

# CANCER AS A LONG TERM CONDITION

Macmillan Cancer Support helps to develop  
the role of Practice Nurses

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'I can envisage practice nurses taking on the role which 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. '

Practice nurse

# Introduction

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.

They already manage 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 nurses and found that 86% would be interested in doing more with people affected by cancer if they could have the necessary training and support.

Macmillan then commissioned a pilot course to discover what the learning needs of practice nurses would be 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 whole and seven half day workshop sessions, with reflective group work, role play and sessions from the course leader and external presenters. Participants were encouraged to do work in their practices between sessions, applying what had been learnt to their everyday work.



Participants at the first practice nurse course showcasing a piece of work around points of intervention for supporting people affected by cancer.

# Evaluation

The evaluation considered how nurses have made a difference for both people affected by cancer and their practice and colleagues, what they are doing differently as a result of the course, and their learnings in terms of knowledge, confidence, skills and strategies.

The findings show that there were considerable learnings for the 10 nurses who took part. The knowledge gained from the course gave a greater sense of confidence and competence in the participants, as shown in the before-and-after self assessment questionnaire (see appendix 4). This in turn led to an increased willingness to have conversations with people affected by cancer, whereas previously these nurses would have avoided this. It also led to the nurses extending their role, conducting both scheduled and opportunistic cancer care reviews as well as offering support on a more ad hoc basis.

At the outset of the course, the hopes of practice nurses included gaining a greater understanding of cancer care and being able to provide better long-term management. Some also hoped to address fears about cancer, to be able to do cancer care reviews and to obtain ideas about starting clinics for all chronic diseases. GP supporters hoped that the nurses would gain increased knowledge, interest and confidence that they could cascade to the rest of the team; and to identify patients in a structured way, having a lead nurse in the practice who would be a first point of call.

There was an appreciation that this approach fitted with the goal of more integrated care that would aid continuity. There was also a realisation that strategies of long-term condition management would be applicable to many people affected by cancer, but that this has implications for the development of the workforce in primary care.

**'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 everything.'**

GP Supporter

The full evaluation gives many examples of changed behaviours on the part of the nurses as well as some altered practice procedures, and there are many stories that indicate clear benefit for patients and their family or carers as a result. These changes were confirmed by interviews with the 10 supporting GPs as well as the patient partnership panel representative who attended all the sessions. At times, GPs may suggest which patients are appropriate for nurses to see at review, and the nurses may also make suggestions. 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 conditions and therefore did not need to consult so often.

This evaluation relates to the first pilot course. There are eight further pilot courses planned or running across the UK to test if the course can be transferred to other areas. As a similar model is used in different contexts it is important that the learnings about meeting particular needs of each area are recognised, and that the course framework is flexible enough to accommodate these – one size will not fit all. Also, it will be interesting to explore different partnerships that may help future sustainability. However, this positive evaluation supports the approach of offering further targeted education to primary and community care nurses already in post, as opposed to developing new or specialist posts.

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Macmillan GP Advisor  
(and originator of the Somerset pilot)**

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# Appendices

**Appendix 1:** Summary benefits of the course

**Appendix 2:** Experiences of practice nurse participants

**Appendix 3:** Experiences of GP supporters

**Appendix 4:** Before and after self-assessment of activity, knowledge and confidence

For a copy of the full evaluation, please contact  
[macmillan\\_primary\\_care@macmillan.org.uk](mailto:macmillan_primary_care@macmillan.org.uk)

# Appendix 1

Summary benefits of the course (see full evaluation for more detail)

