

# **Satisfaction with information provision and health-related quality of life in basal and squamous cell carcinoma patients: a cross-sectional population-based study**

Rick Waalboer-Spuij

Loes M. Hollestein

Tamar E.C. Nijsten

Lonneke V. van de Poll-Franse

*on behalf of the BaSQoL Group*

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## ABSTRACT

This study aims to determine the satisfaction with information provision received by basal cell carcinoma (BCC) and squamous cell carcinoma (SCC) patients and associations with health-related quality of life (HRQoL). 1,173 patients from the Netherlands Cancer Registry, received questionnaires on BCC/SCC-specific HRQoL (BaSQoL), cancer-specific HRQoL (EORTC QLQ-C30), information provision (EORTC QLQ-INFO25) and general satisfaction (EORTC INPATSAT-32). 721 (61%) patients participated. The HRQoL impact (BaSQoL) was higher among female and younger patients. One third (N=237) of all patients indicated to be dissatisfied with the information provision. Dissatisfaction with information provision was associated with younger age, facial tumour, not having a partner and multiple comorbidities. HRQoL was worse in patients dissatisfied with information provision (e.g. BaSQoL-worries mean score satisfied patients: 0.54 (95%CI:0.48–0.59 ), dissatisfied patients: 0.77 (95%CI:0.67–0.87 ),  $p=0.001$ ). Dissatisfaction with provided information was associated with an impact on HRQoL. Possibly, HRQoL could be improved by improving the information provision.

## INTRODUCTION

Patient reported outcome measures (PROMs) and more specifically health-related quality of life (HRQoL) are increasingly being used in dermatology over the past decades. It is an essential and established outcome for clinical studies and in daily practice in inflammatory skin diseases and is increasingly used in skin cancer.[1-3] Patients with keratinocytic carcinomas (KC), which include basal cell carcinoma (BCC) and squamous cell carcinoma (SCC), are likely to develop multiple lesions including actinic keratosis (AK) (so called ‘actinic neoplasia syndrome’).[4] Since the incidence of BCC and SCC continues to rise rapidly, it is important to identify patients with high disease burden in order to intervene appropriately.[5-7] Recently, the basal and squamous cell carcinoma quality of life (BaSQoL) questionnaire was developed to measure disease specific HRQoL in BCC and SCC patients.[8]

An important factor associated with HRQoL is information provision. A systematic review in head and neck, breast, lung, gastro-intestinal, genitourinary and haematological cancer patients showed a positive association between information provision and HRQoL.[9] Information provision is considered as one of the most important aspects of supportive care, as an increase in knowledge about the disease and treatment leads to better illness perception, which could lead to a better HRQoL[10, 11]. However, this relation has not been described in BCC and SCC patients, and may differ from the aforementioned cancers, because the mortality is very low and treatment may have less impact. This study aims to assess current level of satisfaction with received information and the association with HRQoL in a large population-based sample of KC patients in the Netherlands. We hypothesized that patients who were more satisfied with the received information reported a better HRQoL.

## METHODS

### Setting and participants

A cross-sectional study was performed among 1,173 patients, selected from the Southern region of the population-based Netherlands Cancer Registry (NCR), because during the study period, the NCR did not register all BCC and SCC nationwide yet. Patients were selected if they were diagnosed in one of the nine participating hospitals or clinics during the past twelve months before sending the questionnaire. Data was collected during the validation phase of the BaSQoL questionnaire.[8]

## Data collection

Participating patients completed a web-based questionnaire, or paper based on request. Patients were invited to participate through their dermatologist by a postal letter explaining the study. When no reply was received, patients were sent a reminder several weeks later. Informed consent was obtained for the questionnaire and obtaining the clinical disease history data as registered by the NCR.

The questionnaire is part of the PROFILES (Patient Reported Outcomes Following Initial treatment and Long Term Evaluation of Survivorship) registry. PROFILES is a registry studying physical and psychosocial impact of cancer and its treatment. It is linked directly to the data from the NCR[12].

## Disease and patient characteristics

Socio-demographic data (age, education, occupation, partnership) was collected using standardized questionnaires. Disease specific data such as tumour type, location, treatment and date of treatment were gathered from NCR.

