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ORIGINAL ARTICLE

Adapting an Australian question prompt list in oncology to a Norwegian setting—a combined method approach

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Abstract

Purpose A question prompt list (QPL) is an inexpensive communication aid that has been proved effective in encouraging patients to ask questions during medical consultations. The aim of this project was to develop a QPL for Norwegian cancer patients.

Methods A multimethod approach was chosen combining literature review, focus groups, and a survey in the process of culturally adjusting an Australian QPL for the Norwegian setting. Participants were recruited from the University Hospital of North Norway. They were asked to review and comment on iterative drafts of the QPL.

Results Eighteen patients, mean age 54, participated in the focus groups, and 31 patients, mean age 55, participated in the survey. Focus groups suggested that topics related to accompanying relatives, children as next of kin, and rehabilitation were important and should be added to the original QPL. The survey revealed that most questions from the original QPL were considered both useful and understandable. Although half of the patients found some questions about prognosis unpleasant, the vast majority considered the same questions useful. Questions regarding clinical studies, multidisciplinary teams, and public versus private hospitals had lower ratings of usefulness.

Conclusion QPLs require some adjustment to the local cultural context, and a mixed method approach may provide a useful model for future cultural adaptation of QPLs. The present QPL has been adjusted to the needs of oncology patients in the Norwegian health care setting.

Keywords Question prompt list · Communication · Oncology · Cross-cultural adaption · Multimethod approach

Introduction

Communication is an essential component of the physician's role [1], and patient-centered care is widely endorsed as a central element of high-quality health care [2]. Norwegian health care legislation also ensures that patients have the right to receive information and to be involved in decisions regarding their own health [3].

In order to take an active part in decisions concerning treatment, cancer patients must assimilate complex and potentially emotive information such as prognosis. Most patients prefer to

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receive all available information, even if it contains bad news [4]. In a study by Hagerty et al., 98 % of patients wanted their doctor to be realistic, provide an opportunity to ask questions, and acknowledge them as individuals when discussing prognosis [5]. This is in contrast to a Norwegian study of physicians' attitude toward disclosure of prognostic information, where 43 % agreed to the statement "Generally, physicians should wait until asked before offering prognostic information" [6]. Lack of information may decrease patients' opportunity to participate in shared decision making and receive treatment according to their preferences.

A question prompt list (QPL) is a communication aid composed of a structured list of questions that can help patients obtain customized information about the disease/treatment/care and has been developed for various areas of cancer care [7–9]. Patients may read the list and mark the questions that they find useful and want to ask the doctor. QPLs in oncology settings have been shown to increase the number of questions asked, especially concerning prognosis [10]. Evidence also indicates that QPL interventions may influence both psychological (e.g., anxiety) and cognitive outcomes (e.g., recall of information) [11].

However, most QPL research has been carried out in Western countries where English is the first language. It is not clear to what extent this type of intervention translates to different cultural settings, since patients' information needs can be culturally influenced. In a study by Walczak et al. [8], feedback from patients and health care professionals in USA and Australia resulted in two distinct versions of a QPL for patients with advanced cancer in the final year of life. The two versions diverged in terms of language, and two questions regarding treatment and costs were excluded from the Australian QPL, as they were irrelevant to patients. The authors argued that communication aids need to be tailored to individual populations.

To our knowledge, no QPL has previously been translated into Norwegian nor developed for Norwegian cancer patients. The aim of this study was to develop a culturally adapted Norwegian QPL for patients diagnosed with cancer.

Method

Conducting focus groups, and thereby consulting the target population, is advocated as a good method for ensuring content validation [12]. The European Organization for Research and Treatment of Cancer (EORTC) has proposed guidelines for translating quality-of-life questionnaires [13], and cross-cultural adaption of health related quality-of-life measures is a well-defined five-step process described by Guillemin [14]. However, no standard method is described for cultural adaption of QPLs.

