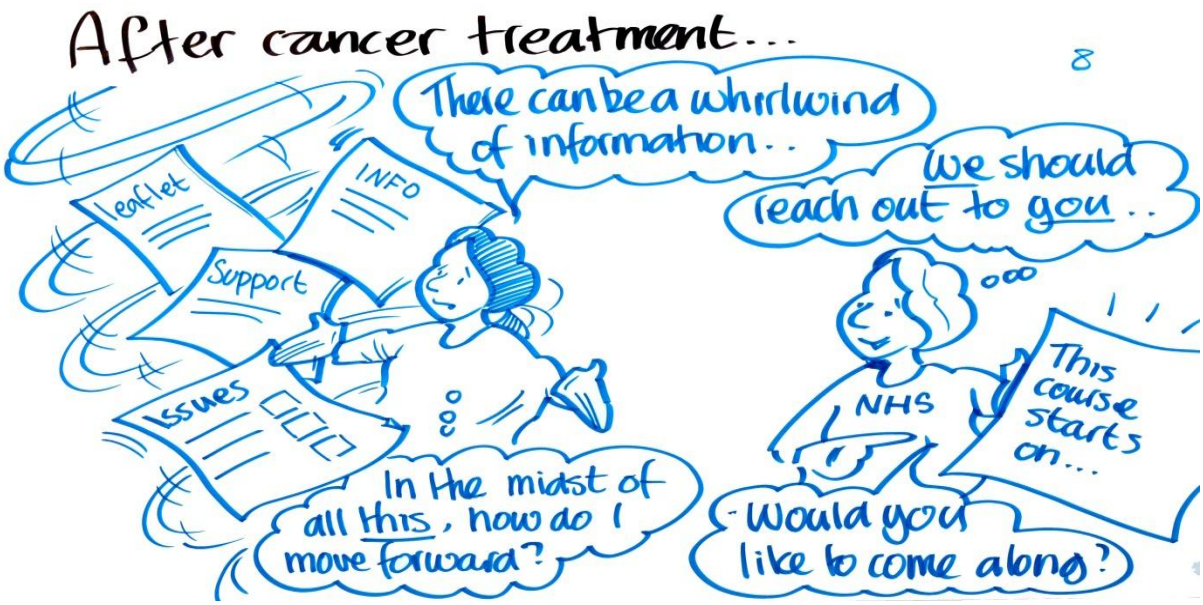
Practice Nurse Led Cancer Care Reviews- Evaluation Report

Transforming Care After Treatment

NHS Lanarkshire
Prepared by Vicki Trim, Macmillan TCAT Project Manager, September 2017



TRANSFORMING YOUR CANCER CARE

WE ARE MACMILLAN. CANCER SUPPORT

NHS SCOTLAND

CONTENTS

ACKNOWLEDGEMENTS

We would like to thank the following practices who have been pivotal in the shaping of this project:

- Ardoch Medical Practice, Cambuslang
- Avondale Medical Practice, Strathaven Health Centre
- Dr I A Hathorn & Partners, Greenhills Health Centre, East Kilbride
- Logan Practice, Wishaw Health Centre
- Medwyn Medical Practice, Carnwath
- Orchard Medical Centre, Motherwell
- St.Lukes Medical Practice, Carluke Health Centre
- Wellwynd Practice, Airdrie Health Centre
- Willow Practice, Viewpark Health Centre

We would also like to extend our thanks to everyone who contributed to TCAT meetings and focus groups for people affected by cancer which helped to shape our work. A special mention must go to Dr Rosalie Dunn who was a visionary for this project.

The statistics in this report are the results of a self-evaluation carried out by local project staff with support from Edinburgh Napier University TCAT Evaluation Team. The views expressed in this report do not necessarily represent those of Edinburgh Napier University or Macmillan Cancer Support.

Cartoon images were sourced from NHS Greater Glasgow & Clyde Macmillan TCAT event and provided by Creative Illustrator Graham Ogilvie. graham@ogilviedesign.co.uk

1. THE CASE FOR CHANGE

This project is part of the National Macmillan Transforming Care After Treatment programme (TCAT). Cancer affects all aspects of life and and with more people living with cancer than dying from it, can bring problems from debt to depression, which may last long after treatment ends. Unfortunately many people don't know where to turn for help and struggle on alone. 220,000 people in Scotland are currently living with the impact of a cancer diagnosis and this is expected to almost double by 2030, it's vital we find better ways to make sure people get the support they need to live their lives as fully as possible. The £5m programme is funded by Macmillan Cancer Support and supported by the Scottish Government, the NHS and local authorities across Scotland.

Whilst the landscape of cancer has changed due to earlier detection, treatment advances and people living for longer; primary care services have not responded to this change. Traditionally, GPs carry out cancer care reviews (CCR) which were part of the Quality Outcomes Framework (QOF) where people who received a new diagnosis were invited for a cancer review within a 6 month period. There was little content guidance for health professionals to use and most adopted a medical model rather than a holistic approach to care.

Research suggests that without a structured approach to addressing and meeting the patient's needs, particularly relating to a return to employment, survivors of cancer will continue to experience poorer outcomes and place further longer-term demands on Health and Social Care organisations (Watson & Rose, 2010). In a 12 month study, Khan et al (2011) found that survivors of cancer consult GPs between one and three extra times per annum and this continues for up to 15 years after diagnosis.

The CCR needs to be a holistic broad-based discussion, taking into account co-morbidities to reflect the changing health needs of our population. The review can also be seen as a platform to trigger further discussions e.g. supporting secondary prevention through advice about healthy lifestyle and physical activity which practice nurses routinely provide as part of their chronic disease management.

GPs are increasingly under greater demands and being able to release them from activities that do not require their medical expertise, can help to reduce the pressure they are under. We wanted to test the acceptability and feasibility of practice nurses taking on the role of delivering cancer care reviews using a Holistic Needs Assessment Tool – the concerns checklist (see Appendix 1). Practice nurses have a range of transferable skills currently used in their chronic disease management role therefore cancer specific training was highlighted as a pre requisite to practice nurses carrying out effective CCRs.

- Khan NF, Watson E, Rose PW (2011) Primary care consultation behaviours of long-term, adult survivors of cancer in the UK *British Journal of General Practice* Mar 61(584),197-199. http://bjgp.org/content/bjgp/61/584/197.full.pdf
- Watson E, Rose P (2010) Views of primary care physicians and oncologists on cancer follow-up initiatives in primary care: an online survey. *Journal of Cancer Survivorship* June 4(2),159-166. https://www.researchgate.net/publication/41563024_Views_of_primary_care_physicians_and_oncologists_on_cancer_follow-up_initiatives_in_primary_care_An_online_survey

2. WHAT WE SET OUT TO DO

We set out with the aim of generating evidence for the acceptability and feasibility of practice nurses carrying out cancer care reviews. The specific objectives were to:

1. **Increase the confidence and competence of 10 practice nurses to deliver cancer care reviews**
2. **Provide evidence of the effectiveness of practice nurse led holistic cancer care reviews**
3. **Empower patients and carers to improve their quality of life**
4. **Improve the quality of the patient experience by offering a person-centered cancer care review**
5. **Report potential reduction in unnecessary (inappropriate) G.P appointments**

The service improvement methodologies that were used to develop the project included Macmillan value based standards where we concentrated on:

Discovering – what is really going on?

Innovating – what interventions may help? Particularly in light of end of QOF

Improving – measure, sustain and spread improvement

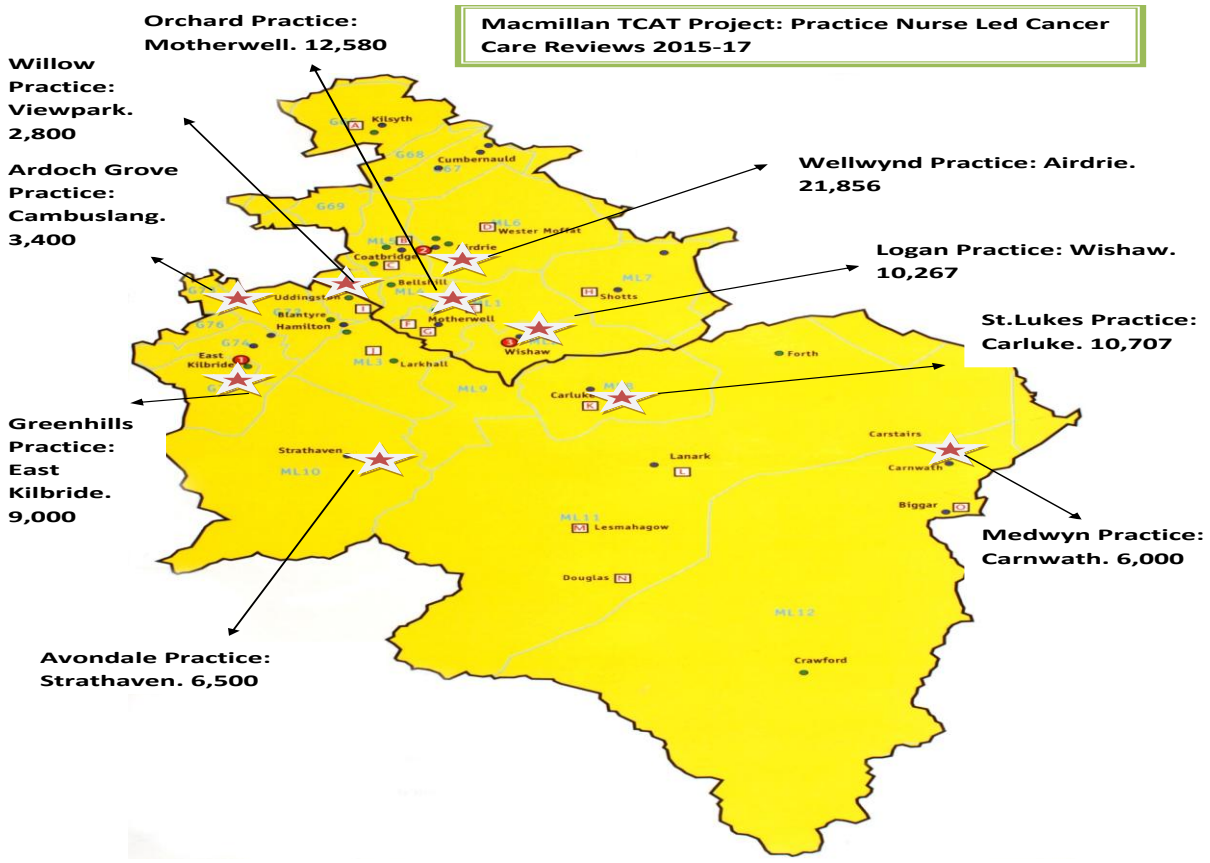
This was also twinned with a LEAN quality improvement approach to ensure that the processes and systems being trialled were as waste free as possible to produce changes in capacity (workforce skill use), quality enhancement and patient satisfaction for cancer review delivery in primary care. Sustainability was a core principle in all operational decisions as well as consideration of scale and spread to other board areas.

