



South West London Health and Care Partnership

Macmillan Primary Care Nursing Project

Scoping Report

Document Creation

Date	Author(s)	Role	Version
05.07.18	Sarah Dewhurst	Macmillan Specialist Clinician	1.0

Document Revision History

Revision date	Author(s)	Change summary	Version*
15.8.18	Sarah Dewhurst	Added Recommendations and Community Nursing section	3.0
25.9.18	Sandra Dyer	Made amendments, added to education chapter	3.1
26.9.18	Sarah Dewhurst	Added patient engagement chapter	3.2

Approvals

This document requires the following approvals before finalisation.

Name and position/group	Date approved	Version
Macmillan Primary Care Nursing Steering Group		

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1. Introduction

The purpose of this scoping report is to present the findings of specific stakeholder engagement events designed to inform our understanding of current practice related to cancer reviews, nurse-led prostate follow ups and cancer education for nurses across South West London.

It has been completed as part of the Macmillan Primary Care Nursing Project which aims to improve patient experience and clinical outcomes by training and supporting primary care nurses to care for cancer as a long-term condition, and increase the capacity to deliver cancer care in primary care settings. The planned outcome is the delivery of consistent, high-quality, patient-focused, out-of-hospital care for those living with and beyond cancer.

The information contained in this report will be used alongside the training needs analysis to inform the Macmillan Primary Care Nursing Project in its work to improve the knowledge and skills of nurses in South West London. Specifically, this report will outline where cancer care reviews and nurse led prostate follow ups are taking place and give examples of good practice. It will also outline the limitations to the scoping work and next steps to increase our understanding of current practice.

2. Aim

- To collate knowledge of current nurse involvement in CCRs and nurse-led follow up for prostate cancer.
- To engage with a range of healthcare professionals across SW London who currently have a role in completing or commissioning CCRs and nurse-led prostate cancer follow up; or who are involved in PCN education.
- To outline patient engagement initiatives.

3. Benefits

- Improved understanding of existing practice and education.
- Increased understanding of barriers and enablers to nurse involvement in CCRs and nurse-led follow up to inform future roll out.
- Establish connections with primary care nurses who are leading on cancer care.
- Ability to inform future LES commissioning.

4. Background and Context

With improved outcomes for people diagnosed with cancer and the increased numbers of those living with and beyond cancer, there is a greater requirement for new models of care that best meet 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 lifetime risk of cancer of 1 in 2 (Ahmad et al 2015)

Given that 70% of patients with cancer have another long-term condition the primary care workforce are seeing patients with cancer daily. The nursing workforce specifically has been identified as well placed to meet the needs of this patient group as they typically routinely manage their other long-term

conditions. Knowledge around the needs of those living with and beyond cancer is however variable and with this group of patients growing in number there is an identified need to develop skills and knowledge.

NICE (2016) outlines best practice for people living with multi-morbidities and emphasises the importance of an integrated and holistic approach to care. Initiatives to move follow-up care out of hospital (e.g. for prostate cancer) enable an integrated approach to be possible.

There are two specific contact points with patients living with and beyond cancer where general practice nurses can develop a leading role:

1. Cancer Care Reviews
2. Nurse-led prostate cancer follow ups

Cancer Care Reviews

The aim of a cancer care review (CCR) is to provide a holistic appointment at key points in a patient's cancer journey where physical, psychological, emotional, spiritual, financial and social needs are addressed and a patient is supported to self-manage their cancer or treatment side effects as a long term condition. These appointments are typically longer than a usual appointment and can be led by any suitably qualified healthcare professional.

Transforming Cancer Services 4-point model (TCST 2015) for CCRs has been endorsed as a model of best practice to align with in South West London.