## Questionnaires

### *Information provision*

Satisfaction with information provision was measured with the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire INFO25 (EORTC QLQ-INFO25) [13, 14]. This is a 25-item questionnaire to evaluate the provided information received by cancer patients. The questionnaire consists of 4 subscales: information about the disease, medical tests, treatment, other services and additional single items. Responses are given in a 4-point Likert scale ('not at all', 'a little', 'quite a bit' and 'very much'), except four items with a dichotomous yes or no response. All scales (excluding the satisfaction with information provision item) were converted to a 0-100 scale with higher scores meaning higher level of information received or higher wishes on information.

For this study, the 4-point Likert scale of the item 'satisfaction with information provision' was dichotomized into satisfied ('quite a bit' – 'very much') and dissatisfied ('not at all' – 'a little').

### *Health-related quality of life*

Cancer-specific quality of life was measured by the EORTC QLQ-Core 30 (EORTC QLQ-C30), which is a 30 item questionnaire, divided in several scales: functional scales (physical, role, emotional, social and cognitive functioning), symptom scales (fatigue, pain and nausea/vomiting) and single items concerning global health and quality of life, financial impact

and symptoms [15, 16]. All scales were converted to a 0-100 scale with higher scores meaning higher quality of life in the functional scales and more impact in the symptom scales.

The BaSQoL questionnaire was used to assess disease specific quality of life [8]. The BaSQoL is a 16 item questionnaire in which responses are given in a 4-point Likert scale ('not at all', 'a little', 'quite a bit' and 'very much'). The questionnaire is divided into 5 subscales ('behavior', 'worries', 'appearance', 'diagnosis and treatment' and 'other people'). All subscale scores are converted to a 0-3 scale with higher scores implicating higher impact on HRQoL.

### ***Patient satisfaction***

The EORTC satisfaction with in-patient cancer care (INPATSAT-32) questionnaire addresses patient satisfaction with aspects of care, relevant to oncological disease [17]. It consists of several domains assessing doctors' skills, nurses' skills, information provision and availability, hospital personnel and the hospital generally, leading to 11 multi item scales and three single item scales. Responses are given in a 5-point Likert scale ranging from 'poor' to 'excellent'. All scales were converted to a 0-100 scale with higher scores representing higher satisfaction with care. In the current study, the domain of INPATSAT-32 addressing nurses' skills was not administered since the participants were predominantly outpatients and were generally not treated by nurses.

### ***Comorbidity***

Comorbidity was measured by the self-reported comorbidity questionnaire.[18]

### ***Statistical analyses***

Mean values of different scales were compared with independent samples T-tests between patients who were satisfied and dissatisfied with information. KC were studied collectively, but separate descriptive analyses for BCC and SCC were performed. Bar charts were created to display the different values of the BaSQoL and EORTC QLQ-C30 subscales, stratified by satisfaction with information provision. Multivariable linear regression analysis was used to assess the association between the HRQoL as outcome measure (i.e., each subscale of the BaSQoL) and satisfaction with information (i.e., satisfaction item of the EORTC QLQ-INFO25) as covariate. In order to take missing data into account in the regression analyses, we applied multiple imputation (25 imputations). In the imputation models we included all covariates and outcomes of the regression models. The model was adjusted for age at time of the questionnaire, time since diagnosis, sex, education, occupation, partnership, location of tumour, type of tumour and comorbidity. The selection of these variables was done a priori. The assumptions of multiple linear regression (no multicollinearity, normality of the residual values, homoscedascity) were met. A bar chart was

plotted to display the possible differences in satisfaction with information between the participating centres. As a secondary analysis, two multivariable logistic regression models were used to test if hospitals/clinics were independently associated with satisfaction with information provision or HRQoL, regardless of any of the aforementioned tumour and patient characteristics.

P-values  $< 0.05$  (two-sided) obtained from regression models were considered statistically significant. All other p-values were corrected for the false discovery rate proportion of true null hypothesis among significant results (Benjamini-Hochberg procedure) [19]. Corrected p-values  $< 0.033$  (two-sided) were considered statistically significant. All analyses were performed in IBM SPSS Statistics for Windows, Version 21.0 (Armonk, New York: IBM Corporation).