Benefits to people with cancer	Benefits to practice colleagues	Benefits to the practice nurse
<ul style="list-style-type: none"> <li>• Practice nurses now have an increased ability to communicate effectively with people living with cancer.</li> <li>• Practice nurses now act as a catalyst in the practice for better support to people living with cancer.</li> <li>• Practice nurses have increased knowledge of what people affected by cancer can do to help themselves.</li> <li>• Practice nurses have an increased understanding of the benefits of exercise and adopting a healthy lifestyle.</li> <li>• 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).</li> <li>• Practice nurses have an increased awareness of the information available to them.</li> <li>• Practice nurses have an increased awareness of available services and resources.</li> <li>• Practice nurses are increasing people's confidence in their ability to self-manage.</li> </ul>	<ul style="list-style-type: none"> <li>• Practice nurses make themselves available to others as a resource in the practice.</li> <li>• All practice staff (GPs, nurses and reception staff) are more engaged on issues relating to cancer.</li> <li>• Practice nurses have a better understanding of issues relating to management of cancer.</li> <li>• Practice nurses are providing better support for people living with cancer.</li> <li>• Patients are using the practice more often as a source of information and support.</li> </ul>	<ul style="list-style-type: none"> <li>• Increased knowledge of cancer as a disease and its treatment.</li> <li>• Increased knowledge of how to support people with cancer to self-manage (health and lifestyle) like patients with other chronic conditions.</li> <li>• Increased knowledge of how to assess people affected by cancers' needs including needs relating to the disease, to treatment and beyond.</li> <li>• Increased confidence in ability to manage cancer as a chronic condition.</li> <li>• Increased knowledge of the indicators of recurrence and of what to do when indicators appear.</li> <li>• Increased awareness of the resources available for people living with cancer.</li> <li>• Increased understanding of cancer as a long-term condition.</li> </ul> <p><b>Skills and strategies:</b></p> <ul style="list-style-type: none"> <li>• Increased ability to communicate about difficult issues to people living with cancer.</li> <li>• Increased understanding of key concepts and developments in cancer care like the Cancer Care Review, assessment and care planning, and treatment summary.</li> </ul>

## Summary benefits of the course (continued)

Benefits to people with cancer	Benefits to practice colleagues	Benefits to the practice nurse
<ul style="list-style-type: none"> <li>• Practice nurses are taking a more active role in managing cancer on an ongoing basis.</li> <li>• Practice nurses have a greater insight into the ongoing needs of people living with and beyond cancer and how to integrate these needs into existing care pathways.</li> </ul>		<ul style="list-style-type: none"> <li>• Increased use and awareness of learning resources, for themselves and colleagues.</li> <li>• Strategies and a readiness to support more people living with cancer.</li> <li>• Routine use of available clinical tools for identifying patient needs.</li> <li>• Signposting patients to other services more often and more effectively.</li> <li>• Making use of other services and sources of information when needed.</li> <li>• Greater insight into the course content and educational materials that can help to meet the learning needs of practice nurses.</li> <li>• Encouraging people living with cancer to be proactive and take action in managing their condition.</li> <li>• Making recommendations to people living with cancer about exercise and lifestyle.</li> <li>• Communicating with people living with cancer more effectively and in relation to a wider range of issues including those that may be sensitive or difficult.</li> </ul>

# Appendix 2

## Experiences of practice nurse participants

'If I'd not have done the course they wouldn't have rung me... they probably would have spoken with the GP and you know I don't know I'm not saying that what I did was anything different to what the GP would have done, but they came in and they were with me for an hour, and they wouldn't have had that with the GP.'

'...I had a lady just now that I saw for a cancer care review and she said it was very useful having me here in the surgery because she said I can make an appointment with you any time and chat to you but I can't at the hospital... I think people often feel nurses have more time than GPs...and they can come and discuss non-medical problems like psychological issues or problems about appearance.'

'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.'

'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.'



## Experiences of practice nurse participants (continued)

'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.'

'I would never have approached someone with cancer about where they were in their cancer treatment.'

'I think 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.'

'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 then... he brought his wife in the next time so I was able to meet her.'

'I feel more understanding and in a better position now to be able to help... 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.'

# Appendix 3

## Experiences of GP supporters

'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.'

'I think from my perspective what I would really like us to start doing is maybe even just the older patients, even with diabetes, and heart failure is advance care planning.'

'One's 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.'

'And the other thing she's going to do is start doing carer assessments more as well.'

## Experiences of GP supporters (continued)

'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.'

