CANCER AS A LONG TERM CONDITION: PRACTICE NURSE PILOT EVALUATION
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Background

There have been marked changes in outcomes for people diagnosed with cancer, with increasing numbers of people living with and beyond cancer. As a result, cancer is increasingly being conceived as a long-term condition with new and alternative approaches being considered for patient follow-up.

Practice nurses have been identified as key professionals in primary care who could have a vital role in managing cancer as a long-term condition. Practice nurses are already managing routine follow-up for other long-term conditions such as asthma, diabetes, chronic heart disease and chronic obstructive pulmonary disease (COPD). Many of the skills required to do this are transferable and could be applied to the follow-up and long-term management of cancer patients.

In January 2011, Macmillan Cancer Support commissioned an online survey of 251 UK practice nurses to gather information about the type of chronic conditions they are managing, the skills involved and their level of confidence in relation to these. The survey found that while a significant number of practice nurses were involved in managing other chronic conditions, few were involved in managing cancer nor did they feel they had the skills and confidence to do so. However, the majority expressed an interest in doing more with people affected by cancer if they could have the necessary training and support.

Introduction

This pilot course was developed to discover what the learning needs of practice nurses are to extend their role in managing cancer as a long-term condition and how best to meet these needs.

Its overall aim was to enhance the knowledge, skills, attitudes and confidence of participating practice nurses to look after people living with cancer and beyond.

The course comprised two full day and seven half-day workshop sessions, with reflective group work, role-play and taught sessions from the course leader and external presenters. Participants were encouraged to do work in their practices between sessions, applying what had been learned to their everyday work.

Specific objectives of the pilot are:

1. To test the process of engaging practice nurses in managing cancer as a long-term condition
2. To determine the learning needs of established practice nurses to take a greater role in the support and care of people after primary cancer treatments
3. To establish how to meet these learning needs effectively
4. To capture learning from the action learning sets to inform the further development of course content for practice nurses
5. To enable practical application of learning by practice nurses in a clinical setting with support and mentorship from the associated GP practice
6. To provide a model for engaging practice nurses in managing cancer as a chronic condition that could be rolled out further.

Specific questions that the evaluation will seek to address were:

- To what extent has the course provided practice nurses with the knowledge and skills they need to support people living with cancer? Is additional knowledge/skill needed?
- Has the behaviour of the practice nurses changed as a result of the course and in what ways?
- To what extent have they taken on an increased role with patients after cancer treatment?
- Have there been barriers to taking on an increased role and are there ways in which these barriers have been addressed?
- Has their learning led to changed activity, relationships and roles in their practices?
- Has there been patient benefit as a result of changed behaviour?
- Which tools and resources covered in the course have they found most useful in practice?
- To what extent have links been made with professionals in secondary care?

This evaluation will consider:

- How nurses have made a difference for both people affected by cancer and their practice and colleagues
- What practice nurses are doing differently as a result of the course
- What the learning has been for practice nurses in knowledge, confidence, skills and strategies.
Methods

The core component of the evaluation is qualitative interviews with the practice nurses participating in the pilot and their nominated supporting GPs.

Qualitative interviews were conducted with all the practice nurses as well as their GP supporters, and a member of the local Cancer Network Patient Partnership Panel who attended all the sessions.

By the time participants took part in interviews, they had had an opportunity to reflect on the course and apply the learning to their everyday work. This was done through one-to-one recorded telephone interviews for up to an hour at a pre-arranged time. An interview guide was used to seek evidence of changes in participants’ knowledge, confidence, attitudes to the care of people approaching the end of their lives, and in their professional practice. Participants were asked specific questions, such as the number of cancer care review consultations conducted, tools used and information recorded, as well as being encouraged to give narrative accounts of their work and the response of patients, carers and their colleagues. They were also asked about any dissemination of learning from the course within their practice. The interview questions were prompted by a guide that was developed in an iterative manner. The participants were asked to reflect on the process of the course, including the facilitated group work and the involvement of patients and users. Interviews with the 10 participant nurses took about an hour each.

The South West REC Centre Manager National Research Ethics Service has advised that this work constitutes service improvement rather than research so does not require formal ethics approval. However, in line with best practice, participants were sent an information sheet and consent form and invited to contact the researchers to arrange a mutually convenient time for a telephone interview for 30–60 minutes. At the time of the interview consent was confirmed and the telephone interview tape-recorded. Participants were assured of the anonymity of their response. We have chosen this approach to encourage an informative response.

The interviews were transcribed and anonymised. The transcripts were searched for significant words and phrases and coded using Aronson’s method for thematically analysing data (Aronson 1994, Boyatzis 1998). The data was coded first for key words, then for themes and links between descriptive labels. A sample of transcripts was analysed by an external researcher to confirm validity.

The interviews relied on self reporting from a small number of respondents but in qualitative method validity is gained through resonance and data saturation.

Analysis and results

This evaluation will look for reports of benefits to patients attributed to changed behaviour by the participant nurses. It will link this to the learning the nurses achieved and looks at aspects of the course that supported or facilitated this.

The findings are grouped under specific questions asked by the researcher Helen Austin (HA) and the subgroups are the hoped-for outcomes in the Macmillan project plan (see appendix).

Hopes and expectations of practice nurses

For their practices the nurses hoped:

• To gain a greater understanding of cancer care, which would help them meet the needs of cancer patients and to provide better long-term management.

• To be able to do cancer care reviews.

For themselves the nurses hoped:

• Communication with cancer patients would be easier.

• To gain greater knowledge of cancer and side effects and long term effect and awareness and that they would gain confidence and to be able to answer questions from cancer patients.

• To network and obtain ideas about starting clinics for all chronic diseases.

This nurse hoped to address her fears when she said:

‘I hope to address the fears I had around caring for cancer. Cancer, I always felt it was a bit of a difficult area to nurse and to work in and so it was all around sort of addressing my fears and hoping for meaningful cancer care reviews for our patient.

My fears were really about not knowing what to say. I just didn’t know how to respond, I think that I would be asked all sorts of questions that I didn’t have the answers, but equally knowing how to phrase questions and you know how to give hope if you like regardless of what the situation the patient finds themselves in.

And so, you know that was my reasoning for wanting to do the course when I spoke to the practice about I’d done all the chronic illness and I look after the diabetic needs and the asthma needs so for me it was a natural progression, as we are now aware there so many people living with cancer, that they are almost like a chronic disease group.’ (PNS)

The GP supporters hoped:

• The nurses would be able to develop their skills.

• For the practice it would be ‘good to have somebody in-house who could offer further support for patients… patients who are coming to the building anyway or had a relationship with the nurses, who would find it easier perhaps than approaching hospice care and getting ongoing support through life with their cancer.’ (GP1)

• The nurses would gain increased knowledge, interest and confidence which they would be able to cascade to the rest of the team.

• To gain a more structured and formalised approach to cancer care, palliative register and a multi disciplinary approach.

• To identify patients in a structured way and having a lead nurse in the practice who would be a point of call.

• To have a nurse who would be a proactive for support and follow-up of patients. If a patient had a new diagnosis of cancer there would be someone there to go to and ask about problems that might be arising in treatment.

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• For better care for patients and more time for nurses to answer patients’ questions at cancer care reviews. This was illustrated by this GP who said: ‘There were two aspects, one was I wanted to increase her awareness of cancer, both, well the whole pathway of cancer really from start to finish so that as a member of staff who was seeing patients with chronic diseases she was more alert to cancer challenges whether or not it was the presentation of cancer or whether it’s the side effects of treatment or recurrence or long term survivorship issues.

So that was the first side of it, I just feel in seeing all the chronic disease patients she’s an ideal interface to be a little bit more aware and then the second aspect of was that I wanted to see, well I knew this was a pilot that Macmillan were running and so there was an opportunity to see whether upskilling nurses to start participating in cancer care reviews more if possible.

It’s an integrated approach for individuals who’ve got multiple problems, and we’re a very big practice and so because we’re a big practice we’re divided into teams to try and help the continuity and having a nurse that would be able to do more integrated role with people that have got lots of different problems, cancer being one of those, that seemed to be something that would be helpful.

Nurses are trained in chronic disease management... and so a lot of it overlaps rather than having an asthma diploma but not being able to see people with cancer, it seemed helpful to have somebody who would be comfortable with all of the things if they were coming into a be a potential option for our cancer care reviews to come to her.’ (GP2)

It was hoped that the practice would be able:
• to offer the best end-of-life care and cancer support.
• To gain a better more cohesive service for cancer patients.

• That the practice nurse would be invaluable to patients who have a new cancer diagnosis, and also to see ‘the frequent attenders that are very very anxious and then probably at the other end of the spectrum when people are beginning to realise that we’re not going to be doing very very much more’ (GP8)

• To know if the practice is doing things correctly and what else the stuff might learn.

How have practice nurses made a difference for people affected by cancer?

Ten themes emerged:

1 Practice nurses have an increased ability to communicate effectively with patients living with cancer.

2 Practice nurses now act as a catalyst in the practice for better support to patients living with cancer.

3 Practice nurses have an increased knowledge of what people affected by cancer can do to help themselves.

4 Practice nurses have an increased understanding of the benefits of exercise and adopting a healthy lifestyle.

5 Practice nurses now support people to make positive choices about exercise and lifestyle and taking action to improve their overall quality of life (e.g. improving/restoring relationships, going back to work).

6 Practice nurses have an increased awareness of the information available to them.

7 Practice nurses have an increased awareness of available services and resources.

8 Practice nurses are increasing people’s confidence in their ability to self-manage.

9 Practice nurses are taking a more active role in managing patients condition on an ongoing basis.

10 Practice nurses have a greater insight into the ongoing needs of cancer survivors and how to integrate these needs into existing care pathways.

1 Practice nurses have an increased ability to communicate effectively with patients living with cancer.

• Nurses say they have developed good relationships with cancer patients and are able to converse better with them.

• Overall, nurses have become more confident in their consultations with cancer patients.

One nurse said that she now had more confidence about open questioning which has ‘made it a lot easier.’ (PN1)

• This nurse described how much more confident she felt when she said, ‘If people came to a blood test for an oncology appointment I would probably have just done the blood test and off they go, but I do tend to say how are you feeling and elaborate a bit more, whereas before I would think I won’t ask as I don’t know the answers.’ (PN3)

2 Practice nurses now act as a catalyst in the practice for better support to patients living with cancer.

• This nurse had regular contact with cancer patients. She said: ‘we’ve built the rapport, they actually ring me now, and one of them has died and his wife has come in thanking me, very much so grateful that we’ve managed to sort out his end of life care’ (PN4)

• She described a crisis situation regarding a patient ‘…whose husband was in the hospital and had come home to die basically and she was being bombarded by an occupational therapist making all sorts of changes to the house and she couldn’t cope when actually he only had days left, and I thought where do I go with this. You know I didn’t have the GP here, which was quite fortunate because it was a learning thing for me, so I contacted the community hospice nurse who was absolutely fantastic, made contact with the patient and the ward and they got him into the hospital and he died 3 days later peacefully and in a nice environment. So that was a biggy, that’s very fresh in my mind and she’s been so grateful ever since, ‘thank you so much’, you know so I feel that was a biggy and that’s a direct outcome from the course. I would have had to go to a GP, ring whoever was on call, I wouldn’t have had a clue what to do. But then I guess the query wouldn’t have come to me before, it’s only because she felt comfortable contacting me in a distressed state. I had met her just once.’

