

# How sharp can a screening tool be? A qualitative study of patients' experience of completing a bowel cancer screening questionnaire

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## Abstract

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### Accepted for publication

21 July 2010

**Keywords:** bowel cancer, screening, self completion questionnaire

**Introduction** There is evidence to suggest that the Patient Consultation Questionnaire (PCQ) is a reliable tool to predict symptomatic left-sided colorectal cancer. While previous research has examined the sensitivity and specificity of the PCQ as a tool, it has not addressed patients' perspectives.

**Objective** To examine qualitatively patients' perspectives on ease of use of the PCQ, and their attitude to completing it.

**Method** The target population were patients in North Wales between 55 and 85 years with colorectal symptoms who had completed the PCQ. A sample of six was randomly selected. The approach was qualitative, using semi-structured, in-depth cognitive interviews, which were recorded and transcribed before content and thematic analysis.

**Results** The study found some areas of concern in relation to the PCQ's design and presentation, concerning such issues as the use of medical jargon or ambiguous wording, and the use of questions to which patients may not have an answer. It also found that patients responded to the form as something more than a screening tool, treating it variously as way of speeding up diagnosis and treatment, an opportunity to 'play the system', and a way of bypassing embarrassing encounters.

**Discussion and conclusions** Although major problems were not identified, the minor issues observed in the PCQ's design and presentation may reduce accuracy and patient satisfaction. A greater understanding of patients' perception of the role and function of the PCQ may help clinicians to interpret responses to the form more accurately.

## Background

The risk of colorectal cancer (CRC) increases with age, and the earlier the cancer is detected, the better the outcome;<sup>1,2</sup> therefore, early prediction and rapid access to diagnosis are crucial. However, diagnosis is not a straightforward matter.<sup>3</sup> The common symptoms associated with left-sided colorectal disease are rectal bleeding, change in bowel habit and left-sided abdominal pain. As these symptoms are non-specific, occur relatively frequently in the population and have a variety of causes, it is difficult to predict and diagnose CRC. In addition to symptom information, accurate family cancer history can contribute to detection of certain types of CRC, although patients may underestimate incidence of cancer among relatives during a consultation.<sup>4</sup>

Since 2000, the NHS has operated the '2 week rule' – a requirement to fast track suspected CRC patients from primary to secondary care, to speed up the process of diagnosis in urgent cases. All patients with suspected CRC should see a specialist within 2 weeks of an urgent referral by their GP, where 'suspected' is defined as 'either a perceived level of probability or a hunch'.<sup>5</sup> Concerns have been raised that the '2 week rule' and associated guidelines may lack both sensitivity and specificity,<sup>5</sup> but it remains an element of the most recent policy framework for Wales.<sup>6</sup> NICE has provided GPs with a framework to guide referrals,<sup>7</sup> although one study has found that fewer than 60% of GPs were complying with the guidelines.<sup>8</sup>

To act as a tool in implementing the '2 week rule', a team of practitioners at a hospital in England developed the Patient Consultation Questionnaire (PCQ).<sup>9</sup> The PCQ is a self-completion questionnaire, which is sent or given to the patient before they are seen in the endoscopy clinic. It is designed to collect a more comprehensive set of information than that which would normally be obtained in an outpatient consultation, with less embarrassment. The four-page questionnaire contains 27 multiple choice questions, covering bowel habits, symptoms of concern, current medication, the patient's medical history and incidence of cancer

in the family. A 'free-text' box at the end allows patients to write down any other information which they think might be relevant.