'There's been this slight reluctance, I'm struggling to use the right words...for them 10 years down the line they might actually want to forget about it, but on the other hand there maybe be people out there who are desperate for help that's the danger.'

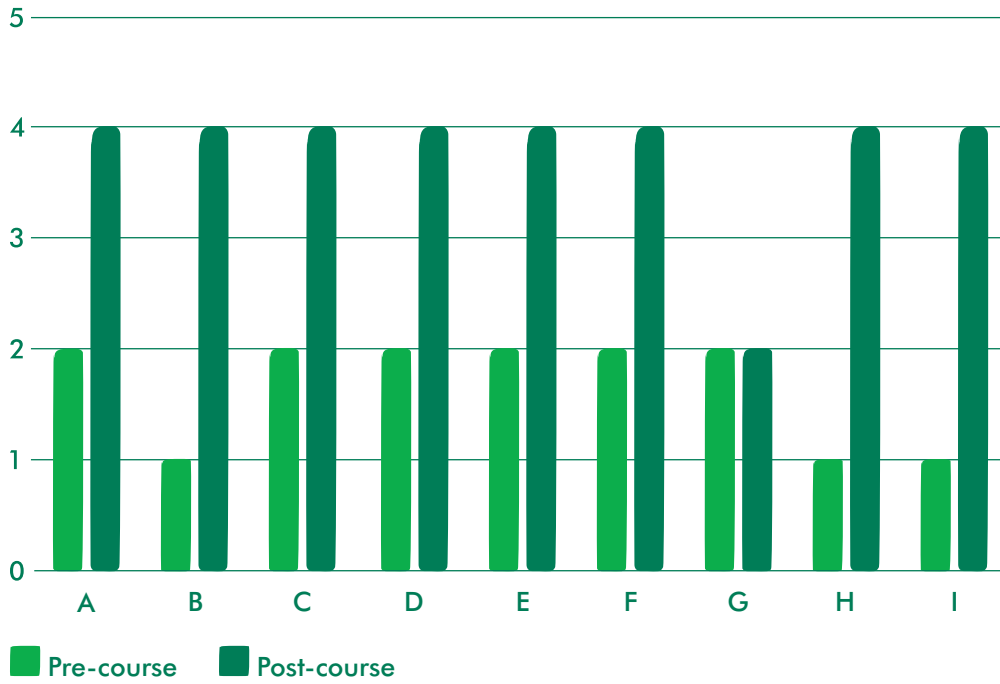
'...I was interested to see that the Macmillan team were learning about the art of chronic disease management from the nurses, as much as the nurses were learning about how to apply that to chronic disease, and I think that that's the whole new concept really isn't it, that cancer really now is another chronic disease and therefore needs to be managed as a continuum and I'm sure it will be.'

# Appendix 4

## Before and after self-assessment of activity, knowledge and confidence

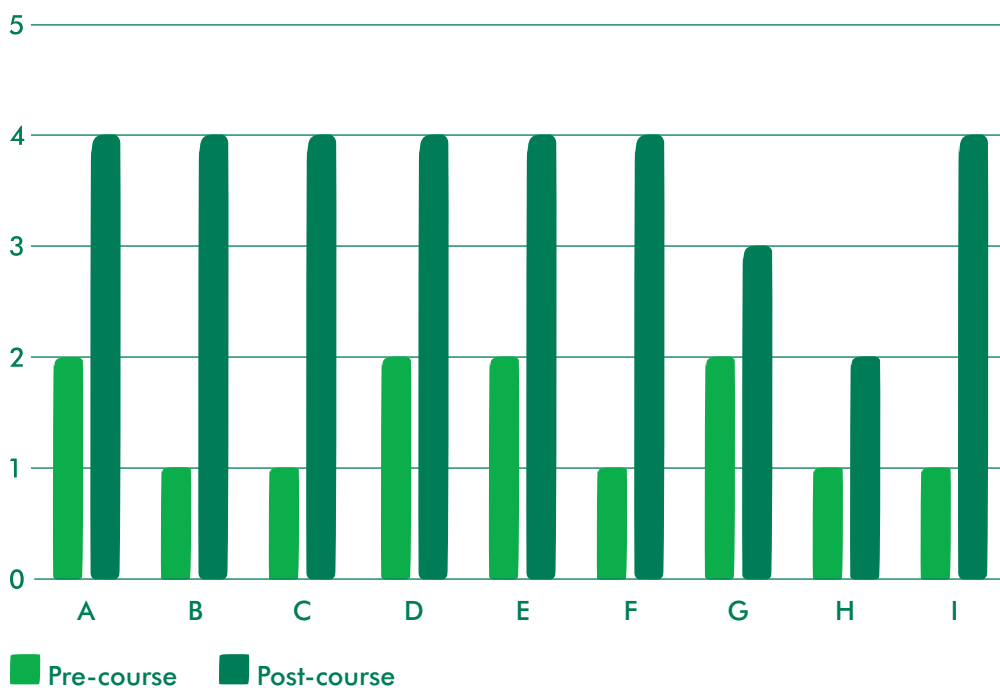
### Involvement in follow up and support