We adopted as a starting point the Australian QPL "So you have cancer" (see Appendix 1). This QPL was developed by researchers at the University of Sydney from focus groups and interviews with cancer patients and specialists [10]. It applies to most oncology settings and contains 49 questions divided into 12 domains. Following a thorough translation process, a mixed method combining focus groups and a survey was used to adjust the QPL to a Norwegian setting.

Translation of Australian QPL

The Australian QPL was translated according to the EORTC quality-of-life translation procedure [13]. Separate translations were made by two Norwegians who were fluent in English, and these two versions were merged into one Norwegian translation by authors TN and AA. A Norwegian linguist checked this merged version and suggested minor changes. A professional translator fluent in Norwegian with English as mother tongue back translated this version into English. All translations were discussed by the authors BE, TN, and AA (research team) who decided upon a final draft Norwegian version with QPL questions retaining their original meaning.

Adding question based on a previous nationwide survey

A nationwide survey of 7212 Norwegian cancer patients [3] showed that patients lacked information about pain/pain relief. A recent study also indicates that approximately 35 % of patients in Norwegian outpatient clinics experience cancer-specific pain [15]. The topic of pain and pain relief was not included in the original Australian QPL, and one question was added to the Norwegian version: "Is it normal to experience pain having my type of cancer, and if I experience pain, where could I get help for pain relief?"

Focus groups

We aimed to conduct three focus groups, each ideally with six to eight participants. Participants were recruited from "Vardesenteret," a center organized by the University Hospital of North Norway and the Norwegian Cancer Society, providing information and support to cancer patient and their families. Posters with information about the study were displayed at Vardesenteret along with the staff actively promoting the study. Author AA informed potential participants, and those agreeing to participate received the translated QPL in advance.

Eligible persons were diagnosed with cancer at least 3 months prior to the focus group.

All focus groups were conducted in meeting rooms at the University Hospital of North Norway with an experienced facilitator (BE) and observer (AA). Written informed consent was collected before the meeting started.

A semi-structured guide was used, containing questions from the translated QPL grouped into six blocks covering the 12 domains. Each block was read to the participants, and they were asked if the questions would be suitable in a Norwegian QPL and whether they felt that questions were missing.

The focus group sessions were audio taped. The recordings were transcribed, and the transcripts were subjected to a thematic analytic approach [16]. Statements were grouped into those addressing existing questions in the QPL and those that did not relate to any existing question. All QPL questions that were discussed by participants and all utterances related to topics that were not present in the existing QPL were discussed considering content and eventual appearance across focus groups. Changes to existing questions and development of new questions were resolved through consensus in the research team.

Survey

The revised QPL was then sent to a wider group of patients to review. Participants in this part of the study were recruited from the Cancer Outpatient Clinic. The Cancer Outpatient Clinic is located at the University Hospital of North Norway and receives patients with a wide range of cancer diagnoses from the three northernmost counties in Norway. Eligibility criteria were minimum 3-month experience as patients and aged 18 to 75. Author AA identified patients scheduled for a consultation with any doctor on prespecified days. All patients who met the eligibility criteria received a letter of invitation one week prior to their appointment. We aimed to achieve a sample size of 30, assumed sufficient to assess individual questions.

Patients consenting to participate when phoned by the study nurse met with her either before or after the consultation. Participants received a detailed explanation of the purpose and design of the QPL. They were then asked to rate each QPL question on three criteria, using a five-point Likert scale (later merged into three when analyzing responses):

1. Is the question understandable?
2. Is the question useful?
3. Is the question unpleasant?

The response options were as follows: “not at all,” “to a lesser extent,” “to some extent,” “to a large extent,” and “to a very large extent.”

Participants were also invited to write comments on any of the questions.

Any exclusion of QPL questions and final wording was resolved through consensus in the research team.

Results

Focus groups

Eighteen persons attended one of three focus groups. Participants’ age ranged from 38 to 69 years (mean age 54 years). Twelve of the participants (67 %) were women, and six (33 %) were men.

