

Delivering Cancer Care Reviews

Findings and Principles

West Yorkshire & Harrogate Cancer Alliance

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Introduction

The start for many people on a cancer is journey is seeing their GP with symptoms that they are concerned with. As patients continue along the stages of diagnosis and treatment, contact with the GP may be less, but that does not diminish the role of Primary Care in the ongoing health and wellbeing support which patients may need to access during this period. We know that the average practice (8000) has approximately 280 patients living with and beyond cancer and that this is set to double by 2040; that over half of these patients will have been diagnosed over five years ago and that they attend the GP practice more frequently than other patients of the same age, often presenting with a range of needs that are both clinical and holistic in nature¹. At the same time the number of people surviving treatment for cancer is increasing with more and more people going on to live with the disease for a number of years akin to other long term conditions such as diabetes, chronic obstructive pulmonary disease and arthritis all of which are managed in primary care settings. Managing cancer patients in a similar way as other long term conditions by providing regular reviews, is a way to monitor and address any changes in health whilst at the same time developing a relationship where advice and support can be accessed when needed without waiting until a specific cancer appointment. We know that patients do not only suffer clinical effects following their diagnosis and treatment for cancer but that they also suffer with emotional, social and financial needs with one in four experiencing consequences of their cancer or treatment that impact their quality of life.²

It is against this backdrop that the project to review the quality and effectiveness of CCRs across the WY&H areas was included in the Living With and Beyond Cancer Programme funded through NHS England Transformation Fund in 2017. This report brings together the activity and learning which has taken place by the Living With and Beyond Cancer Project Team (LWBC) since April 2018.

To do this, it has been necessary to have an understanding of the role of the CCR, to identify how they are carried out across the Cancer Alliance footprint and explore the patient and professional experience in West Yorkshire & Harrogate of completing reviews with patients following a cancer diagnosis. This report is the culmination of the work done during the year and identifies key principles to deliver quality CCRs where patients live with their cancer knowing that they have the necessary support from their Primary Care team to maintain their health and wellbeing. It sets and informs the future direction to ensure the support provided to patients through CCRs across the Cancer Alliance is consistently of a high quality.

To identify the unmet needs and support for these patients, the Macmillan Recovery Package includes a number of interventions such as holistic needs assessments, care planning and treatment summaries which are used to not only identify, but to address patients' needs, and at the same time communicate to patients, carers and other professionals involved in their

¹ <https://canceralliance.wypartnership.co.uk/our-work/living-with-and-beyond-cancer/shared-learning-events-and-conferences/nhs-england-living-beyond-national-event> Cancer care in primary Care

² <https://canceralliance.wypartnership.co.uk/our-work/living-with-and-beyond-cancer/shared-learning-events-and-conferences/nhs-england-living-beyond-national-event> Cancer care in primary care

care the details of their diagnosis, treatment they have received and on-going care and support required.

The cancer care review (CCR) is part of the Recovery Package and builds on the other elements to ensure both clinical and holistic support is offered to the patient outside of the hospital in primary care to support people in their transition into a new 'normality'.³ Across the West Yorkshire and Harrogate Cancer Alliance (WY&HCA) there are two pilots being run in Leeds and Wakefield in which the wider Primary Care team are being used to support patients, information on these can be found on page 7 and it is important that we learn from these pilots and build on the findings to ensure equality in access and provision of personalised care and support following a cancer diagnosis. Going forward the need to provide personalised support for patients with long term conditions such as cancer will be a requirement as stated in the NHS Long Term Plan that by 2021 where appropriate every person diagnosed with cancer will have access to personalised care including needs assessment, care plan and health and wellbeing information and support.⁴

The CCR is a tool which supports the development of personalised care for patients living with a cancer diagnosis. This approach is further supported by the investment in Primary Care in provision of social prescribers to deliver targeted support to all patients as identified as needed.

