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EVALUATION OF MACMILLAN'S CANCER CARE REVIEW TEMPLATE

FINAL REPORT

May 2012

Acknowledgements

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Executive Summary of Key findings

1. Overall, GPs were very positive about the Macmillan Cancer Care Review templates, with the most useful prompts being ‘reviewing medication’ and ‘noting details of main carers’.
2. Patients surveyed were also very positive about the process of a review, with over 71% being very satisfied with the process. Patients felt that the CCR gave them an opportunity to discuss their cancer and general state of health with their GP and appreciated the fact that the GPs made the effort to contact them.
3. Interestingly, several patients who were interviewed did not realise at the time that they were being reviewed, which GPs described as being appropriate as it is seen as normal and supportive care rather than a tick box exercise. One GP also described it as a process rather than a single event, indicating the importance of seeing the review as an ongoing entity.
4. Most GPs (88%) found it useful to have easy access to Macmillan resources although only 20% were aware that signposting information was included.
5. Survey findings confirm that there is variation in what is covered in a review, with only 55% and 61% respectively always discussing the diagnosis and always reviewing medication. Under half of those surveyed were always recording details of whether or not chemotherapy or radiotherapy had been given, and only 18% were always signposting to sources of information on finances and benefits.
6. Interestingly, several patients who did not have specific areas of care discussed said it would have been helpful to do so.
7. In many cases, CCRs are seen as quite different to reviews of other Long Term Conditions (LTCs) as LTC reviews deal with patients who are perceived to be less psychologically fragile than most cancer patients.
8. Whilst there was a great deal of positive reaction to using structured templates, all who used them felt they should be used as a prompt or aide-memoire rather than a tick-box exercise.

Executive Summary of Key Recommendations

1. The Quality and Outcomes Framework indicators for cancer should be clearly defined and measurable in the same way as other conditions, as the lack of rigour within cancer indicators is perceived to be a barrier to reducing variability in care.
2. Patients should be made aware that the Cancer Care Review is an integral part of their cancer pathway, and offered appointments in a format that suits their preferences whether that be face-to-face or by telephone, and with the option of including family members or carers.
3. The CCR needs to be a holistic broad based discussion taking into account co-morbidities and the social, psychological and practical aspects of disease rather than just the medical and physical. The Cancer Care 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.
4. There is a need for education and support to promote use of the Macmillan CCR structured template, as well as to promote the benefits of a CCR more generally to a wider primary and secondary care audience. This should include the potential role of other members of the primary healthcare team.
5. CCRs should be carried out when any significant transition occurs in the patient’s cancer journey, rather than only once after diagnosis. Current processes and perceptions about patient preferences should be challenged.
6. Ongoing work is needed with IT providers to encourage further development of the Macmillan Cancer Care Review template, so that it is available on all clinical systems and can be tailored locally for more flexible use.

Introduction

Cancer is changing. The two million people living with cancer today will become four million by 2030. We know that 300,000 people in the UK are diagnosed with cancer every year and sadly, 157,000 people in the UK will die from cancer every year.

Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care. We are committed to reaching and improving the lives of everyone living with cancer, and inspiring others to do the same. Macmillan has identified nine key outcomes that we want see for people living with cancer; our goal is that, by 2030, the four million people living with cancer will be able to say: *I was diagnosed early, those around me are well supported to help me and themselves, I can enjoy life, I understand so I make good decisions, I am treated with dignity and respect, I feel part of a community and am inspired to give something back, I got the treatment and care that was best for my cancer and my life, I know what I can do to help myself and who else can help me, I want to die well.* “

Cancer policy in England also reflects the need to improve support and care for people living with cancer. The Improving Outcomes Strategy for Cancer (2011) clearly sets out to improve the experience of people with cancer and to increase the support for cancer survivors whilst increasing patient empowerment and choice. The document also highlights that the UK still has some of the worst cancer survival rates in Europe, despite the reductions in mortality and improved survival rates.

Following publication of the earlier Cancer Reform Strategy in 2007, the National Cancer Survivorship Initiative was introduced in England. The survivorship initiative has highlighted the chronic consequences that cancer treatment may have months or years later and the effect that having had a diagnosis of cancer has on a person’s physical, emotional and psychological health. The initiative has resulted in significant progress in testing new models of follow-up arrangements and improving assessment and care planning for people living with cancer. The evaluation of structured cancer care reviews in primary care forms part of this broader stream of work in improving assessment and care planning, building on the earlier work of the Macmillan primary care community to improve the existing QOF cancer care reviews.

More recently, NHS reforms in England will radically overhaul the ways that cancer services are commissioned, with GPs having a key role in commissioning whole pathways of care that will improve cancer outcomes. Primary care has an increasingly important role to play in primary prevention of cancer, improving screening uptake, ensuring early diagnosis and appropriate and timely use of diagnostics, ensuring that treatments occur in an appropriate setting, reviewing and updating outdated models of follow-up, supporting patients in self management of their conditions and ensuring that cancer survivors have a personally tailored care plan. Tools such as the Cancer Care review template therefore become even more important in placing those who are living with or beyond cancer at the heart of any decisions and making sure that they feel supported, informed and empowered.

Background

The Quality and Outcomes Framework (QoF), a voluntary rewards and incentives program introduced as part of the GP Contract in 2004, requires all patients diagnosed with cancer to be reviewed by their GP within six months of the practice receiving confirmation of their diagnosis. However the current Cancer Care Review (CCR) process is relatively imprecise and non-directive with the QoF stating simply that it is an 'opportunity to cover the following issues'. Consequently, it is unclear what GPs actually cover in their cancer care reviews and there is assumed to be wide variability in practice. Furthermore, there is no consistent coding of what is covered in a Cancer Care Review, therefore it is difficult to measure or identify the care and treatment given to people who have previously had a cancer diagnosis.