The original QPL topics discussed in focus groups

Twenty-three of the 49 questions in the QPL received one or more comments from participants in the focus groups. The comments were both of positive and negative characters, the latter of special interest in this phase of the project. The wording of six QPL questions was determined altered by the research team after the focus groups.

The changes to these six questions reflected patients’ use of language/concepts, different organization of the health care system, and alternative sources of information. The changes also reflected the essential role of the general practitioner in Norwegian health system [17].

Table 1 shows detailed description of the original QPL questions that were altered after focus groups.

New topics brought up in focus groups

Some of the utterances in the focus groups did not address specific QPL questions but other areas of concern when being diagnosed with cancer. These topics were of particular interest to us in creating a Norwegian QPL.

Two of the focus groups discussed bringing relatives to the consultation and coverage of expenses for them.

One participant said: “…as a patient, I think it was very, very important to be accompanied all the way because I could not remember everything…”

The discussion also included children’s right to information about their parents’ cancer. In 2009, the Norwegian government revised the act relating to health personnel [18] to include the obligation to identify and safeguard children’s need for information when parents are seriously ill. In the third focus group, these themes did not occur spontaneously, but when introduced by the facilitator, participants endorsed their importance. Members of the research team also endorsed the importance of these themes in clinical practice. Thus, two new questions were added:

> “Is it possible for me to bring a relative to the consultation? Are expenses for their travel/stay refunded?”
> “How should I inform my children about my cancer disease? Is there any place to seek help or advice for this?”

Table 1 Detailed description of how original QPL questions were altered after focus groups

Question number	Original QPL question	Assessment in research team	Norwegian QPL question
2.	Can I ask you to explain any words that I am not familiar with?	This question was slightly rephrased to reflect a less formal approach within the Norwegian vernacular.	Can you explain some words that I don't understand?
18.	Do you specialize in treating my type of cancer?	This question brought up discussions in two of the groups. Participants argued that oncologists do not necessarily need to be specialists in one type of cancer in the Norwegian health system. The question was rephrased to reflect this.	Do you have experience in treating my type of cancer?
24.	How do you all communicate with each other and me?	This question led to two group discussions regarding the important role of the general practitioner (GP). According to the Norwegian primary doctor scheme, all Norwegian residents are entitled to be registered as a patient with a GP. The question was rephrased to reflect the GPs' essential role throughout the course of the disease.	How do you all communicate with each other, my GP and me?
42.	Are there long-term side effects from the treatment?	Two of the groups discussed "late effects" compared to "long-term side effects." Norwegian patients use the two concepts interchangeably, and we chose to include both in the Norwegian version of the question.	Are there long-term side effects/late effects from the treatment?
46.	What will be the costs throughout my treatment, e.g., medication, chemotherapy, etc.?	In two of the groups, participants thought this question to be irrelevant as nearly all cancer treatment in Norway is provided without cost to the patient in public hospitals. In the third focus group, participants argued that the question could focus more on general expenses when faced with cancer.	What extra expenses can I expect due to my cancer?
48.	What information is available about my cancer and its treatment, e.g., books, videos, websites, etc.?	In one of the focus groups, participants argued in favor of brochures as a valuable source of information.	What information is available about my cancer and its treatment, e.g., brochures, websites, books, etc.?

Two focus groups had discussions concerning life after cancer treatment.

One participant said: "...I want to know when I get ready to work again...when I'm healthy enough to work again...when all effects of drugs and radiation, when it is over...when I'm back to how I was before..."

One of the groups emphasized the importance of rehabilitation for cancer patients. After discussion in the research team, one new question was developed:

"When will life be back to normal again? Are there any rehabilitation services available for cancer patients?"