Background

CCRs were introduced as part of the Quality Outcomes Framework (QOF) contract in 2004, which required General Practitioners to put all patients with a diagnosis of cancer onto a register and to offer them a CCR within six months of diagnosis. The current QOF requirement is a measure of the number of patients with cancer, who have had a patient review within 6 months of the date of diagnosis (based on NICE 2012 menu ID: NM62). Primary Care is set targets of 50–90% compliance to achieve QOF standard.⁵ The Macmillan Recovery Package builds on this standard and provides a template upon which CCRs can be used to support patients both clinically and holistically.⁶

The National Cancer Survivorship Initiative (NCSI) set up in 2008 aimed to ensure that those living with and beyond cancer had access to the care and support they needed to lead as healthy and active a life as possible, for as long as possible. The NCSI developed and tested a number of key interventions, which together were called the Recovery Package. One of the key messages was that care plans or advice that a patient has declined a care plan should be sent to the patients GP to support the delivery of the CCR. Its report 'Living With and Beyond Cancer: taking action to improve outcomes' emphasises the importance of the Recovery Package in achieving better outcomes stating that people had greater wellbeing

³ https://www.macmillan.org.uk/_images/recovery-package-sharing-good-practice_tcm9-299778.pdf

⁴ <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>

⁵ <https://www.nhsemployers.org/-/media/Employers/Documents/Primary-care-contracts/QOF/2018-19/2018-19-QOF-guidance-for-stakeholders.PDF>

⁶ https://www.macmillan.org.uk/_images/recovery-package-sharing-good-practice_tcm9-299778.pdf

and their demand for services lower, if they get the support that is relevant to their particular needs, and which promoted a healthier lifestyles and independence.⁷ Macmillan developed this work into the current model which recognises the importance of effective CCRs in supporting patients to live with and beyond their cancer diagnosis.

To further support effective delivery of a CCR, guidance has been developed by Macmillan and locally following research by the Yorkshire and the Humber Clinical Network. Both guides reference the how and when a CCR should be carried out, the need for good timely communication between clinical teams in secondary and primary care with practical suggestions on how the CCR can be used to promote health and wellbeing. The Macmillan guide provides 10 top tips for completing an effective CCR⁸ and to further support this, Macmillan in partnership with GP representatives have developed and introduced a Cancer Care Review Template available on Primary Care patient record systems – EMIS and SystemOne. The Yorkshire and the Humber Clinical Network in 2016 developed a guide to completing cancer care reviews based on research gathered nationally and across Yorkshire and the Humber which indicated that CCRs undertaken by GPs is variable; with some patients being offered extended face to face consultation, others a brief phone call, and in some cases no contact with their GP after diagnosis.⁹

The National Cancer Patient Experience Survey for 2017 showed that across West Yorkshire and Harrogate 63% of people responding indicated that they felt that practice staff did everything they could to support them during their cancer diagnosis, treatment and beyond.

Engagement with primary care colleagues across West Yorkshire and Harrogate confirms that CCRs do take place, but that there is significant variation with regards to the frequency, quality and patient experience of these reviews. These reviews should be a consistent opportunity for patients to discuss the key aspects of their cancer and their concerns around their circumstances following treatment. A British Medical Journal article published in March 2017 stated:

Cancer care reviews (CCR) form an integral part of the shared-care approach; but clearly more can be done to improve the service provided by GPs. What is apparent from this study, and others, is that patients require a comprehensive consultation to discuss key aspects of their condition and social circumstances.¹⁰

The LWBC programme has developed a number of projects to support people following a cancer diagnosis which includes the implementation of all elements of the Recovery Package in West Yorkshire & Harrogate by 2020, of which the CCR in primary care is a part.