• She described another patient she had been seeing: ‘I think I was doing some blood tests or something routine here, he’s got another chronic condition as well diabetes and I think I was seeing him for a follow up for that and of course he’d just had this devastating news that he had a nasty cancer, at which point I thought, I have to say I thought ‘oh my goodness, I’ve only got ten minutes here’, but I couldn’t let that go, the opportunity was there, and I said well okay let’s have a chat about that, sorry to hear that, so that’s how I got to know him and we did an opportunistic lengthy consultation there about that. And then I said well let’s follow this up in a week or two when you know what the treatment is, because he didn’t have a clue what was being offered at the time and was waiting for the scans etc, and I said why don’t we follow things up in a week or two, which is exactly what we did at which point he knew exactly what the treatment was going to be and was palliative, not curative and it sort of was a bit downhill from there... he brought his wife in the next time so I was able to meet her.’ (PN4)

3 Practice nurses have an increased knowledge of what people affected by cancer can do to help themselves.

• This nurse described how one patient had said what helped her prepare prior to chemotherapy: ‘I have used... things like going to the dentist and getting a dental check up, thinking about what foods you would like, thinking about how you would relax and where you will be when you feel particularly awful, so I was able to when I had to pass that information on to a patient just about to go to chemo, and he had particularly horrible teeth, he and his wife were grateful to have a bit of practical advice beforehand when everyone feels so overwhelmed about what’s about to happen.’ (PN3)

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Practice nurses have an increased understanding of the benefits of exercise and adopting a healthy lifestyle.

- One nurse said that the patients ‘have been given greater confidence in managing their condition and being able to do a few ways to help fatigue or diet, exercise …and be involved in their decision making and management.’ (PN3)

Practice nurses now support people to make positive choices about exercise and lifestyle and taking action to improve their overall quality of life (e.g. improving/restoring relationships, going back to work).

This nurse said: ‘Before the course I didn’t really know the importance of lifestyle after cancer you know to prolong your life expectancy and that sort of thing so that’s quite empowering.’ (PN9)

This nurse said: ‘I think I invite them to express their anxieties more than perhaps I did before anyway so therefore I’m able to respond to them, whereas I perhaps wouldn’t have given them the opportunity to do that before hand anyway.

Researcher (HA): ‘Why is that do you think?’

Practice nurse: ‘Just you’re time limited, you sit there at your appointment and you know what bits and pieces you’ve got to go through at that appointment and if I sat down and said so here’s your results and we’d just go down that route really and spend half an hour consultation talking about what you’re going to do for them and not how they can help themselves so that would be perhaps why I didn’t let them… I wasn’t terrible before but it just helps.’ (PN6)

Another nurse spoke about her change in attitude towards cancer patients: ‘I would never have approached someone with cancer about where they were in their cancer treatment.’

Practice nurses are taking a more active role in managing patients’ condition on an ongoing basis.

- Nurses said that they felt empowered as well as the patients.

Another nurse said that when seeing a cancer patient she was able to refer to the GP straightaway with his query about pain relief and constipation, rather than phone the patient back later.

- One nurse said that a patient’s wife (from a different surgery) was able to phone the nurse when there was a problem.

Another nurse said that patients ‘are being empowered in that they know they don’t have to go via their GP they can come and contact me in which case, again they’re going to have more confidence that they can get through to the surgery and be seen by somebody and speak to somebody.’ (PN4)

Nurses felt they now have the confidence to see cancer patients whereas previously they would not have had any input and they also feel well informed and able to use the skills acquired on the course.

- This nurse talked about the importance of hope with patients. She said: ‘I think that all patients, all cancer care patients regardless of where they are on their journey there needs to be that element of hope, whatever that is, needs to be there. Now for some patients they can become very frightened if they feel that something’s out of their control and I know with one particular patient he was desperate to be able to stay at home, he didn’t want to be admitted, he didn’t want to go to hospital at all actually and he didn’t want to go to the hospice, and he wanted to stay at home and so we, you know we involved the hospice nurse who would call on him at home, and I personally didn’t do it, but I said to him that there are things that we can put in place to keep you at home. So if your hope is to stay at home we can do that for you.’ (PN5)
How have practice nurses made a difference to the practice and to their colleagues?

Five themes emerged:

1. Practice nurses make themselves available to others as a resource in the practice.
2. All practice staff (GPs, nurses and reception staff) are more engaged on issues relating to cancer.
3. Practice nurses have a better understanding of issues relating to management of cancer.
4. Practice nurses are providing better support for patients living with cancer.
5. Patients are using the practice more often as a source of information and support.

1. Practice nurses make themselves available to others as a resource in the practice.

- Most nurses had given presentations to their practice, and one had presented at the Nurse Forum. Reactions were favourable but colleagues were concerned that it would not work in practice because of the time element.
- Two nurses found colleagues were not interested as they were recently in post and another had not had time due to colleagues being off sick.
- One nurse had set up a cancer care evening with speakers in order to disseminate information.

2. All practice staff (GPs, nurses and reception staff) are more engaged with issues relating to cancer.

- Nurses spoke of their GP supporters as being very helpful and supportive.
- Another nurse had given information to the administration team as they are likely to build up relationships with patients who may in turn disclose information to them.
- Nurses felt it was important to involve other nurses in seeing cancer patients and giving lifestyle advice.

3. Practice nurses have a better understanding of issues relating to management of cancer.

- This nurse had disseminated information to a colleague in the following way: “I did a session with a colleague about neutropenia and why we do blood tests and about cancer survivorship, so I have got a lot of information about that and it does surprise people, a lot of people don’t realise.” (PN1)

4. Practice nurses are providing better support for patients living with cancer.

- As the time factor was considered to be a problem, nurses suggested they could enlist possible help from colleagues but they felt there was a need for a better system.
- One nurse thought there should be an annual update for practice nurses on cancer management.
- Nurses felt that a combined chronic disease and cancer clinic would ensure all patients are seen annually and followed up.
- Nurses were aware of the potential isolation of cancer patients. One nurse said: ‘They don’t really come back into the realms of the GP practice and in that acute stage sometimes they’re at a loss as to where to go and it’s knowing that actually they can come through to the nurses and, it was even almost just saying you don’t even need to have done this course, you just need to know that the nurses will be receptive to you coming back on a Friday evening if you’ve got a problem because that’s what we’re here for, and it was like oh well I thought I had to stay under the care of the doctor at the hospital so it’s that sort of thing they have found, it’s almost like giving them permission in a way’.

5. Patients are using the practice more often as a source of information and support.

- This nurse spoke about her role within the practice: “I did have a lady who found out she has a malignant melanoma and she came in and wanted to speak to me and I said to her any time I can be of any help to you, you know don’t hesitate to phone me and that was probably the wrong thing to say to this particular lady in the sense that she rings me every time she’s got a three monthly review.’
- HA: ‘So how does that make you feel?’
- PN: ‘Very humbled actually that, taken into their confidence and feel that I can make a difference.’ (PNS)

How have GP supporters felt practice nurses have made a difference to patients?

Most GP supporters were able to give examples to illustrate this, though some were uncertain whether the nurse had made a difference to patients:

- ‘Yes, I know she has with her new found knowledge had conversations with patients, I can’t name patients where as the result of those things she now knows about, or there are resources that she can inform them about. She’s had worthwhile consultations with folk.’ (GP1)
- ‘No, but I guess as an optimist I keep hoping that it might slightly improve care because of her improved awareness.’ (GP7)
- ‘She’s a lot more confident dealing with cancer patients I think. There has been a time in the past where if the nurse sees a patient with cancer and they’ve got a problem they automatically put them in with the GP rather than this is alright for me to deal with, it’s been a kind of no go area really hasn’t it? I think that’s something I’ve observed and also I think she will be a good flagship, the person to lead that change. I was talking to her about the patients she’s seen and phoned and followed up and got into clinic, she’s clearly confident to do that now, in a way that perhaps on other occasions she would have felt she was overstepping the mark and that wasn’t a job for the practice nurse so she put them in with the GP just in case and I think she’s more confident to not go ‘oh no that’s not one of the things on my list’ (GP3)
- At one practice, as a direct result of the course, the nurse is inviting people for review sessions and she is actively and proactively looking for cases and accepting follow-up referrals from the GP. ‘One a lady who was discharged from breast cancer follow up, from the Oncologist and she really appreciated knowing that there was still a named person on her case as it were, so that was very good. The other one was still an active case, which was fairly shortly after diagnosis, so it was support after diagnosis really and again a link with the practice. The first one nothing formal would have happened, we would have just waited for her to come when she wanted to.’ (GP5)
- ‘I know that she has had feedback from a relative of a patient who died saying thank you very much it was a very positive experience. Certainly for me I’ve got a lady I saw who was diagnosed with a vulval cancer who I’ve seen only a couple of times but I know about her through the practice nurse who will keep me updated as to where she is on her pain management and where she is on her treatment. The nurse has come to me and said she’s having this and that, I’ve just spoken to her I think she might need a little bit more regular medication, can you push for her repeat prescription page that sort of thing, so certainly the communication. Because I have to wait for the patient to come and see me but if somebody else is involved in a more proactive way and I’m more aware of what’s going on when I’m not actually seeing them. I’d identified her as a new vulval cancer patient, so the PN then proactively did a cancer care review with her and got more information out of her that I hadn’t had and came back and said that back to me.’ (GP6)
• The changes they have made in one practice, with the nurse now seeing cancer patients, was a result of the course. The GP supporter said: ‘We’re very confident that she’s going to be able to deliver because of her previous training in Oncology and she’s been here a long time she’s got long standing with patients, they value her, she’s got a lovely quiet but helpful attitude so she’s quite confident in doing this. I think from my perspective what I would really like us to stop doing is maybe even just the older patients, even with diabetes, and heart failure is advance care planning.’

‘There is a massive national agenda for end of life, and if you have got a nurse in the practice who’s valued and earned right to seek insight into the patients’ lives because they want to have that respect, and be valued and I think that’s how you could possible sell it to the CCGs and PCTs.’ (GP8)

What are practice nurses doing differently?

The majority of nurses are now involved in cancer care reviews. (See Table 1) There was considerable variation in the number of cancer care reviews carried out in the period leading up to the evaluation, and two nurses had not done any to date.

One nurse was awaiting changes in the practice and plans to doing cancer care reviews in the near future. She said: ‘We have moved to developing more cancer led nurse clinics but with particular emphasis towards the combined clinic where patients are coming in with diabetes, coronary artery disease, asthma, so if you combine those clinics with cancer care as well… and this way it’s using our skills as chronic disease nurses for our cancer care patients.’ (PN8)

However, in contrast to the majority, one nurse who was not carrying out reviews said: ‘Because I don’t think that I would feel competent and qualified enough, even though I’ve been on the course to be able to 100% do a cancer care review and I got some queries about the medication they’re taking and also maybe further treatment needed, I’m not that qualified in cancer to be able to give that advice.’

HA: ‘Did you hope to have got that from the course?’

PN: ‘Yes.’ (PN7)

The nurses gave examples of how they are now acting differently.

Eight themes emerged:

1 Practice nurses are adopting a changed pattern of care that involves more proactive, scheduled interactions with patients living with cancer.

2 Practice nurses are managing cancer as a long term condition with increased confidence.

3 Practice nurses are inviting patients for cancer care reviews.

4 Practice nurses are delivering cancer care review, assessment and care planning as a result of understanding of key concepts and developments in cancer care. Some nurses are doing combined chronic disease and cancer clinics, seeing patients annually, and following them up.

5 Practice nurses are assessing patients needs for information and providing information or refer to other sources as appropriate.

6 Practice nurses are applying their increased understanding of when patients would benefit from referrals (for medical, psychological, financial or social support).

7 Practice nurses are assessing the effect of cancer on family members/carers when appropriate.

8 Practice nurses are using learning resources for themselves and colleagues.

1 Practice nurses are adopting a changed pattern of care that involves more proactive, scheduled interactions with patients living with cancer.

