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Patient Experiences of Continuity of Cancer Care: Development of a new Medical Care Questionnaire (MCQ) for Oncology Outpatients

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Abstract ----------

Objectives: To adapt the Components of Primary Care Index (CPCI) to be applicable to oncology outpatients and to assess the reliability and validity of the adapted instrument (renamed the Medical Care Questionnaire (MCQ)).
Methods: The development and validation of the MCQ took place in four phases. Phase 1 reviewed the literature and examined existing measures. In Phase 2 the selected instrument (CPCI) was reviewed by a panel of experts using a stepwise consensus procedure. In Phase 3 the adapted 21-item MCQ was administered to 200 outpatients attending oncology appointments. The instrument was refined to 15-items and in Phase 4 it was completed by 477 oncology outpatients. The psychometric properties of the new instrument were assessed using exploratory factor analysis, confirmatory factor analysis, multi-trait scaling analysis and by comparing MCQ scores between known groups.

Results: Exploratory factor analysis of the 15-item MCQ suggested 3 subscales with acceptable to good reliability: "Communication" α=0.69; "Coordination" α=0.84; and "Preferences" α=0.75. Comparing known groups showed that patients who saw fewer doctors during their clinic visits reported stronger "Preferences" to see their usual doctor and rated "Communication" with their doctors as better than patients who saw more doctors during their clinic visits.
Conclusion: The MCQ demonstrates good psychometric properties in the target population. It is a brief and simple to use instrument, which provides a valid perspective on patients' experiences of communicating with doctors and their perceptions of the continuity and coordination of their cancer care.

Keywords: cancer, communication, patient-reported outcomes, psychometric properties, questionnaire development.

Introduction

In the late 1990's hospital based oncology practices began to change with the development of new and effective systemic cancer treatments. The delivery of cancer care became more complex with increasing number of patients surviving for longer and increasing number of oncologists and nurses being involved in the care delivery. Multi-disciplinary teams (MDTs) were formed to ensure involvement of the necessary experts in diagnosis, treatment modalities, and patient care, so that all patients received consistently high quality and timely treatment. Such multidisciplinary and team-based structures are common within UK hospitals for the delivery of a variety of medical interventions. However, the involvement of a large number of medical staff for each patient can have a negative impact on the continuity of care that patients receive if medical staff vary in their ability to elicit important symptoms or functional limitations, to assess change over time, or to make an objective medical record of problems [1-3]. Continuity of care is an important issue for modern health service provision, yet assessing continuity is not always straightforward, in part because it has been a difficult subject to define.

Early definitions described good continuity of care quantitatively as a succession of visits by a patient to the same health care provider [4]. More recent definitions have made attempts to evaluate continuity of care within the context of a multidisciplinary and multi-service health system. As part of a National Health Service (NHS) scoping exercise, Freeman et al [5] identified three aspects of health care that were considered important to continuity of care: seeing the same health care provider over time; having continuity when care is shared or transferred between health care providers; and having continuity of information across medical records and providers. Continuity of care is expected to have an impact on the quality of care that patients receive and may improve patient outcomes. For example, higher experienced continuity may be associated with lower health care needs in the future [6]. However, it can be difficult to elicit reliable self-reports of patients' perceptions of the care they receive. For example in oncology, patients tend to report high levels of satisfaction with their care and appear reluctant to rate their medical team negatively [7]. Therefore, measuring satisfaction with care may not offer a true reflection of patients' experiences of the continuity of their care.

Within the context of changes to patient care and management in oncology during the late 1990's we

wished to examine patients' perceptions of the continuity of their care. However, at this time there were no cancer-specific instruments suitable for measuring continuity of care in secondary/tertiary health services. As such, we adapted an existing instrument that assessed continuity of care in the primary health care setting. Over several years we have continued to develop this instrument and have used it in randomised trials to document patients' experiences of the continuity of their care. In this paper we present data showing the development and psychometric validity of the Medical Care Questionnaire (MCQ).

Methods

The development of the MCQ was carried out in four phases. Phase 1 was a literature review to determine whether existing instruments could be used or adapted for outpatient oncology. Phase 2 included modification of an existing instrument (Components of Primary Care Index (CPCI)) [8] by expert review. Phase 3 was a pilot study to explore the psychometric properties of the refined instrument in a patient population. The results of Phase 3 suggested further modification of the instrument, so Phase 4 examined the validity of the instrument in a larger patient sample. Each phase was carried out sequentially and data for Phases 3 and 4 were collected from the same medical oncology outpatient clinic. Table 1 summarises the aims and methods for each phase of instrument development.