⁷ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/181054/9333-TSO-2900664-NCSI_Report_FINAL.pdf

⁸ https://www.macmillan.org.uk/images/carrying-out-an-effective-ccr_tcm9-297613.pdf

⁹ http://www.yhscn.nhs.uk/media/PDFs/cancer/CCR%20insight_%20opportunities%20and%20top%20tips%20FINAL.pdf

¹⁰ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3063046/>

The aim of the Cancer Alliance project has been to understand the level of variation reported by patients and Primary Care across West Yorkshire and Harrogate, to understand from patients the barriers to accessing a CCR and their experience if they have had an identifiable CCR with their GP.

Engagement

The LWBC team reviewed the role of CCRs, looking at how patients are supported to better understand the benefits and barriers of having a specific cancer review; and how these reviews are delivered in a consistent and sustainable way which is of a quality that provides support to patients. This included a number of engagement pieces of work which were conducted with patients and Primary Care.

As part of this engagement, the team found that the language used to describe the relationship of Primary Care with patients when receiving treatment for cancer can often give the impression that Primary Care is not involved in the on-going care of the patient during this time. One GP responded to a comment of 'when the patient returns to Primary Care...' with the statement 'they never left'. This misconception that once a patient has a cancer diagnosis that they are no longer cared for by Primary Care often leads to patients not being aware of the support that is available to them from the GP. During the summer of 2018, 70 GPs completed a short survey based on their experience of completing CCRs. The majority of responses agreed that completing such a review was a benefit for both the patient and the GP. When asked what the barriers were to completing the review 36% responded that the biggest issue was communication with secondary care, the survey reported that the need to receive timely summaries of treatment was the main barrier to completing a meaningful review and that summaries should include:

- details of what is required to be done by general practice,
- the type of cancer treatment received and whether it was curative or non-treatable,
- what symptoms would need to be managed,
- clear information on what the patient knows,
- biopsy results

GPs and patients commented that the timely arrival of treatment summaries prior to the completion of the CCR is essential. The information contained in these summaries informs both patient and GP on diagnosis and treatment of the cancer and should be discussed as part of the review.

The patient survey in the summer of 2018 asked those who had received a CCR what they thought the benefits were, their comments included:

- It helped me to have confidence in what was happening.
- Just to let me know what to expect.
- Helped manage the depression and anxiety that the cancer treatment and complications caused - help to sort medication may be of use.

On 23rd October, members of the LWBC project team met with a sub group of the West Yorkshire and Harrogate Patient Panel to discuss how CCRs support patients following diagnosis and treatment for cancer. The aims of the session were to:

- Establish what a CCR is, what is the patients understanding and what they think it should include
- When is the best time to carry out a CCR
- How is the CCR conducted and who by
- What are the benefits
- What are the barriers to accessing a CCR

Patient representatives were asked why cancer is treated differently to other chronic long term conditions in respect to how it is managed in general practice; stating that advances in diagnosis and treatment in cancer mean more people are living with and beyond cancer. It was recognised that systems have yet to catch up resulting in patients continuing to be managed in secondary care when they could be supported and managed within primary care and how the use of cancer care reviews could support this. Patients were clear about what they wanted from this review, how and where it should be completed and who should be carrying out the cancer care review. When it was discussed what the barriers were for patients in accessing a CCR the group were clear that these included:

- Patient not aware that they should be offered one by the GP surgery
- Self-referral is a barrier, some patients may never make contact
- CCR to be formally included in pathways with secondary care promoting with patients at end of treatment
- Include as part of treatment summary as a prompt to primary care to check that patient has received a review and if not invite
- All agreed that there needed to be more made of the offer of a CCR to raise awareness with patients that this is something which is offered to support and signpost and that if they haven't been offered a CCR that they feel empowered to request one from their GP surgery
- GPs are not specialists and need to take an holistic approach to the CCR
- Promotion of CCR on GP screens, posters, links to collaborative support planning (CSP)

One patient reported that having been made aware the he should have a CCR with his GP attended the surgery and asked to have a cancer review. His experience was that initially the GP didn't know what the patient was referring to but once he understood did complete a short review.