Macmillan Cancer Support wished to evaluate the use of a structured template to support the CCR process, looking specifically at how this template is currently used by GPs, how it might be used more effectively and how patients themselves view the cancer care review process. Tribal was commissioned by Macmillan Cancer Support to undertake an evaluation of Macmillan's cancer care review template amongst GPs and patients in the survivorship phase of their cancer journey. At the same time, an MSc project funded by Macmillan Cancer Support looked at ways in which prescriptive templates for cancer and palliative care reviews in primary care could influence practice. A summary of this MSc project, with similar findings to those found in this study, is available separately from Macmillan Cancer Support.

Aims and objectives of the study

The overall aim of this study was to contribute to the evidence base on the use of structured CCR templates.

- To assess the extent to which the Macmillan CCR template is being used by a sample of GPs
- Obtain views on the available templates; and to introduce the templates (via screen shots in the survey)
- Gain an idea of the usability of the template, and to obtain views and perceptions from GPs about the CCR process.

Methods

Survey of GP Practices and qualitative interviews

Both quantitative and qualitative surveys were used and were available both as hard copy and online. A total of 65 GP Practices were approached to participate in the project with a final number of 47 Practices taking part. A letter inviting GPs to participate in the project was sent as widely as possible within PCTs where Macmillan has a GP presence. Twenty-three of the participating GPs also took part in a qualitative telephone interview

Survey of Patients and qualitative interviews

Participating GPs were asked to invite patients to input to the project, with patients completing the survey from a patient perspective. Qualitative telephone interviews were also carried out with patients. The survey was again available online or in hard copy.

The table below shows the numbers of GPs and patients with whom telephone interviews were held and surveys completed. It was agreed that the interviews should be focused on GPs rather than Macmillan GPs as the evaluation is intended to build an evidence base for use of the templates amongst GPs without a specific interest in cancer

Numbers of Respondents/Interviewees

	Macmillan GPs	GPs	Patients	TOTAL
Surveys	24	85	29	138
Interviews	1	23	9	33
TOTAL	25	108	38	171

Limitations

There were a number of limitations to this study. The GPs sampled were a self selecting group and we are unable to say that they represented the norm of the GP population. All but one of the patients who were involved in the study was white and spoke English as their first language. This means that results may lack applicability to other ethnic groups. An additional issue was that the GPs were responsible for offering patients the option to participate in the study, which means they could have excluded patients if they wished. Whilst this means that there may have been bias it was impossible to do this in any other way as, quite correctly, we did not have access to patient details. The numbers who completed the surveys and participated in the interviews were relatively disappointing, although concerted effort was made to contact and encourage them. Taking into consideration the timing of the project alongside major reforms of the NHS, the impact of which has been huge on GPs, such low numbers were not however unexpected.

Key Findings

GP responses to survey

- Overall, GPs were very positive about the Macmillan Cancer Care Review templates, with the most useful prompts being ‘reviewing medication’ and ‘noting details of main carers’. Any issues raised appeared to be more to do with templates in general rather than this template specifically.
- 79% of GPs found the Macmillan Cancer Care Review Template either “fairly” or “very user friendly”.
- Most GPs (88%) found it useful to have easy access to Macmillan resources although only 20% were aware that signposting information was included.
- 78% of GP CCRs were face to face with 16% done over the telephone. Macmillan GPs tended to do more face to face CCRs (85%) versus the average, and correspondingly fewer telephone CCRs (9%)
- The most common things discussed in the CCR were:
    - Medications (61% “Always” discuss)
    - Diagnosis (55% “Always” discuss)
    - Whether the patient has had Chemotherapy or Radiotherapy (42% “Always” discuss)

- Additionally, 60% of GPs “Always” discussed “Anything else” which could include anything from checking the patients understanding of the diagnosis, going over hospital information or checking general welfare.
- 54% of all the GPs surveyed had experienced challenges with completing CCRs. The main challenge for both Macmillan and non-Macmillan GPs appeared to be patients who did not wish or feel able to discuss their condition, either because it was too emotive, because they were still being treated at hospital or because they were feeling overwhelmed by related appointments.
- Most GPs felt that patients were not aware that they are having a CCR which is borne out in interviews with patients. The GPs felt that this was appropriate as it was seen as normal and supportive care rather than a tick box exercise. In addition, one GP spoke of it as a process rather than a single event, indicating the importance of seeing the care as ongoing.
- In many cases, CCRs are seen as quite different to reviews of other Long Term Conditions (LTCs). CCRs are undertaken almost invariably by the GP.
- On the whole carers are not specifically involved in the CCR, often as patients do not see the meeting as anything different to their routine visit to the GP. As this is seen to be part of normal care delivery, patients do not anticipate the meeting or consultation with their GP to be anything out of the ordinary and therefore tend only to involve their carers/families if that is their normal pattern. Most GPs said that

patients tend to come alone. However, GPs tend to value the involvement of carers or other family members.
- There was a great deal of positive reaction to having templates, although all who used them felt strongly that they should be used as a prompt rather than a tick box exercise. Those that expressed concern about using templates focused on this point as a serious issue.
- Over half the interviewees knew something about Macmillan resources although there was variability in both use and understanding of how to access them.