## RESULTS

721 of the 1,173 patients completed the questionnaire (response rate of 61%). Of all respondents 85% had BCC and 15% had SCC. One third ( $N=237$ ) indicated to be dissatisfied with the information provision as measured by the dichotomized item 'satisfaction with information provision' within the EORTC QLQ-INFO25 questionnaire. Dissatisfied patients were a few years older than satisfied patients (75 vs 71 years of age; table 1). Of all patients, 16% ( $N=116$ ) indicated that they had wanted to receive more information about skin cancer in general, but also about causes, treatment and follow-up plan and how to recognize new lesions. This corresponds to 37% ( $84/225$ ) of all dissatisfied patients and 7% ( $28/416$ ) of the satisfied patients. Three percent ( $N=24$ ) wanted to have had received less information. The information received was considered helpful in 68% ( $N=417$ ) of all patients. There was no difference in satisfaction about the information in the tumour type (BCC vs SCC) or BCC subtype (Table 1). Facial location of the tumour, not having a partner and having more comorbidities did show a statistical significant increase in dissatisfaction (Table 1). Patients who were dissatisfied with the information provision also scored statistically significantly lower on the general satisfaction with in patient care (as measured by the EORTC INPATSAT-32 questionnaire) and also on all other subscales of the EORTC INFO-25 (data not shown).

HRQoL, as measured by the BaSQoL and EORTC QLQ-C30 was statistically significantly lower among patients who were dissatisfied with information provision (figure 1a and 1b).

The distribution of satisfied versus dissatisfied with the information provision differed substantially between the 9 participating hospitals or clinics (Figure 2, Suppl. Table 1).

**Table 1.** Basal cell carcinoma and squamous cell carcinoma patient characteristics according to satisfaction with information provision\*

	Dissatisfied patients <sup>#</sup> N=237	Satisfied patient <sup>#</sup> N=422	P-value
Age at time of survey in years, median (IQR)	75 (16)	71 (15)	0.015
Years since diagnosis , median (IQR)	4 (0.6)	4 (0.5)	0.363
Sex			0.148
• Male (%)	113 (33)	226 (67)	
• Female (%)	124 (39)	196 (61)	
Education			0.051
• Low	74 (41)	104 (58)	
• Medium	142 (34)	279 (66)	
• High	15 (30)	35 (70)	
Current occupation			0.094
• (Self-) Employed	48 (30)	114 (70)	
• Unemployed	168 (37)	289 (63)	
Partnership			0.002
• Partner	163 (33)	339 (67)	
• No partner	70 (47)	78 (53)	
Tumour type			0.548
• BCC	203 (36)	358 (64)	
• SCC	18 (32)	38 (68)	
Location of tumour			0.004
• Face	197 (39)	311 (61)	
• Other	40 (26)	111 (74)	
Type BCC			0.633
• Multifocal superficial	14 (23)	48 (77)	
• Infiltrating	51 (50)	51 (50)	
• Nodular	124 (34)	238 (66)	
• Other	14 (40)	21 (60)	
Comorbidity			< 0.001
• No	100 (28)	260 (72)	
• 1	33 (40)	50 (60)	
• ≥2	95 (49)	100 (51)	

\* Because of missing values numbers do not always add up to 721.

<sup>#</sup> Measured by the dichotomized item 'satisfaction with information provision' of the EORTC QLQ-INFO25 questionnaire.

BaSQoL subscale scores and satisfaction with information provision.

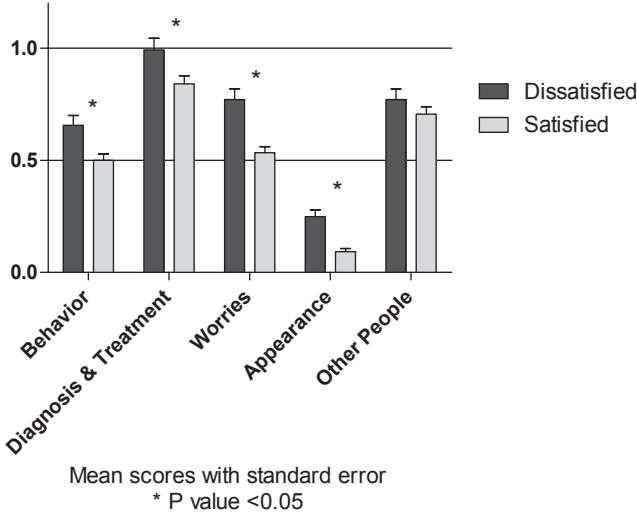


Figure 1a. BaSQoL subscale scores and satisfaction with information provision.

EORTC QLQ-C30 subscale scores and satisfaction with information provision.