The principles detailed in this document build on the outcomes from this engagement. ¹¹

¹¹https://canceralliance.wyhpартnership.co.uk/application/files/8115/5783/9989/20181024_CCR_Patient_Panel_Group_Report.pdf

On 8th November 2019 a Cancer Care Reviews Listen and Design Event was held which aimed to:

- Understand what a CCR is and what it should include
- Understand how the CCR supports the patient
- Understand how the CCR is done in practice and what scope there is to do things differently
- Begin to address the barriers to completing the CCR and develop co-produced solutions
- Identify training and education needs in primary care

This event was supported by a number of patients and professionals which enabled the day to be a co-produced event where the patients were able to input into the discussions as to how CCRs support patients. From the day a number of recommendations were identified some of which will work alongside other projects delivered by the LWBC team such as promoting self-care and supported self-management.

One of the recommendations from the day was to conduct an audit of the current provision and quality of CCRs. A GP attending the day offered to be the pilot site for an audit and to date a tool has been developed and is being piloted by a practice in Wakefield. The audit reviews how the CCR is delivered, the quality from reviewing what is recorded in the patient record and by interviewing patients on their experience. Once the audit data is collected this will be analysed and a report developed and shared with the practice. It is planned to audit a minimum of two practices in each CCG in 2019-20 which will provide a snapshot of how CCRs are being delivered across the six places of the Cancer Alliance.¹²

Macmillan conducted a review of the CCR template developed with GPs and asked patients about their experience of having a CCR. These interviews found that most of the patients were not aware that they had had a CCR. It should be taken into consideration that some patients viewed the CCR as part of a routine GP visit but felt that the CCR gave them an opportunity to discuss their cancer and general state of health with their GP.

Patients also recommended that more needed to be done to raise awareness with the general public that following diagnosis and treatment they should be contacted by their practice and offered a CCR. It was suggested that posters be put in each surgery promoting CCRs and this will be addressed as part of the engagement with primary care across the Cancer Alliance.

In summary this engagement has included three principle activities / approaches:

Recovery package implementation event – this event introduced CCRs as the final component in the Recovery Package. Attending this event were cancer nurses and consultants from across the six acute trusts, patients and GPs. Supporting the event 86

¹²https://canceralliance.wyhpартnership.co.uk/application/files/7815/5316/5355/Cancer_Care_Reviews_Event_8th_November_2018.pdf

patients took part in a survey of their experience of all elements of the Recovery Package including CCRs; the survey showed that 8% of patients reported that they had attended for a CCR

Cancer Care Review listen and Design event - held in November brought together patients, clinicians from both primary and secondary care and commissioners to begin to identify what a model could look like for patients in West Yorkshire and Harrogate. It built on the work started at the Recovery Package event in October to identify barriers to completing CCRs and the benefits to having a CCR. One of the key actions from this event was to carry out an audit of current practice within Primary Care.

Focus group with West Yorkshire & Harrogate Cancer Alliance Patient Panel members - this sub group of the panel was held to enable a more in depth discussion around what constitutes a CCR, how it is carried out and the benefits of having one from the patient perspective.

What makes a good cancer care review?

From the event in November, surveys, engagement with patients through focus groups and working with members of the West Yorkshire and Harrogate Patient Panel it is clear that there are examples of good practice but that very often the patient reported experience is more often one of not having or realising they have had a CCR or where they have the feeling that not enough time was given and that their individual support needs were not discussed or met. It is evident that for this group of patients the need to have a planned approach which factors in sufficient time and information gathering is essential and that this is linked to good communication between care providers in both secondary and primary care.

Taking into consideration the information from patient engagement, professional engagement and the work done by Macmillan and Yorkshire and the Humber into what makes a good CCR, the following principles have been identified.