Patient responses to survey

- All patient responses about the CCR were very positive with 71% of patients declaring themselves very satisfied with the process.
- 92% of patients who completed the survey had a face to face CCR.
- 62% of the patients had a dedicated, set aside appointment and 38% were reviewed when seeing the practice regarding another problem/appointment.
- 68% of CCRs were with the GP while 12% were with the Practice Nurse.
- 75% of patients recalled having their treatment discussed. Of the 25% who didn't. 66% felt it would have been helpful.
- 71% of patients recalled having their medication discussed. Of the 29% who didn't, 85% felt this would have been useful.
- 50% of patients recalled having their information needs discussed. But of the 50% who didn't, only 41% felt this would have been helpful.
- 60% of patients recalled that they had their and their carers support needs discussed. Of the 40% who didn't, only 41% felt this would have been helpful.

Patient responses to interviews

In total, nine patients were interviewed by phone. Most were not aware that they had had a CCR, although this may not be a negative point as patients viewed the CCR as part of a routine GP visit. Patients felt that the CCR gave them an opportunity to discuss their cancer and general state of health with their GP. For example one said 'It was a general how are you doing?'. Invariably patients were positive about the relationship they have with their GPs. They appreciated the fact that the GPs made the effort to contact them.

Aspects covered in cancer care reviews

Figure 1: Aspects covered in cancer care reviews

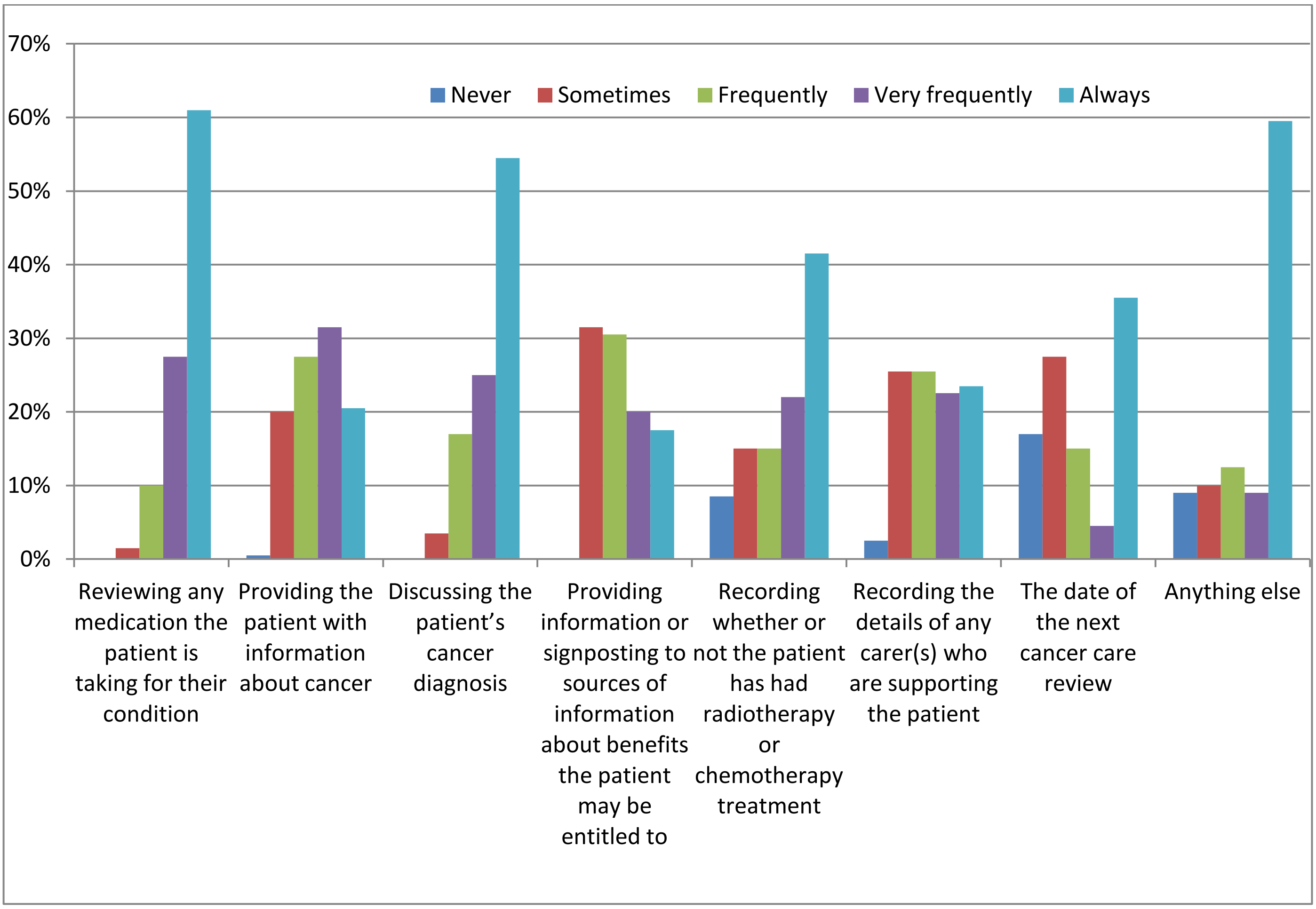


Table 1 shows the areas listed within the templates that GPs cover in the CCR and how often they cover each aspect.