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



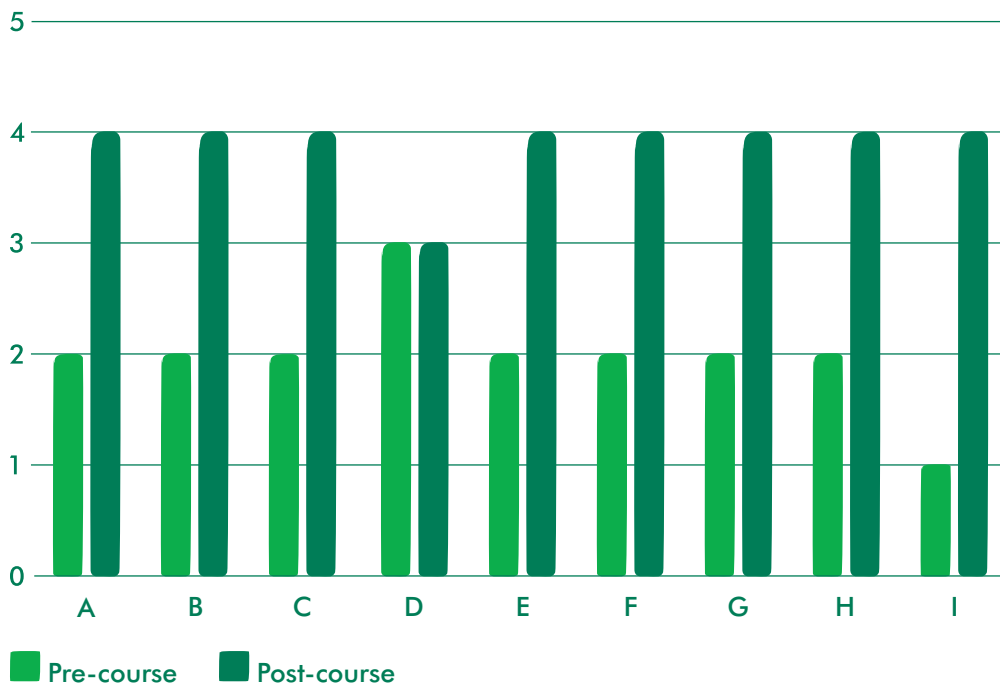
### Use of checklist – physical & psychological