Principles

From the perspective of the patients who have taken part in the engagement on the use of cancer care reviews, the components of a good cancer review include:

- **Time** – designated double appointments with GP so that the patient doesn't feel under pressure
- **Patient led** – appointment made by patient when ready for review with assurance that the practice system will identify and follow up those patients that do not make an appointment for CCR
- **Informed** – GP receives and reviews a copy of the patients treatment summary prior to CCR which details all the information about diagnosis, treatment, next steps, what the patient has been told and who to contact if needed. Patients were very clear that they find the need to repeat their story very hard and GPs have commented that often the patient attends for a CCR before they have received any information from the

hospital. This should also be extended to include a copy of the holistic needs assessment and care plan completed at end of treatment

- **Holistic** – The patients clearly indicated that they would be happy for the holistic needs element of the CCR to be carried out by a nurse who may have more time and knowledge of what support is available. They recognised the time pressures for GPs and were clear that once the clinical aspects of the review had been completed they would be happy to see a member of the nursing team who they suggested may have longer appointments available to address patients identified unmet needs

Taking this information into consideration alongside local and national work into the use of CCRs, the following principles for providing and completing a CCR for patients in West Yorkshire and Harrogate are proposed for consideration:

Timing of the CCR:

1. A CCR should be offered within 6 months of diagnosis
Timing of the appointment should be led by the patient. Patients suggest that this should be an opt-out appointment, however there needs to be a mechanism to ensure patients are encouraged to attend. The current requirement is that a patient is contacted three times to offer a CCR which does give the patient the responsibility to decide when they wish to take up the offer of a review
2. A CCR should be a minimum of 20 minutes to give time for patient to discuss concerns including those around finances, access to health and wellbeing activities

Delivery of the CCR:

1. The CCR should be delivered as a face to face appointment
2. The CCR can be delivered by clinical staff other than the GP
Patients identified that GPs may not be best placed to complete the holistic assessment elements of CCRs and that this could be done by nursing staff with the GP concentrating on the clinical elements such as signs of recurrence, consequences of treatment and medication reviews
3. The CCR should be used to assess patients understanding of their diagnosis and expected outcomes
4. The CCR should build on the holistic needs assessment completed by the cancer nurse specialist (CNS) or other member of the team as part of the end of treatment process and a copy sent to the patient and their GP
Information should also be sent back to the CNS where there are changes in clinical or additional support requirements identified

Informed method for conducting a CCR:

1. A CCR should be completed in a safe place where patients feel able to have an open and honest conversation about their cancer. Ideally this should be face to face but patients report that the option to have this carried out over the telephone should be available

2. The CCR should be holistic and personal in nature, identifying patients' needs and signposting to relevant services for support

Other information to support delivery of CCR:

1. The use of 'flags' on clinical systems to identify patients with a cancer diagnosis to be used to monitor patients who are due a CCR
 - a. This could be for patient diagnosed in last 15 months which is the cohort of patients measured as part of QOF
2. Patient is offered the opportunity to bring a family member/friend to CCR appointment for support
 - a. Patient representatives asked that caution be applied to this as may add to existing stress in managing family issues around diagnosis/existing family dynamics and should be very much directed by the patient
3. Patients be given opportunity to complete holistic elements of CCR prior to appointment
 - a. This would enable patient to identify any unmet needs prior to appointment and enable GP practice to identify support available as part of the preparation for the review appointment
4. Promotion of CCR within Primary Care to raise awareness of the offer.

Other models for delivery of CCR

Across West Yorkshire and Harrogate work is on-going to establish a more patient focussed approach to CCRs with pilots taking place in Leeds and Wakefield. These two projects have taken very different approaches with Leeds developing the cancer nurse specialist role within community settings and Wakefield adapting the Macmillan SystemOne template and training of practice nurses to support the delivery of CCRs in general practice. Both models recognise the necessity for the cancer review to be holistic in nature and that there needs to be scope to refer patients to other agencies for support.