In their own time, patients complete the questionnaire regarding their symptoms and when the data are entered into the computer, a weighted numerical score (WNS) is calculated automatically. The WNS is used by clinicians as a guide to help them decide whether a patient should be called urgently for a physical examination such as flexible sigmoidoscopy. A number of large scale prospective cohort studies have found the PCQ/WNS system to be an effective way to fast-track referrals and thus increase efficiency, as it is able to detect CRCs with both higher sensitivity and specificity than the DOH and NICE guidelines.<sup>8–11</sup>

One of these cohort studies, within a large NHS Trust in North Wales, provided the setting for the small scale qualitative study reported here, which was carried out in 2006 to examine patient experience of completing the PCQ. During this pilot phase of implementation of the PCQ, GPs' referral letters were assessed by a Consultant Colorectal Surgeon who then, if appropriate, arranged for the patient to be sent the questionnaire. The covering letter to patients which accompanied the PCQ described its purpose as saving time, but lacked information on the scoring system. Returned questionnaires were processed by a PCQ clerk who calculated the WNS, before the patient attended for investigation.

The efficacy of the WNS depends on the accuracy of the clinical and family history provided by the patient on the PCQ, which, like any questionnaire, needs to be easily understood by the patient to maximize validity.<sup>12</sup> This study aimed to inform the introduction of the PCQ into routine practice by addressing this issue, through asking patients about their views and experience of completing it.

## Method

The study used the technique of cognitive interviewing, advocated by Drennan<sup>13</sup> as allowing understanding of the questionnaire

from the respondent's perspective rather than that of the researcher, and so identifying any potential problems with the questionnaire. The process involves the researcher asking a respondent to 'think out loud' as they go through a questionnaire, with the researcher asking probing questions of the respondent to find out more about their thoughts. Cognitive interviewing has been used extensively in health research, to develop item banks for research instruments,<sup>14</sup> to refine questionnaires,<sup>15</sup> and to examine problems with completion of questionnaires in practice.<sup>16</sup>

An interview framework was prepared as the basis for in-depth, face-to-face interviews. The main part of the interview consisted of asking patients to read through selected questions from the questionnaire and to say out aloud exactly what they were thinking and feeling as they read. Probing questions were used to explore patients' thoughts on issues such as ambiguity and recall. The remainder of the interview framework consisted of broader questions about the questionnaire design and patients' experience of completing it.

Ethical approval was gained from the Ethics Committee of the organization sponsoring the research (Higher Educational Institution) and from the local Research Ethics Committee.

Six patients took part in the study. They were between the ages of 55 and 78 years, had colorectal symptoms, had been referred for flexible sigmoidoscopy examination, and had been asked to complete the PCQ as a routine part of their care. At the request of the ethics committee, a random sampling process was used to select participants from the eligible population. As the interviews were carried out before the examination, patients did not yet know their diagnosis. The group included four men and two women. Three of the participants were retired and the other three were working, two of them employed as clerical workers within the NHS. All patients chose to complete the interview in English, although they were offered the option of talking in Welsh.

Interviews were tape-recorded and subsequently transcribed. In the results section

below, the male participants are identified as M1, M2, M3 and M4, and the female participants as F1 and F2. The researcher is identified as R. Line-by-line examination across the whole body of the six transcripts, guided by the work of May,<sup>17</sup> led to the development of grids to visualize how categories and codes were distributed across the six interviews, using line numbers to show their location in each transcript, with the grids displaying categories and codes in hierarchical order. The write-up of findings below was drawn from the categories by connecting meaningful units of ideas or experiences.

## Results

Two broad groups of findings emerged from the data. The first concerned aspects of the questionnaire content and design, which may affect the accuracy of patients' responses. The second concerned patients' response to the PCQ, and their perception of its role and function.

### Questionnaire content and design and how it may affect the accuracy of patients' responses

#### *Language*

Three different types of difficulties with language were observed: words which were not understood by the patient at all; everyday words whose meaning is subject to interpretation; and phrasing which failed to convey clearly the meaning of the question. Although majority of participants did not note any problems with the medical language used in the questionnaire, one of them indicated that, for him, the PCQ contained complex words and language that he did not understand. His chosen vocabulary suggests not only that he might be unable to respond to a particular question but also that the PCQ was causing him some agitation:

M1: As for polyps I don't have a clue as to what that is. I'm not a b\*\*\*\*\* rocket scientist you know. Colitis I thought that was a thing a woman had. All I can think is them words should be more appropriate – the words like colitis that don't mean much to the ordinary layman – there's nothing wrong with saying piles or lump.

