

Name of document: Cancer Care Review Survey
Who requested patient reader feedback?
Robina Ahmed, MacMillan Project Manager, Leeds West CCG

Patient reader group - Feedback Report

Brief

A request was made for patients to feedback on a document that patients would receive from clinicians after attending a cancer care review appointment at a local GP surgery. Leeds West CCG is working on a pilot project with MacMillan to deliver cancer care reviews via a MacMillan primary care nurse. Currently the pilot is taking part in four surgeries. The patient reader group was contacted asking for their input.

Patients were sent the draft survey and covering email which outlined the purpose of the sheets and what we were looking for. They were asked to comment on the survey from a patient perspective, looking at formatting, how easy it was to read, whether anything was missing and how suitable it is for other people in the community. The email was sent to NHS Leeds West CCG Patient Network members who are signed up to participate in the reader group work. We received **seven** responses.

Responses

Feedback:

- As a cancer patient, I would have really appreciated this ten years ago.
- Overall, I think it asks the right questions.
- Some of the language is a bit clumsy, particularly the introduction. "Official-ese" is very difficult to avoid – words such as "access". Suggested rewrite of the intro:

"Thank you for attending your recent cancer care review. These reviews are part of a pilot project for our new cancer care strategy. The aim is to ensure that patients have a review of their situation at their GP surgery within six months of diagnosis or treatment. The reviews will be carried out by primary care nurses from MacMillan cancer support.

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We are keen to know if you found your review helpful and whether you have any suggestions as to how we could improve the experience for others. We'd appreciate it if you would take a few minutes to answer the following questions. This will allow us to decide how successful the pilot has been and this will help us plan the best possible service for cancer patients.

All responses are anonymous and don't ask for any personal information. Please return the survey in the enclosed stamped addressed envelope.

If you have any queries...."

- Corrections to questions as follows:

	<p>Q1. Did you receive any information at the cancer care review you had not previously been given?</p> <p>Q2. Have you contacted any additional services as a result of the cancer care review?</p> <p>Q4. If yes, have you contacted any services as a result of the cancer care reviews?</p> <p>Q9. For “please explain why”, start a new sentence.</p>
2	<p><u>Feedback:</u></p> <ul style="list-style-type: none"> • Be sure to put in the logo. • Specify the surgery by name. • “All responses are anonymous and we will not ask for any personal information specifically.” • In the multiple choice questions, it needs to be clearly indicated whether it is single choice or multiple choice, specify as such.
3	<p><u>Feedback:</u></p> <ul style="list-style-type: none"> • The word “cancer” is used too much. Remove some of the “cancer care” in the “cancer care review” phrases. Or use “appointment”. • MacMillan Nurses are so used to using the word cancer they depersonalise it but if I was posted this questionnaire it would upset me as every question reiterates the condition. • My feelings are:- most families know someone or have family members who are challenged by cancer. This is a 4 page questionnaire (I always think anything longer than 2 pages loses patient’s interest or attention span) which has the word cancer in it 25 times!! • For the patients and their families who are having to deal with this they don’t need to see it in print over and over again in every question. They are already acutely aware that this is a deeply disturbing and distressing condition. The heading states that it is a Cancer Care Review – they should leave it at that – not hammer home the fact that the patient has this condition. If it were me I simply would get upset and not complete the questionnaire. • Following corrections other than remove “cancer”: <p>“We are keen to understand if you found this beneficial...”</p> <p>Q3. “Do you know how to get in touch with someone if you have any concerns regarding your diagnosis?”</p> <p>Q9. “Please explain your reasons why.”</p>
4	<p><u>Feedback:</u></p> <ul style="list-style-type: none"> • Second line of second paragraph, “there” should be “their”. • Third paragraph should “your” instead of “you”.
5	<p><u>Feedback:</u></p> <ul style="list-style-type: none"> • This looks very good to me, I have no alterations.

Feedback:

- If you have any queries please contact Sharon Huntley, Macmillan Primary Care Nurse at your GP surgery. Contact details are above. **Is the contact details just for the GP's surgery or for Sharon Huntley - found this a bit confusing?**
- Did you receive any information at the Cancer Care Review you had not previously had? **Should this read '...? Review you have previously had? Maybe reword the question.**
- Do you know how to get in touch with someone if you had any concerns regarding your cancer? **What will happen if the answer to this questions is 'no' - might it be likely that they still do not know who to contact even after the review? Perhaps provide a sentence to get assistance.**
- If someone did attend the cancer care review, do you need to know who it was?
- Add “Don’t Know” option to sub-question of Q4.
- Q9, add “diagnosis” along with “treatment” as this is what is stated at the top of the survey in the introduction. Please explain should be “Please comment below).
- Q9 should also have options that are stated in the examples.
- Move Q10 to the end of the survey.
- Q12 add ‘s’ to the end of “review”.
- Would it be beneficial to ask a question as to whether the review took place on time or did the patient have to wait and also how long is the review appointment time - presumably beyond the normal GP time of 10 minutes?

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Feedback:

- In my opinion this looks fine.

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Key Points for Consideration

- **Language used (is it easy to understand?):**
 - Avoid more ‘official’ sounding terms; use “contacted” instead of “access”, for example.
 - Introduction may benefit from rewording, see **1, 2, 3**.
 - Confirm that a multiple choice question is a multiple choice question and make it clear (i.e. “select all that apply”).
 - Remove the phrase “cancer care” from the majority of the document. Refer to “appointment”, “review” or diagnosis as needed in the questions.
 - Check spelling, grammar and punctuation in some sentences.
 - Question 1 may need rewording to be clear; for example: *“did you receive any information at the review you have not received before?”*
 - Consider rewriting question 9 to be multiple choice with the option to add additional comments. Change to “please comment below”.
 - Q10 should be at the end.

- Decapitalise “cancer care review”.
- **Is there any information missing?**
 - Be sure to add the logo in for the surgery.
 - Specify the surgery by name when relevant.
 - If someone answers “no” on question 3, should there be some information stated that directs that person to the right place to get assistance.
 - Is the information of who attended needed in question 4?
 - Questions 2 and 4 need a “Don’t know” option.
 - Add an extra question about whether the review took place on time or whether it was delayed?
- **Is it suitable for other people in our community?**
 - It has to be as simple as possible; some of the questions are unclear.
 - Some of the language is clumsy, might be difficult for people to understand.

Report completed by:
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