- Point 1: QOF CCRs - a cancer care review completed at the point a patient is added to the cancer register
- Point 2: a holistic CCR completed at first contact point after diagnosis
- Point 3: a holistic CCR completed at the end of primary treatment
- Point 4: cancer is incorporated as part of routine long-term condition review

Nurse-led Prostate Follow Ups

Prostate cancer is the most common male cancer with over 40,000 men diagnosed each year. It is predicted that by 2030, prostate cancer will be the most common cancer in the UK.

Different models of follow-up care exist to support patients following a diagnosis and treatment for prostate cancer including both primary & secondary care follow-up operating the NCSI Risk Stratified model for remote/telephone follow-up. This means that there is variation, inequity and gaps in services such as erectile & sexual dysfunction, incontinence and psychological support.

Using NICE guidance CG175 (2014) and the Croydon project tools the purpose of the new pathway is to improve follow up processes by:

- Improving access by bringing care closer to home.
- improve patient information and experience by ensuring information and care is holistic
- provide training and development for professionals within the prostate follow-up system
- release urology outpatient capacity and generate cost savings for CCGs by shifting care from secondary to primary care for a stable cohort of patients
- ensure safety netting procedures are in place to mitigate patients being "lost" to the system during transfer from secondary to primary care

5. Local Context

Currently in South West London CCRs are only completed at point 1 and 3 of the 4-point model and this does not happen at all practices.

QOF cancer care reviews are completed by most practices however the current template requirement is a tick box, so this does not tend to be an in depth or holistic consultation.

Completion of holistic cancer care reviews is much more variable. There is a LES (local enhanced services) in place in Wandsworth and Richmond – see appendices; however evaluation of uptake or impact was not a requirement and therefore there is no available reporting to indicate how many are completed or by whom.

In Wandsworth 26 out of a total of 42 GP practices are undertaking holistic CCRs (range 1 - 14 per practice). A total of 96 have been completed from January to May 2018. To our knowledge only one nurse in a Wandsworth practice routinely completed CCRs as part of her role, however she has now moved to a different practice.

15 out of 28 practices in Richmond took up the LES but the commissioners have been unable to provide details of numbers completed. To our knowledge no nurses currently complete CCRs in Richmond.

Nurse-led prostate cancer follow up is in place in Croydon and Sutton. A successful pilot was established in Croydon in 2014/5 and as a result all GP practices in the borough now offer primary care led follow up for stable prostate cancer patients. In two known practices, nurses have taken the lead on running clinics for prostate cancer patients as part of their routine cancer management but also to complete a holistic needs assessment.

In Sutton a similar project to transfer the care of stable prostate cancer patients to primary care has just ended. To our knowledge, nurses in two practices are in the process of setting up clinics to lead on managing these patients' care.

It is the intention of SW London to roll out primary care led prostate cancer follow up in all 6 CCGs by the end of December 2018. Primary care nurses will be key to the delivery of the new pathway.

6. Cancer Care Reviews

Nurse Interview – Wandsworth

We interviewed a GPN who was the only nurse we identified who completed CCRs. She undertook the Macmillan GPN course a few years ago with the backing of her practice manager.

Key themes

- Started completing CCRs approx. 6 months after Macmillan GPN course
- Tends to complete CCR opportunistically as part of another appointment e.g. diabetes review
- Not aware of any other nurses doing them, feels she would benefit from peer support/mentorship as aware lots of things have changed since doing the course
- GP colleagues are generally supportive; some prefer to do the CCR for their own patients
- No other oncology training, she feels reasonably confident supporting cancer patients but doesn't feel her knowledge is as good as with other LTCs e.g. diabetes

GP evaluation – Wandsworth

A GP registrar at a practice in Wandsworth completed a quality improvement project (QIP) to try and improve the number of CCRs being completed at her practice. As part of this work she interviewed GP colleagues and highlighted that

- They had heard of the HCCR but did not know what it is or know about the Health Needs Questionnaire.
- They did not know there was an EMIS template.
- They did not know about non-clinical self-management services and how to advise patients to access these; some were wondering if patients could self-refer since they found the current referral process very time-consuming.