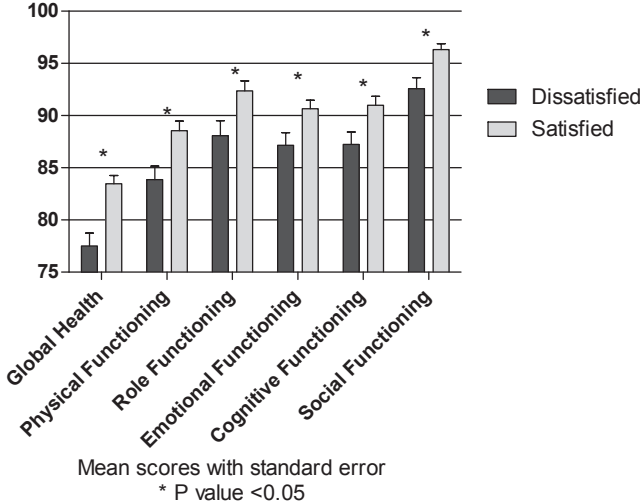


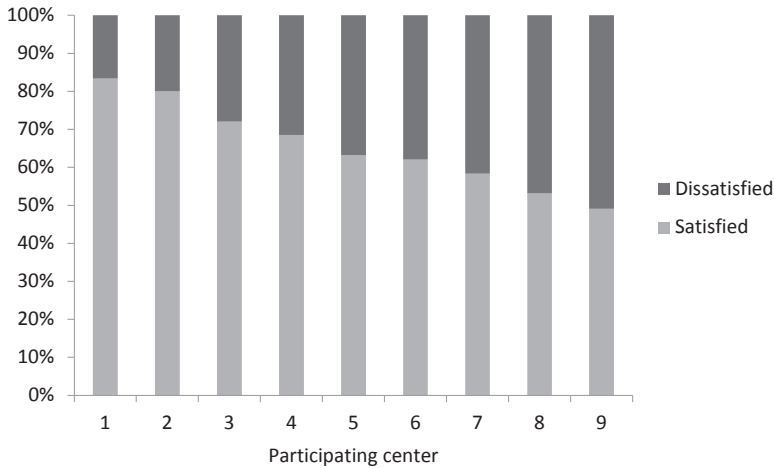
Figure 1b. EORTC QLQ-C30 subscale scores and satisfaction with information provision.

Figure 1a and 1b. Mean BaSQoL And EORTC QLQ-C30 subscale scores and satisfaction with information provision.

Mean scores with standard error

\* p value < 0.033 (FDR corrected)





**Figure 2.** Percentage of patients satisfied and dissatisfied with information provision per hospital / clinic. Ranked descending in percentage of satisfaction.

However, after adjustment for patient and tumour characteristics, participating centre was no longer associated with satisfaction with information provision (Suppl. Table 1). Also, participating centre was not statistically significantly associated with any BaSQoL subscale in a multivariable regression model (data not shown).

Satisfaction with information provision was associated with the behavior, diagnosis & treatment, worries and appearance subscales of the BaSQoL questionnaire with negative Beta's (-0.3 to -0.1), indicating that satisfied patients had a 0.3 to 0.1 lower BaSQoL subscale score, thus lower impact on HRQoL (table 2).

Other factors associated with worse HRQoL scores were younger age (all BaSQoL subscales), recent time since diagnosis (on diagnosis & treatment, worries and appearance subscales of the BaSQoL questionnaire, indicating higher HRQoL impact if diagnosis and treatment was more recent) and being female (on diagnosis & treatment, worries and other people BaSQoL subscales). Facial location of the tumour was also associated with more HRQoL impact in the behavior, diagnosis and treatment and appearance subscales. Having a SCC led to a higher score than a BCC in the worries and other people subscales. No consistent effect on BaSQoL subscales was observed among different categories of patient' education.