13 practice nurses from NHS Lanarkshire attended the Macmillan Cancer as a Long Term Condition course to prepare them to offer CCRs. Of this initial cohort 3 practices decided not to take part in the project due to maternity leave, *"not the right time"* and practice decisions to maintain a GP led cancer review.

9 practices (one practice had 2 practice nurses trained) agreed to the terms and conditions of the project and a financial contract was established to remunerate the practices for the additional administration time that was required for the evaluation tasks and links to Edinburgh Napier University, who were the appointed evaluation team for TCAT. Details of these practices are on the next page.

2.1 PRACTICES INVOLVED AND PATIENT LIST SIZE

As of 2017, there were 106 GP practices in NHS Lanarkshire serving a population of some 640,000 people. Practices have been shaped into 16 clusters with cluster quality leads appointed to assist in integrated working and to perform a facilitation role in achieving quality indicators that are of a common interest to their local area e.g. cancer may be one of the improvement areas. The 9 practices involved in the project are detailed in figure 1 below:



Pre-project focus groups for people with cancer in Lanarkshire were carried out in 2015 and reported that people didn't recall that they had received a cancer care review from their GP, with comments received from people about feeling lost and unclear about who they could speak to after their treatment had finished:

> *"I felt like I was in a pinball machine"*

Many GPs also felt that they didn't have structured guidance as to the content of the review and whilst many had carried out a CCR, this was not recollected as such from their patients. Therefore the current process was not meeting the needs of some health professionals or the person with cancer, therefore the involvement of practice nurses and adoption of a systematic and quality CCR was welcomed.

3. OUR APPROACH

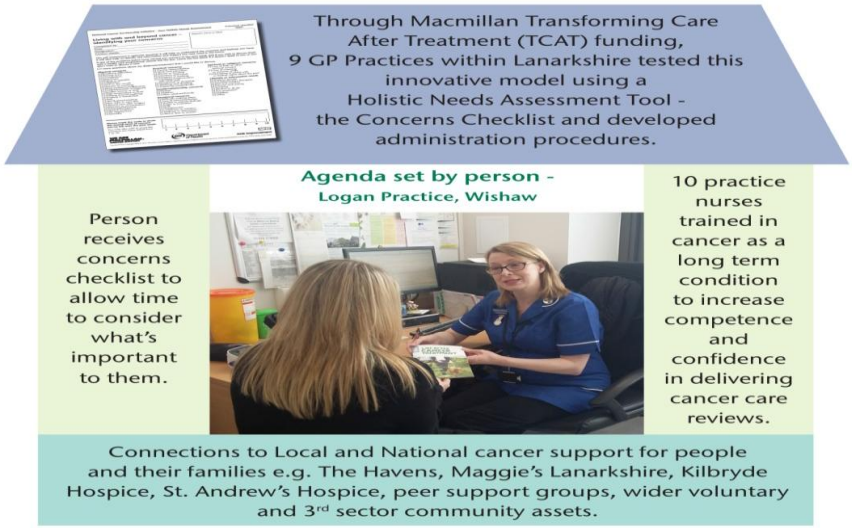
Practice nurses attended the 5 day Macmillan "Cancer as a Long Term Condition" course and £400 backfill was provided to each practice. Practices were then asked to consider their cancer register to provide them with a rough idea of the numbers of cancer care reviews that they could expect, and to ensure that additional appointments could be absorbed into the practice nurse workload. As a rule of thumb, the number of CCRs expected per month were as follows;

- Smaller practices 1 to 2
- Medium sized practices 2 to 4
- Larger practices 4 to 6

Due to the range of demographics and geography that each practice serves, individual practices were encouraged to reflect on their current processes when they received notification of a new cancer diagnosis. Whilst the practices had autonomy to refine their own systems and processes, the following standards were outlined as an essential component to offering holistic CCRs:

- An invitation letter and/or phone call made to the person outlining the purpose of the CCR and offering flexibility in when this could be arranged or declined, including bringing a family member or friend with them (see Appendix 2)
- A copy of the concerns checklist sent to the person prior to the CCR to allow them time to consider what was important to them
- Awareness of support services available including voluntary and third sector options as well as clinical routes. A paper directory was prepared for the practices with the caveat that this will become available on NHS Inform's digital Health & Wellbeing Directory in Autumn 2017

The cancer strategy Beating Cancer: Ambition and Action 2016, recognises that system and organisational changes to promote and deliver the roles and skills necessary for true person centered care are required; and our approach is represented in the House of Care model below:



3.1 GOLD STANDARDS FRAMEWORK (GSF)/ PALLIATIVE CARE

The Gold Standards Framework has been the leading quality improvement programme for GP practices, to make significant improvements and coordination of palliative care. During this meeting (which may be held monthly or quarterly depending on the size of the practice), the practice will review people at end of life and also any new cancer diagnoses; even though the majority of the people with cancer are living with and beyond cancer. It is at this point that practices decide on who to stratify the cancer review to, depending on the complexity of the cancer and perhaps established relationships whether it will be allocated to the GP or practice nurse.

Traditionally, the practice nurse has not been involved in this meeting since it may be district nurses, Macmillan nurses etc involved in end of life. Involvement of the practice nurse in this meeting or for part of the meeting relevant to a new cancer patient has improved communication between cancer and palliative care registers, and has led to consideration of anticipatory care plans as appropriate.

3.2 DATA COLLECTION

Edinburgh Napier University provided evaluation services for the purposes of this TCAT project as part of the wider National TCAT evaluation. The data below was collected and analysed from January 2016 until end of June 2017. Anonymised Lanarkshire data was uploaded to the Napier site on a quarterly basis with accuracy of data confirmed by practices after each submission:

Information uploaded electronically by each practice and collected by Edinburgh Napier University for evaluation purposes only

- CORE DATA (age, type of cancer etc for people who accepted and those who declined a CCR)
- PROCESSES AND ACTIONS (how long the review took, signposting and referral to services)
- CONCERNS RAISED (from the concerns checklist)
- PATIENT FEEDBACK QUESTIONNAIRE (posted to the person 6-8 weeks after CCR)

Focus Groups: Edinburgh Napier University facilitated 3 focus groups with all 10 practice nurses. The project manager facilitated 3 focus groups for people with cancer where a total of 10 people attended, and also carried out GP and practice manager interviews. Practice nurses recruited participants and consent was gained for participation and digital recording. Information was provided on the project scope, aim, analysis and dissemination of findings. The project objectives acted as a coding framework to assist with categorising the focus group and interview transcripts.

3.3 SHARING OF INFORMATION

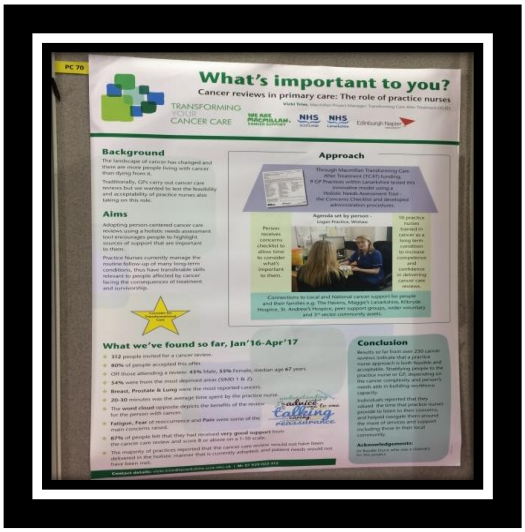
The evolving project findings were shared at every opportunity; here are some examples:

June 2016 NHS Lanarkshire Cancer Strategy Day poster presentation with Dr Rosalie Dunn

October 2016 Workshop presentation at the European Oncology Nursing Society Conference in Dublin

One of the quarterly operational group meetings with practice nurses, practice managers and patient representatives held at Maggie's Lanarkshire

June 2017 NHS Scotland Poster presentation: Glasgow SEC.