• ‘The surprises were very positive… I found it an amazing course, …there was a fantastic plan, we were a group that gelled sort of very well… you could cross them over to your other chronic disease complications that you’re managing, from motivational interviewing… I came back feeling much more empowered to deliver an interview right across the board and no disappointments at all.’ (PN5)

• Although she enjoyed the course a constraining view was: ‘I think I should have waited till we got our new practice.’ (PN10)

• ‘It was very worthwhile, I feel I learnt a lot, I’ve changed my role in a positive way, I feel more open and able to support my patients.’ (PN2)

• One nurse now looks at patients’ history when doing annual reviews, which she did not do before the course.

• Another nurse now has her own directory of specialist nurse contacts.

• This nurse commented that she probably would have held back a bit before when talking to patients, but she now has more confidence: ‘It’s always backed up by knowledge, from the course. I just feel it needs to grow bigger and more nurses having more skills because I think again because they haven’t got the skills and the knowledge they feel scared to talk to the patient and the patient actually picks that up and so it’s very much needed… I think I invite them to express their anxieties more than perhaps I did before anyway so therefore I’m able to respond to them, whereas I perhaps wouldn’t have given them the opportunity to do that before hand anyway.’ (PN6)

• Nurses found the motivational interviewing, role-play, opening consultations and agenda-setting very helpful, and also the patient-directed consultations were useful in managing chronic disease patients. This involves asking the patient what they would like to discuss. One nurse described it in the following way: ‘When a patient comes for a dressing with the nurse, I now say “Is there anything else you want to discuss?” Some of the patients are too scared to ask about… I know somebody who had a dodgy mole and it makes it easier for them to talk about, giving them permission to talk about this other stuff when they feel that I’m just here for my diabetic check up I can’t ask about anything else.’ (PN2)

• This nurse described her behaviour now: ‘Yes, I think, I just felt more, more capable, and more relaxed and actually you know I never really, I know we have patient in for post surgery dressing and that sort of thing, but in the past we’ve done the dressings for them, and it’s been very much this is your wound this is what I’m doing, we’ll have a look at your wound again in three days times or whatever, make them another appointment and you know you’ve parting shot is we’re fine, whereas now, how are you feeling, how are you coping, is there anything you’re struggling with, whereas I wouldn’t have had the confidence to ask those questions before.’ (PN5)

• Another example was a nurse who described a patient who came in to have her blood tests and maintenance of her PCC line, with whom she had developed a rapport. ‘Before the course I would have just, women with these lines usually come in, they tell me about the different treatments they were taking and I would have no idea and just listened and say “Ah how many more weeks have you got to go now?” and that was the limit of my knowledge really. Whereas now I probe more, well “Tell me more” and “What’s the plan?” and I have more of an idea of how many week’s she’d be having the chemotherapy for, what to expect in that time, the plan afterward, the radiotherapy. … to keep in touch with me, “If there’s anything I can do, you know, if you need any answer to any question or not have had said anything like that?” I feel really, really pleased, very positive, you know I feel like I’m… and I make it quite clear from the beginning that I may not have the answers there and then but “I’ll find out for you” I’ll do my best to find out. Then she’d always come in, every single time there was a query about something and quite obviously… she was the one that asked me about what do I then about hair dye, “My hair’s coming back, it’s looking grey, when can I dye it?”, you know, so I had to find out’ (PN4)

This nurse was also able to advise her patient where to seek help for her finances and about her entitlement to free prescriptions.
Another nurses spoke about a patient who had oral cancer and radiotherapy treatment, which has made his mouth so sore he could not eat, and he has lost weight. She said they had given him high nutrition food. ‘You know the ones that you get on prescription and again I kind of wouldn’t have done that before to be honest with you, I wouldn’t know what to do about him, I would have sent him to the doctor and I don’t know if the doctor would have done it either quite frankly… so you know it’s made me more proactive certainly in my walk-in [clinic], and say right, I can tackle this problem or I will find someone who will help me tackle if I don’t know what to do.’ (PN9)

2 Practice nurses are managing cancer as a long-term condition with increased confidence.

This nurse felt more at ease in her discussions with patients. She said: ‘I feel more confident now to talk to patients about their experiences in hospital and even though I don’t know all the answers at least I don’t feel uncomfortable talking about it now I don’t feel as if I’m completely out of my depth it just sort of confirms that you can have the confidence to do it.’ (PN2)

• This nurse described how her confidence has improved since doing the course:

PN: ‘I think I had more confidence about bringing up the subject perhaps, and asking questions in a different way than I would have done to help her to open up.

HA: What sort of way did you use?

PN: I think sort of saying ‘and how do you feel about that?’ and ... ‘what makes you think so and so?’ ‘tell me a bit about how you feel?’ ‘how are you feeling and how you react with your family’. I would never have approached someone with cancer about where they were in their cancer treatment, if they had any problems that sort of thing before.’

4 Practice nurses are delivering cancer care reviews, assessment and care planning as a result of understanding of the key concepts and developments in cancer care. Some nurses are doing combined chronic disease and cancer clinics, seeing patients annually and following them up.

• This nurse talked about an opportunistic cancer care review she had carried out where ‘the patient talked through her fears and everything and afterwards she said I feel so much better and it wasn’t actually anything that I didn’t really feel as if I’d done anything but that was equally something I picked up from the course,

you know as nurses you want to advise and educate and you want to make things better, but actually with your cancer care patients that’s just letting them talk.’ (PN5)

This nurse works with the secretary every month to identify patients who are due for their reviews and checks whether they have seen the doctor.

• Nurses said that the GPs previously did all the reviews but now if they feel the patients need more input and time they refer them to the nurse. Cancer care reviews generally took 20 or 30 minutes but one nurse said she would take as long as needed, which could be up to an hour.

• This nurse described a patient she had seen in a review. ‘I would say the other one that got a bit tearful, and I think she’d been bottling everything up, just seeing her going out of the room smiling whereas when she came in she was really wound up and really anxious and then seeing her going out and saying ‘I feel so much better now’. I think, because I had the time, the allocated time booked, you feel that you’re not going to rush, that you’re just going to sit and listen whereas if that time hadn’t of been allocated I might have really, I couldn’t really hurry her along but I wouldn’t have spoken to her in such depth had I not been allocated the time.’ (PN6)

• Most nurses were using a template which they find is a very useful checklist. Some are using the template from the course and also have a link to Macmillan on it. Although some nurses were not yet doing reviews, other nurses found the course has initiated them to start doing the reviews which have now become more structured, and opened up a dialogue with the GPs about the reviews, the template and allowing the nurses to have protected time to focus on the cancer patients.

• At times, GPs may suggest to the nurses which patients are appropriate for them to see at review and also the nurses may also make suggestions themselves. One nurse thought this could be a way of preventing people from going into hospital because they were learning to recognise problems themselves, or beginning to feel more confident about managing their condition and therefore did not need to consult so often.

• One nurse plans to have an excel sheet to record invited patients.

In doing the cancer care reviews, this has allowed nurses to see into patients lives, regarding the effect the diagnosis has had on them. This nurse described the first review she did: ‘I phoned up a patient who was on the cancer care list as being newly diagnosed and said she would like to come and have a chat with us and she said that she very much would and then came and along and she saw the GP and the GP wasn’t that helpful and then she came and spoke with me and opened up for 25 minutes about all the burden she was going through and all that stuff and it was eye opening.

Because it was probably the first one I did so it was hard in a way, but also you know the family problem that she was having because she had children that were having a lot of emotional difficulties accepting her diagnosis and so it was opening up areas which I hadn’t really thought about prior to starting the conversation, I thought when she said she was having problem it was going to be more physical or emotional about her you know and her main concerns were her children. I phoned up the breast care centre and they had support there, so they had a lady who could support her and talk to her a little bit more about it and she also had social services involvement anyway and so she encouraged her to follow up the counselling the children were having.’ (PN9)
5 Practice nurses are assessing patients’ needs for information and providing information, or refer them to other sources as appropriate.

• This nurse described how she behaves differently as a direct outcome of the course. She informed a patient that he could be having free prescriptions for stockings since the recurrence of his cancer one year ago. He was quite cross about this as he had not known before, and this resulted in a significant event in the practice. She said: ‘As an outcome of that, it made me and everybody else aware that we don’t just assume things, we have to check, because if they’re going to the pharmacy for prescriptions, the pharmacist doesn’t know that they have cancer.’ (PN4)

• This nurse found it helpful to think about the timing of giving information to people. She described it as ‘too much too soon, too little too late’ which makes her systematic about when she gives the information. (PN7)

6 Practice nurses are applying their increased understanding of when patients would benefit from referrals (for medical, psychological, financial or social support).

Nurses have changed their behaviour since the course in the following ways:

• One nurse described how a secretary will pick up somebody who might benefit and pass the name on to the nurse, and similarly another nurse or a doctor in the practice will do the same. This nurse acknowledged that it is not always appropriate for her to see the cancer patient if the doctor already has a close relationship with them.

However she added: ‘A good example of one that was appropriate was a doctor who hadn’t particularly known this patient and they’d gone off, I think it was testicular cancer, and he wrote me a note saying this patient you might want to contact at some stage and I rang them up and the person felt he had good support at the hospital and I just said I’m just making contact from the surgery to know that you’ve got somebody here if you feel, you know and that’s how it’s done and he’s now fully engaged with the hospital but at least I’ve made contact with them and made it easier should they want to, and why not.’ (PN2)

• Communication and referrals have taken place in various areas, such as to the GP, the community nurses, the cancer centre, the local hospice, the breast care nurses, the Macmillan Information Centre to obtain leaflets, and for wig fitting, the disease specialist nurse, the speciality cancer care nurses in hospital, self help groups, the fatigue clinic, radiotherapy, the palliative care district nurse and the oncology registrar. When contacting the cancer nurse specialist one nurse spoke of obtaining information on the side effects of treatment, such as impotence, hair loss, and when patient can dye hair again, watering eyes, and oedema.

• One nurse had spoken at a Dorset Cancer Network meeting and a Macmillan meeting which she described as a big learning curve.

• When one nurse phoned radiotherapy regarding treatment for a patient’s mouth cancer, she said the registrar ‘he was really good and really pleased that you were taking the initiative to sort him out ... so it’s good two-way communication.’ (PN8)

• One nurse is now part of an end of life team. She said: ‘I never would have done before and so suddenly there is a cancer care nurse within the medical practice who’s being proactive which we’ve never had before.’ (PN8)

7 Practice nurses are assessing the effect of cancer on family members/carers when appropriate.

• This nurse described how she felt now: ‘I’m more aware of the patient’s anxieties and more respectful to how they’re feeling.’ (PN1)

• Another nurse described a patient who had been invited for his well man check because he hadn’t been for about five years. She said: ‘I noticed it said something about his wife is very seriously ill with cancer, end stage, ... so I had a choice of mentioning or not mentioning it, but no I think I will, and I just said I can see from your records you’re going through a tough time at the moment’ and it was, just so important to put that into the mix you know. He talked about her, the poor nights he was having and how he was struggling with that... I didn’t ignore if you know what I mean.

But instead of it being a thing in the room with no relevance it was sort of there but alright if you see what I mean it was out in the open. I think that has made a difference with relatives and carers who feel better able to talk about it really. That is a change actually I’m more comfortable doing it now than I was before.’ (PN2)

She also feels that now she explores patients’ anxieties more than she did before the course.

• Another nurse described her contact with a family: ‘I’ve got another lady at the moment who I’ve never met before because she’s one that doesn’t come to the surgery. I know her husband and I know her daughter. They’ve got chronic disease and I have a good relationship with them so at the moment I’m having communication quite a lot with the daughter and when I phoned, well she’s a lady who I had to sort out some extra pain relief for and when I phoned the patient’s house and the daughter answered the phone I knew when she answered the phone so it was kind of communicating with the family.’ (PN1)

8 Practice nurses are using learning resources for themselves and colleagues.

• In order to illustrate resources available to the practice, one nurse had shown groups of colleagues the NHS Choices website with the learning facility and information prescriptions.