**Table 2.** Multiple linear regression analysis evaluating the association between BaSQoL subscales and satisfaction with information\*  $p < 0.05$ 

	Behavior		Diagnosis & Treatment		Worries		Appearance		Other People	
	Beta	95 % CI	Beta	95 % CI	Beta	95 % CI	Beta	95 % CI	Beta	95 % CI
Satisfaction with information (dissatisfied = ref)										
• Satisfied	<b>-0.15*</b>	-0.25 / -0.05	<b>-0.12*</b>	-0.25 / -0.00	<b>-0.25*</b>	-0.35 / -0.15	<b>-0.14*</b>	-0.20 / -0.08	-0.07	-0.18 / 0.05
Age at time of questionnaire										
•	<b>-0.01*</b>	-0.01 / -0.00	<b>-0.01*</b>	-0.02 / -0.00	<b>-0.01*</b>	-0.02 / -0.01	<b>-0.01*</b>	-0.01 / -0.01	<b>-0.01*</b>	-0.01 / -0.00
Time since diagnosis										
•	-0.01	-0.04 / 0.03	<b>0.07*</b>	0.02 / 0.12	<b>0.07*</b>	0.02 / 0.12	<b>0.06*</b>	0.02 / 0.09	-0.02	-0.5 / 0.08
Sex (male = ref)										
• Female	0.07	-0.02 / 0.16	<b>0.29*</b>	0.17 / 0.40	<b>0.12*</b>	0.02 / 0.21	0.02	-0.04 / 0.07	<b>0.20*</b>	0.09 / 0.30
Education (low = ref)										
• Medium	<b>-0.14*</b>	-0.24 / -0.04	-0.03	-0.16 / 0.10	-0.04	-0.14 / 0.06	-0.04	-0.10 / 0.02	<b>0.13*</b>	0.01 / 0.25
• High	<b>0.20*</b>	0.02 / 0.38	-0.15	-0.38 / 0.08	-0.15	-0.33 / 0.03	-0.08	-0.19 / 0.02	-0.06	-0.16 / 0.28
Occupation (self-employed = ref)										
• Unemployed	-0.08	-0.22 / 0.06	-0.14	-0.32 / 0.03	-0.05	-0.19 / 0.09	0.08	-0.00 / 0.16	-0.02	-0.18 / 0.15
Partnership										
• No partner (partner = ref)	0.08	-0.03 / 0.19	0.12	-0.02 / 0.26	-0.07	-0.18 / 0.04	0.05	-0.01 / 0.12	-0.00	-0.13 / 0.13
Location of tumour (face = ref)										
• Other	<b>-0.11*</b>	-0.21 / -0.01	<b>-0.14*</b>	-0.26 / -0.01	0.02	-0.09 / 0.12	<b>-0.09*</b>	-0.15 / -0.03	0.07	-0.05 / 0.20
Type tumor (BCC= ref)										
• SCC	0.04	-0.11 / 0.18	0.14	-0.05 / 0.32	<b>0.29*</b>	0.14 / 0.44	0.05	-0.04 / 0.13	<b>0.25*</b>	0.07 / 0.43
Comorbidity (no = ref)										
• 1	-0.08	-0.22 / 0.06	0.09	-0.09 / 0.27	0.01	-0.13 / 0.15	0.07	-0.01 / 0.15	0.03	-0.14 / 0.20
• $\geq 2$	-0.02	-0.13 / 0.08	0.11	-0.02 / 0.25	0.04	-0.07 / 0.15	<b>0.07*</b>	0.00 / 0.13	0.13	0.00 / 0.25

## DISCUSSION

In this cross-sectional population based study we demonstrated that patients who were dissatisfied with information provision had statistically significant higher impact on four of the five subscales of the BaSQoL and all of the EORTC QLQ-C30 subscales. There are two possible explanations for this correlation. First, patients dissatisfied with provided information may not have sufficient knowledge about the disease and treatment and therefore have inadequate illness perception which causes more impact on HRQoL. Second, patients who reported a more negative impact of their disease on HRQoL are generally more dissatisfied with care, thus also with information provision. Since our study had a cross-sectional design, satisfaction with information and HRQoL were assessed at a single time point, so we cannot differentiate on which explanation is correct. Worse HRQoL on all BaSQoL subscales was found in younger patients. This is similar to the results of a pooled analysis studying the relation between age and HRQoL in cancer patients which showed that social functioning (as measured by the EORTC QLQ-C30) is better in older patients in comparison to younger cancer patients. [20]

In contrast to our hypothesis, being female did not show a significant association on the appearance subscale whilst it was associated with the diagnosis & treatment, worries and other people subscales. To improve the HRQoL impact in BCC and SCC patients, the BaSQoL could be used to identify patients with higher impact and provide supportive care accordingly. Further research is necessary to identify which scores require additional attention.