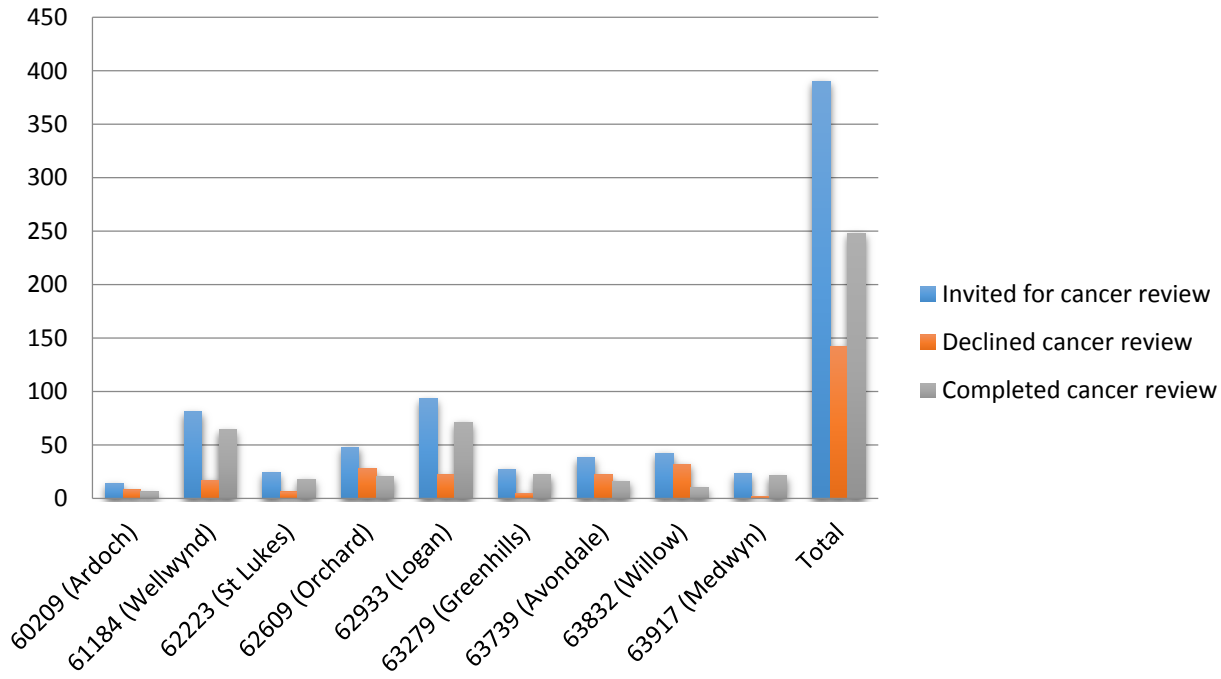
Also: presentations at NHS Lanarkshire clinical forums, Medical Leadership Group, Primary Care & Mental Health Transformation Fund group, practice managers' forum, WoSCAN Primary Care Cancer Network , NoSCAN learning event Inverness, TCAT National Conference, posters presented at NHS Lanarkshire Practice nurse forum, Scottish Oncology Summit 2017.

4. RESULTS

From the 9 practices involved in the project, 390 people with cancer were invited to receive a CCR. Data was collected for 248 people who attended a cancer care review (Following data cleaning, final numbers based on the data available for reviews that contained core, processes and concerns data) and also core data for those who declined the offer of a CCR (142 people). The number of people with a new diagnosis of cancer varied between practices, with areas of deprivation and more affluent areas (where people tend to live longer), having an impact on the incidence of cancer. The breakdown of this is shown in table 1 and figure 2 below:

Table 1 Practice	Patient list size	Invited to CCR (over 18 months)	Declined CCR	Accepted CCR
Ardoch, Cambuslang	3,400	14	8	6
Wellwynd, Airdrie	21,856	81	17	64
St Lukes, Carluke	10,707	24	6	18
Orchard, Motherwell	12,580	48	28	20
Logan, Wishaw	10,267	93	22	71
Greenhills, E.K	9,000	27	5	22
Avondale, Strathaven	6,500	38	22	16
Willow, Viewpark	2,800	42	32	10
Medwyn, Carnwath	6,000	23	2	21
Total		**390**	**142**	**248**

Figure 2: Cancer Care Reviews Completed and Declined Jan '16-end Jun'17

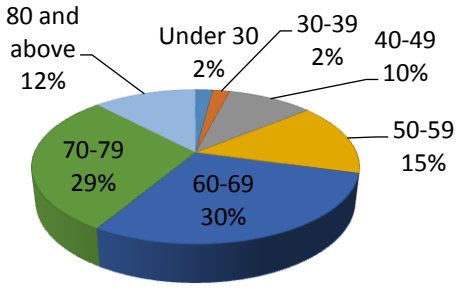


4.1 DEMOGRAPHICS OF PEOPLE WHO ATTENDED A CCR

4.1.1 AGE

Of 246 people there were 112 (46%) males and 134 (54%) females. The median age of participants was **67** years with a breakdown shown in the figure below:

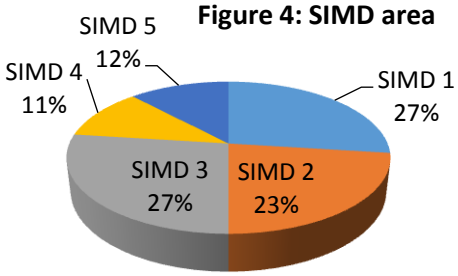
Figure 3: Age of person attending a CCR



4.1.2 SIMD (SCOTTISH INDEX OF MULTIPLE DEPRIVATION)

The area data of participants was available for 245 participants and is provided below with 50% of people living in areas of greater poverty i.e. SIMD 1, & 2.

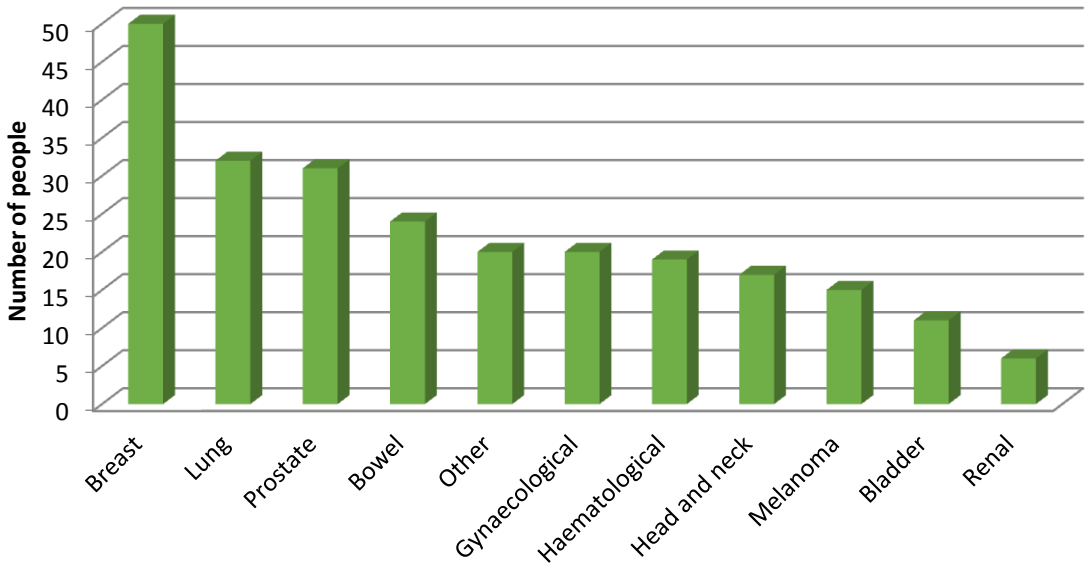
Figure 4: SIMD area



4.1.3 TYPE OF CANCER

Cancer type was available for 245 people and showed a variety of cancers with the most common cancers being Breast (20%), Lung (13%), Prostate (13%), & Bowel (10%), see figure below:

Figure 5:Types of cancers



4.1.4 STAGE OF CANCER

The stage of cancer was available for 236 people with the majority having a primary cancer disease (89%): Table 2:

Stage	Number	Percentage
Primary	211	89%
Secondary	25	11%

4.1.5 LIVING SITUATION

The living situation was available for 241 people and the majorities were living with a spouse/ partner (63%). Table 3:

Living situation	Number	Percentage
Living alone	61	25%
Living with spouse/partner	153	63%
Living with children/ relatives	26	11%
Living with friends	1	0%

4.1.6 ETHNICITY

The ethnicity was available for 246 people. 245 were either White, Scottish, White, Other or White, Irish. 1 other person was classified as Asian, Indian.

4.1.7 ECONOMIC ACTIVITY

The economic activity was available for 237 people, the majority were retired (62%) but with a considerable portion of people still in employment (24%) and a further 3% self employed. Table 4:

Economic activity	Number	Percentage
Employed	58	24%
Self employed	8	3%
Unemployed	9	4%
Retired	146	62%
Student	1	0%
Looking after home or family	3	1%
Long term sick or disabled	12	5%

An example from one of the focus groups highlights the impact that cancer has on both a person and their husband's work scenario:

"My husband has just handed his notice in at work, it's too much (supporting his wife with cancer).....for some forms we had to sit in social security and have to sit 2-3 hours to do it, I couldn't sit for that time!!!....then I did get a home visit.....I got that side of it, then your work sends for you for a day when are you coming back to your work? I don't think I'm fit enough" (person with cancer)

4.1.8 ECOG PERFORMANCE STATUS

The ECOG performance status (named after the Eastern Cooperative Oncology Group) is a functional ability assessment and is an attempt to quantify cancer patient's general well-being and activities of daily life. 0 denotes full health and 5 death (5 does not feature on our results since all participants were not palliative). Information was available for 244 people, a total of 80% reported either full or restricted activity (ECOG 0 & 1) and is shown below:

Table 5: ECOG	Number	Percentage
ECOG 0- Fully active, able to carry on all pre-disease performance without restriction	86	35%
ECOG 1- Restricted in physically strenuous activity but ambulatory and able to carry out work of a sedentary nature	109	45%
ECOG 2- Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours	40	16%
ECOG 3- Capable of only limited self care, confined to be or chair more than 50% of waking hours	5	2%
ECOG 4 – Completely disabled. Cannot carry out any self-care. Totally confined to bed or chair	4	2%

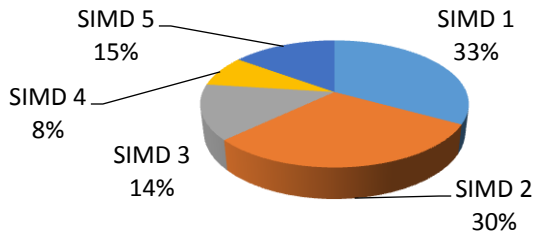
4.1.9 HOLISTIC NEEDS ASSESSMENT

99% of people had not received what they perceived as a holistic needs assessment from any other cancer specialist prior to speaking to their practice nurse.