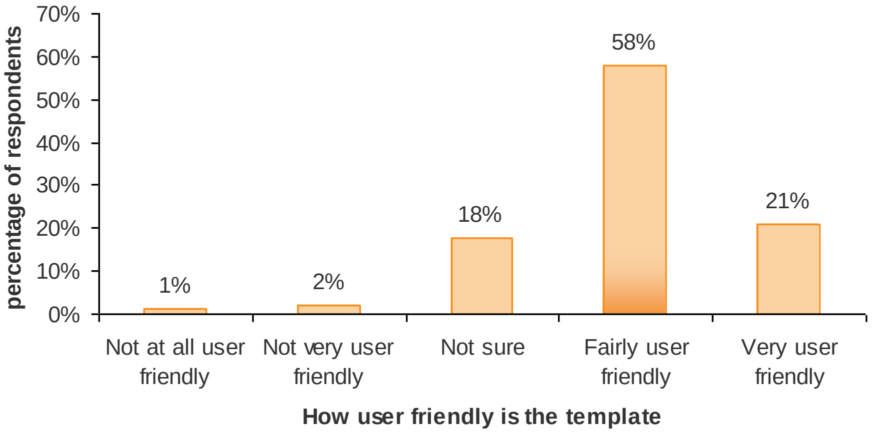
Table 1: Aspects covered in cancer care review

Response	Reviewing any medication the patient is taking for their condition	Providing the patient with information about cancer	Discussing the patient's cancer diagnosis	Providing information or signposting to sources of information about benefits the patient may be entitled to	Recording whether or not the patient has had radiotherapy or chemotherapy treatment	Recording the details of any carer(s) who are supporting the patient	The date of the next cancer care review	Anything else
Never	0%	1%	0%	0%	3%	1%	21%	18%
Sometimes	3%	23%	7%	33%	17%	33%	29%	9%
Frequently	7%	29%	17%	31%	25%	21%	8%	14%
Very frequently	29%	28%	24%	23%	21%	23%	5%	18%
Always	61%	19%	52%	13%	33%	21%	36%	41%
Total	100%	100%	100%	100%	100%	100%	100%	100%
N=	75	75	75	75	75	75	75	22
Macmillan GPs								
Never	0%	0%	0%	0%	14%	4%	13%	0%
Sometimes	0%	17%	0%	30%	9%	17%	26%	11%
Frequently	13%	26%	17%	30%	5%	30%	22%	11%
Very frequently	26%	35%	26%	17%	23%	22%	4%	0%
Always	61%	22%	57%	22%	50%	26%	35%	78%
Total	100%	100%	100%	100%	100%	100%	100%	100%
N=	23	23	23	23	22	23	23	9
All								
Never	0%	0.5%	0%	0%	8.5%	2.5%	17%	9%
Sometimes	1.5%	20%	3.5%	31.5%	15%	25.5%	27.5%	10%
Frequently	10%	27.5%	17%	30.5%	15%	25.5%	15%	12.5%
Very frequently	27.5%	31.5%	25%	20%	22%	22.55%	4.5%	9%
Always	61%	20.5%	54.5%	17.5%	41.5%	23.5%	35.5%	59.5%
Total	100%	100%	100%	100%	100%	100%	100%	100%
N=	98	98	98	98	97	98	98	31

User friendliness

Those who used the templates were asked about the user friendliness. The majority found these fairly or very user friendly.

Figure 2: User friendliness



N = 95

Table 2: How friendly is the template

	GPs	Macmillan GPs	All
Not at all user friendly	0%	4%	1%
Not very user friendly	1%	4%	2%
Not sure	18%	17%	18%
Fairly user friendly	58%	57%	58%
Very user friendly	22%	17%	21%
Grand Total	100%	100%	100%
N=	72	23	95

Prompts

Those who used the templates were also asked about the prompts in the template.