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



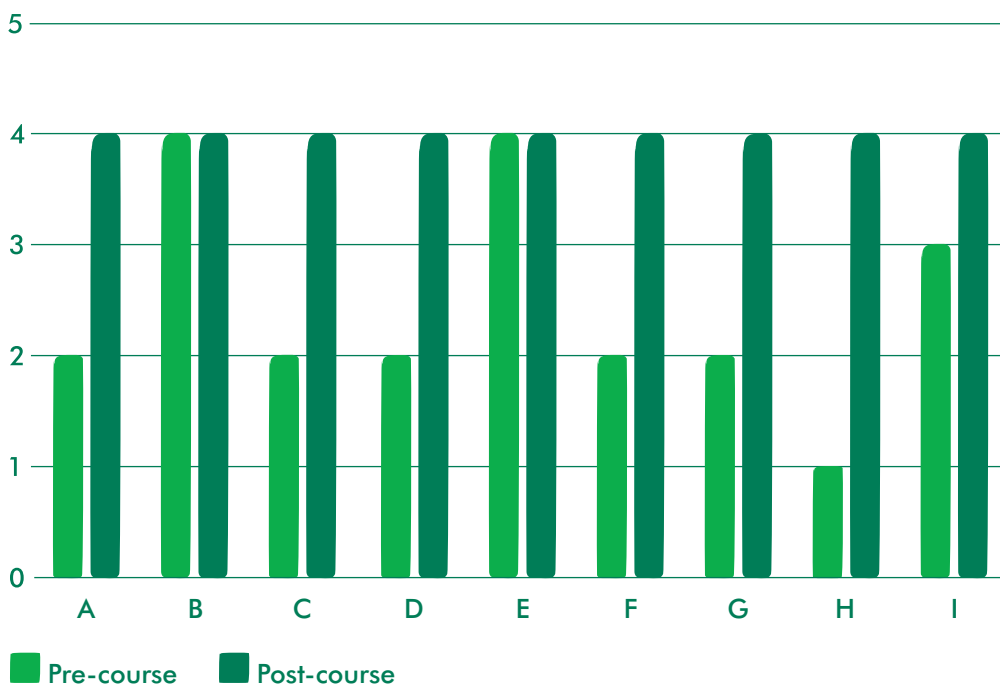
## Written information

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



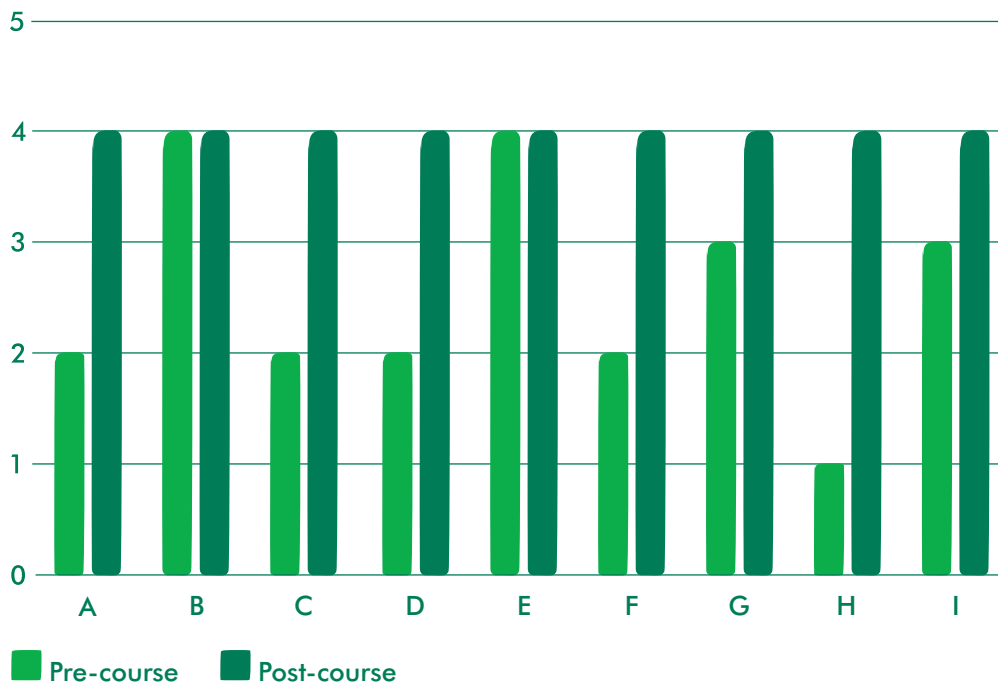
## Having a good understanding of cancer