4.2 DEMOGRAPHICS OF PEOPLE WHO DECLINED A CCR

There were 142 people who declined a CCR. The median age was 69 years which is slightly older than those who chose to attend a CCR (67 years). The SIMD of people who declined is shown in the figure below and indicates that those from a lower SIMD were less likely to attend for a cancer care review (there was a statistically significant difference, p=0.03 in comparison to the attenders):

Figure 6: SIMD of those who declined a CCR

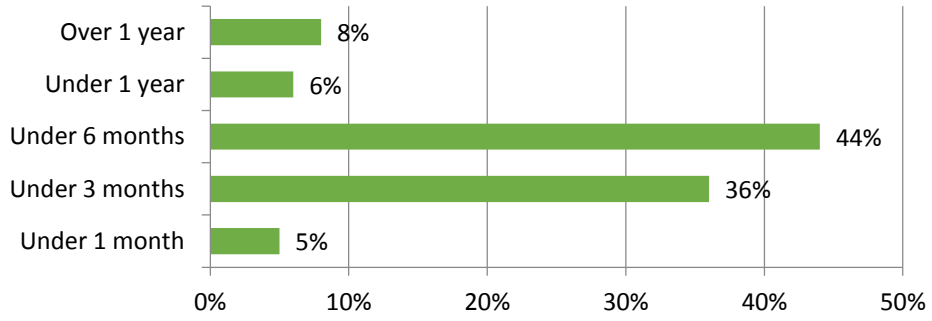


There was no meaningful difference between economic status of those who attended a review and those who declined. Whilst people had declined within the timescales of this project they may still chose to take up the offer of a review when the time is right for them.

4.3 CANCER CARE REVIEWS

4.3.1 TIME FROM DIAGNOSIS TO CCR

The time from diagnosis to attending a cancer care review was available for 243 people. The median length was 3 months with 86% attending a CCR within 6 months of receiving their diagnosis. A further breakdown is given below in figure 7:



Of the people who attended a CCR, 64% of patients were still receiving treatment for their cancer whilst 36% had finished their cancer treatment, giving weight to a flexible approach to offering a CCR when the time is right for the person. The issue of when to invite for a CCR tends to be divided between those who feel that they have been offered the CCR too early and those who feel that they appreciated the offer of support at an early stage. This polar opposition in views was also raised during practice nurse focus groups:

"If you get them too soon, they don't know what their treatment is even…and they're not getting the same benefits (of the CCR) *of somebody who's maybe a bit further on in it"* "*They're in the midst of treatment and it's just too early"*	*"I think it opens a door then, so that they know you're there"* *"I think the fact that they know there's someone else in their corner that's not directly involved in family or in the heavier side of their treatment, but that they've got another port of call. Some of the patients have said, it's just good to know that you're there"* *"if they have not been coming to the practice then it just gets them a name, a face, if they need anything"*

However all practice nurses were in agreement of the communication benefits of the health centre knowing someone has cancer:

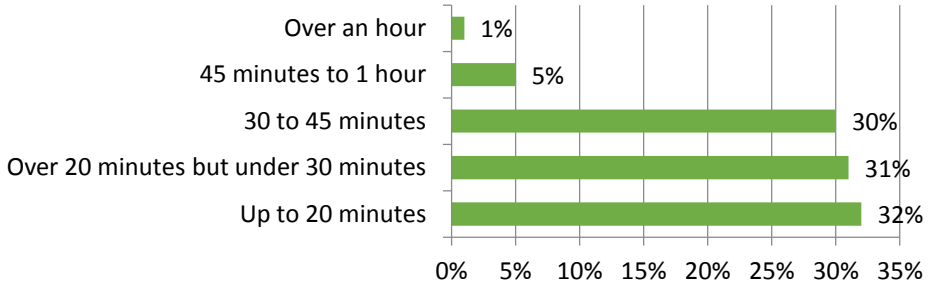
> *"I think it just runs smoother for them"* (i.e. contacts with primary care)
>
> *"It's taking the pressure off the patient, which then enables their recovery a bit better"*

Person with cancer's comment on timing of reviews:

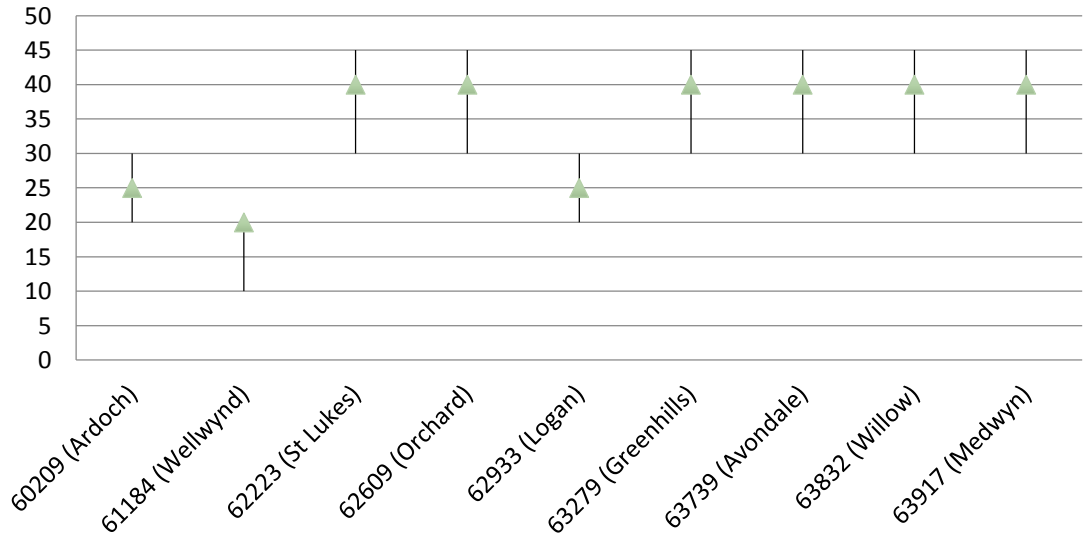
> *"I don't know maybe 2 or 3 months down the line, I mean I enjoyed speaking to her but a lot of the things developed after that time.....oh yes I could come back at anytime"*

4.3.2 DURATION OF REVIEW

The length of cancer care review was available for 224 people, 63% of reviews lasted for less than 30 minutes, the breakdown is provided below in figure 8:



The range in length of time for each practice is given below in figure 9:



The most frequently valued elements of the cancer care reviews that were reported from patient feedback questionnaires were being: afforded the time to talk, being listened to and having a point of contact to discuss their cancer. The comments from 77 people are represented in figure 10 as a word cloud:

In addition to the time afforded by the practice nurse for the CCR, people also recognised the practice nurse as "*point of contact*" rather than immediately asking to see a GP. The time saving and competence nature of practice nurses was also recognised in that they are able to risk assess symptoms and access the doctor when required:

> *"…but then things took a brilliant turn for me was when I was connected to x (*the practice nurse*) because she's like a project manager for me, anything you ask her she will tell you then and there if she doesn't know and she will find out or she'll phone you. She actually saved me a lot of trouble cause once I was in and she gives me the injections in my stomach, she said I don't like the look of the swollen tummy and jaundice, would you mind if I went in and spoke to a doctor about it...no, no on you go...so she went in and the Doctor had a spare minute or two and he gave me a letter to go straight to the hospital" (*Person with cancer)

4.3.3 HOW THE REVIEW WAS CARRIED OUT

The CCR invite letter offered people the option of having a face to face review or over the telephone. 20% of people opted to have the review over the telephone, supporting the need for a flexible approach in how we deliver CCRs.

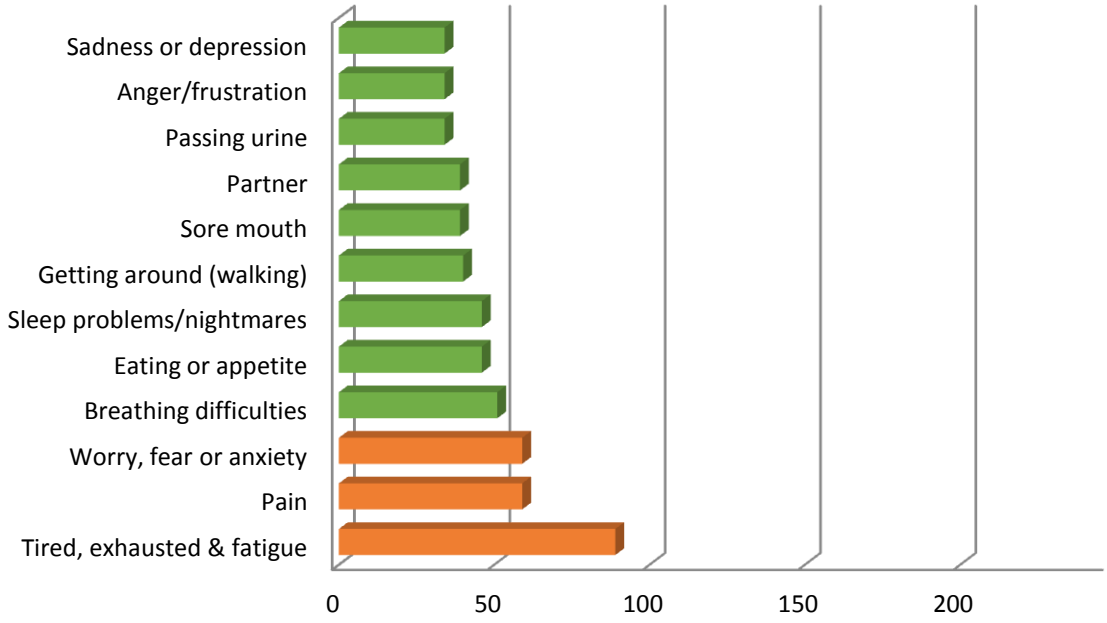
One focus group participant could not remember being invited for a cancer care review by the practice nurse (even though he had been selected by the practice for this purpose and had received a CCR), although he did thoroughly rate the support provided to him by the practice nurse, he felt this was more for his COPD since his family were providing any additional support that he required surrounding his cancer concerns. This highlights the skills required to carry out a holistic review and take into consideration other long term conditions when the person feels that is more important.

4.4 CONCERNS RAISED

Practice nurses reported that they valued the formal approach to CCRs by using the structured Concerns Checklist to guide the CCR. It provided patients an opening to discuss concerns but also as an effective way to 'open' or 'start' the review process with patients. Most patients completed or had reflected on the concerns checklist prior to the review with a minority receiving extra support at the CCR to look at the listed concerns.