A more common problem, raised by three respondents, was that of everyday English words whose meaning can be ambiguous – for example, the questionnaire uses the word ‘rush’, a word whose exact meaning is subjective.

The problem of unclear phrasing was revealed most clearly in relation to questions 2a and 2g. They are intended to ask two different things, but many of the respondents answered them as if they were the same:

M1: That is the same question isn't it?

R: You see those two questions to be the same?

M1: Yes

R: Would you give the same answers to these questions?

M1: Yes

R: We are in fact asking two different questions here – 2a is asking ‘what changes have there been in your normal bowel habit?’ and 2g are asking ‘what has been your normal bowel habit?’

M1: Ah yes I see now

R: How could we make it clearer to you that these questions are different?

M1: [pause] I don't know, maybe by saying something like ‘before your latest trouble was your motions normal?’ and ‘did you have that before?’ – if you put the word ‘before’ it would be more clear. I can see now that question 2g is asking about before changes happened.

#### *‘Difficult to answer’ questions*

Some respondents observed that, at certain points, the language used in the questionnaire described a clarity of circumstance, which did not necessarily correspond to real life, and so could cause confusion. M2, for example, struggled with a question which asked him to choose between the descriptions ‘mixed’ and ‘separate’:

M2: The blood comes out on the stool like striped toothpaste – I was unsure if that meant ‘mixed’ or ‘separate’ – the question didn't work for me.

Aside from the issue of ambiguity, there were other ways in which some questions proved hard to answer. In one case, this was due to the

questionnaire assuming a level of knowledge which not all respondents had – the fact that old blood can be distinguished from fresh blood by its darker colour. Although three respondents outlined this difference quite clearly, M2 was one of two respondents who found this question confusing:

M2: I'm not absolutely clear about the distinction between fresh and dark blood – it would be helpful if there were something there to help make the distinction.

The questionnaire assumed not only that respondents understood the visible difference between old and fresh blood, but also that they could readily study the contents of their toilet pans. One respondent had burgundy coloured porcelain, which made such observations impossible.

Another question proved hard to answer for different reasons: it asked respondents about family members who had had cancer, but three of the six respondents had incomplete knowledge of the lives and deaths of uncles, aunts, or, in one case, a parent. Even where this information was known to respondents, it may not have made it onto the questionnaire form:

M4: After I filled it in and sent it back I remembered that my brother died with lung cancer.

The PCQ asked for a ‘snapshot’ picture of respondents’ symptoms, but, they reported, this did not necessarily correspond to their experience of considerable variability over time. Three participants stated that they could have chosen more than one answer for some of the multiple-choice questions within the PCQ, as M2 explained:

M2: I could tick more than one box in question 1f – on the day the questionnaire came it was improved but over the week it was bad but as it was better on that day – was it improved? – I could have answered this in all sorts of different ways...it made me feel frustrated because I couldn't answer it properly.

M2 went on to make specific suggestions for tackling this problem by changing the way in which the PCQ was used:

M2: I would have preferred to have a PCQ to hang on to when I could have then kept a diary – you ask for the PCQ to be sent back quickly but then I thought it will only give details of how I felt on that day...because of that I couldn't do justice to the PCQ...it was like looking at a snapshot... a snapshot method does not tell the complete story.

For three other respondents, their suggestion for dealing with the inflexibility of the response categories was simply to provide more space for respondents to write in their own answers.

#### How patients respond to the PCQ

The second set of findings which emerged from the study concerned patients' response to the PCQ, and their perception of its role and function. Discussion ranged over all stages of using the PCQ, from initial screening to waiting for the results of the screening process.