GP supporters views

The GP supporters were asked to give examples of evidence of the nurses’ learning and how it has made a difference in the practice.

• The GP supporters confirmed that in general the nurses found the course useful and a good learning experience.

• This GP said: ‘Charles in his teaching techniques, teaching adult techniques he inspires people to try and look outside the box.’ (GP10)

• GP supporters confirmed that most nurses are now actively involved in cancer care reviews.

• One GP said that they now had a good template produced by the nurse and they were going to have an annual review for all chronic diseases and cancer would be included.
A contrasting view expressed by one GP was that she was very disappointed as she had envisaged that the nurse would be seeing patients in reviews, but this turned out not to be. She speculated that there may have been a misunderstanding that the nurse did not feel able to do so, but when she spoke to her, the nurse said she is going to ‘stick with what I’m doing’. (GP2)

Since taking on the reviews, some GPs were aware that nurses were feeling extra busy and more stressed.

GPs were unable to allocate more of their own time to the reviews and were sometimes of the opinion that the nurses would do them better.

This GP said that since the nurse had started doing cancer reviews she had become more knowledgeable on assessing patients and their different symptoms and she was now doing them in addition to the doctors and said: ‘I think yeah, I was surprised how it’s developed in that she’s gone to a national conference and different things and has had some opportunities to speak on it to other people, I’m very surprised how it’s developed personally. Yes, she’ll need more appointment time. We have a cancer care meeting once a month so she has a more useful input to that. She also keeps our cancer list and updates our cancer list.’ (GP5)

She added that previously there had not been a well structured recall system for cancer reviews, but now the nurse is calling all patients in.

Another GP said the practice had mistakenly been omitting telling patients about their eligibility for free prescriptions.

GPs gave examples of changes within the practices which they felt had resulted in better quality of patient care. As a result of the course and other issues there was now a new protocol for managing palliative care patients, an integrated clinic, and improved out-of-hours contact and communication. There is now a proactive follow-up for patients and a feeling that the practice is available to them.

In one practice, cancer patients were now being formally identified and are having their cancer care review and if anything crops up, it is brought to the attention of the GP much sooner than previously. This GP said: ‘When patients have a diagnosis of cancer they can very easily be completely forgotten by primary care because all their care or a lot of their care is transferred to secondary care to the Oncologists who then see them in clinic, look at their medication, look at their treatment and they almost disappear from our radar, whereas this brings them back a bit.’ (GP6)

In one practice, their newsletter is used to advertise to patients who have cancer related issues that they can contact the practice nurse. He added that now the nurse is doing reviews, nursing and administration time is being lost, but he feels it is worth it to provide the service for cancer patients. The review has become more structured as the nurse contacts the patients at key times and the administration and data staff look out for patient letters with any particular change in their treatment or any episode of or completed treatment which might prompt an invitation by letter.

One GP emphasised that the nurse had started doing cancer care reviews and there is ‘better communication between patients and the practice, between the nurse and the GP or between the GP who’s seeing the patient.’ (GP6)

Another GP added: ‘And the other thing she’s going to do is start doing carer assessments more as well.’ (GP5)

This GP was aware of getting the balance right when it came to contacting cancer patients. He said: ‘There’s been this slight reluctance. I’m struggling to use the right words, the thing with … not rubbing people’s faces in it. Okay they’ve got cancer they may be getting on with their lives quite happily. It’s one of the reasons we haven’t called people with existing diagnosis because for them 10 years down the line they might actually want to forget about it, but on the other hand there may be people out there who are desperate for help that’s the danger. One of the barriers has been not to unnecessarily recall people who may not actually wish to be recalled.’ (GP1)

GPs were of the opinion that funding and resourcing would be necessary.

Politically, this GP said: ‘I definitely think the CCGs are central to affecting the care given to patients, they’re working much looking at the bigger picture at the moment.’ (GP3)

### What have practice nurses learnt?

Practice nurses reported a wide range of learning from the course.

18 themes emerged summarized as follows and subsequently described in detail (see appendix for extended narratives).

**A Knowledge and confidence**

1. Increased knowledge of cancer as a disease and its treatment.
2. Increased knowledge of how to support people with cancer to self-manage (health and lifestyle), like patients with other chronic conditions.
3. Increased knowledge of how to assess patients’ needs, including needs relating to cancer, its treatment and beyond.
4. Increased confidence in the ability to manage cancer as a chronic condition.
5. Increased knowledge of the indicators of recurrence and what to do when indicators appear.
6. Increased awareness of the resources available for patients living with cancer.
7. Increased understanding of cancer as a long-term condition.

**B Skills and strategies**

8. Increased ability to communicate about difficult issues to patients living with cancer.
9. Increased understanding of key concepts and developments in cancer care like the cancer care review, assessment and care planning, and treatment summary.
10. Increased use and awareness of learning resources, for themselves and colleagues.
11. Strategies and a readiness to support more people living with cancer.
12. Routine use of available clinical tools for identifying patient needs.
13. Signposting people to other services more often and more effectively.
14. Making use of other services and sources of information when needed.
15. Greater insight into the course content and educational materials that can help to meet the learning needs of practice nurses.
16. Encouraging patients to be proactive/take action in managing their condition.
17. Making recommendations to patients about exercise and lifestyle.
18. Communicating with patients living with cancer more effectively and in relation to a wider range of issues including those that may be sensitive or difficult.
1 Increased knowledge of cancer as a disease and its treatment.

- The knowledge and skills gained on the course enabled many of the nurses to behave differently.
- They found the Royal Marsden nurses’ teaching very helpful. One commented: ‘I can understand now when people are going through chemo or radio, the background and I can give information about what might happen.’ (PN1)
- Another said: ‘It’s the red flags and the side effects from the Royal Marsden, they were the keys, and about the Macmillan support resources, and that I don’t have to feel daunted and can contribute. The course has increased my awareness and enabled patients to raise concerns…whereas before I must have been giving off messages, ‘don’t… ‘but they do tend to raise more concerns now’ she also found the Marsden nurse helpful in that ‘they demonstrate practical, use of phrases …to give you examples of how you might say something to a patient’ (PN2)

2 Increased knowledge of how to support people with cancer to self-manage (health and lifestyle) like patients with other chronic conditions.

- This nurse described how she is now able to give ongoing support to a patient, because she feels more confident as a result of the course: ‘I had another lady who does ring me regularly, she’s one, I heard her in the corridor talking about a problem with her dressing on her breast and I called her in because you know and I helped her with that, and at that point and ever since then I’ve kept in touch with her and probably are in contact once or twice a month, if she’s had a bad time at chemo or if she’s just had more bad news she’ll ring me up.’ (PN2)
- In contrast, one nurse said that the course ‘did not equip me with the knowledge and the training to be able to do a 100% cancer care review and being able to answer any questions.’ However, she did feel there was an overlap with the patients who had chronic diseases. (PN7)

3 Increased knowledge of how to assess patients’ needs including needs relating to cancer, its treatment and beyond.

- This nurse found the patient input on the course useful as she was able to ask questions to the patients themselves as ‘somebody who’s actually going through it is a far more accurate response than sort of third party.’ (PN2)
- Another nurse also felt this was useful as ‘you’re able to be perhaps more empathetic dealing with your own patients.’ (PN9)
- A contrasting view from one nurse was: ‘I didn’t find that bit helpful at all as everyone’s different.’ (PN10)

4 Increased confidence in ability to manage cancer as a chronic condition.

Nurses had increased confidence, shown in the following examples:

- ‘I can envisage Practice Nurses taking on the role and it would be rolled out across the country. I think Practice Nurses have a great role to play and building on our chronic disease management skills I think it fits in very well.’ (PN3)
- ‘I feel much more able now to raise subjects with patients, and I feel I know the missing bit, I mean I’m in primary care, but I didn’t really know what was happening in secondary care and therefore it gave me the time and the energy to look at that more and I mean I could have researched it myself but it give you the information to do that and having access to those people from the Marsden was just so valuable and so great because you do feel you’re completely out of touch.’ (PN2)

5 Increased knowledge of the indicators of recurrence and of what to do when indicators appear.

- Another nurse has now changed the way she speaks to patients at their diabetic checks. After she has asked them about their blood tests and blood pressure, she now asks if there is anything else they want to talk about or discuss.

6 Increased awareness of the resources available for patients living with cancer.

- Nurses highlighted the NHS Choices website as very informative for cancer information and information prescriptions, including leaflets which can be emailed as well as downloaded. One nurse said: ‘You can store it so that if you get another patient with a similar request you can just press a button and print out a leaflet. The access to information is fantastic.’ (PN2)
- The input from patients on the course was felt to be very helpful to the nurses. This nurse spoke about how she feels cancer is one of the most sort of fearful diagnoses you can have and to listen to one patient was still frightening but she was very very brave. ‘She made me think that it’s something that’s needed because since this course I’ve interviewed the cancer care review patients and they are very very emotional and they do need to be listened to.’ (PN6)
- Another nurse said she was so glad she had done the course and she ‘wanted to offer a really good quality care to somebody I can make a difference to at a time when everything is doom and gloom.’ (PN4)
9 Increased understanding of key concepts and developments in cancer care like the cancer care review, assessment and care planning, and treatment summary.

Most nurses are now carrying out cancer care reviews and feel more able to undertake them because:

a) The fear has gone from the nurse and they have a more positive relationship with their patients.

b) There is the facility of seeing the patients opportunistically.

c) Macmillan funded the course by payment of the venue and the speakers’ costs, and a payment of £1000 to each nurses’ practice.

This nurse said how the input from patients has helped her when seeing her own patients, ‘Hearing their stories, very powerful and what helped them on a sort of practical level, their feelings about it and their worries and positive aspects as well, that was really useful.’ (PN3)

10 Increased use and awareness of learning resources, for themselves and colleagues.

Nurses learned a lot about the resources available.

One nurse said she had not known about the Macmillan website before and she would now keep herself updated.

11 Strategies and a readiness to support more people living with cancer.

This nurse said: ‘The course, myself I thought was first class but it has left me frustrated because I want to do more.’ She was ‘feeling so much more equipped to address cancer patients.’ (PN5)

• One nurse is now attending meetings with hospice care. As a result of the course this has enabled her to speak to the hospice nurse, as she, the nurse did not feel comfortable cold calling phoning the cancer patients. The hospice nurse was very helpful and gave her some phrases to use on her opening consultation, which she now has written on a card as an aide-memoire.

• Another nurse said: ‘I feel more understanding and in a better position now to be able to help.’ She thought that the course helped with ‘knowing which avenues to take, they can be referred and sometimes the anxieties are just the fact that they want somebody to talk to and pour out to and it’s just a question of listening.’ (PN7)

12 Routine use of available clinical tools for identifying patient needs.

These tools from the course were identified as useful:

• Distress thermometer – can be scanned into patient’s notes.

• Checklist provided by Gregory Tanner (and adapted by Macmillan) regarding treatments, psychological state, social situation, physical and mental wellbeing and plans for the future and storage of hospital and Macmillan phone numbers. This checklist makes it more comfortable for nurse and for the patient.

• Information leaflet regarding care, next of kin, professionals involved, cancer diagnosis (curative or palliative).

• Nurses found the Macmillan leaflets very useful and easy to understand.