Phase 1: Literature Review

A literature search was performed in Medline, using the key words "continuity of care", co-ordination of care", "patient satisfaction" AND "cancer". The purpose of the review was twofold: 1) to identify definitions of "continuity and co-ordination of care" applicable to secondary/tertiary hospital care; and 2) to find instruments that measure coordination and continuity of medical care from patients' perspective. The literature review did not identify any self-reported instruments suitable for hospital based oncology practices. One instrument, the Components of Primary Care Index (CPCI), which was designed for use in primary health care, was found to employ a useful taxonomy and included a number of items and subscales that were of relevance to the cancer care setting. This questionnaire consists of 19 items, organized into 4 domains "Patient preference to see usual doctor", "Interpersonal communication", "Physician's accumulated knowledge of the patient", and "Co-ordination of care". The internal consistency reliability of the 4 subscales ranged between 0.68 and 0.79. The instrument demonstrates good psychometric properties and was originally developed and evaluated in a sample of 2899 primary care patients visiting 138 family physicians' offices in the USA [8, 9]. All items have a 5-point Likert scale response format anchored by strongly agree and strongly disagree. The way in which items are phrased requires patients to report rather than rate their interaction with the physician. Since cancer patients are typically reluctant to rate their physicians poorly [6], the less judgemental reporting style may serve to reduce ceiling effects from responses.

Phase 2: Expert Review

Whilst the CPCI provides a valuable scale structure and taxonomy, many items are phrased in a manner unsuitable for the purposes of team-based hospital care. The CPCI was reviewed for applicability to outpatient oncology by an expert panel of 3 consultant medical oncologists and the experimenter (GV) an oncologist in training. The experts were selected from medical oncology and were chosen as they had experience in managing team-based patient care across different cancer specialities. A stepwise procedure (similar to the Delphi technique) was used to adapt the original CPCI and consensus was reached for each decision to alter, remove, or add an item. The first step included a review of item content to determine applicability to cancer patients. The second step examined the wording of the remaining items and the final step was item generation to replace items that had been removed. See Table 2 for each modification step. The modified questionnaire was renamed the Medical Care Questionnaire (MCQ).

Phase 3 and 4: Evaluating the psychometric properties of the new instrument

In Phase 3, as part of an outpatient audit 285 cancer patients were invited to complete the new MCQ instrument during their visit to the hospital or by post. Of those contacted, 200 (70%) patients returned completed questionnaires. For Phase 4, MCQ responses were collected from patients taking part in two separate studies. The first study was a postal audit to determine patient experiences of their care; 313 cancer patients were contacted by post and asked to complete and return the MCQ. Two hundred and fifteen (69%) completed questionnaires were returned. The second study was a randomised controlled trial (RCT) examining the impact of routine quality of life assessment on patient-doctor communication [10]. In this study patients were asked to complete the MCQ at baseline. Of the 286 cancer patients who took part in the RCT 262 (92%) completed the MCQ. In total, 477 patients completed the MCQ questionnaire in Phase 4.

The MCQ was administered at a regional hospital (North England) with a specialist cancer service (Medical Oncology Unit). The audits carried out in Phases 3 and 4 were performed as part of a service improvement and as such were not subject to NHS ethical approval. Adult patients from all tumour groups attending the Medical Oncology Unit were eligible to take part in Phases 3 and 4, provided they could read and understand English and in the opinion of the investigator they were not exhibiting overt cognitive dysfunction or signs of distress. The Phase 4 RCT received NHS ethical approval and all patients gave written informed consent prior to data collection in accordance with the Declaration of Helsinki.

Demographic Details

For all studies in Phases 3 and 4 patient medical details, such as the primary tumour site, were recorded from medical notes. Patients completed a socio-demographic survey which included details on the patients' age, gender, marital status, and employment status. Medical and social demographic details are summarised in Table 3. Patients were predominantly female (81% in Phase 3; 74% in Phase 4) and diagnoses of gynaecological, breast, and genitourinary cancers were most common. The biases in distribution of gender and diagnosis reflect the demographics of the unit, with three specialised clinics in breast and gynaecological cancers and one general oncology clinic.

