EVALUATION OF MACMILLAN'S CANCER CARE REVIEW TEMPLATE

Contents

Executive summary of key findings

- Overall, GPs were very positive about the Macmillan cancer care review (CCR) templates, with the most useful prompts being 'reviewing medication' and 'noting details of main carers'.

- 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 their GP made the effort to contact them.

- Interestingly, several patients who were interviewed did not realise at the time of the CCR that they were being reviewed. GPs described this as being appropriate, as the review was 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.

- Most GPs (88%) found it useful to have easy access to Macmillan resources, although only 20% were aware that signposting information was included as part of the CCR.

- Survey findings confirm that there is variation in what is covered in a review, with only 55% of GPs always discussing the diagnosis and 61% 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% of GPs were always signposting to sources of information on finances and benefits.

- Interestingly, several patients who did not have specific areas of care discussed said it would have been helpful to do so.

- 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.

- 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

- 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.

- Patients should be made aware that the cancer care review is an integral part of their cancer pathway. Appointments should be offered in a format that suits their preferences, whether that is face-to-face or over the phone, and with the option of including family members or carers.

- 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, eg supporting secondary prevention through advice about healthy lifestyle and physical activity.

- There is a need for education and support to promote the use of the Macmillan CCR 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 in the CCR.

- 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.

- 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 300,000 people in the UK are diagnosed with cancer every year and sadly 157,000 people in the UK will die from the illness over the same period.

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.

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 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 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. It also builds on the earlier work of the Macmillan primary care community to improve the existing Quality and Outcomes Framework (QOF) cancer care reviews.

More recently, NHS reforms in England will radically overhaul the way cancer services are commissioned, with GPs having a key role in commissioning whole pathways of care that will improve cancer outcomes. This means primary care will have an increasingly important role to play in:

- the 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
- ensuring that cancer survivors have a personally tailored care plan.

Therefore, tools such as the cancer care review template become even more important in placing those who are living with or beyond cancer at the heart of any decisions and making sure they feel supported, informed and empowered.

Macmillan has identified nine key outcomes that we want all four million people living with cancer to be able to say by 2030:

- 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.

Background

The Quality and Outcomes Framework (QOF), a voluntary rewards and incentives programme 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 their 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, leading to an assumption there is a wide variability in practice. Furthermore, there is no consistent coding of what is covered in a cancer care review. This means 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 with 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 the MSc project, which produced similar findings to 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 cancer care review templates. This included:

- assessing the extent to which the Macmillan CCR template is being used by a sample of GPs

- obtaining views on the format of the available CCR templates

- gaining an idea of the usability of the CCR template, and to obtain views and perceptions from GPs about the CCR process.

Methods

Survey of GP practices and qualitative interviews

Quantitative and qualitative surveys were used and made available as a hard copy or 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 participate in 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 as a hard copy or online.

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, which means we are unable to say they represented the norm of the GP population.

All but one of the patients involved in the study is white and speaks 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 there may have been bias, it was impossible to carry out the survey in any other way, as, quite correctly, we did not have access to patient details.

The numbers who completed the surveys and also participated in the interviews were relatively disappointing, although concerted effort was made to contact and encourage survey respondents to give an interview. However, taking into consideration the project was running when major reforms were announced for the NHS, which will have a huge impact on GPs, the low numbers were not totally 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 the Macmillan 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 as part of the review.

- 78% of GPs conducted CCRs face-to-face and 16% over the phone. Macmillan GPs tended to do more face-to-face CCRs (85%), and correspondingly fewer telephone CCRs (9%).

- The most common things discussed in the CCR were:
  - o medications (61% 'always' discuss)
  - o diagnosis (55% 'always' discuss)
  - o 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 Macmillan and non-Macmillan GPs appeared to be patients who did not wish or feel able to discuss their condition. This was because it was a too emotive subject; they were still being treated at hospital; or they were feeling overwhelmed by related appointments.