13 Signposting patients to other services and sources of information when needed.

This nurse described how she was able to advise a patient before her hospital appointment: ‘I talked to somebody, quite a young lass who’s had ovarian cancer and an ovarian cyst removed which turned out to be cancerous and she was feeling quite confused and anxious about the next step of her treatment or whether she should go for the chemo and she was going for an appointment at hospital with the consultant, so I actually gave her one of the Macmillan booklets on what questions to ask which she found quite helpful, so I gave her an idea of what to ask when she went for her next appointment’. HA: ‘And that’s something that you wouldn’t have done otherwise before the course?’

PN: ‘No, I mean I didn’t know Macmillan produced all this literature which is… I mean things like fatigue, I’ve given one to the gentleman who I’d offered an appointment to come back and chat to me about, he’d been feeling very tired so I gave him one of the things about that. Yes, I think we learned a lot about resources available, that was another thing which was pretty good.’ (PN3)
15 Greater insight into the course content and educational materials that best meet the learning needs of practice nurses.

Nurses found accessing the Macmillan documents very helpful as they are able to send them to patients via email or print them out. They could give patients information and keep a basic set of Macmillan leaflets as a resource for the practice. They gave the following examples:

- The Macmillan website was ‘easy to access, easy to learn and a great way of learning.’ (PN3)
- Having sessions with the haematology and chemotherapy nurses and finding the Macmillan booklets very interesting and useful. ‘I actually realised what a wealth of education that Macmillan cover, I was staggered.’ (PN5)
- Using the Macmillan learning site to become well-informed which has helped one nurse ‘being more comfortable talking to people about cancer and feeling a bit more knowledgeable.’ (PN9)

One nurse felt she was able to help with a patient who was feeling isolated: ‘Identifying where they felt there was this void or black hole or suddenly being alone like for example after treatment and knowing then now with the course and knowing they’ve got a contact with the surgery rather than feeling like I’ve finished treatment what happens now.’ (PN4)

16 Encouraging patients to be proactive and take action in managing their condition.

17 Making recommendations to patients about exercise and lifestyle.

Nurses found the exercise and patient-centred information very helpful. One nurse said: ‘I’m finding the benefits around the self help that’s available to the patients, how a patient can sort of self motivate.’ (PN5)

18 Communicating with patients living with cancer more effectively and in relation to a wider range of issues, including those that may be sensitive or difficult.

- In using phraseology from the course, one nurse said patients do open up and are able to talk about things more easily and have raised things themselves and asked questions. For example she uses phrases like ‘I’m here too, if you’ve got questions about... if you’ve got worries about that.’ (PN2)
- Nurses described how they felt uncomfortable phoning cancer patients who they did not know, but now using phraseology from the course, makes it easier for the nurses who previously would not have known what to say.
- This nurse felt the phraseology equipped her to cope with a patient who said: ‘I just feel everything is so hopeless’. The nurse asked her why and was told: ‘I’ve got cancer so that’s that, isn’t it?’ She then replied: ‘Actually that’s not it anymore, you know there’s so much more we can do these days and you know your treatment will be very much on an individual basis and they’ll be looking at it and you’ll be kept involved in your treatment, you’re not just going to be told what your treatment is and that’s it, you’re very much part of your treatment.’ Then if the patient says ‘I’m really worried I’m going to end up in so much pain’, ‘that gives us a chance to chat about long-term pain relief.’ (PN5)

This nurse found the phrases from the course useful as previously she would not have felt confident that she could cope with the next question. If she does get stuck she’s honest and says ‘let’s explore this together’.

- This nurse described how she had now more confidence to speak to cancer patients: ‘I talked to another lady who, another youngish lady who had lung cancer and, about her feelings, she obviously tried to hide her feelings from her family and from herself and by doing that was, that was her way of coping and we talked about opening up to family and friends a bit more and about talking to children about it, and we did discuss, we discussed some counselling, specific counselling but she was not keen at the moment, at the time, but knew that help was available, she has since died unfortunately...’

HA: ‘Right, and so how did you approach that differently from what you might have done before the course?’

PN: ‘I think I had more confidence about bringing up the subject perhaps, and asking questions in a different way than I would have done to help her to open up.’

HA: ‘What sort of way did you use?’

PN: ‘I think sort of saying ’and how do you feel about that?’ and... ’what makes you think so and so?’ ’tell me a bit about how you feel?’ ’how are you feeling and how you react with your family’. (PN3)

- Another nurse said: ‘I haven’t got that fear, no I’m very aware that you can hope, and I’m not being unrealistic, I’m listening to see where they’re coming from first of all.’ (PN4)

Others commented:

- ‘I feel more confident now to talk to patients about their experiences in hospital and I think from hearing other patient perspectives I feel, even though I don’t know all the answers at least I don’t feel uncomfortable talking about it now. I don’t feel as if I’m completely out of my depth.’ (PN2)
How has the course helped the practice nurses?
The nurses all had very positive reactions to the course.

1 This nurse said she was so glad she had done the course and she ‘wanted to offer a really good quality care to somebody I can make a difference to at a time when everything is doom and gloom.’ (PN4)

2 The nurses all felt the small group learning was beneficial for instance: ‘I think it’s the best way, we are all able to relate to the patient and if one nurse is struggling in a group we’re often very able to offer a positive suggestion.’ (PN5)

3 The nurses were generally not overwhelmed by the pre course material.

4 The nurses found that the pre-course quiz highlighted their lack of knowledge, which was helpful, for instance: ‘It was useful in that it made you read the literature that you sent us and from reading you gained the answers but actually it educated, it just helped with the whole learning and gave you an idea of what the course would be about a little bit so that was good.’ (PN6)

5 The nurses found the fast feedback forms useful, for instance: ‘It made you reflect straightaway. Normally when you do a course you do an evaluation but you don’t hear everyone else’s viewpoint on the evaluation so when it’s fed back in the following session it’s really useful.’ (PN1)

6 A contrasting view was to have preferred to have posted off the form the next day.

7 The nurses found the input from patients very important.

8 Another perspective was: ‘One patient was very vulnerable and I felt very vulnerable for her...she might have been better looking after herself than trying to educate us...I felt she shouldn’t really have been there because I don’t think she was in the right psychological place at that time to be there.’ (PN8)

9 ‘It was good having targets they did say by next week can you have gone to see the specialist...it’s good to have some targets without the pressure.’ (PN2)

10 ‘It was a very inspiring course, and because it was led by us to a certain extent, you know things that we wanted to cover were done.’ (PN3)

11 ‘It was a really positive learning experience. I was learning a lot with the knowledge and skills and Charles was very good...the atmosphere was very relaxed and you didn’t feel embarrassed if you want to talk about something you felt he was very positive and encouraging and we had the support from... (patient panel representative) all the time and that was very good, it was really positive the way it was organised, a nice comfortable place, the food was nice and the topics were really interesting.’ (PN1)

12 ‘It was definitely a good course and had good learning tools as well with the website, there had been lots of information and the speakers and Charles and everybody was wonderful.’ (PN7)

13 ‘The whole thing was just outstanding...and the speakers were outstanding.’ (PN8)

How did practice nurses demonstrate that their colleagues and the practice had benefited or learnt from the course?

1 Cancer patients need more time, hence delegating the cancer care review to the nurse.

2 Learning about how the Macmillan service is developing, in particular the education programme and the nurse training.

3 Macmillan has raised the profile of cancer care and the nurse practitioner is well placed to support our patients with cancer diagnoses.

4 Certain cancer patients are better looked after by secondary care and some are not and it is useful for them to have a particular point of contact within the GP practice.

5 The need to keep a better register of cancer patients. This GP said: ‘I think that the big thing was that I was interested to see that the Macmillan team were learning about the art of chronic disease management from the nurses, as much as the nurses were learning about how to apply that to chronic disease, and I think that that’s the whole new concept really isn’t it, that cancer really now is another chronic disease and therefore needs to be managed as a continuum and I’m sure it will be, I will be, I’m sure 5 years from now that’s exactly what it will be, people will be on the register called up every year, how you doing you know and this sort of thing and so I suppose that was, that had quite an effect on me and because it is a new concept I definitely see that so but I think also it’s going to be really good with the increase, our district nurses and our end of life team are now what we have as a social enterprise, I don’t know if you have that where you are, but they’re a social enterprise so they have a financial driver to their services now. So increasingly I can imagine with GP commissioning every time we ask them to do something there’s going to be a financial implication. Now that we’ve got a palliative care type of a cancer care nurse within our practice I think that’s going to be a big driver to actually us doing quite a lot of our management if it’s going to come down to pennies and pounds. That might not have been an answer that you wanted to hear.’ (GP8)

Views of the patient partnership panel representative

The patient panel representative who attended all the sessions of the course was interviewed by HA.

The emerging points from this interview are as follows: He made several observations on how he felt the nurses had progressed in their learning which confirm the views expressed in the interviews with the nurses.

• ‘I remember rightly most of the Practice Nurses admitted to having very little knowledge of cancer patients and so I think one of the great things was the fact that as they progressed through the course, a) how they took in and accumulated the various different strands of knowledge that was present but most important is how they, well two things, one the sessions were of the patients, their own personal talks about where they were on the cancer journey and on, the big impact that had on the nurses. And b) as they progressed through the course and in the feedback sessions they recounted in general terms the sessions they’d had with individual patients in their practices.

• And it was quite clear that these patients that they’d talked to it was the first opportunity they’d had of being able to open up to someone and that made a very great impact on the nurses as well as the patient. I think the nurses also underwent a bit of an emotional journey themselves in some cases and the things that I’ve always plugged and I certainly tried to plug it during the course was the fact that many cancer patients when they completed their primary treatment in that hospital, they’re then signed off back to the GP.

• He felt there was a significant number of cancer patients who just feel totally isolated and cut off ‘so they obviously need to have in the practice a nurse who knows something about cancer generally and even if they don’t know themselves, can call and be given direction, it is just having someone there that they can ring up and chat to. I mean the very significance of that is remarkable.’
This observation was borne out in the interviews where nurses gave examples of how they had made a difference to patients who were feeling isolated.

- He also confirmed the effect these patients had on the nurses as contributing to their learning, and how this may have helped them to become confident when seeing their own patients. He said: ‘I felt the input from patients on the course made a big impact on the nurses when they came to talking to their own patients. They’d had these one to one sessions with face to face with a few patients and you know these patients just opened up to them and a flood of information came, and I think in one or two cases that the nurses weren’t quite sure to initially how to cope with it, but I think as they progressed through the course and they perhaps did know.’

- He found the session by the Royal Marsden specialist quite valuable, in particular the details of causes and effects of cancer.

- He felt the direct communication between the nurses, patients and some of the presenters worked well.

- He felt the other outstanding session was the use of role play, the use of phraseology, and how the nurses progressed in their communication skills.

- He was pleased to have been asked for his input and also that there was patient input on the course. He felt it was important to ask the patients what they thought: ‘When these things are designed the first people you ask are the end users.’

- He felt that the present group could be helpful in the future as a mentor group for other courses. He endorsed what the nurses had said about the importance of face-to-face learning, and how some aspects of the course could possibly be delivered online.

### How might future courses be different?

The participants were asked for ideas as to how the course might be modified in the future. The nurses felt the course did not need a lot of changes, however the two key points were:

- The session on cancer diagnosis and treatment could have been the second session rather than the third, as it underpinned all the knowledge for the treatment.

- The nutrition session could have been done online.

Individual nurses made other suggestions, including:

- The context of the course would have benefited from more clinical information, for example on the clinical guidelines of cancer and its treatment.

- It was felt the session on medications would have been more beneficial if it had been right at the beginning and more in depth information regarding medications for cancer would be an advantage, particularly if this course becomes a six month diploma.

- Nurses who had to travel greater distances would have preferred full day sessions.

- The types of treatments for specific cancers could have come at the end of the course.

- Preparation from each nurse for each session would have been a good idea.

- Memory sticks that could be downloaded on the end of each day.

- More academic subject matter and fewer anecdotes.