Sample Size

For factor and multitrait analyses, sample size is typically recommended to require 5-10 times the number of participants as the number of items included in the instrument [11]. In Phase 3, the MCQ included 21 items and was completed by 200 patients, giving a subject to item ratio of 9.5:1. In Phase 4, the MCQ contained 15 items and was completed by 477 patients, giving a subject to item ratio of 31.8:1.

Descriptive analysis

In Phase 3, descriptive data were examined to assess the acceptability of each item to patients and to evaluate the contribution of each item to the scale. Positively worded items on the MCQ were reversed scored to be consistent with the remaining items. After recoding, a lower score on each item indicated poorer perception of continuity and coordination of care. Criteria for retaining items included: 1) response ranges spanned 3 or more response categories (i.e., categories 1 through to 4, or 2 through to 5 were selected); 2) mean values ≤4; and 3) no ceiling effect i.e. frequency of responses for less favourable response categories should be > 20%. Items not meeting these criteria were removed prior to exploratory factor analysis as they were deemed likely to contribute to a ceiling effect.

Exploratory Factor Analysis

Kolmogorov-Smirnov tests showed the MCQ data in both Phases 3 and 4 were not normally distributed ($p<.05$), therefore the latent structure of the instrument was examined using principle axis factoring. Oblique (direct oblimin) rotation was applied because the original CPCI reported that the factors "coordination" and "accumulated knowledge" were correlated [8] and correlations between factors were expected for current data. The criteria for factor extraction were a minimum eigenvalue of 1.00 and that each component accounted for at least 5% of the variance among items. Scree plots assisted the decision to retain factors. Data with more than 40% missing values were removed prior to analysis and remaining missing data were replaced by mean values for the item.

Confirmatory Factor Analysis

The suggested factor structure of the MCQ (from Phase 3 exploratory factor analysis) was examined using confirmatory factor analysis (CFA) with data in Phase 4. Goodness of fit of was deemed acceptable if the chi square value was low with a non-significant p-value, and if the RMSEA was below 0.080.

Reliability

In Phase 4 the reliability of each subscale was examined using multitrait analysis. This analysis examined the item-convergent and item-discriminant validity of the subscales that were derived from Phase 3 exploratory factor analysis and supported by Phase 4 confirmatory factor analysis. Item convergent validity was supported if items had correlations >0.40 with their own hypothesised subscale. Item-discriminant validity was supported if items correlated more highly with their own hypothesised subscale than they did with other subscales. The internal consistency reliability of each subscale and the total scale was assessed by calculating Cronbach's alpha (α) coefficients. Values above 0.70 were accepted as moderate, whilst values above 0.80 were accepted as showing good internal consistency.

Validity

In Phase 4 an objective measure of "continuity of care" was derived to explore the external validity of the MCQ. The literature describes several indexes for continuity of care developed mainly for family practice [12]. The simplest measure considers the number of visits each patient has made and the number of care

providers seen, this is called the 'K index' [13, 14]. The K index can be applied to a team-based hospital oncology practice by recording the number of doctors each patient has seen and the total number of clinic visits over time.

K index = (Number of visits – Number of doctors) / (Number of visits – 1)

The K index has a value between 0 and 1. When a patient has seen only one doctor over time the K index will be 1. When a patient has seen different doctors at each visit, the K index will be 0.

The validity of the MCQ subscales was explored against medical and demographic known groups. MCQ subscale scores were derived by computing the mean of subscale items and linearly transforming the data to a 0-100 scale. One-way Analysis of Variance (ANOVA) tests (with Bonferroni corrections for post hoc analyses) were carried out to determine any differences in subscale scores for the following groups: diagnosis (breast, genitourinary, gynaecological, melanoma, sarcoma, or other); and K index quartiles (quartiles were calculated using SPSS to identify the score boundaries for the 25^{th}, 50^{th}, and 75^{th} percentiles: 1^{st}=0-0.24; 2^{nd}=0.25-0.49; 3^{rd}=0.50-0.59; 4^{th}=0.60-1.00). Independent samples t-tests compared subscale scores between age groups (under or over 60 years) and between genders.