Q5 I have a good understanding of cancer as a disease



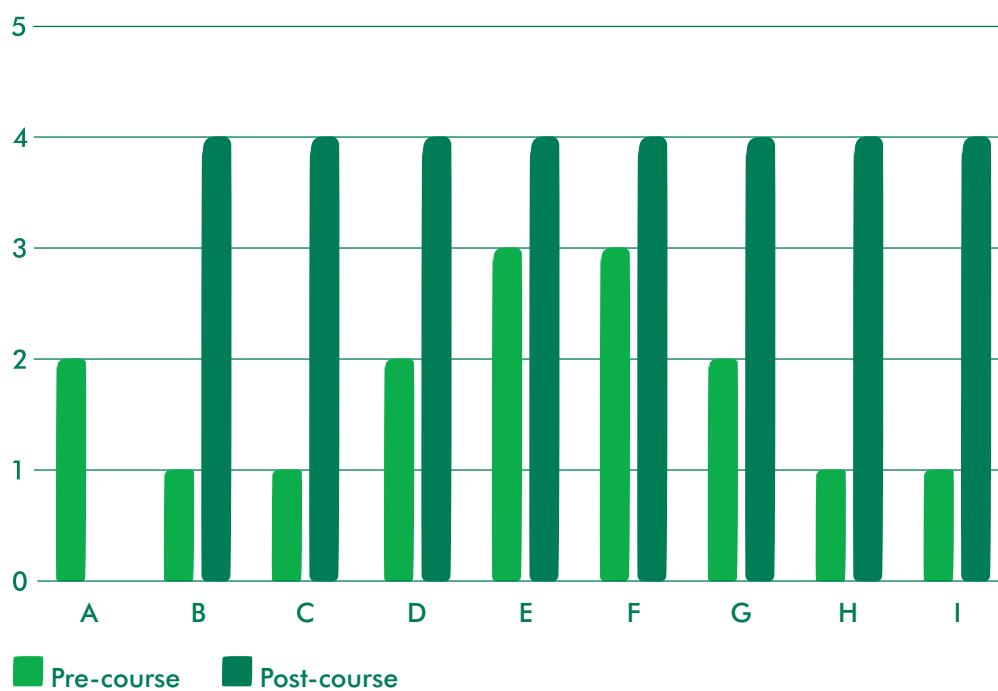
## Having a good understanding of short and long term effects of cancer

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



## Confidence about responding to patients' questions about cancer

Q9 I feel confident about my ability to respond to patients' questions about cancer



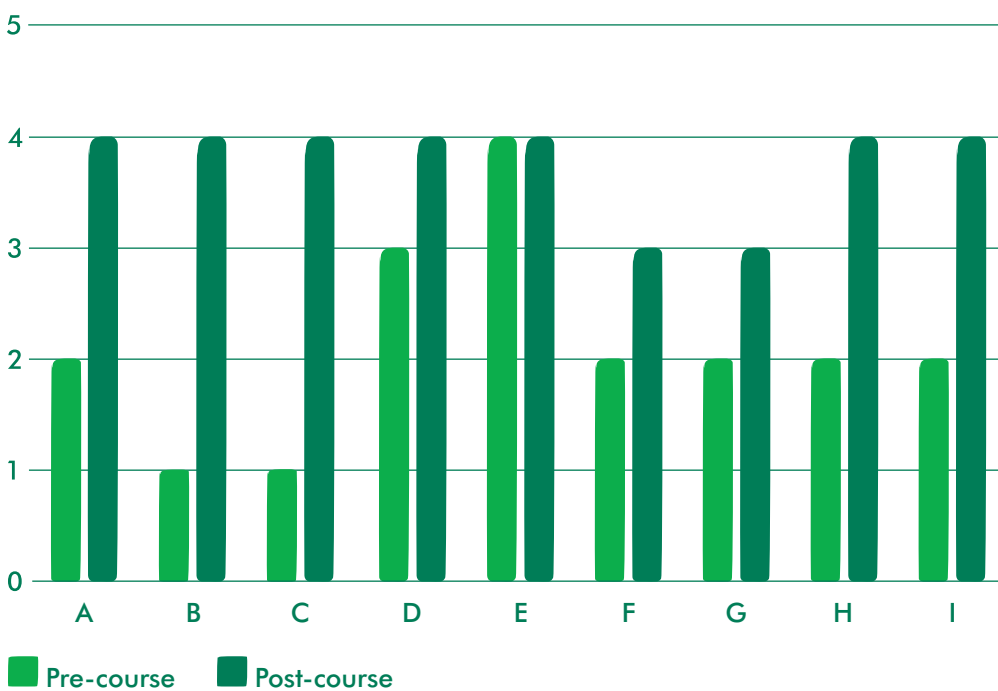
### Confidence about ability to assess needs