Across all practices; fatigue, pain and worry were the top three concerns raised with a number of other concerns highlighted below:

Figure 11: Main areas of concern from 248 reviews



Interestingly, finance was not raised enough to feature in the top 12 concerns although during patient focus groups at least one member of each of the three groups expressed their lack of information about finance prior to being linked up to their practice nurse.

"No I didn't get support but I found out recently that I should have and it's too late now..because I'm back at work, and the nature of my husband's job is an issue....we're under pressure. You worry it's adding more stress and stress can make you ill, so you worry….." (person with cancer)

Another person described the emotional impact on their life that they were able to discuss with the practice nurse during their CCR:

> *"there's a terrible loneliness, you're no longer at work so any contacts you would have are not there, you have side effects so are not socialising and my social life is going to doctors, going to hospitals, and the only other place is my sisters……" (person with cancer)*

Evidence of the concerns checklist acting as an "opening" to find out the persons needs is provided in the quote below where emotional concerns were the person's main priority but also an ear infection and holiday insurance was addressed too in a holistic approach:

> *I feel as though they've (hospital) just put me out. I mean I have seen a psychologist, I did ask to see someone, I know my story is different.....I seen x (practice nurse) in February, and again it was just filling in one of them (concerns checklist), she's a lovely girl, but it was ok I was alright then….. she said come and see me if you need me, so I had an ear infection too and she was able to sort that out and my insurance too"* (person with cancer)

4.4.1 CONCERN DOMAIN

The concerns checklist has 6 domain areas of physical, practical, family/relationship, emotional, spiritual and lifestyle/information. Physical and emotional domains were highlighted most frequently by people having a concern in this area. These results are presented below:

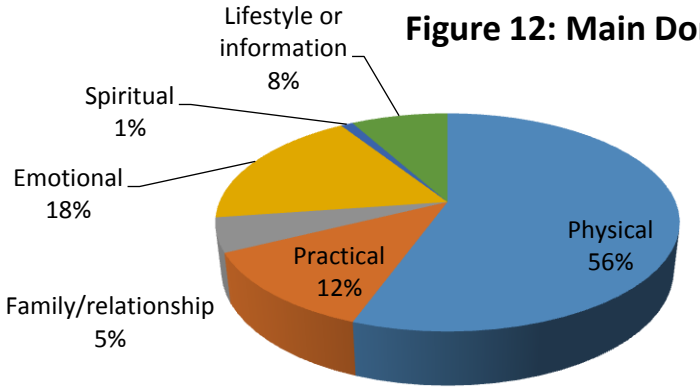
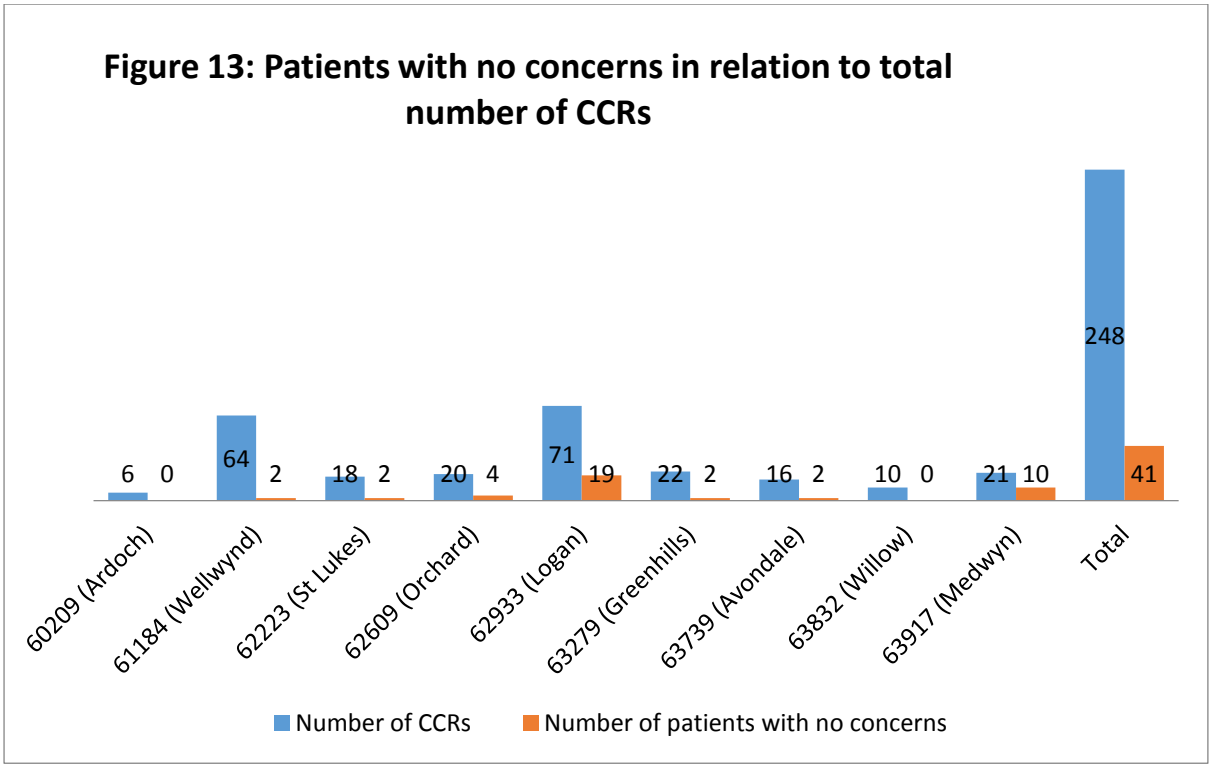


Figure 12: Main Domains from Concerns

4.4.2 PEOPLE WITH NO CONCERNS

People who had “no concerns” ranged considerably between practices, 14% was the median value across the 9 practices. So whilst people felt that they didn’t have a concern at that time, they still chose to attend a CCR. The figure below displays the individual practice results:



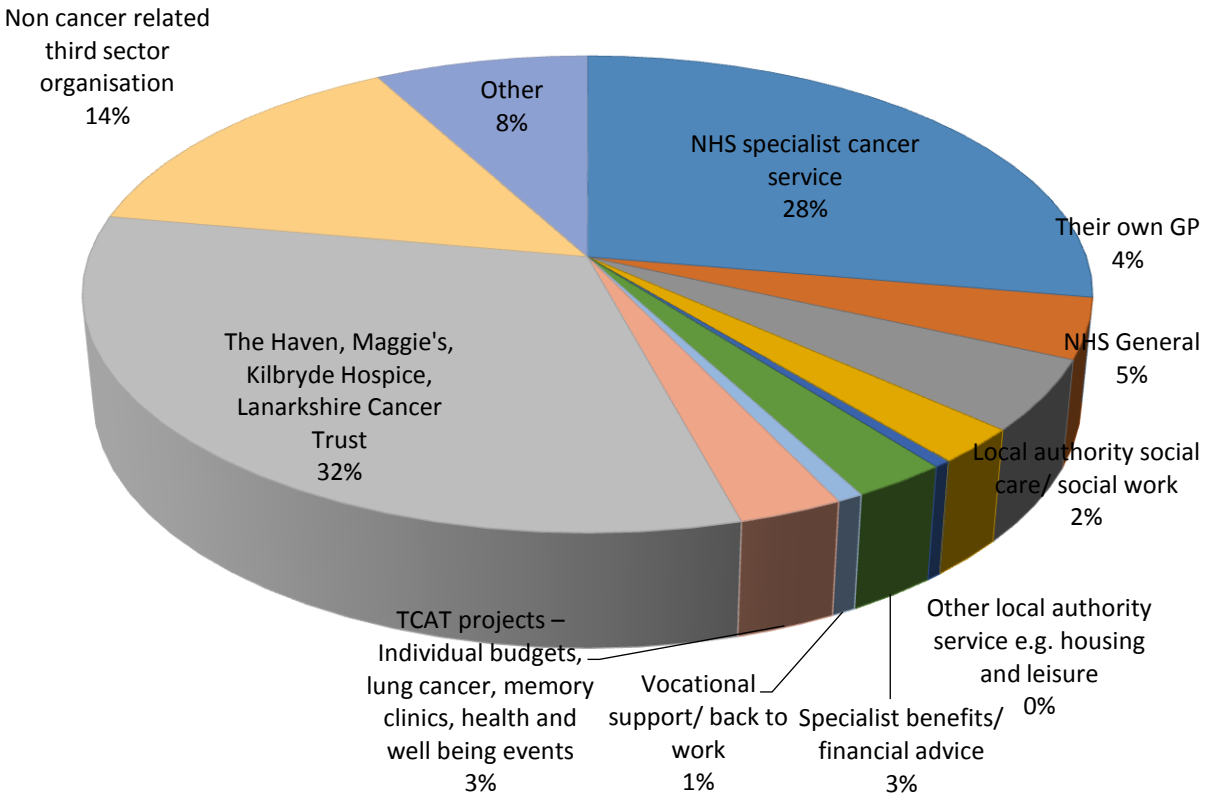
4.5 REFERRAL AND SIGNPOSTING TO SERVICES

From the CCR, 415 signposting and formal referrals were made from the practices. Signposting to third sector cancer organisations and charities such as The Haven, Maggie's, Kilbryde Hospice, Lanarkshire Cancer Trust and also NHS specialist cancer services are by far the greatest number. Some people were referred or signposted to more than one service.

- Almost 50% of referrals to the third sector and voluntary agencies
- 28 % of referrals to NHS specialist cancer services
- 4% of referrals to their GP
- 3% of referrals to specialist benefits/financial advice

The pie chart figure provides a breakdown of the referrals and signposting made to the various services:

Figure 14: Referrals & Signposting from CCR (415 in total)



Some comments from the focus groups highlighted the impact that services had on people with cancer and their partners:

"I used the fabulous service of the cancer care drivers, that service was great....so I had someone waiting outside (whilst attending for radiotherapy)" (person with cancer)

"The practice nurse was….is very welcoming to my wife and has said to her to come and speak to her if she'd like, she's (his wife) also just started going to Kilbryde and they do a different topic each week and she's really needed that, cause outside of this she's got my face all day to look at!! I was really welcomed down there too" (person with cancer talking about his wife as a carer)

4.5.1 SUPPORTED SELF MANAGEMENT

Practice nurses reported that the use of the concerns checklist and the training that they had received at the Macmillan "Cancer as a long term condition" course was a significant factor in adopting a person centered approach to CCRs.