- Most GPs felt that patients were not aware when they were having a CCR, which is also reflected in interviews with patients. The GPs felt that this was appropriate, as CCRs are 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. Therefore, patients tend to only involve their carers/families in CCRs if it's normal for them to attend general appointments. 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 of the interviewees knew something about Macmillan resources, although they showed variable understanding in how to access and use 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. 38% were reviewed when visiting their GP 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 this 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 their support needs and those of their carer/s had been 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'd 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 interviewee 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

Legend: Never, Sometimes, Very Frequently, Frequently, Always
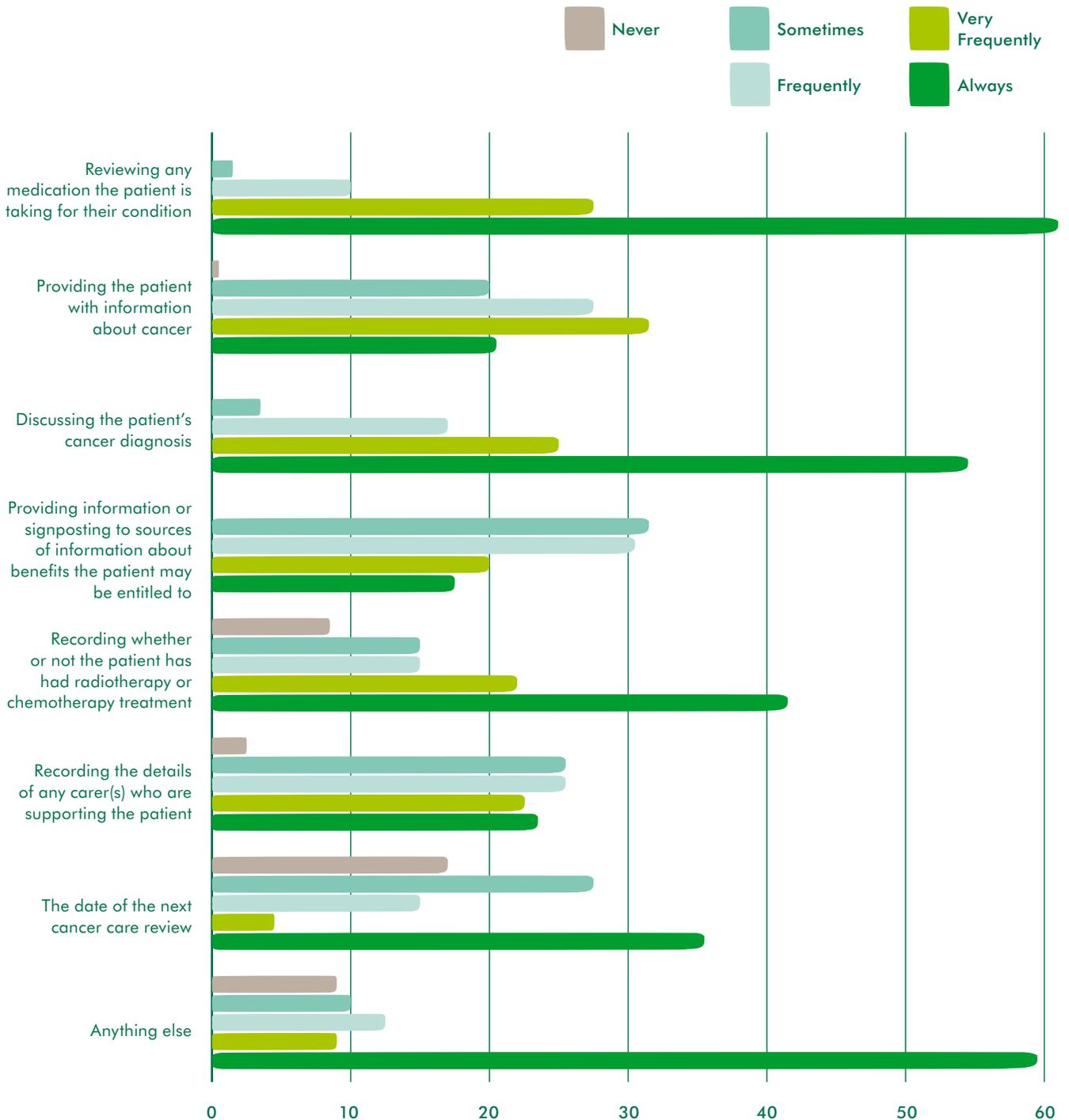
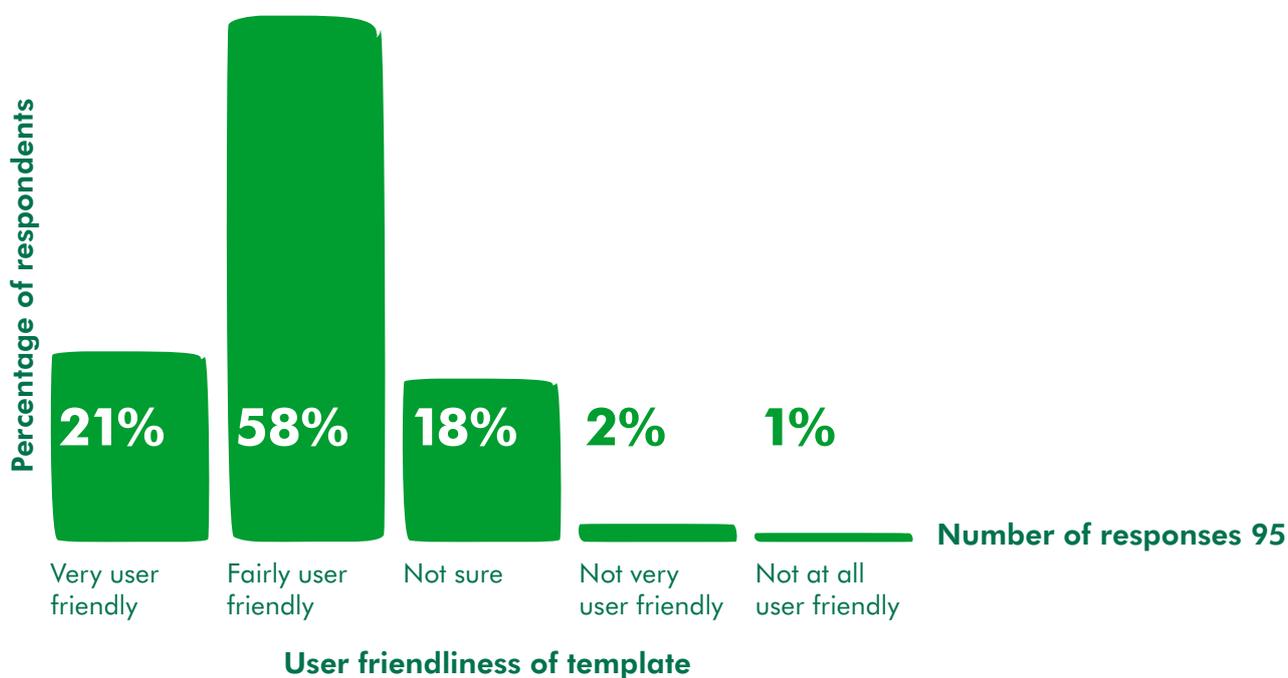## Table 1: Aspects covered in cancer care reviews