Figure 3: Prompts

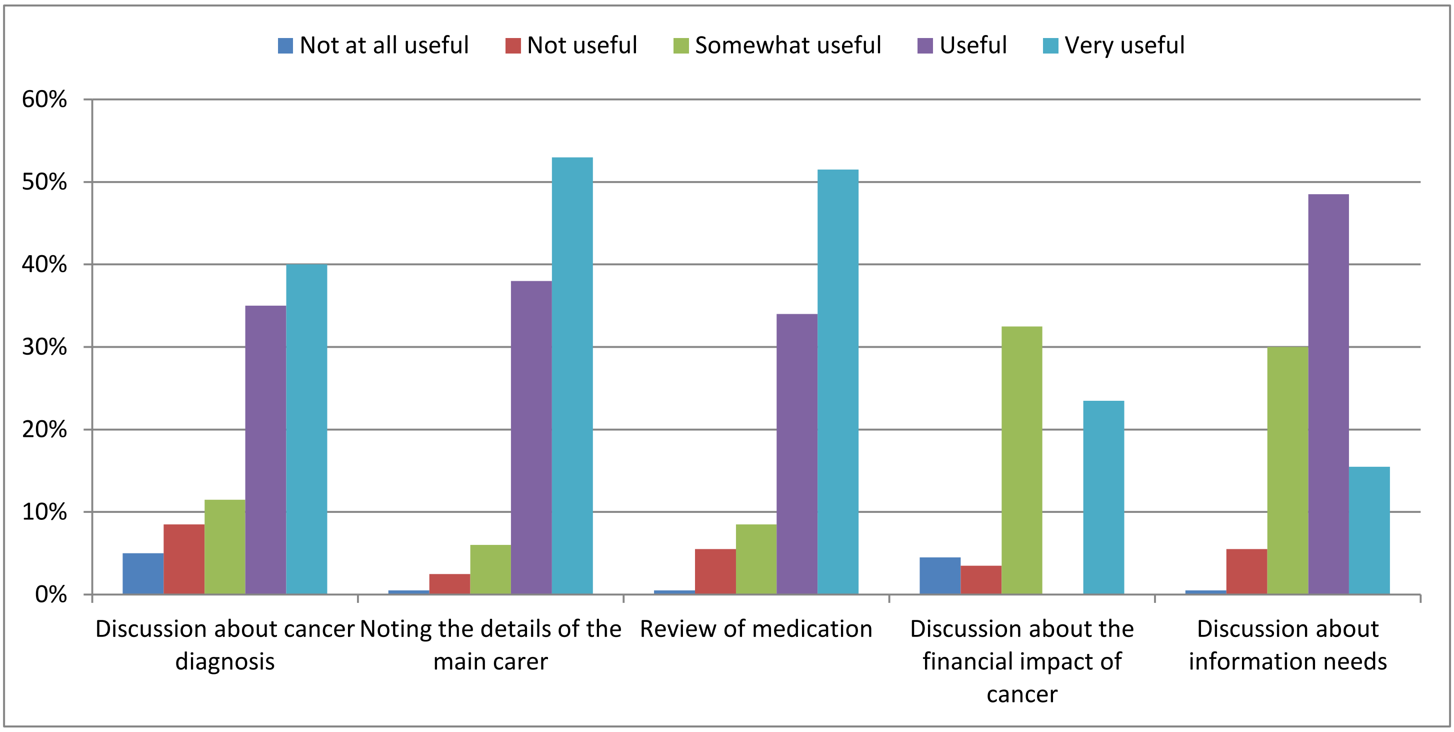


Table 3: Prompts

Response	Discussion about cancer diagnosis	Noting the details of the main carer	Review of medication	Discussion about the financial impact of cancer	Discussion about information needs
GPs					
Not at all useful	5%	1%	1%	5%	1%
Not useful	7%	0%	1%	3%	7%
Somewhat useful	9%	7%	12%	26%	30%
Useful	37%	33%	35%	45%	49%
Very useful	42%	59%	51%	21%	14%
Grand Total	100%	100%	100%	100%	100%
N=	76	76	5	76	74
Macmillan GPs					
Not at all useful	5%	0%	0%	4%	0%
Not useful	10%	5%	10%	4%	4%
Somewhat useful	14%	5%	5%	39%	30%
Useful	33%	43%	33%	26%	48%

Very useful	38%	48%	52%	26%	17%
Grand Total	100%	100%	100%	100%	100%
N=	21	21	21	23	23
All					
Not at all useful	5%	0.5%	0.5%	4.5%	0.5%
Not useful	8.5%	2.5%	5.5%	3.5%	5.5%
Somewhat useful	11.5%	6%	8.5%	32.5%	30%
Useful	35%	38%	34%	35,5%	48.5%
Very useful	40%	53.5	51.5%	23.5%	15.5%
Grand Total	100%	100%	100%	100%	100%
N=	97	7	96	99	97

Usefulness of Macmillan resources

88% found it useful to have easy access to Macmillan information resources during a cancer care review. 20% were aware that sign-posting order codes and a telephone number were provided with the resources.

GPs were asked to score the usefulness of the Macmillan resources. Overall the most used resources seemed to be "***Help with the cost of cancer"***, "***Money worries: how we can help"*** and ***"Hello and how are you?"***