"I think it is very patient led…you're saying to them what do you think would help? You know whereas (before) you'd have said to them, well I think you need x, but now you're saying to them what do you think? What do you think would help?" (TCAT Practice Nurse)

Practice nurses identified that self-management is a lifelong process and not a one off exercise, and compared it to their ongoing input to people with long term conditions such as diabetes:

"yes I think the approach is like - that is not really self managing when they come in and they tick boxes and hand it to you……I think it's your approach……what you give them back is about the self management"

"*I think that is a bit difficult, because it is for us, maybe we see them initially…with our long term management patients…it's through time isn't it, that you're helping them to self manage their conditions, support themselves" (Practice nurse focus group)*

The increased knowledge of services to refer or sign post people to, contributed to empowering patients to manage the consequences of their cancer:

"It is allowing them (the patient) *to take control of the consultation, rather than the nurse taking control of it"*
"There are lots of positives to the holistic needs assessment….I think the fact that the patients feel a bit more enabled, it's almost as if they can take a wee bit of control back" (practice nurse example of referral to scarf tying workshop)

4.6 PATIENT QUESTIONNAIRES

In addition to patient focus groups, a feedback questionnaire was posted to the person following their cancer care review. 77 patients returned their questionnaire (31% response rate).

4.6.1 CONFIDENCE TO MANAGE

As a result of attending a cancer care review *how confident are you that you can now manage your condition by yourself? Here "managing" means understanding ways to cope and knowing where to seek help if needed.*

83% (64 people) scored 8 or above on a 1-10 scale (10 being very confident) of their confidence levels.

4.6.2 SUPPORT FROM CCR

Overall, ***how would you rate the support*** *you received from your cancer care review? Here 'support' includes any appointments, advice, and information, being referred to or signposted to*

85% scored 8 or above regarding the support they received from their cancer care review

4.6.3 IMPROVING CANCER CARE REVIEWS

Do you have any ideas /comments about ***improving cancer care*** *reviews?*

There were 13 comments in relation to this question, and fell mainly into three categories of timing, frequency of follow up and information provision. One person felt that their G.P should be more involved.

Timing

"It was very good, I would suggest it could be done earlier in the treatment but that may be because the nurse struggled to get a hold of me!"

Frequency of follow up

Having a follow up meeting 1 year on

An odd phone call would be nice

Information

Possibility of booklet/hand out to read subsequent to meeting

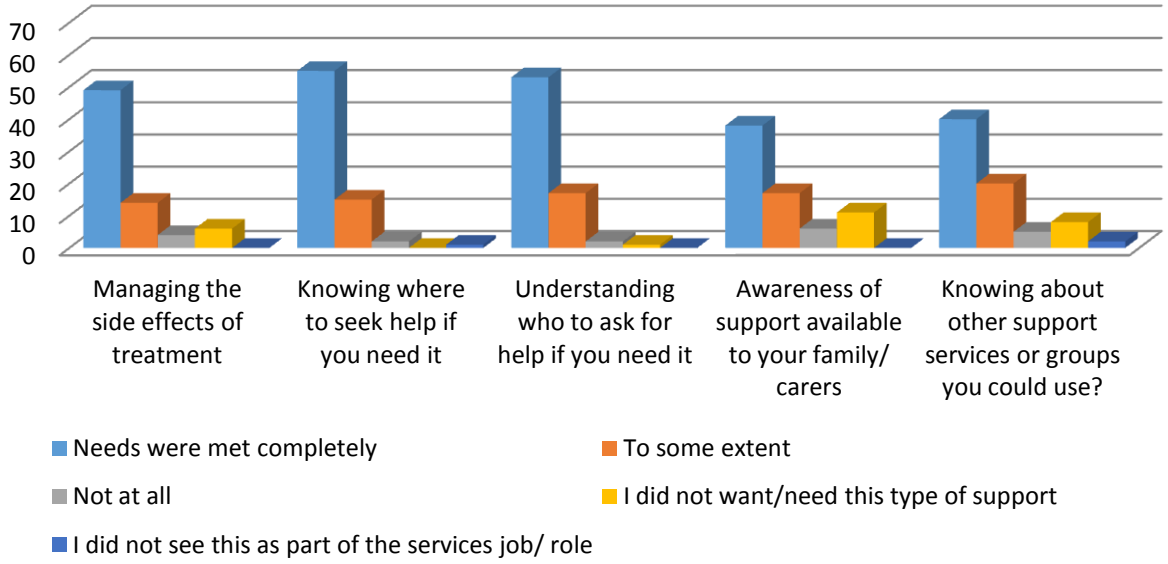
Possibly another such appointment could be offered some time in the future depending on need

4.6.4 WERE YOUR NEEDS MET?

Thinking about the support provided *by the cancer care review, to what extent were your needs met in relation to the following?*

75 people responded to this question with the majority feeling that their needs had been completely met in relation to: managing their side effects of treatment, knowing where to seek help and who to ask if you need it. Awareness of support for family/carers and knowing about other support groups were also reported in the majority but less than the first three categories.

Figure 15: Feeling that needs were met

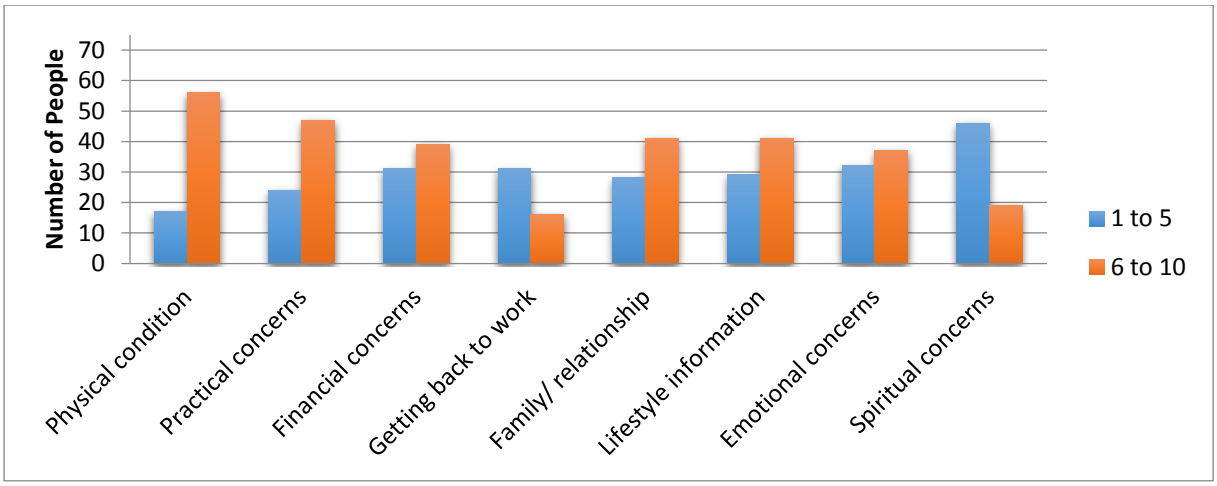


4.6.5 RATING THE CANCER CARE REVIEW

An overwhelming majority of people rated on a 1-10 scale that they had been highly involved in decisions about their care and that the CCR had helped them to get to other services and help put everything together. People also reported that they did not feel they had been passed around without support and therefore rated this very low. Figure 16:

4.6.6 CONFIDENCE TO MANAGE POTENTIAL CONCERNS

People felt that they were confident in dealing with future physical and practical concerns, scoring a 9 or 10 (most confidence). They were less confident in feeling that they would manage future concerns around finance, getting back to work, family/relationship, lifestyle information and emotional concerns where they had rated themselves 5 out of 10. It is also notable that the majority of people opted to rate their confidence around dealing with spirituality concerns as a 5 out of 10.Figure 17:



4.6.7 SUPPORT OR INFORMATION SERVICES

When asked if the cancer care review provided information on other organisations, 66 people answered this question, 48 said yes they had gained more information and 22 said no they had not. Those that said yes provided examples of the following organisations that they have made contact with:

- Cancer care voluntary drivers (2)
- Department for work and pensions
- Dietician (2)
- Money matters
- Haven
- Hospice East Kilbride
- Insurance Agency
- Monklands Hospital
- Macmillan cancer support (3)
- Maggie's (16)
- Support days that run in the community
- Access wigs and reflexology

4.7 CONFIDENCE & COMPETENCE OF PRACTICE NURSES

Feedback from practice nurse focus groups depicted the increased confidence and competence of the practice nurses through delivering CCRs and following training. With terms such as "anxious" and "uncomfortable" when dealing with someone with cancer prior to their training and now feel that they are growing in confidence. Ability to attend the training was regarded as pivotal to conducting a successful CCR, particularly in light of some quite "sad" and "emotional" circumstances that the

practice nurses were exposed to during a CCR with some complex or approaching end of life patients. This support was extended to family members and carers too.

"Before it was kind of like oh no…they're coming in, they've got cancer, hope they don't ask me something I don't know. But now I am quite happy now to say, well I don't know that but get in contact with x,y,z and they'll be able to help you" (TCAT practice nurse)

The quality and delivery style of the CCR was further backed up by comments from a number of GPs who recognised both an increase in competence and confidence in their practice nurse and commended the holistic approach that was been taken. In addition to ensuring that practice nurses received continual professional development and job satisfaction, there were also unseen benefits in that some practice nurses were now also more involved in anticipatory care plans too.

"The Macmillan course is enhanced continual professional development for practice nurses; it came at the right time where the practice nurse was looking for some additional learning/challenge. This has now provided a good preparatory level of knowledge so that the practice nurse is now going to be more involved in ACPs and home visits" *GP TCAT*

A practice nurse commented that she would not have felt confident in raising the issue of cancer prior to the course and this has resulted in many more opportunistic conversations with great results such as the woman who had expressed concerns about her son's cancer experience and experiencing financial difficulties. The practice nurse was able to provide the Macmillan phone line number to enquire about financial help. The son was put in touch with the relevant area and managed to resolve his concerns and resulted in the knitting of a pink hedgehog for the PN as a way of thanks!