Data were analysed using SPSS version 16.0 for Windows and LISREL 8.80 Student. The threshold for statistical significance was set at $p<0.05$. Effect sizes for ANOVAs (Cohen's *f*) were calculated using G*Power 3.0.10 [15]. Cohen's *f* values are interpreted as small=0.10, medium=0.25, and large=0.40 [16].

Results

Phase 2: Expert Review

Five items were removed from the original CPCI instrument because they were not considered applicable to the cancer outpatient population. Minor changes were made to 8 items, such as the replacement of 'this doctor' with 'the doctors' or the addition of a few words to specify the setting, i.e., 'this clinic', and major changes were made to two items. Seven new items were added to the instrument, which covered aspects of medical care specific to oncology and the system of delivery of cancer care. The expert review resulted in a 21-item instrument renamed the Medical Care Questionnaire (MCQ). See Table 2 for the expert review stages including the original CPCI items and the adapted MCQ items.

Phase 3: Descriptive Analysis

The proportion of missing responses to the 21-item MCQ was low (1%-5%). Five items did not meet the criteria for retention because they had high mean scores (range 4.4 - 4.5 across items) and had a low cumulative frequency of less favourable responses (range 9%-12% across items). As such these five items were removed. One item ("I don't mind seeing different doctors because everyone in the team knows my case") was deleted despite meeting the criteria because it was a double statement with ambiguous meaning. After descriptive analysis the MCQ instrument was reduced to 15-items. These remaining items were subject to exploratory factor analysis.

Phase 3: Exploratory factor analysis and reliability

Three factors were extracted with eigenvalues greater than 1 and which accounted for at least 5% of variance in the data. Examination of the inflexion point of the Scree plot confirmed the retention of 3 factors. The 3 factors accounted for 45.47% of the common variance and were labelled: "Coordination" which included items on the coordination of patient information and accumulated physician knowledge about the patient; "Preferences" which included items on patient preferences to see their usual doctor; and "Communication" which included items on communication with doctors and knowledge about non-medical issues. Each of the three subscales showed satisfactory internal consistency (Cronbach's alpha) Coordination α= 0.76; Preferences α= 0.83; and Communication α= 0.80. The subscale scores were interpreted as follows: patients with higher "Communication" and "Coordination" scores on the MCQ rated their communication with doctors and coordination of their medical information as better than patients with lower scores; patients with higher "Preferences" subscale scores had a stronger preference for seeing their usual doctor (or fewer doctors) during clinic visits than patients with lower scores.

Phase 4: Confirmatory factor analysis

The 3 factor model derived by exploratory factor analysis (EFA) of the Phase 3 data was examined in the Phase 4 data with confirmatory factor analysis (CFA). We were concerned that the Coordination subscale derived by EFA could have been an artefact because the items contributing to this subscale were all negatively worded. To determine whether the Coordination subscale should be kept as an independent subscale or merged with the Communication subscale, we compared the goodness of fit of two models. The first model contained 2

factors: factor 1 combined all items from the Coordination and Communication subscales and factor 2 contained the items from the preferences subscale. The second model contained 3 factors, with the items remaining within the 3 factors described in the Phase 3 EFA.

The 2 factor model had poorer fit than the 3 factor model. Goodness of fit for 2 factor model: X^2=405.04; df=89; p=.000; RMSEA=0.086; Confidence Interval of RMSEA = 0.078-0.095. The modification indices suggested adding paths between factor 1 (combined Coordination / Communication subscale) and item 13; and paths between the Preferences subscale and items 1, 2, 8, and 14. The 3 factor model showed improvement in goodness of fit compared to the 2 factor model: X^2=269.15; df=87; p=.000; RMSEA = 0.066; Confidence Interval of RMSEA = 0.057-0.075. The modification indices suggest adding a path between the Preferences subscale and item 1 and adding paths between the Communication subscale and items 1 and 13.

Despite the improvement in fit between the 2 factor and the 3 factor models, the chi square value remained high and significant. However, the chi square is often reported to be inflated by large sample sizes, and the acceptable RMSEA score for the 3 factor model suggested adequate fit of the 3 factor model. The reliability of the 3 factor model was explored further with multitrait analyses, to determine whether any items should be removed or moved from the three subscales.