Two of the participants talked about the PCQ functioning as a less embarrassing alternative to going to see a doctor, reflecting one of the original intentions of the questionnaire's designers:

F2: I much prefer to fill the questionnaire than go to the doctor. Embarrassment puts you off going to the doctor – it shouldn't but it does.

M3: People of my age find it hard to talk about these things and filling the form is much less embarrassing than going to the doctor – you can do it in your own surroundings – in your own home.

Another perceived advantage of the PCQ was that patients felt it was a way to speed up the process of diagnosis, reflecting a promise of greater efficiency which is made in the letter sent out with the form:

F1: I thought it was a very good idea...rather than having to go on a waiting list to be seen in Out-patients...

F2: When I got the questionnaire I thought this is fantastic – I could put down exactly what was wrong with me and whatever tests they want to do will be organized and cut out the clinic session which is just a waste of time and in my case they are sending me straight away for a sigmoidoscopy.

One respondent, at least at first, held a contrasting view, regarding the questionnaire as a source of delay rather than efficiency:

M3: I said to my partner – look at this form... I told the doctor what's wrong with me and now they've sent a form to ask what's wrong with me – I thought I haven't got anywhere! That was my first reaction...

The intended purpose of the PCQ was not simply to speed the process up for all, but to select those for whom the process of diagnosis should be faster. Those respondents who did not receive urgent referrals after having completed the form reported feeling disappointed to find that they had a long wait before the flexible sigmoidoscopy.

M1: Now I've been waiting 6 weeks. I've filled this in to bypass a clinic and whereas my wife went to a clinic and was sorted straight away and I am still waiting so this has not helped me in any way.

For M3, the delay led to frustration and worry, and he suggested that patients should more promptly be given information on their WNS:

M3: The more information you have the better. Since I've been to the doctor I feel as if though nothing has happened – I'm still in limbo – I went to the doctor four to five weeks ago and I'm still in the same position.

R: How would knowing your score make you feel?

M3: [pause] I suppose that knowing I had a low score might put my mind at rest and help me understand the wait.

During the interviews, the researcher explained the scoring and prioritizing process, which led to M1 readily admitting that, given another opportunity, he would exaggerate his answers to create a high WNS and so 'play the system':

M1: If I knew about the scoring in the future I think I would put down a lot more things that wasn't wrong – for example I'd say that I've still got the bleeding.

R: Why would you do that?

M1: Because I'm worried and I would be seen quicker.



## Discussion

The research gained valuable knowledge of participants' perception of the purpose of the PCQ and learnt how they felt when they first received it in the post. A series of minor issues with the questionnaire were identified, any of which may make it less likely that full and accurate information will be collected on the PCQ. Many of these problems correspond to themes which are familiar from the literature on questionnaire design: ambiguous or jargonistic wording,<sup>18</sup> limitations on respondent knowledge,<sup>19</sup> and the inflexibility of closed question structures.<sup>20</sup> Although none of the patients had major difficulty with completing the questionnaire, these minor problems should still be a cause for concern. A screening tool such as the PCQ should be aiming for 100% accuracy; the information it gathers is not simply of academic interest, but is potentially of life or death significance. But it may be impossible to design a perfect questionnaire: some issues may always need to be discussed face-to-face and some things may be too subtle to be recorded in questionnaire form; variability over time is hard to capture by taking a 'snapshot' approach such as this. Putting a greater emphasis on 'free text' responses, as some respondents advocated, would present a challenge to those charged with processing the completed forms: would or could such text be transformed so it could contribute to the final weighted score? Overall, however, there is potential for patient input to help refine and improve the validity of forms such as the PCQ.