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

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
GPs								
Always	61%	19%	52%	13%	33%	21%	36%	41%
Very frequently	29%	28%	24%	23%	21%	23%	5%	18%
Frequently	7%	29%	17%	31%	25%	21%	8%	14%
Sometimes	3%	23%	7%	33%	17%	33%	29%	9%
Never	0%	1%	0%	0%	3%	1%	21%	18%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**
Number of responses	**75**	**75**	**75**	**75**	**75**	**75**	**75**	**22**
Macmillan GPs								
Always	61%	22%	57%	22%	50%	26%	35%	78%
Very frequently	26%	35%	26%	17%	23%	22%	4%	0%
Frequently	13%	26%	17%	30%	5%	30%	22%	11%
Sometimes	0%	17%	0%	30%	9%	17%	26%	11%
Never	0%	0%	0%	0%	14%	4%	13%	0%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**
Number of responses	**23**	**23**	**23**	**23**	**22**	**23**	**23**	**9**
All								
Always	61%	20.5%	54.5%	17.5%	41.5%	23.5%	35.5%	59.5%
Very frequently	27.5%	31.5%	25%	20%	22%	22.55%	4.5%	9%
Frequently	10%	27.5%	17%	30.5%	15%	25.5%	15%	12.5%
Sometimes	1.5%	20%	3.5%	31.5%	15%	25.5%	27.5%	10%
Never	0%	0.5%	0%	0%	8.5%	2.5%	17%	9%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**
Number of responses	**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