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



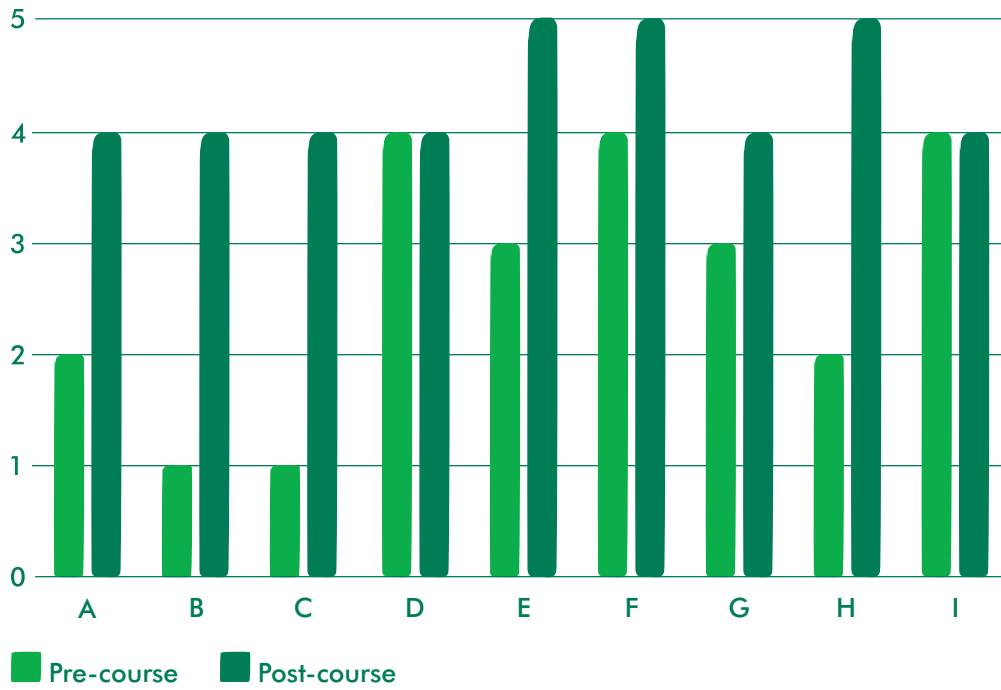
### Confidence about ability to support patients