Of the few members of staff who were aware of HCCRs, some expressed:

- Lack of time during the consultation was a barrier.
- Lack of willingness – “it is the practice nurse’s job”.
- One doctor mentioned he would complete the review “just to code it” but did not see the value in it for the patient.
- Two doctors felt it was inappropriate to bring a patient in “for yet another cancer appointment they probably don’t want”; one of these doctors did feel however that it was the role of the patient’s usual GP to do this, if the patient wanted to take part in the review, as opposed to allocating all patients to the practice nurse.

A small amount of anecdotal feedback was obtained from patients as the CCR was completed. In keeping with the Macmillan guidance patients said they would prefer a face to face consultation as they felt less comfortable discussing sensitive issues over the phone with a clinician they didn’t necessarily know. They also understandably preferred a set appointment rather than an unplanned phone call.

Discussion with the registrar completing the QIP highlighted that education to practice staff about the role and value of CCRs, both to patients and financially to the practice, favourably influenced their attitude and appeared to increase the likelihood of them completing CCRs with patients. Undoubtedly there are still significant barriers present which are likely to be typical more widely, even with the financial remuneration from the LES.

General Practice Nurse engagement events – Merton

We attended three separate education and networking events reaching approximately 40 general practice nurses working in Merton. At each event we gave a presentation about the recovery package, the enhanced role of GPNs within cancer as a longterm condition and an outline of the project. Feedback and discussion confirmed a low level of existing knowledge regarding the recovery package but a positive interest in developing their roles going forward.

Nurse interview - Richmond

We did not identify any nurses completing CCRs in Richmond however some nurses within the CCG had attended the Macmillan GPN course and one agreed to complete a questionnaire to explore how this had affected her role.

Key themes

- Spends approx. 20-30% of her clinical time with cancer patients and is aware her role is expanding to support cancer patients live with and beyond their cancer
- Typical issues include symptom management, anxiety about recurrence, coping mechanisms/self-help, lymphedema, hickman lines/post-op dressings, bladder/bowel function, hormone injections
- Aware of CCRs taking place within GP practices but feels she would need specific training and allotted time to complete them herself
- No knowledge of other nurses locally with an interest or expertise in cancer

Commissioning meeting – Richmond

It has been difficult to ascertain how many CCRs have been completed by GPs as collection of any data or evaluation was not a part of the LES. To try and explore this we met with two members of the cancer commissioning team in Richmond.

15/28 practices have taken up the LES. Reasons why they have not taken up the review are outlined below:

Issues	Solutions
Staffing Levels - Not all practices have a practice nurse. However, some of the large practices with nurses haven't taken it up.	Inter-practice referral
Time	Could explore using the same money to fund a locality nurse.
Money - £60 per review with a lower payment if a nurse completes.	
Primary care attitudes and perceptions towards the LCS	Macmillan GPs to do practice visits to improve take up.
The process of doing the LCS and being part of it may not be straight forward	
<p>Identifying which patients need a review. At what point are GPs triggered to do a review.</p> <p>Some hospitals follow up for a while with patients. So, at what point do they hand over care.</p> <p>Trigger is a treatment summary received from the hospital. But note that not all patients are getting a treatment summary. GPs would need to do the coding properly.</p>	

<p>Patients perception of the review – do they find the review useful. The treatment summary could suggest that the patient contacts the GP and asks for a review.</p>	<ul style="list-style-type: none"> - Could do a survey of patients who have had a review - Use the friends and family test – but that is just generic. - Go to the practice PPG of practices - Review as part of the review of Richmond LES - Kingston Hospital patient cancer group- could approach patients asking for ideas and feedback.
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7. Nurse - led Prostate Cancer Follow-up

Nurse Interview - nurse-led prostate follow up (Croydon)

A meeting with a GPN identified she is successfully managing the routine follow up of stable prostate cancer patients at her practice. She undertook this role with the support of her GP colleagues following the implementation of the pathway as part of the Croydon pilot.