Survey

A total of 49 patients were invited to participate in the survey, and 38 (76 %) consented. Of those, four patients did not show up for their appointment with the study nurse and three questionnaires included incomplete data and were excluded, leaving 31 questionnaires available for analysis. Responders were 16 women (52 %) and 15 men (48 %). Their age ranged from 22 to 72 years (mean age 55 years).

Descriptive statistics was conducted, and histograms displaying the percentage distribution of responses to each question were created to provide a summary of responses. Appendix 2 shows the numbered questions from survey.

We received 23 comments relating to individual questions.

Unpleasantness

Ratings regarding unpleasantness are summarized in Fig. 1.

Nine out of ten questions concerning prognosis were rated as unpleasant to a large/some degree by at least 20 % of patients. QPL question number 8: "How bad is this cancer and what is it going to mean for me?" was rated the most unpleasant by patients, with 14/30 (47 %) rating it as unpleasant to some/large extent. Nonetheless, 28/30 (93 %) found this question useful to a large extent. No questions were excluded or altered due to being unpleasant.

Usefulness

Responses regarding usefulness are summarized in Fig. 2.

These responses were very diverse. Forty-three of the 53 QPL questions were rated useful to a large extent by more than 80 % of patients, suggesting quite similar information needs among cancer patients in Australia and Norway. The remaining ten questions were discussed more thoroughly in the research team. Questions concerning private versus public health services, multidisciplinary teams, clinical trials, and complementary therapy received lowest scores on being useful, and details

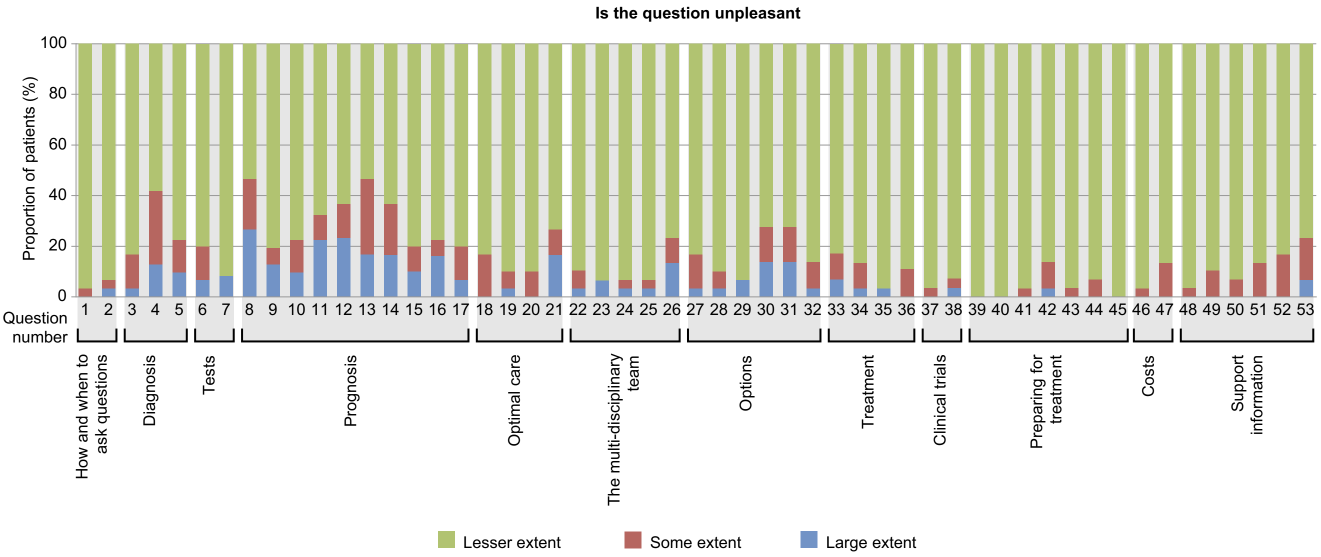

Fig. 1 Patient ratings of each question regarding unpleasantness

from the research teams' assessment of these questions are provided. Five questions concerning private versus public health service, multidisciplinary team, and clinical trials were removed or altered.