4.8 CAPACITY AND COST

The table below highlights the number of cancer care reviews that have been delivered by practice nurses over an 18 month period and the estimated saving of GP time from not delivering the reviews as part of the previous QOF and GMS contract. In addition to time saved, the final column reports a total of 496 GP appointment slots that have been freed up thus improving patient accessibility to GP time. Whilst a few GPs carried out a cancer care review they still recommended that the person make an appointment with the practice nurse for a "holistic" review.

Table 6: Practice	Patient list size	Cancer Care Reviews delivered over 18 months	GP time saved in minutes (20 min GP appt for CCR)	Potential number of freed up GP appointments (10 min appt. slot)
Ardoch, Cambuslang	3,400	6	120	12
Wellwynd, Airdrie	21,856	64	1280	128
St Lukes, Carluke	10,707	18	360	36
Orchard, Motherwell	12,580	20	400	40
Logan, Wishaw	10,267	71	1420	142
Greenhills, E.K	9,000	22	440	44
Avondale, Strathaven	6,500	16	320	32
Willow, Viewpark	2,800	10	200	20
Medwyn, Carnwath	6,000	21	420	42
Total		**248**	**4960 minutes (83 hours)**	**496**

415 referrals & signposting were made to a number of support agencies and services. Almost half of these referrals were to third sector and charitable organisations such as The Haven, Maggie's, Kilbryde Hospice and non cancer related organisations such as carers support, walking groups etc. These social prescribing links potentially free up GP time since patients are receiving the support they need from non NHS sources. Arguably these referrals would not have been made to the same extent from a GP cancer care review.

> *"…..it's hard to say but I would say yes it has increased capacity as our nurses are now more skilled and where appropriate the Cancer Care Review leads on to an anticipatory care plan" (Practice Manager TCAT practice)*

Some practices had very small numbers (one per month) of cancer reviews and the GPs perhaps did not "feel" a difference in their capacity or workload shift in the short term, however we are aware of the incidence increase in cancers in the future and their investment in their practice nurse learning at this point may bear fruition in the long term.

The improvement in both the quality and outcomes for the person with cancer and for the practice as a whole is summed up in this GP comment:

"I would say that we are so stretched at the moment with a partner on maternity leave that it is difficult to feel the difference. Patients are not currently finding it any easier to access appointments, but that is because we are short of GP sessions. It is good to know that the cancer care reviews are being carried out systematically and thoroughly and that takes a stress off me. It has also really helped our practice nurse develop new skills which she is taking forward to anticipatory care planning more generally." GP TCAT Practice

4.9 OTHER AREAS OF IMPROVEMENTS

4.9.1 SECONDARY CARE TO PRIMARY CARE COMMUNICATION

During a GP interview, it was expressed that the information received from the hospital to the GP surgery was also an area of potential improvement:

"There is a lag in information being received from cancer appointments in the hospital and then relaying this information to the practice- not necessarily a barrier to cancer care reviews but difficult not having the full information to continue conversations with patients who are left relying on their understanding of the meeting and keeping me up to date with any changes/decisions"

(GP TCAT Practice)

4.9.2 PRE-CHEMOTHERAPY BLOODS

There has been an example of change in practice in one large surgery where the patient fed back to the manager that she was alarmed about having to sit in the waiting room prior to her pre-chemotherapy bloods which is likely to be one of the most infectious public spaces that she could be exposed to. The surgery took this on board and now offers a separate area for the patient to wait in prior to her appointment. This is an example of a small procedural change that has had a big impact on a person's cancer journey.

"I got a phone call to say to come in and speak to (the practice nurse) but I hadn't finished my treatment at that point. I was sitting out in the waiting room and you know how easy it is to get infections and other things, so I did highlight, to the surgery, which they did take up I'll give them their due, I said I shouldn't be sitting out in amongst all of these people with colds, flus, chicken pox… could have anything and I hadn't finished my treatment at that point and I was going for my second last treatment, so anytime that I came into the surgery, it was highlighted in my notes they took me and sat me in a separate room so that I wasn't sat out in amongst people , so that was a good outcome……..so from that point of view I didn't have to do that" (person with cancer)

4.9.3 PRACTICE SYSTEMS RESOURCE

Another output of the project has been the production of a “how to guide” with the view of sharing this resource to other practices locally, regionally and nationally. The operational steering group decided to name the resource “Getting started with Practice Nurse Cancer Care Reviews” (see Appendix 3). We hope that this offers clear practical ideas and instructions to go from a practice receiving notification of a new cancer diagnosis to offering a holistic cancer review.

5. WHAT DOES THIS MEAN?

There are currently more people living with cancer than dying from it but some primary care services have not shifted in their systems and processes to reflect this need. Training practice nurses to support people with cancer has been shown to be both acceptable and feasible for practices to adopt, hence allowing stratification of patients to the appropriate practice staff member and shifting some of the workload from GPs.

From the extensive evaluation that has been carried out with almost 400 people affected by cancer, with practice nurses, GPs and practice managers we feel that we have provided significant evidence to demonstrate both the increase in confidence and competence of practice nurses carrying out cancer care reviews. Releasing practice nurses to attend a five day Macmillan cancer as a long term condition course is helping to prepare primary care for the tidal wave in cancer incidence that will be realised in the next decade, since age is the biggest risk factor for cancer development.

The use of the concerns checklist as the holistic needs assessment tool has been received well by both practice nurses and people with cancer and aids in providing a structured format to the review, but more importantly allowing people to set their agenda and receive information when they require it. Practice nurses are progressively becoming a lynchpin in community health care and particularly for long term conditions where cancer is increasing being regarded as such. By ensuring that people are aware that they can contact the practice nurse regardless of the time from their diagnosis is key to offsetting their feelings of abandonment often reported by people finishing their treatment.

Many consequences of treatment develop several months and often years later therefore being able to pick up their cancer conversation with the practice nurse is critical for continuity of care and prevents the dread of having to “retell” their cancer story to another health professional. Some people may require specialist input beyond the practice nurse’s boundary of competence but this is not dissimilar to many other long term conditions and the signposting and referral results depict the quarter of people that were referred to NHS Cancer specialist services from their cancer review.

Holistic cancer care reviews using the concerns checklist enabled practice nurses to adopt a “House of Care” approach whereby they prepared the person prior to their review so that a person centered review could be facilitated, and then draw upon the rich community assets of support available in Lanarkshire. An overwhelming majority of people rated that they had been highly involved in decisions about their care and that the CCR had helped them to get to other services and address their concerns; the time provided for the CCR was a significant factor in achieving this stage. This is further supported by the connections made to third sector and voluntary agencies thus ensuring that people are being navigated through the maze of services.

Local community support centers such as the Havens, Maggie's, Kilbryde Hospice, Lanarkshire Cancer Care Trust volunteer drivers featured frequently but with fewer than anticipated people referred or signposted to Macmillan benefits advisors. Finance was not rated within the main list of concerns that people selected, where fatigue, pain and fear of recurrence were the top three most reported concerns. However 27% of people were still classified as in employment so either they are being supported well by their employers or perhaps finance still remains an area of taboo and sensitivity for people to raise with health professionals and the promotion of the Macmillan helpline number can aid in reassuring people of the discretion of this service.

There were also fewer than expected referrals to physical activity options particularly when the ECOG functional status for over 80% of people put them in a scale of being able to participate in the likes of Macmillan Move More programme and with fatigue being rated as the top concern. The cultural shift of *"Rest is not best*" is still to resonate with many people despite the compelling evidence available from Macmillan on the benefits of physical activity. Physical activity is promoted during treatment and afterwards, particularly in decreasing the likelihood of recurrence, but also to empower people with small lifestyle changes that can make a big difference to their quality of life.

We were unclear whether people would voice their concern that it was not a GP carrying out their cancer review, however this was not the case. GPs acknowledged the quality of the cancer review that their practice nurses were able to offer as is provided in the quote below:

> *"Patients do not feel short changed that a practice nurse is carrying out the review in fact the reverse is true where they see it as an enhanced or extra service that is provided."* *(GP TCAT practice)*

Practices also stated that whilst they adhered to the use of the concerns checklist, they appreciated the autonomy of finding out what worked for them operationally and enabled them time to reflect on their current systems and communication and to

make refinements. There has been a greater involvement with the whole practice team and this has highlighted the impact that the administration team play, and who also require cancer awareness training to emphasise the shift of cancer to a long term condition for many people. There was an understanding of the role of cancer care reviews in a whole person's cancer journey i.e. practice nurses are only one part of the person's support and care structure and therefore should not be or feel burdened as if responsible for "*everything"* or for "*fixing everything*" but felt that they were an important point of contact for people. White, Nimmo & Munro, 2017 provide further evidence of the critical role that practice nurses play in cancer care in their recently published paper.

The average time spent with the practice nurse was 30 minutes, which was similar whether it was a face to face review or over the telephone. The flexible approach was helpful since the timing of *when* a review was valued varied amongst people depending on their treatment plan and personal circumstances. Of the 248 people that attended for a review 64% were still undergoing treatment and 36% had finished treatment highlighting the need for support during treatment in addition to afterwards. People were given the option of deferring their review until later but still chose to attend whilst they were in treatment. A small number of people also chose to attend for a review even though they had no current concerns but felt that it would be beneficial to attend and know that the practice nurse could be contacted in the future.

Generally, we know that a GP appointment slot costs more, and is shorter in time than for a practice nurse, therefore if needs are addressed during a review with a practice nurse then the practice is not having to allocate costly appointment times with GPs if not required. We can also speculate that earlier intervention is less costly, with better outcomes for the patient than later presenting concerns. A minority of GPs voiced that they had not felt an increase in their capacity however this was generally where there were very small numbers of CCRs carried out for example one per month. The cost effectiveness of this approach is being further analysed by the research team at Edinburgh Napier University with findings available in 2018.

The added benefit and value to the NHS as a whole is that we now have an evidence based model of practice which offers tailored, high quality and person centered cancer care reviews led by a practice nurse. This work can provide strength to the current transformation of primary care and be maintained with ongoing training to uphold the quality of cancer reviews.