**Figure 4:	Usefulness of Macmillan resources**

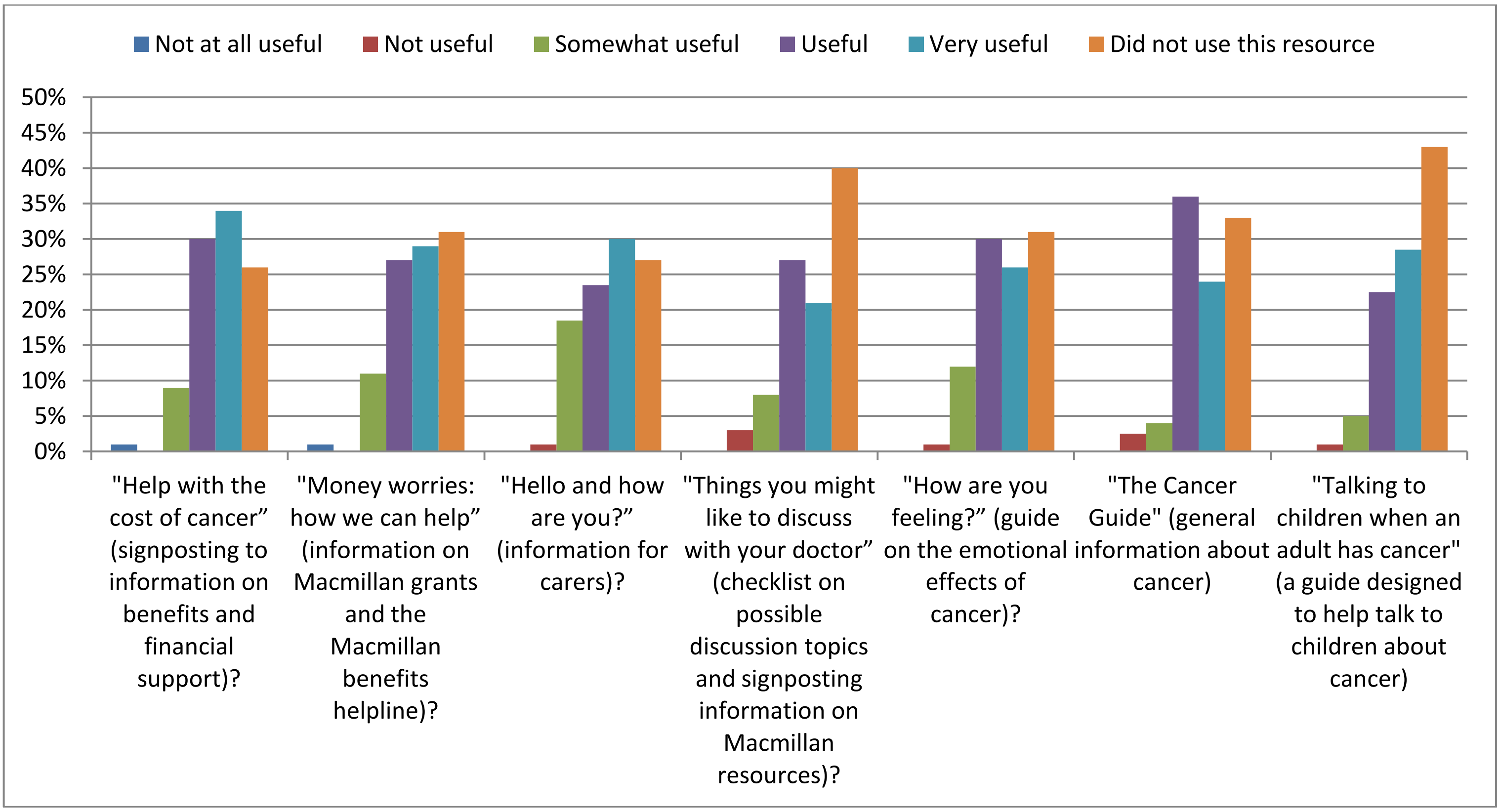


Table 4: Usefulness of Macmillan resources

Response	"Help with the cost of cancer" (signposting to information on benefits and financial support)?	"Money worries: how we can help" (information on Macmillan grants and the Macmillan benefits helpline)?	"Hello and how are you?" (information for carers)?	"Things you might like to discuss with your doctor" (checklist on possible discussion topics and signposting information on Macmillan resources)?	"How are you feeling?" (guide on the emotional effects of cancer)?	"The Cancer Guide" (general information about cancer)	"Talking to children when an adult has cancer" (a guide designed to help talk to children about cancer)
GPs							
Not at all useful	2%	2%	0%	0%	0%	0%	0%
Not useful	0%	0%	2%	2%	0%	0%	2%
Somewhat useful	2%	2%	5%	5%	3%	3%	5%
Useful	29%	34%	26%	29%	28%	25%	19%
Very useful	26%	21%	24%	21%	26%	27%	25%
Did not use this resource	42%	42%	44%	44%	43%	45%	49%
Grand Total	100%	100%	100%	100%	100%	100%	100%
N=	62	62	62	62	61	60	59
Macmillan GPs							
Not at all useful	0%	0%	0%	0%	0%	0%	0%
Not useful	0%	0%	0%	5%	0%	5%	0%
Somewhat useful	16%	21%	32%	11%	21%	5%	5%
Useful	32%	21%	21%	26%	32%	47%	26%
Very useful	42%	37%	37%	21%	26%	21%	32%
Did not use this resource	11%	21%	11%	37%	21%	21%	37%
Grand Total	100%	100%	100%	100%	100%	100%	100%
N=	19	19	19	19	19	19	19
All							
Not at all useful	1%	1%	0%	0%	0%	0%	0%
Not useful	0%	0%	1%	3%	1%	2.5%	1%
Somewhat useful	9%	11%	18.5%	8%	12%	4%	5%
Useful	30%	27%	23.5%	27%	30%	36%	22.5%
Very useful	34%	29%	30%	21%	26%	24%	28.5
Did not use this resource	26%	31%	27%	40%	31%	33%	43%
Grand Total	100%	100%	100%	100%	100%	100%	100%
N=	81	81	81	81	80	79	78

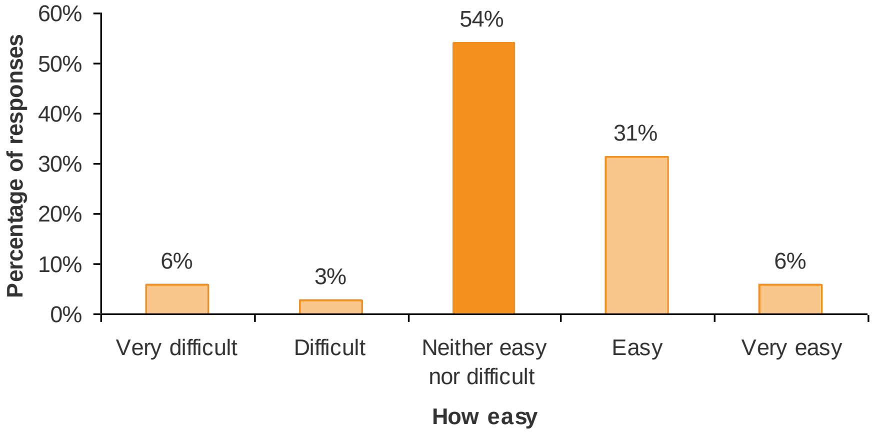
When asked for any comments on the usefulness of the Macmillan resources provided with the templates, it was the non-Macmilan GPs who were more vociferous. Comments included:

- “Really useful especially knowing that there is a booklet to help discuss with children.”
- “Good resource.”
- “Great feature that I had no idea about!”
- “Look extremely useful - would like to obtain copies to use in the practice.”
- “Useful and will form part of my CCR in future.”
- “I have not been aware of the resources but would definitely make use of them if I had access to them.”
- “They are all helpful.”
- “All useful but rather bulky for storage in the surgery.”

The Macmillan GPs who commented were more concerned about practical issues, such as wanting a single A4 sheet that is easy to print out, rather than the many pages which are impractical to print during a consultation. The point was also raised that while leaflets are useful for patients that can read, they had many patients who could not.

They were asked how easy it was to obtain the Macmillan resources and over half commented neither easy or difficult or easy; with 37% finding it easy or very easy.