- There could have been something more quantitative about the course which would make it more measurable meaning the course could develop along the lines of a modular or degree, which might mean it became part of the QOF framework and targets. Tests could be done at the end of each module if it were distance learning, to show evidence of learning. The participants could then meet up as a group half way through the course when there could be speakers.

When asked about distance learning options, responses included:

- Knowledge such as cancer diagnosis and complications could be done online – but an acknowledgement that you would miss out on questions, sharing experiences and activities.

- A distance learning package with modules and one module could be completed prior to the course.

- Initial induction day, the resources and preparation from each nurse for each session would have been a good idea.

- It was felt the session on medications would have been more beneficial if it had been right at the beginning and more in depth information regarding medications for cancer would be an advantage, particularly if this course becomes a six month diploma.

- Nurses who had to travel greater distances would have preferred full day sessions.

- The types of treatments for specific cancers could have come at the end of the course.

- Preparation from each nurse for each session would have been a good idea.

- Memory sticks that could be downloaded on the end of each day.

- More academic subject matter and fewer anecdotes.

- One GP illustrated this point: ‘I could have done much more had I been invited to. If she’d come to me and said right I need your help to construct a plan what’s the best meeting for us to get this into, I could have then talked to the practice managers, one of the partners and I could have helped to construct a plan and helped her to get a forum within one of the meetings so that she could come there and say look this is what I’ve learned and this is what I want to do and we’d have got everybody inspired and kind of instead she just didn’t do the presentation and didn’t come back to me and then nothing really happened.’ (GP2)

- The inclusion of homeopathy and complimentary therapies in future courses. Reflecting his personal interest in the topic, one GP said: ‘Perhaps one of the ways that Macmillan could go, would be that they could encourage people to see what alternative therapies are available to complement what’s already happening and for them to be the people that have enough data to do the necessary evidence based research.’ (GP10)

He suggested a speaker for the course: Dr Elizabeth Thomson who runs the cancer unit at Bristol and is the Director of the homeopathic department.

Suggestions for future courses from GP supporters:

- In future courses there should be more structured contact from the course to the supporting GPs to ensure that the nurse was fulfilling the expectations of the course, so the course could support both sides as necessary. It should be important to impress upon nurses undertaking the course more specific targets for meeting with her practice and making an individualised practice plan either during the course rather than at the end of the course, or being followed after the course maybe at 3 and 6 months to see what has actually happened.
Discussion

All the nurses and all the GP supporters who took part in the course were interviewed.

There was data saturation and resonance within the interviews.

There was a high attendance rate at the course overall, but four nurses each missed one of the sessions. It is possible that this absence of learning may have influenced those who felt less well prepared to take on aspects of cancer care reviews.

One limitation of the study was that it was reliant on the self-reporting of the nurses.

This method of learning resulted in changed practice and behaviour on the part of the nurses. The course met its intended aims for most participants. The nurses were able to demonstrate and give examples of how their thinking and behaviour had made a difference to patients and their families, and to their own way of working as well as the their practice and colleagues.

The interviews allowed the nurses to explore their emotional journeys, from fear to becoming confident in their new roles. This common thread of emotions was evident throughout the interviews. The nurses expressed a variety of emotions in relation to themselves. They also described how they perceived patients felt in relation to their cancer.

The majority of the nurses were now carrying out cancer care reviews and had found ways of seeing cancer patients within their working time in addition to their other work.

Acknowledgements

Dr Charles Campion-Smith MB chB, MA, FRCPG, DCH, for his valuable help and support.

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Total: 91
Appendix 1: Stories

- Nurses gave examples of how they felt they had made a difference to patients. This nurse described how she was giving a patient hormonal treatment. She said: ‘He’s quite a reserved chap and there’s no way we would have just talked about the injection and off you go, but I did say I am the person here who links with the patients undergoing cancer treatments and I’m trying to make a link with you, with the GP and the practice and so that if there is anything you can come through me and you know, that was good because I wouldn’t have done that before because he’s quite a difficult person to talk to, but I felt empowered if you like to do that.

And okay he might not, but the scene might be set, and if he needs to come back to me again in a month and maybe as the months go on, yeah funnily enough actually he did, because as he left he did say to me ‘oh will, is this likely to affect my libido and my sex life’, and I thought that’s great, you felt, because he certainly wasn’t the sort of person that would have volunteered that without me first saying the other bit do you know what I mean?’ (PN2)

- Another example was a nurse who was able to ask the right questions to a patient. She said: ‘Somebody had come in for a review and she knew there was something not right and she admitted she’d been worrying about something and again if I hadn’t have been thinking about it, or you know I wouldn’t have perhaps known the right questions to ask or whatever. I mean these people probably would have managed fine without but you hope that it might just have made a bit of a difference.’ (PN2)

Another nurse said she had a patient who came in for regular blood tests: ‘ we gave him permission to come in every week if he wanted ‘because sometimes you’re frightened to do that.’ (PN1)

- Another nurse described how she is now able to talk to patients about cancer when they come and see her for another reason: ‘I just thought I’ll listen to you and we’ll talk everything through whereas probably if I hadn’t have done this course say for instance she was coming in for a blood test and said oh I really don’t like the breast care nurse I can’t talk to her, I would have felt well you know because I hadn’t been on this course I wouldn’t have felt able to say, well come and we’ll go through everything so it’s given me that added permission really.

I’m trying to think if you’ve just got diabetes or asthma I think, I think it’s probably... I suppose I feel quite open to the whole range of questions on those subjects because I felt quite experienced and knowledgeable about it, whereas with cancer I didn’t feel like that, whereas now I do feel more like that so I suppose I’m more at ease you know, if they bring up something.

And I can point them more in the way of resources as well. Because it’s very similar to things like diabetes because you’re trying all the time to empower.’ (PN6)

- Similarly, a nurse spoke of a patient who came for a routine blood test and she asked him how he was. She said: ‘Although he was very, very grateful for the treatment given to him at the hospital he then said, but now it’s finished I’m feeling really quite fearful and quite vulnerable and that was when I said well, please come and see me and we can talk about it, obviously I couldn’t at that particular time because he only had a ten minute appointment for a blood test, but he looked so relieved and went away feeling much, much more relieved, and I think that helped.’ (PN3)

- Another nurse described a patient she had been seeing: ‘He was coming in regularly for injections every three months and so I had a long relationship for years, you know, he’d come every time, and so I knew him fairly well and then he was diagnosed with cancer, and I phoned him up and asked him if he wanted to come in for a review and he said no he’s fine he was having treatment at the moment and he would give me a ring, and I thought that’s fine, just call me. And eventually he called it must be about three to six months after his diagnosis and he came in with his wife who was registered at another surgery.

HA: ‘Oh you hadn’t met her before’.

PN: ‘Yeah and we had a good chat we talked through all his treatments and he was always a really fit person and he was going on off on his, he was still going on his bike riding, he’d recently retired so you know he was cycling and we did all his check, the blood pressure and talked about diet and everything and you know it seemed to be quite a positive review and I said, I don’t know everything but if they need anything just give me a ring and I’ll hopefully try and sort things out and off he went and the same evening he phoned me up and said he’d got a bit of diarrhoea and I said okay, and I said do you think there’s any blood in it, and he said well yeah I think there is some blood in it, and I said well okay, I’ll speak to the GP and so I went up and spoke to the GP and the GP said he’d give him a ring and I phoned him back and said the doctors going to ring you in ten minutes and he said oh it’s got worse since then and I said okay, I’ll pass on a message to the GP and this was about half past five, so I went off home and the next morning I kind of looked on his notes and the bleeding had actually got really bad and he was admitted into hospital and I’d phoned his wife and spoken to his wife in the morning and she told me that he’d been admitted and everything and then spoke to her a week later and he was home and so you know, she would phone me regularly. Little things really like prescriptions got lost or if I can get the GP to visit and ... was having panic attacks and so, I was kind of just there for her really.

...Giving confidence to the wife so that you know she could just ask something and it would done, rather than if you go through reception and it can, they just don’t realise the urgency ...

I think she’d just give me a ring and there was a note up on the board to say just put her through as he was terminal and as I said subsequently he died and then the message got passed back to me from one of our registrars that the wife said thank you for the support and help.

I don’t think I would have contacted him initially to come in, I would never have met his wife.

HA: And you contacted him because of the cancer care review is that right?

PN: Yeah, yeah. So I would never have met the wife, so she wouldn’t have been able to contact me because she wouldn’t have known who I was so it just made that contact.’ (PN4)
Appendix 1: Stories

- This nurse went on to give another example of making a difference in helping the patient change his attitude to what he could do. She said: ‘I’m thinking of one gentleman in particular recently who has died and he’s not long been married for example and they had planned a cruise in October, next month, and it was quite obvious he wasn’t going to get on the cruise and he said, I don’t know whether he thought I was going to say well of course you can, so he said well that looks as if that’s not going to be possible because you’re on medication and the way you’re feeling, but is there anyway have you thought, could it be possible for you to have a couple of days locally in Goodrington where they had been before. Oh yes, yes, and actually they did have a couple of days away and it was looking as if okay that’s not really possible but what is possible.’ (PN4)

- Another nurse described how she had behaved differently as a result of doing the course: ‘I had one gentleman who’d just finished his radio and chemotherapy and I mentioned I’d done the course and he was full of praise for his hospital treatment but he said now I've finished I’m feeling really quite frightened and vulnerable and I was able to explain about the course I'd been doing and offered him an appointment to come and see me and talk about it in greater depth and he looked so relieved that someone had taken him seriously, he was worried if he would be taken seriously, and someone would spend time talking about.

HA: 'And is that something different offering him that, that you wouldn’t have done before if you hadn’t done the course?’

PN: ‘Yes, definitely.’ (PN5)

Programme map: cancer as a long-term condition: practice nurse pilot

Context/rationale
(key issues/problems that you are trying to address)

There have been marked changes in outcomes for people diagnosed with cancer, with increasing numbers of people living with and beyond cancer.

As a result, cancer is increasingly being conceived as a chronic condition with new and alternative approaches being considered for patient follow-up.

Practice nurses have been identified as key professionals in primary care who could have a vital role in managing cancer as a chronic condition.

Practice nurses are already managing routine follow-up for other long-term conditions such as asthma, diabetes, chronic heart disease and Chronic Obstructive Pulmonary Disease (COPD). Many of the skills required to do this are transferable and could be applied to the follow up and long-term management of cancer patients.

In January 2011, Macmillan commissioned an online survey of 251 UK practice nurse to gather information about the type of chronic conditions they are managing, the skills involved and their level of confidence in relation to these.

The survey found that while a significant number of practice nurses are involved in management of other chronic conditions few are involved in managing cancer nor do they feel they have the skills and confidence to do so.

The purpose of this pilot is to explore the role of practice nurses in managing cancer as a chronic illness.

The pilot is in line with one of Macmillan’s strategic outcomes: I get the treatment and care which are best for my cancer and my life.
**Inputs/activities**

_The activities you are delivering through the programme/service_

- 8–10 participating GP practices from Central and South West of England.
- Mentor packs provided for participating GP practices.
- Cancer scenarios/action learning sets developed to build nurses’ skills and confidence regarding management of cancer.
- Learning materials relating to the action learning sets and other course components developed.
- Course delivered through 8 workshops (6 half-day and 2 whole days) for participating practice nurses over a six-month period.
- Support and mentorship for each nurse provided by a nominated GP from their practice.
- Reflective log kept by practice nurses about the course and application of learning.
- Payment of £1,000 made to each participating practice (to cover release of practice nurses, engagement of the practice in the project and GP mentorship).
- Technical advice from Cancer Network Patient Participation Panel in relation to development of course content.