Table 2 shows detailed description of the QPL questions that were altered/removed from the Norwegian QPL after the survey

QPL question number 49: "Are there any complementary therapies that you believe may be helpful or that are known to be bad for me?" was found useful to a large extent by 16/29 (56 %) of patients. Despite its relatively low score on usefulness, it was considered important by the researchers. A nationwide survey from 2003 [19] found that 22 % of Norwegian cancer patients use some form of complementary therapy. The research team thought it important to facilitate cancer patients' discussion of the use of complementary therapy with their doctor, and the question was retained in the Norwegian QPL.

Understandability

Ratings regarding understandability are summarized in Fig. 3.

Eight of 53 questions were rated as understandable to some/lesser extent by at least 20 % of patients. The QPL questions rated as less useful also tended to be rated as less understandable. No question was excluded or altered due to understandability.

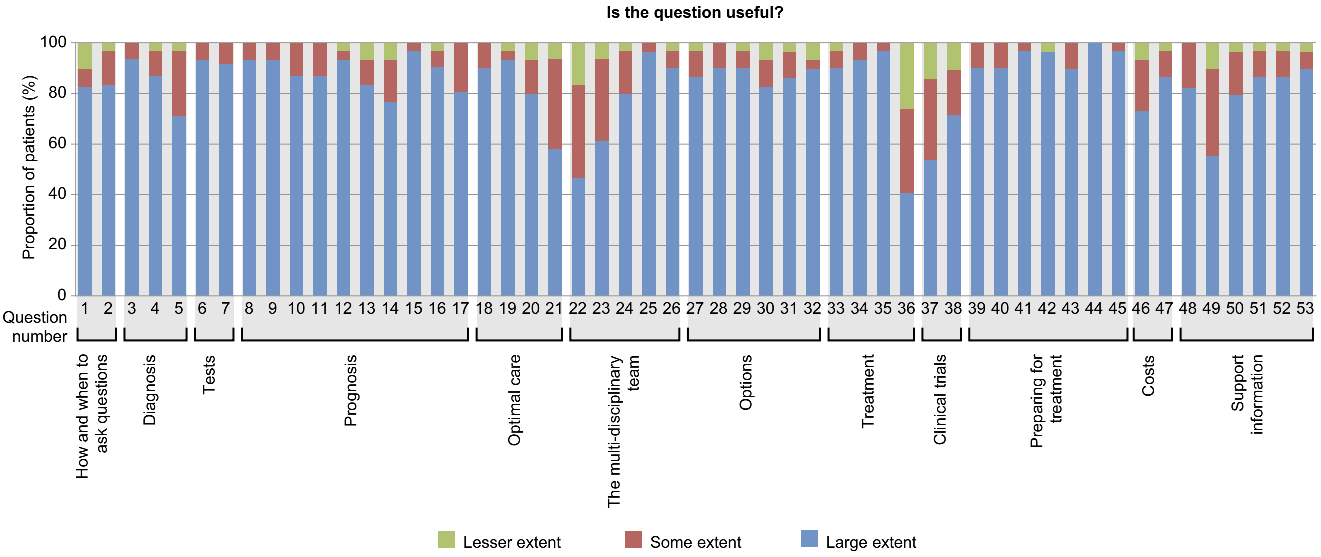

Fig. 2 Patient ratings of each question regarding usefulness

Table 2 Detailed description of how QPL questions were excluded or altered after survey.