Phase 4: Multitrait Item-Subscale Correlations

Data from Phase 4 was used to examine item-convergent and item-discriminant validity of the 3 factor domain structure using multitrait correlation analyses (Table 4). Items 1 and 10 showed low item-convergent validity (0.36 for both items) with the Coordination subscale but did not show higher correlations with other subscales. Item 11 showed low item-convergent validity (0.38) with the Communication subscale, but did not have a higher correlation with any other subscale. Item 13 showed good item-convergent validity with the Preferences subscale. The Coordination and Communication subscales were positively correlated (r(469)=0.45, p<.001). The internal consistency (Cronbach's alpha) for the three subscales was: Communication=0.69; Preferences=0.84; and Coordination=0.75. Cronbach's alpha "if item deleted" values were examined to determine whether the subscales would be improved with the removal of items 1, 10 and 11. Cronbach's alpha for the Coordination subscale showed no improvement for removing item 10 and showed only a small improvement of 0.01 with the removal of item 1. Cronbach's alpha for the Communication subscale showed no improvement with the removal of item 11. We decided to retain items 1, 10, and 11, and 13 in the original subscales, as suggested by Phase 3 EFA.

Phase 4: Known Groups Comparisons

Patients were divided into groups based on demographic and medical details and their scores on the MCQ subscales were compared (Table 5). Patients with breast cancer had lower Coordination subscale scores (F(5, 468)=2.53, p=0.028, f=0.16) than patients with melanoma cancer but had higher Preferences subscale scores (F(5, 451)=3.75, p=0.002, f=0.20) than patients with gynaecological cancer. Breast cancer patients also had lower Communication subscale scores (F(5, 465)=3.09, p=0.009, f=0.18) than patients with gynaecological (p=0.027) or melanoma (p=0.050) cancers. Individuals with the highest K index (4th quartile) had higher Preferences subscale scores (F(3, 435)=6.46, p=0.000, f=0.21) than patients from lower K index quartile groups (1st quartile p=0.083; 2nd quartile p<0.001; 3rd quartile p=0.049). There were no between group differences by K index quartile for Coordination or Communication subscale scores. There were no between group differences in MCQ subscale scores for age group or gender.

Discussion

We have presented the various stages of development and validation of the MCQ, to measure oncology patients' perceptions of the continuity and coordination of their medical care and communication with their doctors. The MCQ was adapted from the Components of Primary Care Index by a process of expert review and psychometric evaluation. This process led to a number of changes being made to the original 19-item CPCI to make it applicable to an oncology setting. This included removing or rewording items and generating new items. Although the item adaptation process was based on consensus methods using expert reviewers, it could have been improved by including patient opinions and feedback. Although not reported in this study, patient feedback was elicited during Phase 3. During this phase patients were encouraged to comment on the items and give feedback on the questionnaire. Patient feedback was analysed qualitatively and was taken into consideration alongside the descriptive analysis. In summary most patients confirmed the importance of the identified subscales: many patients reported that it was important for them to see the same doctor at each visit and that the coordination of their medical information between individual doctors and the wider medical team was very important to their care. The

adapted instrument was renamed the MCQ and contained 21 items.

Initial psychometric evaluation of the 21-item MCQ suggested removal of 5 items that contributed to a ceiling effect in responses. Of these items, two were from the original CPCI questionnaire, two were adapted from the original CPCI, and one was a new item. One additional new item was removed as it was considered a double statement and was ambiguous to interpret. The psychometric evaluation of the remaining 15 items suggested the MCQ measured three domains of continuity of care: "Communication" with doctors; "Coordination" of medical information and physicians' accumulated knowledge about the patient; and "Preferences" to see usual doctor. The "Preferences" subscale remained from the original CPCI, with the addition of a new item (item 1) "I rarely see the same doctor when I come to this clinic". Subsequent evaluation of the hypothesised domains in a new patient population showed that the three subscales had reasonable internal and external reliability and validity in the target population. Whilst the item-factor structure of the MCQ differs from the CPCI, the two instruments remain conceptually similar in the measurement of patients' preferences to see their usual doctor, their evaluation of communication, and their perception of the coordination of their medical information between doctors. The differences in factor structure between the two instruments might be expected given the removal of seven original CPCI items and the addition of three new items to the MCQ. The differences in factor structure may also be due to differences in medical setting (primary versus secondary/tertiary care) and the different patient population sampled in the current study.