The findings about participants' response to and feelings about the PCQ also have implications in terms of minimizing worry for patients, and in terms of understanding any threats to validity which may come from patients' interpretation of the forms and their role. These findings relate not just to the PCQ itself but also to the way it is administered, including the covering letter sent out with the form. The findings suggest that if patients were aware of the scoring purpose and knew they had a low WNS it could help them understand the

long wait to be seen. In turn, information given in a sensitive way to people with high scores could prepare them for the need for more urgent flexible sigmoidoscopy appointments.

Although the study shows that many would benefit from knowing the scoring system, there was also a suggestion that some patients might exaggerate their answers and use the PCQ to speed up their journeys to diagnosis. The findings have raised an ethical dilemma: on one hand, with exaggerated answers the PCQ could be less reliable as support for clinicians, block the way for other more urgent cases and create distrust between patients and healthcare workers; on the other hand, it could be argued that it is a moral right to inform patients fully to encourage patient autonomy and to promote relationships based on honesty and trust.

Finally, if the PCQ is to replace a clinic session in which a two-way conversation would be held, then it may be appropriate to provide patients with the name and contact number of someone who could answer clinical and non-clinical questions.

The concerns raised by this study relate to a larger debate about health literacy and its role in maintaining and promoting health. The concept of health literacy refers to people's ability to obtain and process information about health and health care,<sup>21</sup> and is a function of the social and cultural environment, as well as of the individual.<sup>22</sup> Clinical systems which depend on health literacy can present a challenge to the individual, and ultimately may increase health inequalities at population level. In the UK, more than 20% of the population has reading skills at a level, which makes it difficult to cope with everyday demands of life,<sup>23</sup> whereas in the US, high rates of literacy problems<sup>24</sup> mean that according the Ratzen and Parker,<sup>25</sup> 'the average skills of US adults are not adequate for understanding and using the health system.' Specifically in relation to screening for CRC, a number of studies have raised concerns that lower levels of health literacy may reduce both patients' awareness of screening and the likelihood of take-up of screening.<sup>26-29</sup>

An important limitation of the study is the small sample size, as, although the research topic meets Morse's<sup>30</sup> criteria for a small sample by being straightforward and clearly defined, it is not certain that the sample is sufficient for category saturation to have been reached,<sup>31</sup> that is, to have no more new insights emerging from the data. Acknowledging that this is a common problem in studies using cognitive interviewing, Beatty and Willis<sup>32</sup> describe an iterative model, in which successive 'rounds' of between 5 and 15 interviews are interspersed with revisions to the questionnaire. The present study is of a size to function as one of the 'rounds' of interviewing in Beatty and Willis's model, though, in practice, as the PCQ was already being implemented, the full process of repeated rounds of interviewing was not carried out.

The literature on cognitive interviewing tends to present it as a formal tool for designing and refining research instruments. This study showed how cognitive interviewing, in addition to allowing for exploration of the face validity of an instrument, can act as a way of gathering broader data on patients' perspectives of the functioning of health care processes and patients' expectations.

Finally, it is worth putting this study of the PCQ in context. While the Trust continues to work to embed the PCQ in primary care practice, other developments in the field of CRC screening in the UK should, in due course, help reduce the need for screening of symptomatic patients. Survival rates are highest when CRC is diagnosed before symptoms appear, and the only way to achieve this is through screening of the general population.<sup>33</sup> Accordingly, a national programme of Faecal Occult Blood testing among the general population over the age of 60 has been phased in since 2006 in England, and since 2008 in Wales.

## Conclusion

The study did not identify major problems with the PCQ, but it did find many minor concerns with the content and design of the questionnaire and with the way it is first presented to patients.

Although minor, these issues may reduce the accuracy of the PCQ and patient satisfaction. This suggests that patients need to be involved in its review to help make it a more patient-focused questionnaire that could be completed with more ease; in addition, it may be worth reviewing the letter which accompanies the PCQ. Despite the difficulties identified within this study, it should be remembered that previous studies show that the PCQ is accurate most of the time and that it can predict symptomatic left-sided CRC.

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