Percentage of respondents

| 21% | 58% | 18% | 2% | 1% |

Number of responses 95

| Very user friendly | Fairly user friendly | Not sure | Not very user friendly | Not at all user friendly |

User friendliness of template

Table 2: User friendliness

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

Prompts

Those who used the templates were also asked about the prompts in the template.
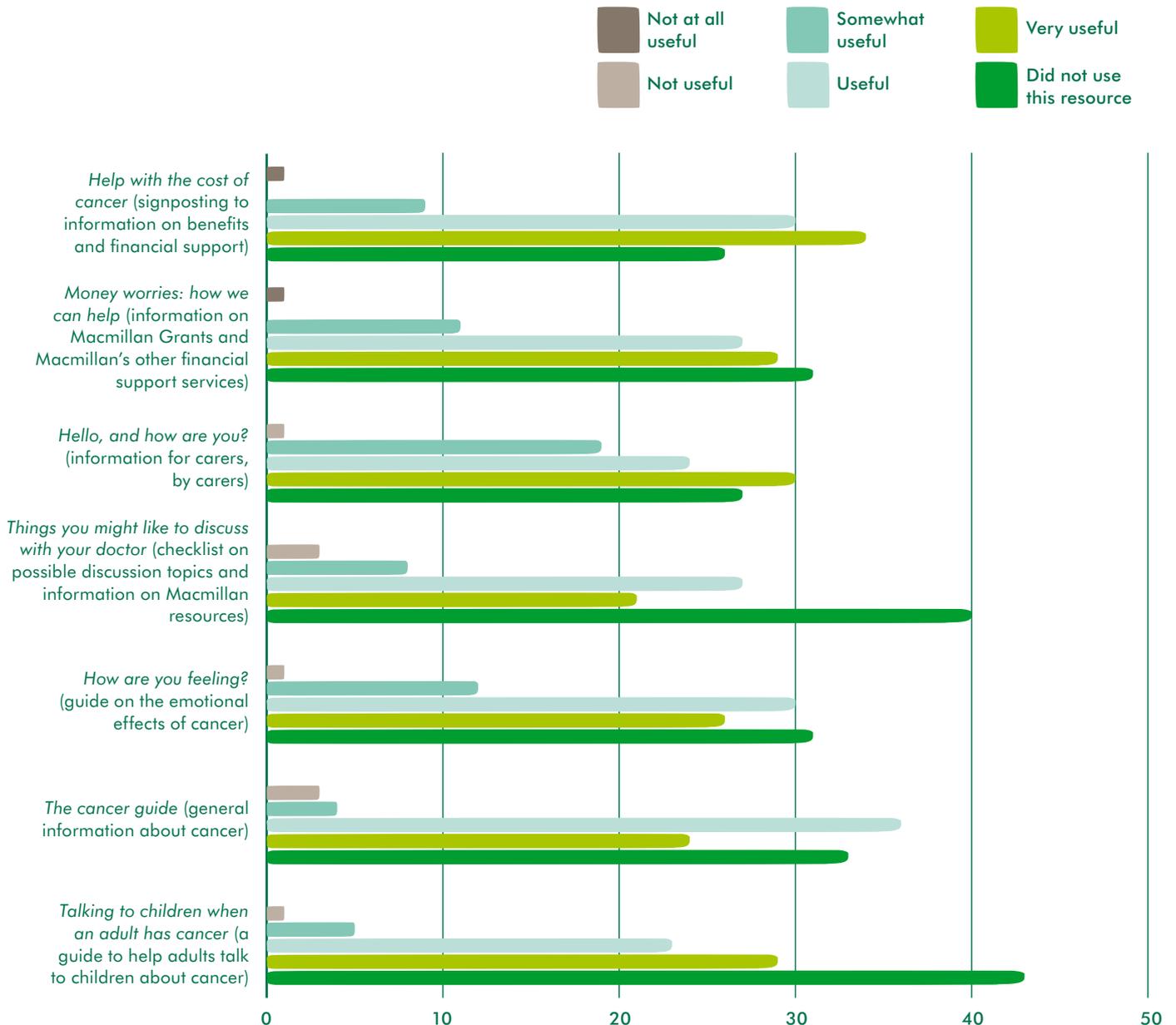
Figure 3: Prompts
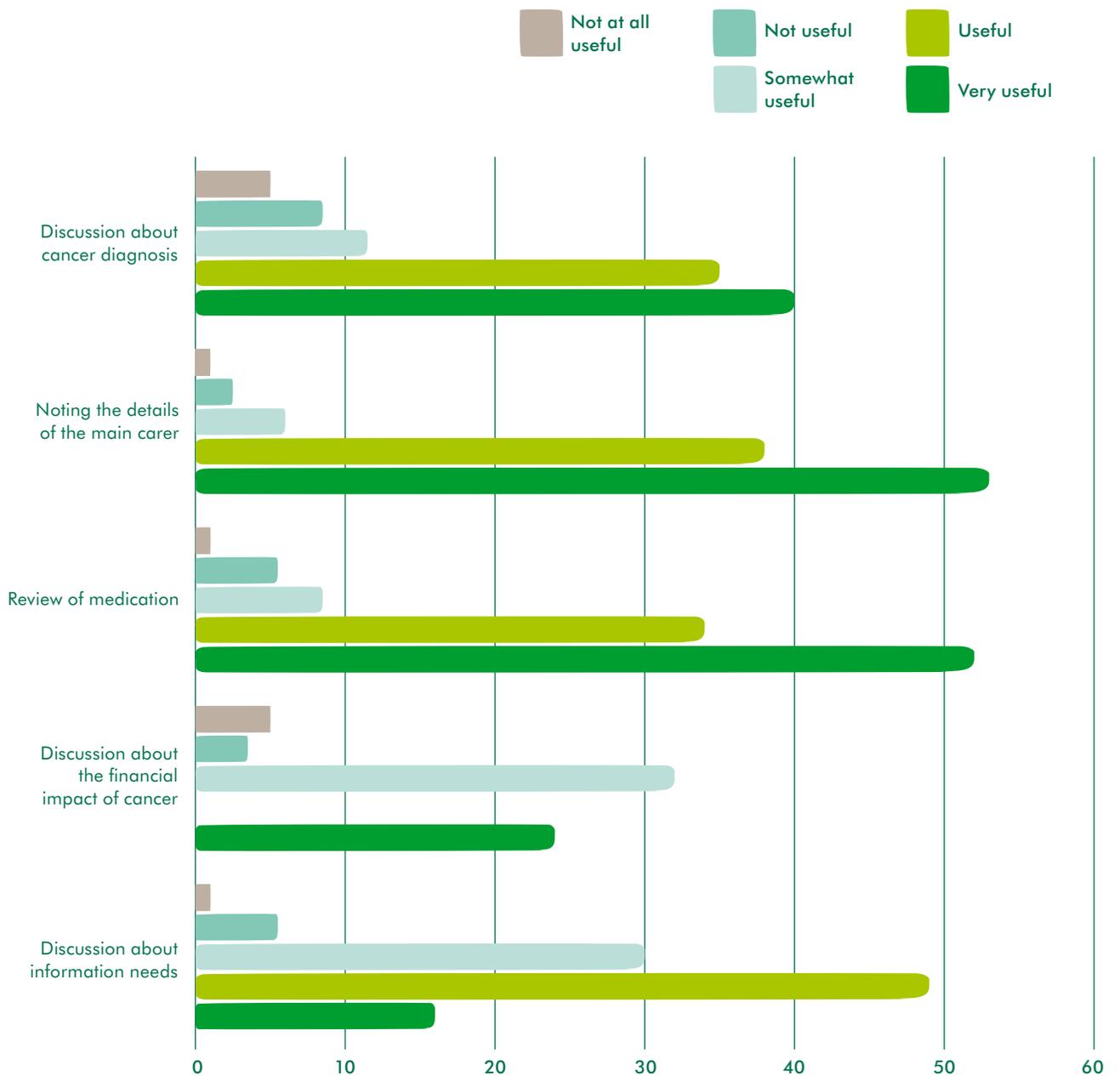
Table 3: Prompts