Question number	Original QPL question	Assessment in research team	Conclusion/Norwegian QPL question
36.	Are there any advantages/ disadvantages of the private versus public health system?	Only 41 % (11/27) found this question useful to a large extent. Nearly all cancer treatment in Norway is provided in public hospitals, and at this point of time, the question is irrelevant to most Norwegian cancer patients. The research team decided to remove this question from the Norwegian QPL.	Excluded from the Norwegian QPL
22. 23.	Do you work in a multidisciplinary team and what does this mean? Can you explain the advantages of a team approach?	The question numbers 22 and 23 were assessed by, respectively, 14/30 (47 %) and 19/31 (61 %) to be useful to a large extent. One patient commented that he/she was not familiar with the concept of a multidisciplinary team. In the researchers' opinion, discussions in multidisciplinary team/meetings raise the quality of patient treatment. A question concerning the multidisciplinary team could increase the patients' awareness about where decisions regarding treatment are made. Taking into account that patients did not find it very useful, we excluded one question and rephrased the other.	Is my treatment discussed in a multidisciplinary meeting?
37. 38.	What are clinical trials? Are there any that might be relevant for me? Will I be treated any differently if I enroll in a clinical trial?	These questions were also rated quite low on usefulness. Respectively, 15/28 (54 %) and 20/28 (71 %) found these QPL questions to be useful to a large extent. In the researchers' opinion, all cancer clinics should participate in clinical trials and thus contribute to medical development. In a situation where patients use the internet to obtain information about cancer treatment, this question might become more and more important to patients. Following a discussion in the research team, only question 37 was retained and was rephrased.	Are there any clinical trials that could be relevant for me to participate in?

New questions from focus groups and a nationwide survey

The survey also explored the new questions derived from focus groups and the nationwide survey related to the following: accompanying relatives, how to inform children about their parents' cancer, rehabilitation services, and pain/pain relief.

Between 87 and 90 % of patients found these questions useful to a large extent. The same questions were found understandable to a large extent by between 87 and 100 % of patients and found unpleasant to some/large extent by between 3 and 23 % of patients.

Two of these questions received positive comments in the survey.

These scores confirmed these new QPL questions to be relevant for Norwegian cancer patients and suitable to be included in the Norwegian QPL.