Key Themes

- Fortnightly clinic, able to see 5 patients a clinic, currently managing 65 on her list
- Well supported by GP colleague
- Generally, patients are well and do not raise multiple or complex issues
- Barriers include: lack of DC summary from referring hospital, did PCUK masterclass a little while ago so feeling rusty- need for ongoing CPD opportunities

Nurse Interview - nurse-led prostate follow up (Sutton)

A GPN is about to start undertaking prostate follow ups for stable patients. She has been supported by her GP colleagues and the project team establishing stratified prostate follow up in Sutton.

Key Themes

- Planning to see prostate patients in routine clinic, no specific slots/clinic
- Identified 20 patients from existing register
- Ex-oncology nurse so feels well equipped to support these patients, not completed any oncology specific training since being a GPN

Prostate project evaluation – Sutton

Full evaluation pending.

8. Community Nursing

Engagement with community nursing providers has been completed at a slower pace. Four individual meetings were held with senior Community Nurse Managers and Clinical Leads in Central London Community Healthcare Trust, Kingston Your Health Care and Hounslow and Richmond Community Healthcare Nhs trust

A workshop with attendees from the above providers was held in August. Time was spent discussing the role of community nursing staff in relation to cancer. By the end of the discussion, general consensus had been reached that community staff would frequently come into contact with people with cancer and would therefore benefit from a greater understanding of treatment pathways and likely side effects. It was agreed that their role would be enhanced if they could be supported to take on a more active role in providing emotional and practical support, signposting and acting as a link between primary and secondary care. It was agreed that a competency document was not required at this point but instead efforts should focus on understanding the role of community nurses in relation to cancer as a long-term condition and an inclusive training programme to improve awareness of cancer amongst community teams. In addition a more specialist training programme for nurses with a special interest in long term conditions or DNs in a more highly skilled role (such as Community matron or Long Term Condition Specialist Nurse) would be valuable.

9. Higher Education

As part of the project scoping the team have also engaged with higher education providers to understand how the current post registration offer for primary care nurses includes content on cancer.

Kingston University/ St Georges Faculty- the GPN module is an introductory course for new GPNs aimed at foundation L6 level. They gain 30 Level 6 credits on completion of the module. The current content includes cancer in the context of cervical screening only with no content that relates to cancer as a long-term condition

London South Bank University- Introduction to General Practice Nursing- with three core modules leading to a PG cert (level 7) or CPD points at level 6. Semester one is an over view of the GPN role and covers public health issues and screening (cervical.) and semester two is a long-term condition module. Currently there is no cancer content on module two but there appears to be flexibility to include this.

City University- TBC,

Kings College London - TBC

Greenwich University- Run a Fundamentals of General Practice Nurse module for nurses new to practice nursing. This currently has content on cervical screening but no other cancer specific content. An Advancing Practice Nurse Module is also run which focuses on long term condition follow up, with no cancer content currently. There is an also a generic Long-term Condition module- again with no cancer content. There is flexibility in all these programmes to add in cancer as a long-term condition content.

10. Patient Engagement

This project can learn from the small amount of patient engagement completed by projects elsewhere which found:

1. In Lanarkshire 77 patients responded to a survey and were positive about their experience of a CCR; for example, 83% scored 8 or above on a 1-10 scale (10 being very confident) in their confidence to self-manage, 85% scored 8 or above regarding the support they received from their cancer care review

2. In Hackney 189 patients responded to a survey and were also overwhelmingly positive about their experience of a CCR; for example, 93% felt they could bring up what they wanted to, 78% felt the appointment had increased their confidence in managing their health, and 89% said the appointment was helpful

However we felt it was also important to understand the patient voice in SW London where no feedback on cancer care reviews or primary care led prostate follow up has currently been collated directly from patients.