After item deletion in Phase 3, the 15-item MCQ was administered to a new oncology outpatient population in Phase 4. This data was used to re-examine the hypothesised domain structure and internal validity of the MCQ and examined its external validity by comparing known groups. Although this second administration of the 15-item MCQ showed slightly poorer internal validity of the subscales than in the previous sample, each subscale showed reasonable internal consistency and reliability and appears suitable for use in a mixed oncology outpatient population.

The Communication domain of the MCQ is an element of continuity of care that was not identified by Freeman et al [5] as being important to continuity of care. However, in oncology, it is important that the patients and doctors maintain good levels of communication to enable the identification of symptoms and toxicities during treatment and to monitor the impact of disease and treatment on broader social and psychological well being. The items in the communication domain of the MCQ reflect the importance of communication about non-medical issues with items such as: "The doctors know how I feel emotionally while they are treating me", "The doctors know about non-medical things in my life" and "I can easily talk about person things with the doctors". Amongst the patient groups we found that patients with breast cancer reported lower Communication scores than patients with gynaecological and melanoma cancers.

The Coordination domain of the MCQ was considered to reflect patients' experiences of continuity when they saw different doctors for their medical care. Although we have given this subscale the label Coordination, it is clear from the items included in this domain that patients' experiences of coordination are dependent on the quality of communication and the flow of information between health professionals and across clinic visits. As may be expected, we found the Communication and Coordination subscales were correlated. In line with this correlation we found that patients with breast cancer reported lower Communication scores than patients with gynaecological and melanoma patients also reported lower Coordination subscale scores than patients with melanoma cancer.

The Preferences subscale was considered to reflect the importance that patients place in seeing the same health professional at each hospital visit. This has been identified in previous research as an important component of continuity of care [4, 5]. We found a small negative correlation between the Preferences subscale and the Coordination subscale suggesting that those patients who rated the coordination of their medical information between doctors as poor might be more likely to place greater value in seeing fewer health professionals for their medical care. In this study patients with breast cancer were more likely than patients with gynaecological cancer to endorse items from the Preferences subscale. Perhaps counter intuitively we found that patients with high K index values (who saw a fewer doctors per hospital visit) were more likely to endorse items from the Preferences subscale. This result may reflect that some clinics within the Medical Oncology Unit endeavour to accommodate patients who have strong preferences to see a particular doctor for their clinic visit. It could be that a number of patients with higher scores on the Preferences subscale were more active in ensuring their care was delivered by particular health professionals.

There were several limitations to this study. Although we believe our sample provided good representation of the patient population seen in the Medical Oncology Unit, the majority of the patients were female with breast or gynaecological cancers and the results may be biased towards female opinion. Whilst the comparison of MCQ subscales scores between males and females did not show any significant differences, further validation of the questionnaire to include a larger number of men with cancer would be desirable. Another limitation to generalised interpretation of the results is that the study phases 3 and 4 were carried out in a single Medical Oncology Unit, part of a tertiary referral cancer centre. A typical feature of this setting is the large number of doctors looking after the patients (teams of approximately 4-8 doctors), which was reflected in the relatively low K-index in our study populations. Thus, further validation of the MCQ may be required before it is applicable to hospitals where the oncology care is delivered by a smaller team of doctors.

Whilst the validity of the MCQ has been shown to be good in a general cancer population, it is important that further work is carried out to establish test-retest validity and to gather stronger data on the relationship between patient scores and indicators of clinical practice that are predicted to affect continuity of medical care. Until the psychometric properties of the MCQ have been validated further we recommend that patient responses to the MCQ are interpreted at the level of the three domains rather than calculating a 15-tem total score.

We have provided preliminary evidence that the MCQ instrument can provide valuable information on patients' experiences of communicating with doctors and their perceptions of the continuity and coordination of their medical care. The MCQ instrument is brief (5-10 minutes to complete), easy to administer, and is simple to score, therefore we feel it would be a valuable and suitable patient-reported measure to be used in busy oncology practice, clinical trials and service improvement programmes.