**Outputs**

_Direct outputs from the programme – usually things that can be quantified and collected through monitoring data eg no. of staff trained, no. of people using the service_

- Number of workshops held.
- Number of nurses who complete the course.
- Attendance rates at the workshops.
- Number of practices in which learning sessions on cancer were organised by participating nurses.
- Number of patients living with cancer being supported by each practice nurse (and their cancer type).
- Type of activities relating to care of cancer patient (eg managing ongoing treatments, monitoring side effects, monitoring for long-term effects of treatment) in which practice nurses are engaging.
- Number of nurses inviting patients for cancer care reviews.
- Number of nurses using assessment and care planning tools.
- Number of nurses who have contacted colleagues in secondary care.
- Number of nurses who have given presentations to practice staff.
- Practice nurses ratings of their levels of confidence in relation to specific elements of cancer management.

**Outcomes**

_The outcomes you would expect to see during the lifetime of the programme, ie in the short to medium term, for the main beneficiaries and any other key stakeholders_

**Outcomes for nurses’ learning:**

- Increased knowledge of cancer as a disease and its treatment.
- Increased knowledge of the indicators of recurrence and of what to do when indicators appear.
- Increased understanding of cancer as a long-term condition.
- Increased knowledge of how to support people with cancer to self-manage (health and lifestyle) like patients with other chronic conditions.
- Increased knowledge of how to assess patients’ needs including needs relating to the disease, to treatment and beyond.
- Increased awareness of the resources available for patients living with cancer.
- Increased understanding of when patients would benefit from referrals (for medical, psychological, financial or social support).
- Increased ability to communicate effectively with patients living with cancer.
- Increased ability to communicate about difficult issues to patients living with cancer.
- Increased understanding of key concepts and developments in cancer care like the cancer care review, assessment and care planning, treatment summary.
- Increased awareness of where learning resources are available for themselves and colleagues.
- Increased confidence in ability to manage cancer as a chronic condition.

**Behaviour:**

- Deal with more patients living with cancer.
- Adopt a changed pattern of care that involves more proactive, scheduled interactions with patients living with cancer.
- Invite patients for cancer care reviews.
- Use available clinical tools routinely for identifying patient needs.
- Encourage patients to be proactive/take action in managing their condition.
- Make recommendations to patients about exercise and lifestyle.
- Communicate with patients living with cancer more effectively and in relation to a wider range of issues including those that may be sensitive/difficult.
- Signpost patients to other services more often and more effectively.
Outcomes (continued)

Behaviour (continued):
Assess patients’ need for information and provide information or refer to other sources as appropriate.
Assess the effect of cancer on family members/careers when appropriate.
Make themselves available to others as a resource in the practice.
Act as a catalyst in the practice for better support to patients living with cancer.

Outcomes for practices:
All practice staff (GPs, nurses and reception staff) are more engaged on issues relating to cancer.
Have a better understanding of issues relating to management of cancer.
Provide better support for patients living with cancer.
Some practices start to have discussions about disinvestment in routine standard follow-up.

Outcomes for patients’ learning:
Increased knowledge of what they can do to help themselves.
Increased understanding of the benefits of exercise and adopting a healthy lifestyle.
Increased awareness of the information available to them.
Increased awareness of available services and resources.
Increased confidence in their ability to self-manage.

Behaviour:
Take a more active role in managing their condition on an ongoing basis.
Make positive choices about exercise and lifestyle.
Take action to improve their overall quality of life (e.g., improving/restoring relationships, going back to work).
Use the practice more often as a source of information and support.
Make use of other services and sources of information when needed.

Outcomes for Macmillan:
Increased understanding of practice nurses’ learning needs in relation to the management of cancer as a chronic condition.
More insight into the course content and educational materials that best meet the learning needs of practice nurses.
More insight into the potential role of practice nurses in long-term cancer management and opportunities and challenges relating to this.
More insight into how the transformed care pathway element of care coordination in the survivorship phase can be practically delivered.
Contributes to achieving strategic objective 3 (I get the treatment and care which are best for my cancer and my life).

Impact (longer term impact resulting from the outcomes – often the ultimate aims of the programme which are unlikely to be achieved within its lifetime)
The pilot informs Macmillan’s future learning and education activities for practice nurses, including possible roll-out of the pilot.
Information and experience gained from the pilot informs Macmillan’s activities in workforce development – both in the development of new primary care nurse roles and an increased utilisation of existing roles for cancer care.
Practice nurses are more involved in managing cancer as a chronic condition.
More people living with cancer are supported by their GP practices in relation to long-term management of their condition.
More people living with cancer receive better care and support and enjoy a better quality of life.
Appendix 2:
Self assessment evaluation data for nurses: aggregated charts

Q1 Our practice invites most patients who have been treated for cancer for regular nurse led reviews

Key
5 Agree strongly
4 Agree
3 Don’t know/unsure
2 Disagree
1 Disagree Strongly

Pre-course  Post-course
88.8% disagreed before the course  33.3% agreed after the course

Q2 I am heavily involved in the follow up and support of patients who have been treated for cancer

Pre-course  Post-course
100% disagreed before the course  77.7% agreed after the course

Q3 I usually use a checklist to assess a patient’s physical and psychological state after cancer treatment

Pre-course  Post-course
88.8% disagreed before the course  88.8% agreed after the course

Q4 I often give patients written information about cancer and its treatment

Pre-course  Post-course
88.8% disagreed before the course  88.8% agreed after the course
Q5  I have a good understanding of cancer as a disease

66.6% disagreed before the course  100% agreed after the course

Q6  I have a good understanding of the different types of treatment for cancer

55.5% disagreed before the course  55.5% agreed after the course

Q7  I have a good understanding of the short term and long term effects of cancer

55.5% disagreed before the course  100% agreed after the course

Q8  I have a good understanding of the short term and long term effects of cancer treatments

66.6% disagreed before the course  55.5% agreed after the course
Q9. I feel confident about my ability to respond to patients’ questions about cancer

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Key:
5 Agree strongly
4 Agree
3 Don’t know/unsure
2 Disagree
1 Disagree Strongly

77.7% disagreed before the course  77.7% agreed after the course

Q10. I feel confident about my ability to assess the needs of patients who have recently completed cancer treatment

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<tr>
<td>D</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>E</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>F</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>G</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>H</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>I</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

Key:
5 Agree strongly
4 Agree
3 Don’t know/unsure
2 Disagree
1 Disagree Strongly

77.7% disagreed before the course  59.9% agreed after the course

Q11. I feel confident about my ability to support patients living with cancer to manage their condition

<table>
<thead>
<tr>
<th></th>
<th>Pre-course</th>
<th>Post-course</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>B</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>C</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>D</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>E</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>F</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>G</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>H</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>I</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

Key:
5 Agree strongly
4 Agree
3 Don’t know/unsure
2 Disagree
1 Disagree Strongly

77.7% disagreed before the course  77.7% agreed after the course

Q12. I understand the risks of exercise for patients who are undergoing or who have completed cancer treatment

<table>
<thead>
<tr>
<th></th>
<th>Pre-course</th>
<th>Post-course</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>B</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>C</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>D</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>E</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>F</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>G</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>H</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>I</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

Key:
5 Agree strongly
4 Agree
3 Don’t know/unsure
2 Disagree
1 Disagree Strongly

66.6% disagreed before the course  100% agreed after the course
Q13 I understand the benefits of exercise for patients who are undergoing or who have completed cancer treatment

Key
5 Agree strongly
4 Agree
3 Don’t know/unsure
2 Disagree
1 Disagree Strongly

Pre-course Post-course
44.4% disagreed before the course 100% agreed after the course

Q14 In consultations with patients living with cancer, I regularly make recommendations about exercise

Pre-course Post-course
66.6% disagreed before the course 77.7% agreed after the course

Q15 I feel confident in facilitating and encouraging patients living with cancer to take responsibility for their health

Key
5 Agree strongly
4 Agree
3 Don’t know/unsure
2 Disagree
1 Disagree Strongly

Pre-course Post-course
55.5% disagreed before the course 100% agreed after the course

Q16 I am aware of information prescriptions

Pre-course Post-course
77.7% disagreed before the course 55.5% agreed after the course
Q17 I feel confident in identifying the indicators of cancer recurrence

77.7% disagreed before the course 44.4% agreed after the course

Q18 I feel confident in signposting patients living with cancer to other services and resources

77.7% disagreed before the course 44.4% agreed after the course

Q19 I regularly signpost patients living with cancer to other services and resources

55.5% disagreed before the course 88.8% agreed after the course

Q20 I feel confident discussing the wider effects of cancer on patients’ lives (e.g. self-image, sexuality)

77.7% disagreed before the course 77.7% agreed after the course
Appendix 3: PPiC overall nurse report

Patient Partnership in Care

Report

Overall Nurse Report

March 2013

Introduction

The Patient Partnership in Care (PPiC) questionnaire was designed to help you gain an insight into how patients view your skills to enable and motivate them to self-care and to assess their confidence to do this.

This report is an indicator of the quality of the partnership you have with your patients (questions 1-11) and provides you with their current level of motivation and confidence to self-care (questions 12-19). Reflection on your report may help you to further encourage self-care, reinforcing the partnership and the motivation, confidence and enablement process. In addition it could be useful feedback for your professional development.

Reading the report

When reading through your report, it is really important to note your strengths as well as any development needs. It can be too easy to focus on low scores or scores you are not happy with, therefore avoid simply scanning the report. The summary sheet is useful for rapid reflection in the workshop but time is needed to digest the feedback as a whole. There is important quantitative and qualitative information within the report which can be overlooked at a glance.

Full explanation on how to interpret the graphs and tables can be found in the report. All feedback comes with benchmarks for each evaluation question.

Suggestions for Reflection

The review record provides a few suggestions as to what to look for in the comments, graphs and tables that make up your patient feedback. These are merely a guide and possibly a helpful starting point for reflection. You may find it useful to make a few notes here prior to the meeting with your trainer. It has been designed to make your report more relevant to your appraisal process and enable you to present the summary report as part of your portfolio evidence should you wish to. Please note that the emphasis in the questionnaire is not about clinical competency but rather on the interpersonal and motivational dimension of the consultation process.

It may be important to think about any special or unusual things happening in your life around the time the survey was done (at the surgery, at home, elsewhere). How might these have impacted on the way you related to your patients at this particular time?