This work is ongoing but to date the following methods of engaging with patients have been utilised:

1. Two survey monkeys asking patients about their experience of a cancer care review or a primary care led prostate follow up respectively
2. Two planned focus groups for each type of service user (CCR and prostate)
3. Option to have a telephone interview with a member of the project team

Patient identification has been challenging as it is a relatively small cohort but the following approaches have been made:

- The practice managers of all GP practices signed up to the Richmond LES were telephoned and asked if they would identify the past 10 patients to have a CCR and send them an invitation letter on our behalf. One practice agreed to do this.
- The Macmillan GP and a nurse partner in Wandsworth both sent out 10 invitation letters to patients from their practices who had recently had a CCR.
- The Macmillan 'patient and public involvement coordinator' send out an email invitation to 50 members of the St Georges patient engagement group for cancer.
- An advert including the survey link and an email address for further information was included in the Richmond Health-watch bulletin and to members of the Richmond patient participation group; with the latter being encouraged to raise this work with their practice manager.
- The nurse completing primary care led prostate follow up reviews in Croydon initially sent out 10 invitation letters retrospectively and is currently handing out an invitation to every patient she sees in her follow up clinic.

11. Other Related Projects

Over the course of our scoping work we have identified some related projects which are briefly outlined below.

1. Macmillan funded project in Lanarkshire concluded in 2018.

<https://www.woscan.scot.nhs.uk/wp-content/uploads/NHS-Lanarkshire-Cancer-Care-Reviews-Final-Report.pdf>

Project's objectives:

- Increase the confidence and competence of 10 practice nurses to deliver cancer care reviews
- Provide evidence of the effectiveness of practice nurse led holistic cancer care reviews

- Empower patients and carers to improve their quality of life
- Improve the quality of the patient experience by offering a personcentered cancer care review
- Report potential reduction in unnecessary (inappropriate) G.P appointments

Nurses were trained using the Macmillan long term conditions module.

6 focus groups for patients and nurses and interviews with GPs were conducted to evaluate the objectives.

Data was collected on 248 patients who attended for CCR.

They concluded that training practice nurses to complete CCRs was acceptable and feasible, leading to better outcomes for patients and potential for cost saving in GP hours.

2. Telford and Wrekin CCG Audit

The CCG completed an audit into the quality and outcome of CCRs

One of their questions was whether practice nurses could complete CCRs; 50% of GPs felt they could with support and training, 50% felt it was part of a GP role

Currently practice nurses completed CCRs in 22% of practices

3. Hackney Evaluation – see comments above in ‘Patient Engagement’

4. Tower Hamlets feedback

The Macmillan GP in Tower Hamlets led a successful project aiming to improve the quality of CCRs within her CCG. Her main achievement was to incorporate cancer within long term condition reviews and to enable this via the LTC template. Key messages were not to underestimate the need for education about the survivorship needs of patients even to experienced GPs and to use the patient story to help get the message across.

Primary Care Facilitator Roles in London and SE.

The project team also made contact with nurses in the above roles in CCGs in London (Lambeth) and the South East in order to share resources and project outputs.

12. Conclusions

Cancer Care Reviews

There are very few nurses currently completing CCRs in SW London.

Barriers include:

- Lack of GP sign up to recovery package and importance placed on CCRs being completed in general practice; evidenced by incomplete sign up to LES in Richmond and no equivalent LES existing in Kingston, Croydon, Merton or Sutton.
- Some GPs seeing themselves as best placed to complete CCRs and reluctant to support GPNs to develop this skill

- Macmillan GP role is currently vacant in Richmond and Merton
- Cancer as a long term condition is not currently covered on undergraduate or post graduate training courses for nurses, GPNs or DNs
- Limited awareness amongst GPNs of recovery package and potential/necessity for their role within cancer to expand
- Current Macmillan GPN training not always accessible for nurses, despite being free, time away from practice and location are thought to be biggest barriers
- Current Macmillan GPN training possibly not sufficiently in depth to equip nurses to take on additional cancer role in practice

Enablers include:

- Financial incentive for CCGs with a LES in site (Wandsworth and Richmond)
- Existing Macmillan GPN course is free for nurses in SW London to attend and there is potential to revise content to increase accountability for learning outcomes and role of mentor/peer support
- Initial engagement with post graduate providers has been positive to include cancer as a longterm condition within their syllabus
- The nurse who is currently completing CCRs is doing so successfully and enjoying this element of her role which provides a useful case study to promote nurse involvement
- Supportive Macmillan GP in Wandsworth

Nurse led Prostate Cancer Follow Up

Although the numbers of nurses completing prostate follow ups is also low, in contrast to CCRs, the pilot projects established in Croydon and Sutton have paved the way for nurses to lead on delivering prostate follow ups. The nurses we spoke to had each developed a local system for identifying and contacting patients and were not encountering many difficulties, they felt well supported by the initial project team and their GP colleagues.

Barriers include:

- Roll out has been slower in the CCGs where a dedicated project team have not been in place
- No specific ongoing training to equip nurses to perform this role

Enablers include:

- Supportive GPs who have helped establish the role of the GPN within the pathway
- Nurses who attended the Prostate Cancer UK Primary Care MasterclassUK found it helpful
- On hand project teams who have assisted individual practices to establish the follow up pathway

Community Nursing

Community nurses are not currently in a position to take on a more specific role within cancer care. Work needs to focus on developing their understanding of their ability to support cancer patients in their own homes and providing appropriate education to enable this.

Barriers include:

- Cautious engagement from community nursing leaders who have legitimate concerns about the impact of increased workload on their staff
- Absence of any existing training for community nurses on cancer with the exception of end of life care.
- Cancer as a longterm condition is not included on current DN training

Enablers include:

Potential funding via cancer transformation funding to pilot a training programme for community nurses

13. Limitations

This scoping report has been limited by the absence of exact data on the numbers of CCRs being completed in GP practices and the profession of the person completing them. We have therefore had to rely on knowledge gained from colleagues on the steering group and contacts made throughout the duration of the project. Due to clinician's time constraints we were unable to interview a few nurses who might have added additional insight into reasons why nurses are not currently completing CCRs.

Having said that we are confident that we have presented an accurate a picture as possible of current practice across South West London.

We are continuing to look for examples of similar work in this area nationally and will utilise the upcoming Macmillan conference in November to improve this network.

The patient engagement work continues and will inform the education strategy in due course. Access to patients has been limited by poor engagement from GP practices

14. Next Steps and Recommendations

The project team will share the scoping report with Richmond CCG for information to help inform the review of the Cancer Care Review LES

The project team will develop an education strategy and plan as the next phase in the project plan . This will include:

- Project Team to work with Macmillan to help shape the offer to GPNs through the Mcmillan Affiliate offer and the new Macmillan Practice Nurse course. The project team will also work with Macmillan and SWL CCGs to support the increased uptake of the revised course
- Project team to scope specialised training that could support a GPN with a special interest in cancer to develop higher level knowledge and skills
- Project team to work together with RM Partners and the Royal Marsden School to develop a module for community nurses and cancer.
- Project team to carry out specific engagement work with individual community nurses to understand their preferences for community nursing and cancer module. This will also be an enabler to promote the module and ensure it is fully utilised.

- Project team to work with SW London Prostate Cancer working group to help map opportunities for ongoing cpd opportunities for nurses completing prostate cancer follow ups
- Bespoke piece of work identifying barriers for GPs in promoting role of their GPN colleagues- project team to take to project steering group.
- Project team to engage with all higher education providers across SW London and promote inclusion of cancer as a longterm condition on post graduate primary care nursing training as a sustainable output from the project.
- The project team will continue with the patient engagement work and add the results to this scoping document. One or two focus groups dependent on numbers will take place towards the end of the year and the results of the survey monkey and any telephone interviews will be analysed accordingly.

Appendices:



Richmond LES.docx



Example TNA survey
(hard cop)

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