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Table 1 Aims and methods for each study phase

Phase	Year	Aim	Procedure
Phase 1	1999	Review literature relevant to continuity of care issues for outpatient oncology and identify relevant instruments	1. Literature search 2. Review existing instruments
Phase 2	1999	Obtain expert opinion on the relevance of the CPCI and to modify the instrument to be applicable to outpatient oncology practice	1. Expert review of CPCI 2. Removal of incompatible items 3. Rewording existing items 4. Construction of new items
Phase 3	1999-2000	Test the acceptability and relevance of the adapted questionnaire and explore its measurement properties	1. Patient completion of questionnaire 2. Descriptive analysis and modification of questionnaire 3. Psychometric exploration of factor structure
Phase 4	2000-2003	Examine the hypothesised subscales in a new patient population. Explore the validity of the modified questionnaire between groups.	1. Patient completion of questionnaire 2. Patient completion of secondary instruments 3. Psychometric exploration of factor structure, reliability, validity, and known groups

CPCI, Components of Primary Care Index

Table 2 Adaptation process of CPCI to MCQ showing item wording and factor loading of final MCQ items

	Phase 2 Expert Review	Phase 3 Psychometric Evaluation		
Original 19-item CPCI	21-item MCQ	*Factor	Factor Loading	Final MCQ Item Number
I rarely see the same doctor when I go for medical care	I rarely see the same doctor when I come to this clinic	1	.403	1
Sometimes this doctor does not listen to me	Sometimes the doctors do not listen to me	1	.506	2
I want one doctor to co-ordinate all the health care I receive	I want one doctor to co-ordinate all the care I receive	2	.639	3r
This doctor communicates with the other health care providers I see	The doctors I see in this clinic communicate with each other	3	.555	4r
This doctor do not always know my medical history very well	The doctors do not always know my medical history and problems very well	1	.678	5
My medical care improves when I see the same doctor that I have seen before	My medical care improves when I see the same doctor that I have seen before	2	.620	6r
It is very important to me to see my regular doctor	It is very important to me to see my regular doctor	2	.878	7r
This doctor and I have been through a lot together	The doctors know how I feel emotionally while they are treating me	3	.785	8r
This doctor does not always know about care I have received at other places	The doctors do not always know about the care and treatment I have received previously in this clinic	1	.677	9
I don't always feel comfortable asking questions of this doctor	I don't always feel comfortable asking the doctors questions	1	.513	10
This doctor knows a lot about the rest of my family	The doctors know about non-medical things in my life (family, job, hobbies, social life)	3	.642	11r
NEW	I sometimes have to repeat my problems to the different doctors I see in this clinic	1	.506	12
NEW	I would rather wait for the doctor who saw me last than be seen by the next available doctor in clinic	2	.736	13r
NEW	The doctors usually know about the problems that have bothered me at the previous visits	3	.591	14r
I can easily talk about personal things with this doctor	I can easily talk about personal things with the doctors	3	.458	15r
How many years have you been a patient of this physician?	REMOVED			
I go to this doctor for almost all of my medical care	REMOVED			

If I am sick, I would always contact a doctor in this office first	REMOVED	
This doctor clearly understand my health needs	The doctors clearly understand my medical needs	REMOVED
This doctor knows the results of my visits to other doctors	The doctors know the results of my previous visits to this clinic	REMOVED
This doctor always follow up on a problem I've had, either at the next visit or by phone	The doctors always follow up on a problem I've had before	REMOVED
This doctor always explain things to my satisfaction	The doctors always explain things to my satisfaction	REMOVED
NEW	The doctors I see in this clinic know what my treatment or care plan is	REMOVED
NEW	I don't mind seeing different doctors because everyone in the team knows my case	REMOVED

* The three factors were labelled as follows: factor 1 = "Coordination" of medical information and Dr's accumulated knowledge about patient; factor 2 = "Preferences" to see usual doctor; and 3 = "Communication" with doctor.
r represents that the item has been reversed scored
CPCI, Components of Primary Care Index; MCQ, Medical Care Questionnaire