Sources of Support

It is important that there are resources available for support following feedback. It is advisable to discuss your results with someone else to get their objective perspective, e.g. trainer, appraiser, colleague, spouse/partner etc as long as it is someone you can trust and who you feel can provide you with the support you need. Relevant professional bodies may also be sources of support.
Patient Partnership in Care

Report Contents

1. Summary
   - Summary of evaluation results

2. Patient feedback from the FPIC survey

Questions 1 – 11
   - Interpersonal skills and patient partnership, rated on a 1 - 5 scale
   - Distribution and frequency of ratings (table 1)
   - Percentage of ratings by question (graph 1)
   - Mean percentage scores and benchmarks (table 2)
   - Mean percentage scores in ascending order of performance (graph 2)

Questions 12 - 16
   - Patient confidence to self care, rated on a 1 - 10 scale
   - Distribution and frequency of ratings (table 3)
   - Mean percentage scores and benchmarks (table 4)

Patient demographics

Breakdown of patients undertaking the survey
   - Categorised according to age, gender, visit type and EPP (table 7)

Patient comments

From the free text component of the questionnaire
   - Categorised according to age, gender and visit type

Supporting documents

Score Explanation
   - Appendix 1

Sample questionnaire
   - Appendix 2

Patient Partnership in Care

Summary of evaluation results

<table>
<thead>
<tr>
<th>Question</th>
<th>Your mean score (%)</th>
<th>National mean (%)</th>
<th>Performance band (current)</th>
<th>Performance band (previous)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1 Ability to ask you what you wanted to talk about</td>
<td>84</td>
<td>80</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Q2 Ability to give you the information you wanted</td>
<td>83</td>
<td>81</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Q3 Opportunity to talk about your concerns and fears</td>
<td>89</td>
<td>81</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Q4 Ability to really listen to you</td>
<td>91</td>
<td>82</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Q5 Your understanding of your health condition</td>
<td>78</td>
<td>74</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Q6 Understanding your personal situation</td>
<td>90</td>
<td>79</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Q7 Patient understanding of healthcare issues</td>
<td>93</td>
<td>78</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Q8 Support for managing your care</td>
<td>83</td>
<td>76</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Q9 Getting answers to future questions</td>
<td>83</td>
<td>75</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Q10 Following up on your health care</td>
<td>88</td>
<td>79</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Q11 Your partnership with your care</td>
<td>89</td>
<td>81</td>
<td>2</td>
<td>-</td>
</tr>
</tbody>
</table>

Q1 2 Confidence to carry out your plan
   - Your mean score for this question falls in the highest 25% of all means (above Q3)
   - Your mean score for this question falls in the highest 50% of all means (above Q2)
   - Your mean score for this question falls in the lowest 25% of all means (below Q3)
   - Your mean score for this question falls in the lowest 25% of all means (below Q1)
Patient Partnership in Care

Interpersonal skills and patient partnership - Questions 1 - 11

Table 1 Distribution and frequency of ratings

<table>
<thead>
<tr>
<th></th>
<th>Blank</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td>Q2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Q3</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Q4</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Q5</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>6</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Q6</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Q7</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>4</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Q8</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Q9</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Q10</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Q11</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>6</td>
<td>11</td>
</tr>
</tbody>
</table>

Blank responses are not included in the score calculation.

Graph 1 Percentage of ratings by question

Graph 2 Mean percentage scores in ascending order of performance

Table 2 Mean percentage scores and benchmarks

<table>
<thead>
<tr>
<th></th>
<th>Your mean score (%)</th>
<th>Deviation from the national mean (%)</th>
<th>National mean (%)</th>
<th>National quartiles (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>84</td>
<td>+4</td>
<td>80</td>
<td>78 81 85</td>
</tr>
<tr>
<td>Q2</td>
<td>83</td>
<td>+2</td>
<td>81</td>
<td>80 82 85</td>
</tr>
<tr>
<td>Q3</td>
<td>83</td>
<td>+2</td>
<td>81</td>
<td>78 81 85</td>
</tr>
<tr>
<td>Q4</td>
<td>91</td>
<td>+8</td>
<td>83</td>
<td>80 85 87</td>
</tr>
<tr>
<td>Q5</td>
<td>78</td>
<td>+4</td>
<td>74</td>
<td>72 75 79</td>
</tr>
<tr>
<td>Q6</td>
<td>80</td>
<td>+2</td>
<td>76</td>
<td>76 78 82</td>
</tr>
<tr>
<td>Q7</td>
<td>83</td>
<td>+5</td>
<td>78</td>
<td>75 79 82</td>
</tr>
<tr>
<td>Q8</td>
<td>83</td>
<td>+5</td>
<td>76</td>
<td>75 79 82</td>
</tr>
<tr>
<td>Q9</td>
<td>83</td>
<td>+8</td>
<td>75</td>
<td>73 77 79</td>
</tr>
<tr>
<td>Q10</td>
<td>85</td>
<td>+7</td>
<td>78</td>
<td>76 79 82</td>
</tr>
<tr>
<td>Q11</td>
<td>89</td>
<td>+8</td>
<td>81</td>
<td>78 81 85</td>
</tr>
</tbody>
</table>

*Based on data from 77 health professionals participating in CCII with 18 or more patient responses.
### Patient Partnership in Care

#### Patient confidence to self care - questions 13 - 16

Table 3 Distribution and frequency of ratings

<table>
<thead>
<tr>
<th>Q</th>
<th>Confidence to carry out your plan</th>
<th>No of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>0/0/0/0/1, 0/1/4/3/10</td>
<td>5</td>
</tr>
<tr>
<td>14</td>
<td>0/0/0/0/0, 0/3/2/4/9</td>
<td>5</td>
</tr>
<tr>
<td>15</td>
<td>0/0/0/0/0, 0/0/1/4/15</td>
<td>5</td>
</tr>
<tr>
<td>16</td>
<td>0/0/0/0/0, 0/2/3/4/9</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q 13</th>
<th>Importance to maintain/improve health</th>
<th>No of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>13</td>
<td>0/0/0/0/0, 0/1/2/3/14</td>
<td>5</td>
</tr>
</tbody>
</table>

**Blank = Blank**

Blank responses are not included in the score calculation.

Table 4 Mean percentage scores and benchmarks

<table>
<thead>
<tr>
<th>Q</th>
<th>Confidence to carry out your plan</th>
<th>Mean</th>
<th>Lower quartile</th>
<th>Median</th>
<th>Upper quartile</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>0/0/0/0/1, 0/1/4/3/10</td>
<td>86%</td>
<td>81</td>
<td>84</td>
<td>86</td>
</tr>
<tr>
<td>13</td>
<td>0/0/0/0/0, 0/3/2/4/9</td>
<td>95%</td>
<td>92</td>
<td>94</td>
<td>95</td>
</tr>
<tr>
<td>14</td>
<td>0/0/0/0/0, 0/3/2/4/9</td>
<td>87%</td>
<td>75</td>
<td>79</td>
<td>83</td>
</tr>
<tr>
<td>15</td>
<td>0/0/0/0/0, 0/3/2/4/9</td>
<td>97%</td>
<td>87</td>
<td>90</td>
<td>92</td>
</tr>
<tr>
<td>16</td>
<td>0/0/0/0/0, 0/2/3/4/9</td>
<td>86%</td>
<td>78</td>
<td>81</td>
<td>84</td>
</tr>
</tbody>
</table>

* Based on data from 77 health professionals participating in CCH with 16 or more patient responses - benchmarks not currently available.

Please note if there are less than 15 valid responses, please treat your mean score with caution. A valid response does not include questions left blank or marked as N/A (see Table 3).

### Patient Partnership in Care

#### Patient demographics - breakdown of patients undertaking the survey

Table 7 Numbers of patient responses by age, gender, visit type and EPP

<table>
<thead>
<tr>
<th>Age</th>
<th>No of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt; 60</td>
<td>15</td>
</tr>
<tr>
<td>25 - 69</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>No of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>10</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How often you have seen nurse</th>
<th>No of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blank</td>
<td>5</td>
</tr>
<tr>
<td>More than once</td>
<td>15</td>
</tr>
<tr>
<td>First Visit</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Main reason for consultation</th>
<th>No of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>An appointment for blood test/injection/other</td>
<td>13</td>
</tr>
<tr>
<td>Other reason</td>
<td>2</td>
</tr>
<tr>
<td>A planned cancer care review appointment</td>
<td>7</td>
</tr>
<tr>
<td>I had questions I wanted to ask/things to discuss</td>
<td>2</td>
</tr>
</tbody>
</table>

* Number of responses = Total number of responses as more than one response option could be selected.
Cancer as a long-term condition: Practice nurse pilot evaluation

**Patient Partnership in Care**

Patients Surveyed: 20

**Patient Comments - from the free text component of the questionnaire**

Comments are provided in their entirety apart from any personal identifiers to ensure patient anonymity.

- I have found it very difficult to complete this questionnaire as my treatment for cancer was years ago, so I have given my answers really in relation to other serious health problems not related to the cancer. I have received wonderful care from all the nurses at all times.
- I need to be more clear about my needs and not afraid to ask questions about my treatment and available support.
- I forgot to ask about pain control - the pain that sometimes and unpredictably follows an injection and chemotherapy (e.g. bone pain). Should I contact Chemo Doc or my nurse?
- Excellent overall care from nurses.
- Contact with nurse mainly for weekly PAS injection only might help if allocated to same nurse. Some nurses very helpful.
- Everything is made very clear. Nurses are positive, constructive and helpful.
- Need to monitor effects of chemotherapy during gap between treatments.
- Continue appointments to fit work commitments.
- Be able to talk over the phone or have an appointment with my nurse if I am struggling.

*For less than 2 responses in any category combined, demographic details have been suppressed to maintain patient anonymity.*
# Cancer as a long-term condition: Practice nurse pilot evaluation

## Patient Partnership in Care

### Score Explanation

The score for each evaluation question in the PPC survey is expressed as a mean (average) for all patients who rated the question. The scores are expressed as a percentage of the maximum possible score, so the best possible score in each case is 100.

<table>
<thead>
<tr>
<th>Percentage Score (%)</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
<th>Not Specified</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>25</td>
<td>50</td>
<td>75</td>
<td>100</td>
<td>n/a</td>
</tr>
</tbody>
</table>

See example from your question 7 below

### Questions

<table>
<thead>
<tr>
<th>Rating</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
<th>Not Specified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1 Ability to ask you what you wanted to talk about</td>
<td>0</td>
<td>5</td>
<td>2</td>
<td>12</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

\[
\text{Percentage Score (\%)} = \frac{Q1 \times 25 + (5 \times 50) + (2 \times 75) + (12 \times 100)}{20} = 94\% \text{ mean percentage score}
\]

### Q12 - Q16 Percentage Score

<table>
<thead>
<tr>
<th>Rating</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
<th>Excellent</th>
<th>Not Specified</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q12 Confidence to carry out your plan</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

\[
\text{Percentage Score (\%)} = \frac{Q12 \times 25 + (5 \times 50) + (2 \times 75) + (12 \times 100)}{20} = 86\% \text{ mean percentage score}
\]

### Explanation of Quantiles

In statistics a quartile is any one of the three values that divide data into four equal parts, each part represents 25% of the sampled population.

Quantiles are a useful measure of the dispersion of a statistical distribution because they are not affected by freak extreme values.

They comprise:
- First quartile = lower quartile, below which lies the lowest 25% of the data
- Second quartile = the median, cuts the data set in half
- Third quartile = upper quartile, above which lies the top 25%

<table>
<thead>
<tr>
<th>Your mean score (%)</th>
<th>National mean</th>
<th>National quartiles (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1 Ability to ask you what you wanted to talk about</td>
<td>84</td>
<td>Q1 25%</td>
</tr>
</tbody>
</table>

\[
\text{Q1} = 25\%
\]

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**Survey provided by**

[Link to CFEP UK Surveys](https://www.cfep.org.uk)

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After seeing your nurse today
Out of a scale 0 to 10 please rate the following

<table>
<thead>
<tr>
<th>Example</th>
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<tr>
<td>Not confident 0</td>
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12 How confident are you that you can carry out what you and your nurse planned today?

13 How confident are you that you can maintain and improve your health?

14 How confident are you that you can cope with your health condition in a day to day situation?

15 How confident are you that the nurse will follow up on the plans you made today?

16 How confident are you that you can do things to care for yourself?

Do you have any comments on things you and your nurse could do to help you to further manage your condition?

What extra support would be useful to you (for example information about support groups or organisations, or help with use of devices and equipment)?

The following questions give us general information about the range of people who have filled in this survey. This information will not be used to identify you and will remain confidential.

Please could you give the main reason for your consultation today (please tick one box only)

A planned cancer care review appointment

Because I had questions I wanted to ask or things to discuss

How old are you in years? Under 25 | 25 - 59 | 60+

Are you: Female | Male

How often have you seen this nurse? First Visit | More than once

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Rev 1.0
More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of loneliness and isolation that so many people experience make it even harder.

No one should face cancer alone. And with your support no one will.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call us free on **0808 808 00 00** (Monday to Friday, 9am–5 pm) or visit [macmillan.org.uk](http://macmillan.org.uk)