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					
Very useful	42%	59%	51%	21%	14%
Useful	37%	33%	35%	45%	49%
Somewhat useful	9%	7%	12%	26%	30%
Not useful	7%	0%	1%	3%	7%
Not at all useful	5%	1%	1%	5%	1%
Total	**100%**	**100%**	**100%**	**100%**	**100%**
Number of responses	**76**	**76**	**5**	**76**	**74**
Macmillan GPs					
Very useful	38%	48%	52%	26%	17%
Useful	33%	43%	33%	26%	48%
Somewhat useful	14%	5%	5%	39%	30%
Not useful	10%	5%	10%	4%	4%
Not at all useful	5%	0%	0%	4%	0%
Total	**100%**	**100%**	**100%**	**100%**	**100%**
Number of responses	**21**	**21**	**21**	**23**	**23**
All					
Very useful	40%	53.5	51.5%	23.5%	15.5%
Useful	35%	38%	34%	35,5%	48.5%
Somewhat useful	11.5%	6%	8.5%	32.5%	30%
Not useful	8.5%	2.5%	5.5%	3.5%	5.5%
Not at all useful	5%	0.5%	0.5%	4.5%	0.5%
Total	**100%**	**100%**	**100%**	**100%**	**100%**
Number of responses	**97**	**7**	**96**	**99**	**97**

Usefulness of Macmillan resources

88% of GPs found it useful to have easy access to Macmillan information resources during a cancer care review. 20% of GPs were aware that order codes for Macmillan information resources, and the support line number are provided with all Macmillan resources.

GPs were also asked to score the usefulness of the Macmillan resources. The resources they seemed to use the most being *Help with the cost of cancer*, *Money worries: how we can help* and *Hello, and how are you?*

Figure 4: Usefulness of Macmillan resources

Legend:
- Not at all useful
- Not useful
- Somewhat useful
- Useful
- Very useful
- Did not use this resource

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 Macmillan's other financial support services)	Hello, and how are you? (information for carers, by carers)	Things you might like to discuss with your doctor (checklist on possible discussion topics and 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 to help adults talk to children about cancer)
GPs							
Very useful	26%	21%	24%	21%	26%	27%	25%
Useful	29%	34%	26%	29%	28%	25%	19%
Somewhat useful	2%	2%	5%	5%	3%	3%	5%
Not useful	0%	0%	2%	2%	0%	0%	2%
Not at all useful	2%	2%	0%	0%	0%	0%	0%
Did not use this resource	42%	42%	44%	44%	43%	45%	49%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**
Number of responses	**62**	**62**	**62**	**62**	**61**	**60**	**59**
Macmillan GPs							
Very useful	42%	37%	37%	21%	26%	21%	32%
Useful	32%	21%	21%	26%	32%	47%	26%
Somewhat useful	16%	21%	32%	11%	21%	5%	5%
Not useful	0%	0%	0%	5%	0%	5%	0%
Not at all useful	0%	0%	0%	0%	0%	0%	0%
Did not use this resource	11%	21%	11%	37%	21%	21%	37%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**
Number of responses	**19**	**19**	**19**	**19**	**19**	**19**	**19**
All							
Very useful	34%	29%	30%	21%	26%	24%	28.5
Useful	30%	27%	23.5%	27%	30%	36%	22.5%
Somewhat useful	9%	11%	18.5%	8%	12%	4%	5%
Not useful	0%	0%	1%	3%	1%	2.5%	1%
Not at all useful	1%	1%	0%	0%	0%	0%	0%
Did not use this resource	26%	31%	27%	40%	31%	33%	43%
Total	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**	**100%**
Number of responses	**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-Macmillan GPs who were particularly positive.

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 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.

When asked how easy it was to obtain the Macmillan resources, over half of the GPs commented 'neither easy or difficult', while 37% found it 'easy' or 'very easy'.