Sustainability is not just about funding it is also about building momentum, maximising resources and generating community champions to develop long term buy in. We have used a sustainable approach in that we add value to existing systems and have changed *who* carries out the review and *how* it is delivered. The value from dissemination of effective strategies and tools that have been evidenced

White, F, Nimmo, S & Munro, D. (2017). All GPNs play a vital role in cancer care. General Practice Nursing, Vol 3, No 2. https://www.journalofpracticenursing.co.uk/journal/06-2017/cancer/237-all-gpns-play-a-vital-role-in-cancer-care/

from the project may act as a substantial lever to encourage other practices to consider offering holistic cancer care reviews and embed this way of working. The reach of the work into communities will also be enriched by the newly appointed Macmillan Libraries and Leisure programme in Lanarkshire, and may also gain momentum from the anticipated changes in the GMS primary care contract around cancer care reviews.

In conclusion, over 70% of people with cancer offered a review with the practice nurse have taken up this offer thus supporting the acceptance of this approach. The reviews also fit within the chronic disease management work, therefore adds value to people with co-morbidities since the practice nurse can also raise the issue of cancer and continue to support the person's whole health. We have successfully generated evidence to confidently say that on the whole we have improved:

- **Quality** of the cancer care review
- **Satisfaction** for both the person with cancer and also the practice
- **GP capacity** through a shift in work load
- **Operational guidance** for primary care to share and spread learning

6. NEXT STEPS

The project has received confirmation that they will receive funding to support the spread of learning locally and to a regional basis for another year. The project manager's post has been secured until October 2018 with the aims of:

1. Dissemination of project finding at a Celebration and Learning event in Lanarkshire October 2017.
2. Promoting and recruiting 15 additional practice nurses to attend the Macmillan Cancer as a long term condition 5 day course starting January 2018.
3. Co-ordinating the hosting of a Lanarkshire practice nurse cancer care course in 2018.
4. Disseminating the "Getting Started with practice nurse led cancer reviews" guide.
5. Offering support to Cluster groups who select cancer as a quality improvement topic area and to those practices who are working on the Macmillan Quality Modules.
6. Developing a test of change plan with NHS Lanarkshire Telehealth care team and the "Florence" system to explore possible follow up messages for people with cancer that can be accessed on a mobile phone.
7. Establishing an awareness of the programme of work with the Transforming Primary Care Work group for redesigning primary care services.
8. Regional WoSCAN spreading of learning as and when requested with Lead Cancer clinicians and the Regional Lead for WoSCAN.
9. Continuing to represent NHS Lanarkshire and TCAT on the steering group for NHS Inform's Health & Wellbeing Directory to support signposting, referral and self management.
10. Continuing to maintain partnership working with CRUK primary care facilitator such as the quarterly e-cancer bulletin "Finding and Following up cancer" published in the Knowledge Network.

    In addition, this project has been shortlisted for the Health & Social Care Alliance self management project of the year and Changemaker awards.

7. RECOMMENDATIONS

- ✓ We recommend multi pronged tactics to bridge the gaps for people in their cancer journey and practice nurse cancer care reviews can bolster this. Access to local primary care clinical forums, practice nurse forums and practice manager networks to promote holistic cancer care reviews are key platforms to promote a shift in practice.

- ✓ The Scottish Government Primary Care and Mental Health Transformation (PCMHT) fund is enabling a broad range of 'models of change' across Scotland. The programme will encourage the development, thematic change and support sharing and learning to redesign primary care services. Highlighting the shift in workload from GPs to practice nurses for cancer care reviews fits within the vision for this transformational change therefore it is recommended that board areas approach their local PCMHT groups for backing to enable cancer care work to be driven forward.

- ✓ On an operation basis, three key control areas of 1) before, 2) during and 3) after the review are detailed below to provide guidance for service transformation of cancer care reviews:

1. Before: Processes and Systems

- Practice nurse attendance at 5 day Macmillan cancer as a long term condition course. Provide backfill to enable this to happen with a suggestion of £400 per practice
- Reflection on practice team approach to carrying out cancer care reviews to stratify patients to relevant team member, timing of invite, flexibility of times and formats i.e. face to face, telephone and perhaps electronic assessment for some people to complete a review are warranted
- Promote a standardised quality cancer care review using a Holistic Needs Assessment approach such as the concerns checklist

2. During the review: Person Centered Care

- Using the concerns checklist selected by the person to guide the content of the review and adopt an ethos of self management where appropriate
- Care planning provided in agreement with the person to highlight available support in dealing with the physical, mental, emotional, practical and lifestyle consequences of cancer treatment
- Use of Macmillan website, NHS Inform: National Service Directory and other local directories to signpost people to the range of services on offer including community and third sector. Take a whole practice approach to increasing awareness of local support services, there are many valuable conversations that occur with reception staff who can be pivotal in promotion of community support services

3. Following the review: Person Led Follow up

- The person can request follow up as and when needed and use the concerns checklist as a guidance to set the agenda
- Improve integration between the practice and community service providers particularly voluntary and third sector sources of support to enhance self management. Some practices may have access to link workers/community connectors to navigate people around the maze of services
- Highlight Macmillan Library and Leisure programmes that may be on offer in your area
- Communicate with the wider cancer team since some important information may arise during a Cancer Care Review which would be important for the hospital to know

✓ Previous communication from the Lead Cancer clinician for Primary Care Cancer Network, WoSCAN (Dr Paul Baughan) is still relevant whereby; the previous quality and outcomes framework (QoF) had a focus on the number of cancer care reviews undertaken within a specific time-period. Whilst all patients should still be offered a cancer care review, it is better to spend the time on a quality Cancer Care Review with those that want one rather than attempting a superficial review with everyone.

✓ **Promotion of RGCP Toolkit:** More information on Cancer Care Reviews, including recommended READ codes on the RCGP toolkit: Visit www.rcgp.org.uk and search for 'consequences of cancer and treatment'.

APPENDIX 1:

National Cancer Survivorship Initiative – Your Holistic Needs Assessement Concerns checklist 0001

Living with and beyond cancer – identifying your concerns

Patient's name or label

Completed by:

Date:

Designation:

Contact details:

This self assessment is optional, however it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need in the future.

If any of the problems below have caused you concern in the past week and if you wish to discuss them with a health care professional, please tick the box. Leave the box blank if it doesn't apply to you or you don't want to discuss it now.

☐ **I have questions about my diagnosis/treatment that I would like to discuss.**

Physical concerns
- ☐ Breathing difficulties
- ☐ Passing urine
- ☐ Constipation
- ☐ Diarrhoea
- ☐ Eating or appetite
- ☐ Indigestion
- ☐ Sore or dry mouth
- ☐ Nausea or vomiting
- ☐ Sleep problems/nightmares
- ☐ Tired/exhausted or fatigued
- ☐ Swollen tummy or limb
- ☐ High temperature or fever
- ☐ Getting around (walking)
- ☐ Tingling in hands/feet
- ☐ Pain
- ☐ Hot flushes/sweating
- ☐ Dry, itchy or sore skin
- ☐ Wound care after surgery
- ☐ Memory or concentration
- ☐ Taste/sight/hearing
- ☐ Speech problems
- ☐ My appearance
- ☐ Sexuality

Practical concerns
- ☐ Caring responsibilities
- ☐ Work and education
- ☐ Money or housing
- ☐ Insurance and travel
- ☐ Transport or parking
- ☐ Contact/communication with NHS staff
- ☐ Housework or shopping
- ☐ Washing and dressing
- ☐ Preparing meals/drinks

Family/relationship concerns
- ☐ Partner
- ☐ Children
- ☐ Other relatives/friends

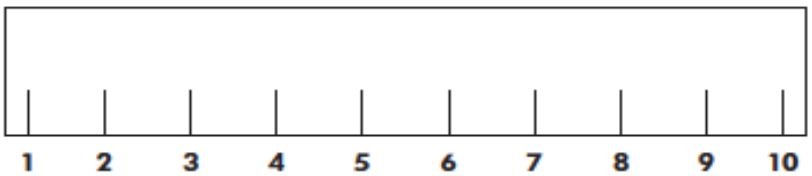
Emotional concerns
- ☐ Difficulty making plans
- ☐ Loss of interest/activities
- ☐ Unable to express feelings
- ☐ Anger or frustration
- ☐ Guilt
- ☐ Hopelessness
- ☐ Loneliness or isolation
- ☐ Sadness or depression
- ☐ Worry, fear or anxiety

Spiritual or religious concerns
- ☐ Loss of faith or other spiritual concern
- ☐ Loss of meaning or purpose of life
- ☐ Not being at peace with or feeling regret about the past

Lifestyle or information needs
- ☐ Support groups
- ☐ Complementary therapies
- ☐ Diet and nutrition
- ☐ Exercise and activity
- ☐ Smoking
- ☐ Alcohol or drugs
- ☐ Sun protection
- ☐ Hobbies
- ☐ Other

Please mark the scale to show the overall level of concern you've felt over the past week.

You may also wish to score the concerns you have ticked from 1 to 10.



WE ARE MACMILLAN. CANCER SUPPORT

DH Department of Health

NHS Improvement

APPENDIX 2: TEMPLATE INVITE LETTER FOR CANCER CARE REVIEW & SENDING OUT CONCERNS CHECKLIST PRIOR TO REVIEW

Surgery address

Cancer care review appointment

Dear _____

NHS Lanarkshire is working in partnership with Macmillan Cancer Support to improve the follow up care of cancer patients and finding out what is important to you.

- To do this, we would like you to complete the concerns checklist that we have enclosed with this letter, and then bring it along to your appointment, or, discuss it with the practice nurse over the telephone; it's really important that you have a think about what matters to you before your appointment.
- You are welcome to bring a partner/ friend /carer along with you
- Please call the surgery to let us know if you would like an appointment for a cancer care review.
- If this is not the best time for you then let us know when you have finished your treatment and an appointment can be made for a later date.

For support from Macmillan, call free on 0808 808 00 00 or visit macmillan.org.uk

Yours sincerely

Practice nurse

APPENDIX 3: GETTING STARTED WITH PRACTICE NURSE LED CANCER CARE REVIEWS

Embedded resource accessed here:

Getting started with practice nurse led car