Figure 5: Ease to obtain resources



N = 35

Table 5: Ease to obtain resources

Response	GPs	Macmillan GPs	All
Very difficult	9%	0%	6%
Difficult	4%	0%	3%
Neither easy nor difficult	52%	58%	54%
Easy	30%	33%	31%
Very easy	4%	8%	6%
N =	12	23	35

When asked how easy it was to obtain the Macmillan resources there were GPs from both sets who agreed that both the Macmillan resources and the templates themselves were easy to use and to access. Macmillan GPs said:

- “Macmillan is efficient in providing leaflets and information, and can print info from Macmillan nurse.”
- “Linked to template Palliative care documents."
- “Easy for a Macmillan GP. A "normal" GP may find this more difficult.”

Other GPs said:

- “I have used them to find more information to inform patients.”
- “Easy to use and able to access Macmillan resources if needed.”
- “Check and it is there!”
- “Usually straightforward.”
- “Simple to use and not too many questions.”
- “Easy to use, can free text other details of consultation.”
- “Easy to record, easy to extract info from them.”
- “Prompts re: important issues to be reviewed that are easily forgotten in dealing with the diagnosis itself.”

Other positive comments included from other GPs included:

- “We have our own template in System1 and have introduced codes to it used in the Macmillan template.”
- “Ensures consistency of review.”
- “Like the look a lot. Love to use it if available on a system or if there was a link to it.”

Discussion and Recommendations

1.1 Potential of CCR

1.1.1 Better care

GPs believe that undertaking a CCR should be normal good practice and should be undertaken systematically by GPs. The process of undertaking a CCR can contribute positively to the doctor-patient relationship, especially if the CCR is perceived by the patient as good quality holistic care rather than a required exercise.

Most happened within six to eight weeks post diagnosis and although an opportunistic review seemed to work well for some patients and GPs, it was felt that a more planned approach possibly involving carers might work better.

There is a clear connection between the areas flagged on the template to be discussed in the review and supporting the cancer survivorship agenda. The review can be used as an opportunity to identify information and other needs and also to support self management.

The survey showed that patients generally found CCRs to be very useful for a wide range of reasons. Many patients said that during their CCR their GP had not covered all the areas for discussion covered in the template. However, a very high proportion of patients said that they found it useful to discuss the areas they had covered with low numbers considering that the areas not included may have been useful to discuss. This may indicate that GPs are making effective decisions about which areas to cover in their CCR and are responsive to the needs of their patients. It is however possible that a patient or a GP may not realise how useful it could have been to discuss topics that were not covered. It is important that GPs are encouraged to explore with the patient the option of discussing all areas covered by the CCR template. The patient can then make choices about the areas to be covered.

1.1.2 Timing of CCR

There appears to be some variation in the timing of the CCR in relation to the cancer diagnosis, with some GPs reviewing very soon and others around the six month mark. On average most reviews were done 6-8 weeks after diagnosis. Some GPs undertook reviews in an opportunistic way when the patient came in about another matter whilst others scheduled an appointment for the review is a systematic and structured way. Scheduling a specific appointment for a review may not always be realistic but has a number of advantages. It sends a signal to the patient that the GP has a role to play in the patient’s cancer journey and will give them time and space to discuss their diagnosis, treatment and ongoing needs. It also enables the patient to consider whether they would like a carer or family member to be with them during this discussion. Slotting the review into an existing appointment means that potentially either the CCR or the patients agenda is margalised, neither of which is good.

The CCR has a role in supporting secondary prevention by advising on a healthy lifestyle and physical activity.

1.1.3 Information flows between primary and secondary care

Ensuring joined up services with other areas of the health service is both fundamental and central to supporting the Quality, Innovation, Productivity and Prevention agenda (QIPP). The CCR also complements other developments such as the Treatment Summary which is designed to pass information on an individual patient from the hospital to the GP, to create a more seamless level of care for patients with cancer.

Lack of timely and accurate information provided by secondary care to primary care can be a source of irritation on the part of the patient and frustration for the GPs. Having a document that provides a more complete picture of a patient's diagnosis, current and planned treatment and expected side effects and complications, as well as who to contact if problems occur, is extremely helpful for a GP. This information can be explored further with a patient and provide enrichment to the CCR. Similarly, depending on the circumstances and timing of the review, there may be benefits to secondary care providers to be provided with information gathered by the GP during this review. Secondary care providers may be unaware of the review and this presents an opportunity to build on work to enhance communication, continuity and coordination across the sectors.

1.1.4 Links with pathways

The CCR provides an important basis for the continual care or overview of a patient both in the treatment and the survivorship phase of their cancer journey. Although the patient may not necessarily recognise the process they have been through as "having a CCR" they do feel supported by the process (which they may see as normal holistic care) and their relationship with their GP may be strengthened. Even for those patients,within the study, who didn't feel the need to see their GP, the knowledge that they had this access if they needed it was important. No-one within this study expressed the opinion that primary care was inadequate or irrelevant.

Some patients going through the CCR will have other co- morbidities and it will be important that the professional undertaking the review is aware of any co morbidity so that the patients needs can be considered comprehensively and holistically.

1.1.5 Comparisons with reviews for other long term conditions

Purely due to its seemingly non routine nature and the emotive components of the diagnosis the CCR is much more likely to be undertaken by a GP than other reviews of long term conditions Rather than an annual review, as with other long term conditions, the CCR needs to be intrinsically more flexible. This is not a case of “one size fits all” since the circumstances of individual patients will vary and for some the discussion may be around palliative care rather than cancer treatments.This may also be a review which is repeated more frequently to capture and support the changing nature of the disease and the patient’s experiences and needs.

The discussion within the CCR was described by some as having less of a medical emphasis and more of a focus on social, emotional, practical and in some cases spiritual matters than reviews for other long term conditions. Patients are often perceived as being more psychologically fragile at this stage than patients with other long term conditions. As a consequence the CCR is perceived to require an adept approach to medical, social, spiritual and emotional issues which often GPs feel best placed to provide.