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



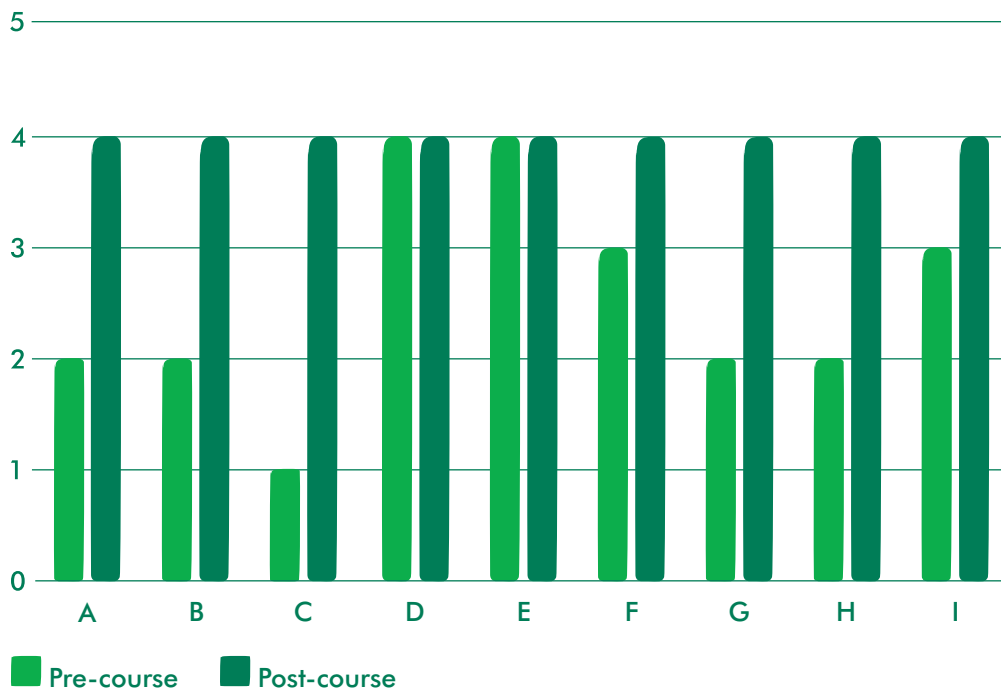
## Understand the benefits of exercise

Q13 I understand the benefits of exercise for patients who are undergoing or who have completed cancer treatment



## Confidence in encouraging patients to take responsibility for their health

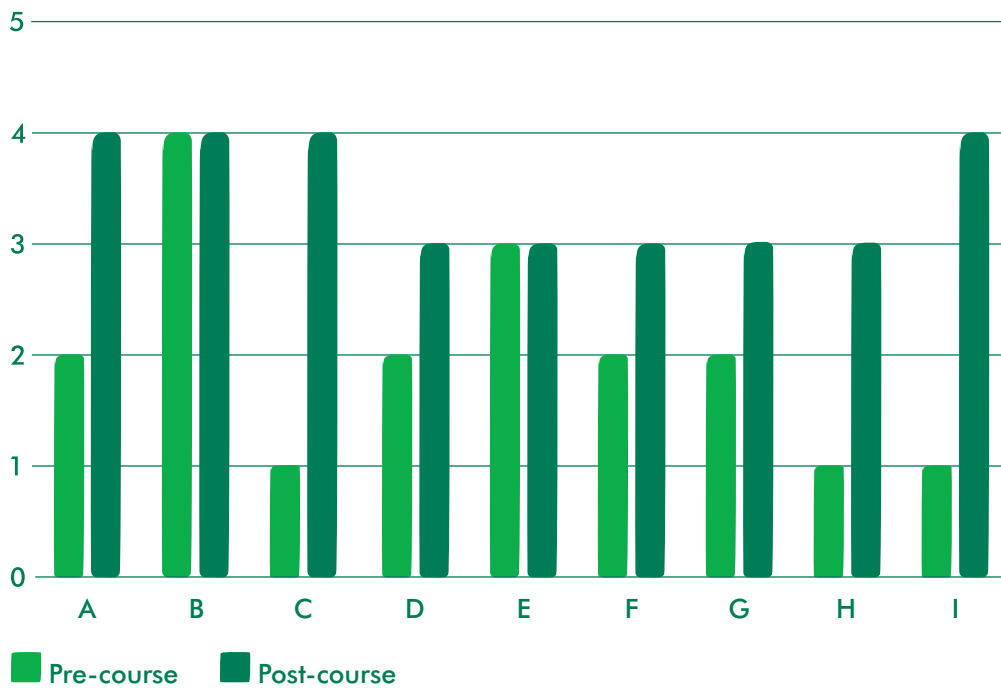
Q15 I feel confident in facilitating and encouraging patients living with cancer to take responsibility for their health





### Confidence in identifying indicators of recurrence

Q17 I feel confident in identifying the indicators of cancer recurrence



### Regularly signposting services and resources

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



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.

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on **0808 808 00 00** (Monday to Friday, 9am–5 pm)  
or visit **[macmillan.org.uk](https://www.macmillan.org.uk)**