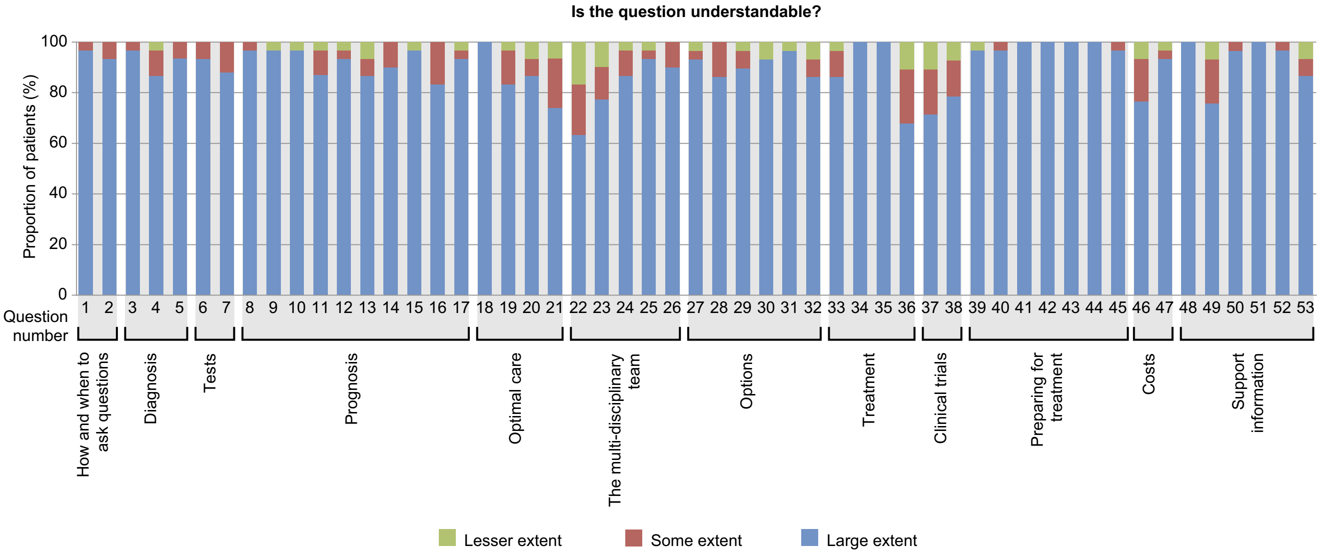

Fig. 3 Patient ratings of each question regarding understandability

Final Norwegian QPL

The final Norwegian QPL contains 50 questions. The ultimate design of the QPL should also be considered. In a study by Volz [20] in a breast cancer clinic, 90 % of patients who were prompted to create a self-generated list of questions used it during the consultation. These patients may have been encouraged to use their lists because they were personally generated. In the final design of the Norwegian QPL, we decided to leave room in the front of the QPL for patients' own questions. The title and introduction were slightly rephrased in the Norwegian QPL to be more in line with Norwegian language (see Appendix 3).

Discussion

Our main goal was to develop a culturally adapted Norwegian QPL and thereby provide Norwegian oncology patients with a tool to assist them to ask relevant questions.

We adapted a 49-question Australian QPL. Generally, these 49 questions received high ratings of usefulness and understandability and low ratings of unpleasantness in our survey. This suggests relatively comparable information needs among cancer patients in Australia and Norway. However, some differences emerged. As the Norwegian health care system is almost exclusively public, we excluded a question on private versus public health care. Additionally, two questions concerning clinical trials and multidisciplinary teams were rephrased and two questions concerning the same topics were removed, as participants rated them less useful.

Even though the original QPL questions were generally well received, focus group discussions revealed that patients found three additional topics missing: questions concerning accompanying relatives, how to inform children about their parents' cancer disease, and when life would normalize/rehabilitation. A nationwide survey from 2009 also identified that Norwegian patients reported lack of information about pain/how to manage pain. Four new QPL questions were developed to cover these topics. Survey respondents rated these four new questions very positively.

Language and wording of questions were minimally altered throughout the process, except for small adjustments to make the QPL more in line with everyday-spoken Norwegian language.

We found no consensus in the literature regarding the ideal length for a QPL, although a review by Brandes et al. suggested that QPLs with many questions lengthen the consultation [11]. The final Norwegian QPL contains 50 questions.

Recent cultural adaption of the same QPL to Italian [21] was conducted in a similar way to the current study, applying the cross-cultural adaption process described by Guillemin [14] and Beaton [22]. In this Italian study, the Italian expert group replaced the Italian word for "cancer" with "tumor" or "my illness." No such adjustments were required in the Norwegian version, suggesting that Norwegian patients are more similar to Australian patients in accepting direct language.

One of the strengths in our process of cultural adaption is the use of mixed methods in terms of combining focus groups and a survey. Specific expert guidelines for the cultural adaption of QPLs do not exist. Our assumption was that Norwegian cancer patients might want to ask additional questions not present in the Australian QPL and that focus groups could identify missing questions. We believe that our mixed method approach may provide a useful model for future cultural adaptation of QPLs.

The recruitment process for focus groups was not random and that might have affected the result. The participants attending focus groups were also mainly women (67 %), and the results may be less relevant to men. However, in the survey, the distribution was more equal with 52 % women and 48 % men; thus, we hope that this gender imbalance was redressed. In addition, the relative small sample size and missing information on cancer site/stage and time since diagnose are a limitation to determine sample representativeness.

The results from this study suggest that QPLs require some adjustment to the local cultural context and a mixed method approach may provide a useful model for cultural adaptation. The final Norwegian QPL is believed culturally adjusted to Norwegian conditions. A study to evaluate the impact of QPL in a clinical setting is being planned. If proven useful, the Norwegian QPL could be introduced on a national health web site.

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Compliance with ethical standards All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Patients provided written informed consent before any study-specific procedures.

Conflict of interest The authors declare that they have no conflicts of interest.

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