Table 5: Ease of obtaining resources

Response	GPs	Macmillan GPs	All
Very easy	4%	8%	6%
Easy	30%	33%	31%
Neither easy or difficult	52%	58%	54%
Difficult	4%	0%	3%
Very difficult	9%	0%	6%
Number of responses	**12**	**23**	**35**

Figure 5: Ease of obtaining resources

Percentage of respondents

6%   31%   54%   3%   6%

Very easy | Easy | Neither easy or difficult | Difficult | Very difficult

Number of responses 35

Ease of obtaining resources
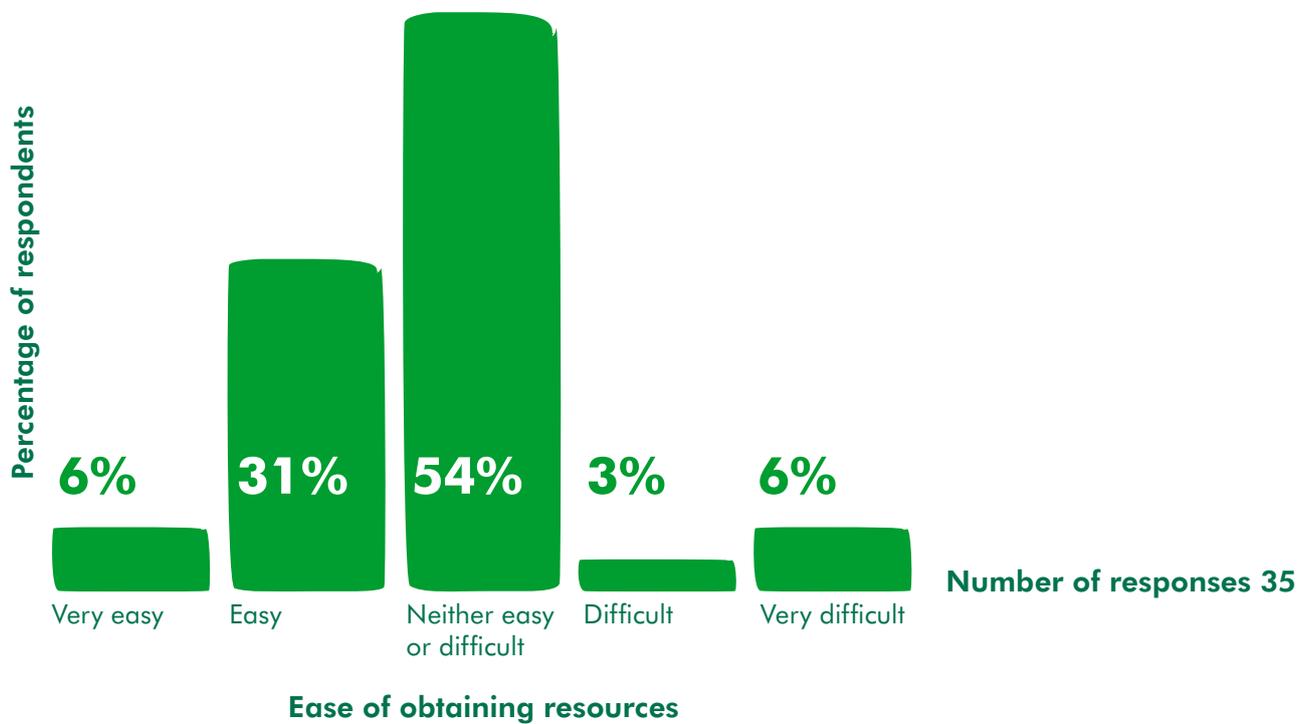
When asked how easy it was to obtain Macmillan resources, Macmillan and non-Macmillan GPs agreed Macmillan resources and the CCR templates were easy to use and to access.

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.'

Non-Macmillan 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 received from 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 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 CCRs happened within six to eight weeks of 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 discussion areas flagged on the CCR template 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. Although 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 they found the points covered useful, while only a low number said they thought the areas not covered 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 the cancer care review

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 six to eight 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 in 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 ember to be with them during this discussion.

Slotting the review into an existing appointment means potentially that the CCR or the patient's agenda is marginalised, neither of which is beneficial.

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 fundamental and central to supporting the Quality, Innovation, Productivity and Prevention agenda (QIPP).

The CCR supports QIPP and complements other developments such as the Treatment Summary. This is designed to make sure information about an individual patient is passed from the hospital to the GP, creating 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, it may be beneficial to provide secondary care providers with information gathered by the GP during this review.

