates Access Guide	Macmillan worked collaboratively with a group of frontline GPs in Nottinghamshire to develop a comprehensive electronic Cancer Care Review template, which is now integrated into the EMIS Web, TPP SystmOne and INPS Vision clinical systems
	Macmillan: Evaluating the impact of a CCR template in primary care	The Macmillan 'Cancer Care in Primary Care: A Quality Toolkit for General Practice' was offered to GP practices in 2018/2019 as part of a pilot programme in England. This evaluation shows the impact of that toolkit in delivering structured CCRs using clinical templates.
	RCGP/Macmillan: Consequences of Treatment Toolkit	The toolkit provides resources and information for primary care professionals to identify and manage the consequences of cancer treatment, and support patients to live well after a cancer diagnosis. It is designed to be used by any general practice in the UK and is appropriate for everyone who provides or commissions services for people living with and beyond cancer.
	Macmillan: Concerns Checklist	This self-assessment is for used by patient, to help professionals understand the concerns and feelings patient may have. It will also help professionals to identify any information and support patient may need.
	TCST: Cancer Care Review toolkit	This toolkit includes 4 separate documents: 1) Cancer care review (CCR) business case A template business case to support London's sustainability and transformation partnerships and CCGs in implementing the four-point model for cancer care reviews. Commissioners can use it to create a business case for their board recommending introducing the four-point model. It includes a sample local incentive scheme; a holistic cancer

		care review; a sample service specification; patient letters and a template to conduct holistic cancer care reviews. 2) Transforming primary care for people living with and beyond cancer event report A summary of the ‘transforming primary care for people living with and beyond cancer event (October 2017) held for primary care providers 3) Guidance on clinical coding of cancer patients in primary care This guidance provides a comparative analysis of national Quality and Outcomes Framework (QOF) practice register data with the National Cancer Registration & Analysis Service (NCRAS) prevalence data between 2003 and 2017. 4) Commissioning and delivery toolkit for cancer as a long-term condition The document aims to provide STP cancer leads a mechanism to develop a business case to support cancer patients as part of long-term conditions. We know that people experience effects of treatment years after receiving it. It is for these reasons that for a large proportion of people who get cancer, it will become a long-term condition that needs managing.
5. Care plans including health & wellbeing	**NHS England/Improvement**: personalised care model	The NHS Personalised Care Model will help us to deliver this shift in practice by bringing together six, evidence-based components or programmes, each of which is defined by a standard set of practices. These are: • Shared decision making • Personalised care and support planning • Enabling choice, including legal rights to choice • Social prescribing and community-based support • Supported self-management

		- Personal health budgets and integrated personal budgets
	Macmillan: Mind the Gap Report	This report explores inequalities in cancer care that exist in London. Analysis that Macmillan commissioned recently, shows that people living with cancer in London report worse experiences of cancer care than those elsewhere in England. This is worse still for minority ethnic groups who account for around two in five – that's 42.5%4 – of all people living in London. We also found that patient experience is worse for those who live in the most socioeconomically deprived areas. It may be counterintuitive but, in fact, our capital city has a higher proportion of people in poverty (after housing costs) than the rest of England (27% compared to 21%). These differences matter. In terms of clinical outcomes, we know that there are differences at a national level for those from minority ethnic groups and those living in deprived areas. London has the most ethnically diverse population in the country and significant pockets of socioeconomic deprivation.
6. Inequalities	To consider health equalities in the local population. E.g. how virtual consultation impact on certain groups of the population.	
	TCST: Cancer Inequalities Toolkit	The toolkit covers clinical, psycho-social and patient experience dimensions and provides recommendations for all organisations that plan, commission and deliver cancer care for Londoners.
7. Communication	When mapping local stakeholders within a PCN/ICS. It is important to include primary and community care, secondary care, social care and voluntary sector.	

	Macmillan: Treatment summary and HNAs	The Cancer Personalised Care interventions (previously Recovery Package) has four main interventions: Personalised care and support planning based on Holistic Needs Assessments, End of Treatment Summary, Primary Cancer Care Review, and Health and Wellbeing Information and Support.
	Macmillan: Top Ten Tips includes advice and guidance on late effects of cancer and support from social prescribing	Macmillan GP advisers have collaborated with members of the Macmillan primary care community to develop a '10 top tips' series of downloads, offering practical hints, tips and information on a variety of different primary care situations and scenarios.
8. Evaluation	**HEE/TCST:** Framework for the evaluation of training and education programmes for cancer in primary care	This framework aims to support high quality and consistent evaluation of training and educational interventions in primary care to support early diagnosis of and living with and beyond cancer.
	NHS England/Improvement: PDSA cycle	Use plan, do, study, act (PDSA) cycles to test an idea by trialling a change on a small scale and asses its impact, building upon the learning from previous cycles in a structured way before wholesale implementation.