Table 3 Patient demographic and clinical details for study phases 3 and 4

	Phase 3 N=200	Phase 4 N=477
Sex, n (%)		
Female	162 (81%)	354 (74.2%)
Male	38 (19%)	123 (25.8%)
Age Group (years), n (%)		
15-29	8 (4%)	14 (2.9%)
30-44	27(13.5%)	74 (15.5%)
45-59	84 (42%)	195 (40.9%)
60-74	67 (33.5%)	160 (33.5%)
75+	14 (7%)	34 (7.1%)
K index, median (range)	0.3 (0-1)	0.50 (0-1)
Marital status, n (%)		
Single	12 (6%)	30(6.3%)
Married/ cohabiting	148 (74%)	358 (75.1%)
Divorced/widowed	37 (18.5%)	84 (17.6%)
Missing	3 (1.5%)	5 (1.0%)
Employment status, n (%)		
Working full time	26 (13%)	211 (44.2%)
Working part time	23 (11.5%)	43 (9.0%)
On sick leave	51 (25.5%)	58 (12.2%)
Homemaker	16 (8%)	40 (8.4%)
Retired	76 (38%)	112 (23.5%)
Other	4 (2%)	5 (1.0%)
Missing	4 (2%)	8 (1.7%)
Diagnosis, n (%)		
Breast cancer	53 (26.5%)	112 (23.5%)
Gastrointestinal	9 (4.5%)	0
Genitourinary	33 (16.5%)	102 (21.4%)
Gynaecological	76 (38%)	161 (33.8%)
Melanoma	2 (1%)	40 (8.4%)
Sarcoma	11 (5.5%)	36 (7.5%)
Other	16 (8%)	26 (5.5%)

K index = (Number of visits – Number of doctors) / (Number of visits – 1)

K index has a value between 0 and 1, when a patient has seen only one doctor over time K index = 1. When a patient has seen different doctors at each visit, the K index = 0.

Table 4 Multitrait item-subscale correlations (phase 4)

	MCQ Domains		
	Coordination	**Preferences**	**Communication**
Coordination	**-**	**-0.292‡**	**0.450‡**
1	*0.362**	0.130	0.298
2	0.533*	-0.242	0.302
5	0.562*	-0.183	0.376
9	0.591*	-0.231	0.353
10	*0.361**	-0.166	0.225
12	0.556*	-0.225	0.356
Preferences	**-0.292‡**	-	**-0.066‡**
3	-0.202	0.683*	-0.034
6	-0.218	0.643*	-0.009
7	-0.246	0.769*	0.009
13	-0.276	0.645*	-0.139
Communication	**0.450‡**	**-0.066‡**	-
4	0.277	-0.118	0.418*
8	0.266	0.028	0.503*
11	0.235	-0.052	*0.379**
14	0.344	0.019	0.504*
15	0.409	-0.102	0.472*

* Item correlation with own scale, corrected for overlap

‡ Correlation between subscales (subscale values derived by computing the mean of subscale items and linearly transforming the data to a 0-100 scale)

MCQ, Medical Care Questionnaire

Items in italics (1, 10, 11) indicate low item-convergent validity with own subscale

Table 5 Known group comparisons (phase 4)

Groups	**Communication**				**Coordination**				**Preferences**			
	N	Mean	SD	*p* value	N	Mean	SD	*p* value	N	Mean	SD	*p* value
Gender				* 0.728				* 0.985				* 0.925
Male	121	70.80	16.86		121	69.22	22.23		117	67.20	25.78	
Female	350	67.79	17.72		353	66.33	22.51		340	70.10	26.07	
Age				* 0.907				* 0.205				* 0.396
< 60	280	67.74	17.61		281	66.35	21.73		272	71.10	25.78	
> 60	191	69.78	17.42		193	68.11	23.48		185	66.80	26.17	
Tumour Group				‡ 0.009				‡ 0.028				‡ 0.002
Breast	110	63.17	18.66		111	63.03	23.30		106	77.44	21.56	
Genitourinary	102	69.32	17.34		102	66.47	23.02		99	68.50	26.58	
Gynaecological	159	69.93	16.41		161	68.83	21.14		154	64.46	28.13	
Melanoma	40	72.63	18.22		40	73.38	20.66		39	65.55	23.47	
Sarcoma	34	69.60	17.87		34	65.77	22.71		34	68.57	26.49	
Other	26	72.45	14.91		26	63.08	23.41		25	75.75	22.99	
K index Quartiles				‡ 0.079				‡ 0.177				‡ 0.000
0 - 0.24	103	64.94	17.04		104	64.77	22.59		102	67.97	25.34	
0.25 - 0.49	117	69.46	18.36		117	65.25	22.90		112	62.78	28.40	
0.50 - 0.59	72	67.88	17.70		72	70.30	21.36		69	66.21	26.80	
0.60 - 1.00	161	70.53	17.19		162	69.34	22.20		156	76.02	22.79	

* P value from independent samples t-test.
‡P value from One Way ANOVA showing overall group effect.
SD, Standard Deviation