Secondary care providers may be unaware of the review, which 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, 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). Additionally, 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 this access is available 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 their CCR is aware of any co-morbidity, so the patient's 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 nature of a cancer 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.

The CCR 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.

Compared to reviews for other long-term conditions, 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.

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. Therefore, it is important that their needs for information, advice and support are addressed.

The template contains a prompt to record the details of carers, which is an important element of the review. However, this is not being done systematically by all GPs.

Generally, GPs would welcome the input and involvement of the carer, but they usually do not attend the review with a patient. 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 focused on the 'patient', rather than the wider context of the disease.

Alternatively, it may be that carers are more likely to attend hospital appointments. This is because logistically they need to provide transport. Also, these appointments may be valued more, as they are with a 'specialist' and seen as having more impact on the future of the patient.

The Carers Strategy identified as priorities: the need to help carers identify themselves as carers at an early stage; more recognition to be given to the valuable contribution carers make; the need to involve carers from the outset in the designing of local care provision and planning of individual care packages. It would seem that encouraging carers to attend the CCR would provide an opportunity to move towards these strategic aims.

1.1.7 Templates

Macmillan Cancer Support has recommended to the Quality and Outcomes Framework (QOF) review panel, and more recently NICE, that these structured templates are adopted as a solution to better defining what should reasonably be covered and recorded in a cancer care review.

This study provides evidence that GPs would find the prompts in the Macmillan 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 to support secondary prevention of cancer in the Improving Outcomes Strategy for Cancer (2011), eg 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. GPs are able to see the benefits of having a more structured approach which can be used as an aide-memoire 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 a 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.

Another difficulty is trying to not constrain the CCR (which should be an intuitive multi-faceted, often patient-led, interaction) whilst gaining the information needed to plan personalised support and care, and support any wider strategic agenda.

For example, in this study one important finding was that GPs were not systematically recording whether or not a patient had received radiotherapy or chemotherapy. For the individual patient, this may make it more difficult to 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 of treatment, as it can support the commissioning of services to support people with cancer who are affected by them. It is therefore important that details of the treatment given are recorded and can be audited.

Some GPs suggested ways of making the templates more effective. These ranged from linking them to 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. However, a high proportion of all GPs said 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

- 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.

- CCRs should be offered in a format that suits the patient's preferences, whether that involves receiving one face-to-face or over the phone. Ideally, they should be 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 or carers, if they wish to. This would help to increase their involvement in decisions about treatment and care.

- 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 do not want a CCR, are reluctant to discuss their illness or support they need, or are too busy with hospital appointments should be challenged.

- CCRs should be holistic and broad based and not concentrate solely on the physical aspects of the disease. As well taking into account co-morbidities, they should also focus on the social, psychological and practical aspects of the cancer and its treatment; issues relating 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.

- Awareness should be raised that the CCR provides an excellent opportunity for secondary prevention through the promotion of better diet and more exercise.

- Awareness of the data being elicited by the CCR and its benefits should be promoted amongst secondary care clinicians. This should include the potential for improved patient experience and communication between professionals by continuous sharing of information gathered by GPs through regular and ongoing CCRs.

- The potential role of other members of the primary healthcare team, with appropriate training and support, should be considered, given their experience of reviews for 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, in terms of their content and the frequency of the review.

- In the future, it may be useful to include additional areas for discussion onto the template, eg to cover anxiety and psychological wellbeing.

- GP awareness of the template and associated Macmillan resources needs to be raised. These resources need to be built on and improved in-line with the feedback from the study, and made easier to use in primary care.

- IT providers should be encouraged to further develop the existing templates and promote wider use amongst those not currently using them. They should also consider adapting the existing templates so they are more flexible to use locally, and explore the feasibility of developing a CCR for other clinical systems.

Acknowledgements

Cancer is the toughest fight most of us will ever face. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The fundraisers who make it all possible.

Together, we are Macmillan Cancer Support.

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CANCER SUPPORT

Our cancer support specialists, benefits advisers and cancer nurses are available to answer any questions you or your patients might have through our free Macmillan Support Line on

0808 808 00 00

Monday to Friday, 9am to 8pm

We couldn't provide all the support we do without you. If you want to get involved, in whatever way you can, call us today on

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