Leeds Model

Leeds completed a two year Macmillan funded CCRs pilot project in December 2018. The pilot saw a Cancer Nurse Specialist carrying out CCRs with 213 patients in the community six months post-treatment in the Aire Valley and Harehills areas of Leeds. Evidence from the CCR project indicates that patients felt better informed and supported following their CCR, going on to contact a variety of different services as a result of their CCR. Patient feedback has shown overwhelming satisfaction with the service, with 59% of patients reporting more confidence in managing their own health and wellbeing following their review, and 77% of patients reporting finding the CCR useful or very useful. From review of a small sample of patients who received a CCR 45% of these patients would have made an appointment to see their GP, or contacted the hospital nurses if they had not had a CCR appointment, indicating cost effective use of services.

In April 2019, NHS Leeds CCG confirmed funding to design and tests an expanded version of this community care and support for patients on a cancer pathway with two Local Care Partnerships. This will build upon the pilot CCRs project, and the focus will be on the

integration of existing services being delivered in communities, improved sign-posting to relevant cancer and cancer related services available for patients and the ability to tailor the service to the needs of the local population. Findings will then be used to develop a methodology and plan for citywide rollout of the service in line with the emerging LCPs. The exact model is currently in development, and further information will be shared in due course.

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Wakefield Model

The project for Mid Yorks LWBC centres on care which is wrapped around the patient. A central hub for information and support has been developed to enable one simple referral for non-clinical support, so health care professionals (HCP) do not have to know about all the local services and equitable support for patients. Referrals to the central hub can be made on the local Integrated Clinical Environment (ICE) system with a template for completing CCR available on SystemOne (Macmillan template also available on EMIS). This template has been developed by Macmillan but has been adapted locally to support the local model of referral through ICE. A user guide for completing CCR with details on the template and useful contacts for HCPs and further resources has been developed to support primary care. Alongside this, an education package is available that can be delivered in primary care adapted to suit what HCPs would like to know more about, such as side effects of treatment, the impacts of cancer, late effects of treatment and emotional support. A diagram of the Mid Yorks LWBC Support Framework can be found as appendix 1.

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Next Steps

The increased profile of personalised care detailed in the NHS Long Term Plan¹³ and the Five-year Framework for GP Contract Reform¹⁴ provides an opportunity to raise the role of

¹³ <https://www.longtermplan.nhs.uk/>

the CCR in tailoring support to patients. In 2019-20 raising the awareness of the need to deliver CCRs which support a personalised approach to care for patients will be a priority within the LWBC Programme. Information on how CCRs are delivered across the Alliance footprint is limited, to address this we will be carrying out an audit to assess the current activity in general practice. This action builds on a recommendation following the CCR event in November and the offer from a Wakefield General Practice to be the pilot site. The audit will look at the process in the practice for delivering CCRs, the quality as recorded in the patient record and will include patient interviews carried out by a member of the West Yorkshire and Harrogate Patient Panel. Following the audit, data will be analysed and a report compiled which will be shared with the practice as a tool to begin to support effective reviews of patients following treatment for cancer, ensuring that the patient is in receipt of care which is personalised to their needs both clinically and holistically. The audit will be rolled out across a minimum of two practices in each of the six localities with support from the Patient Panel to conduct the interviews with patients identified by the individual practices.