1.1.6 Carers

Carers play a vital role in supporting people with cancer and it is important that their needs for information, advice and support are addressed.

The template contains a prompt to record the carers details, which are an important element of the review, but this is not being done systematically by all GPs. Generally GPs would welcome the input and involvement of the carer but they are not attending with patients for the CCR. This may be because patients are unaware that they are going to have a CCR. As a consequence the patient and carer may perceive that this is a “medical” appointment focussed on the “patient” rather than the wider context of the disease. Alternatively it may be that carers are more likely to attend hospital appointments both logistically to provide transport and also because these appointments are valued more as they are with the “specialist” and are seen as more impactful.

The Carers Strategy identified as a priority the need to support those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages. It would seem that encouraging carers to attend the CCR would provide an opportunity to move towards this strategic priority.

1.1.7 Templates

Macmillan Cancer Support has recommended to the QOF review panel and more recently to NICE, that these structured templates are adopted as a solution to better defining and recording what should reasonably be covered in a cancer care review. This study provides evidence that GPs would find the prompts in the cancer care review template useful, and also that their use would support better recording of information to support the future commissioning of cancer services. Furthermore, the use of structured templates could provide a trigger or platform to discuss other areas of care that are advocated in the Improving Outcomes Strategy for Cancer (2011) to support secondary prevention of cancer (e.g. physical activity).

On the whole, having a structured approach for conversations like the CCR, which are often intrinsically patient-led and unstructured, was seen as a good thing by GPs and having a template which supports such a structured CCR is well received. GPs are able to see the benefits of having a more structured approach which can be used as an aide-memoir or prompt in their consultation. Use of the template may provide them with the tools to better explore the wider context of the patient’s disease.

The risk of templates being used as tick box exercise in order to gain points rather than improve patient care, was mentioned by several GPs. This is indeed an established danger when using templates, especially for QOF criteria. The difficulty is taking an intuitive multi-faceted, often patient led, interaction of the type which primary care excels, and trying to not constrain it whilst gaining the relevant information needed to not only provide personalised support and care planning but also link to a wider strategic agenda. For example in this study one important finding was that GPs were not systematically recording whether or not the patient has received radiotherapy or chemotherapy. For the individual patient this may make it more difficult to later link their late effects with their initial treatment but it also has a wider strategic implication. The Improving Outcomes Strategy advocates better recording of late effects and incentivising commissioning of services to support people with cancer who are suffering from late effects of treatment. It is therefore important that details of the treatment given are recorded and can be audited to support the commissioning of new services.

Some GPs suggested ways of making the templates more effective. These ranged from linkage into clinical systems to allow better cross pollination of information to the use of standard editable text which could be inserted via macros. One GP even suggested that the template should come already filled in with default answers!

Many GPs only knew about the template because they were involved in the study. It is therefore likely that most GPs are unaware of the template. The Macmillan template is only currently available on Vision and EMIS whilst SystemOne, which is growing in prominence, does not have a Macmillan template.

1.1.8 Macmillan resources

Unsurprisingly the study has shown that Macmillan GPs are more likely to use Macmillan information resources than other GPs and were more aware of how to access them. A high proportion of all GPs however said that they found it useful to access these resources. Some GPs identified the need for the resources to be concise, easier to print and linked to the templates.

1.2 Recommendations

1. The Quality and Outcomes Framework indicators for cancer should be clearly defined and measurable in the same way as other conditions. The current lack of rigour for cancer in the framework is perceived to be a barrier to reducing variation in care.
2. CCRs should be offered in a format that suits the patient's preferences whether that be face-to-face or by telephone; ideally as a planned appointment with enough time for discussion of the elements of the CCR. Patients should be made aware of the importance of the CCR as an integral part of their cancer journey as well as the support structures which exist in primary care. Patients should also be offered the opportunity to bring family members and /or carers if wished, thus helping to increase their involvement in decisions about treatment and care.
3. CCRs should be carried out when any significant transition occurs in the patient's cancer journey, rather than only once after diagnosis. The perceptions that patients either do not want a CCR, would be reluctant to discuss things, or that they are too busy with hospital appointments, should be challenged.
4. CCRs should be holistic and broad based and not just concentrated on the physical aspects of the disease. They should take into account not only co-morbidities but also the social, psychological and practical aspects of the cancer and its treatment as well as issues related to living with cancer and potential late consequences of cancer and its treatment. Patients should be provided with the opportunity to discuss personally appropriate areas of the CCR especially the less clinical aspects.
5. Awareness should be raised that the CCR provides an excellent opportunity for secondary prevention by the promotion of better diet and more exercise.
6. Awareness of the data being elicited by the CCR and its benefits should be promoted amongst secondary care clinicians, including the potential for improved patient experience and improved communication between professionals by continuous sharing of information gathered by GPs through regular and ongoing CCRs.
7. The potential role of other members of the primary healthcare team, with appropriate training and support, should be considered given their experience of disease reviews in other chronic diseases. It is important however that CCRs do not become too closely aligned with annual reviews for other long term conditions as they can be quite different in nature both in terms of their content and the frequency of the review.

8. It may be useful to include additional areas for discussion onto the template in future, e.g. to cover anxiety and psychological wellbeing.
9. GP awareness of both the template and the associated Macmillan resources needs to be raised. These resources need to be built on and improved in line with the feedback within this study, to make them easier to use in primary care.
10. IT providers should be encouraged to further develop the existing templates and promote wider use amonst those not currently using them. IT providers should also consider adapting the existing templates so that they are more flexible to use locally, and the feasibility of developing a CCR for other clinical systems should be explored.