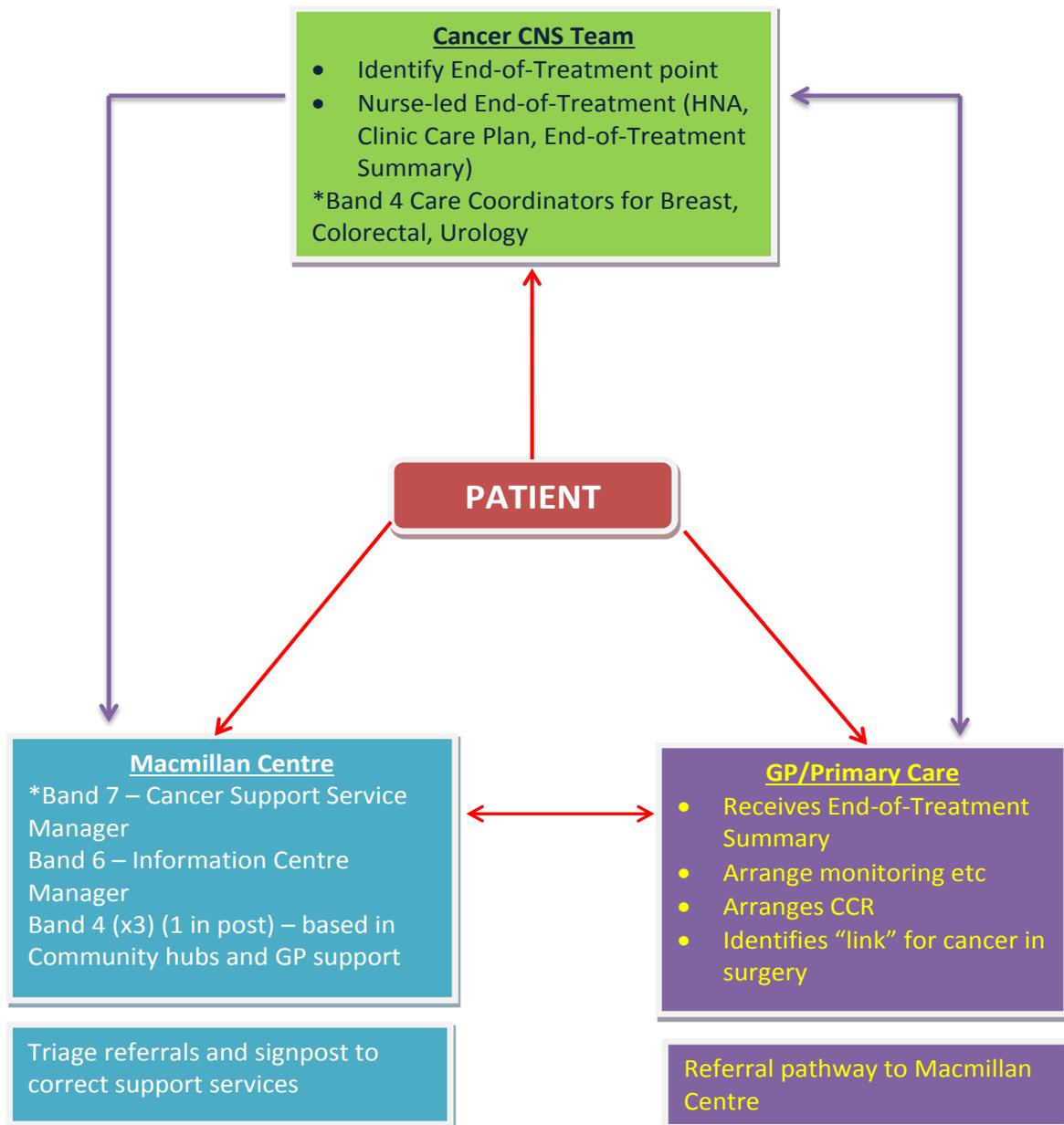
This report will be used to socialise the findings from the work done in 2018-19. It proposed that this will be done through the following methods:

- Engagement with Primary Care Leads in each CCG with the request to include this report in their local newsletters with the offer to come and talk to any network groups, protected learning times or other groups to talk about what we are wanting to achieve in partnership as a Cancer Alliance
- Lead GP for the Cancer Alliance to communicate with members of the Primary Care Community of Practice Group
- Socialise through our the West Yorkshire and Harrogate Integrated Care System communications networks and the Cancer Alliance website
- Utilise existing communication methods to share report with cancer teams in the six acute trusts
- Share report with members of the West Yorkshire and Harrogate Patient Panel

¹⁴ <https://www.england.nhs.uk/wp-content/uploads/2019/01/gp-contract-2019.pdf>

Appendix 1 - LWABC Support Framework

LWABC Support Framework



**Needs funding*