This study also showed that one third of Dutch BCC and SCC patients were dissatisfied with the received information provision. These dissatisfied patients showed substantially lower scores on all subscales of provided information provision (EORTC INFO-25) in comparison to satisfied patients. Comparable results have been described earlier in patients with prostate cancer, multiple myeloma, lymphoma, endometrial cancer, colorectal cancer and thyroid cancer. In these studies the perceived receipt of disease-specific information was associated with better understanding of the disease and more personal and treatment control. [10, 11, 21] Especially in the dissatisfied with information provision group there is a wish for receiving more information. By taking into account the role of information provision in understanding, coping with the disease and choosing treatment, meeting the patients' needs for more information is desirable. [9, 22] In this study factors associated with dissatisfaction with information provision were younger age, facial location of the tumour, not having a partner and having more comorbidities. Another study described lower income and education, female, unmarried status and type of cancer with good prognosis associated with patients' perception of inadequate information provision. [23] In comparison to our study the role of having no partner is similar. Lower education

level was not significant ( $p = 0.051$ ) but did show a similar trend. No difference was seen between SCC and BCC.

We observed a large difference in how patients scored their satisfaction with information provision per hospital or clinic. These differences can partially be explained by the patient and tumour characteristics. But there is still room for improvement. These demonstrated differences underline the need for optimizing and standardizing the way to inform patients about their KC and possibly other diseases. The Dutch Society for Dermatology and Venerology has developed several disease specific patient leaflets with general information about the disease and treatment. The results of our study suggest that the BCC and SCC information leaflets of the Dutch Society for Dermatology and Venerology (NVDV) are not fully satisfactory to all patients, that the leaflet may not always have been provided to the patient upon diagnosing BCC or SCC, or that certain subgroups of KC patients may require more detailed information (e.g., patients with facial tumours). Unfortunately, no specific questions about the general patient leaflet were included in our questionnaire. A recent discrete choice experiment (DCE), regarding patient preferences among patients with BCC in the Netherlands, indicated that patients prefer personalized information, rather than general information. [24]

### Strengths & Limitations

Strengths of this study include, that it was a population-based disease-specific HRQoL assessment of BCC and SCC patients, a validated questionnaire was used and a large sample was included. Therefore, the results can be generalized to the general population with BCC and SCC. A limitation of this study was the cross-sectional design and thus satisfaction with information and HRQoL were assessed at a single time point, therefore we cannot differentiate if dissatisfaction with information provision leads to more HRQoL impact or vice versa. In addition, the time since diagnosis is different for patients within our sample and it would be informative to follow the BaSQoL scores at several time points after diagnosis within the same patient. For example, the scarring shortly after (surgical) treatment is more present so the appearance subscale score could decrease over time. The behaviour subscale score on the other hand could fluctuate over time with the changing of the weather and therefor the necessity to protect the skin against sunlight.

### CONCLUSION

There is room for improvement in providing satisfactory information to BCC and SCC patients, especially in younger patients, patients with a facial location of the tumour, those who do not have a partner and have more comorbidities. Dissatisfaction with provided

information is associated with an impact on HRQoL which may be improved by improving the satisfaction in information provision. In addition to satisfaction with information, females and younger patients experienced a higher impact on several subscales of the BaSQoL. Possibly, these subgroups may require more supportive care, but further research is necessary to identify these patients based on their BaSQoL scores.

## **ETHICAL CONSIDERATIONS**

This study was approved by the local ethics committee of the Erasmus Medical Centre Rotterdam (Reference number MEC-2013-420)

## **CONFLICTS OF INTEREST AND FUNDING**

The authors state no conflict of interest.

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**Supplementary Table 1.** Satisfaction with information across participating centres.

	Satisfied	Dissatisfied	Univariable		Multivariable *	
	N	N	OR (95%CI)	p-value	OR (95%CI)	p-value
<b>Participating centre</b>						
A	74	34	Ref.		Ref.	
B	48	12	1.84 (0.87 – 3.90)	0.11	2.02 (0.93 – 4.40)	0.08
C	36	14	1.18 (0.56 – 2.47)	0.66	1.39 (0.64 – 3.05)	0.41
D	20	4	2.30 (0.73 – 7.24)	0.16	1.89 (0.58 – 6.16)	0.29
E	34	30	0.52 (0.28 – 0.99)	0.05	0.53 (0.27 – 1.04)	0.07
F	49	35	0.64 (0.36 -1.17)	0.15	0.70 (0.37 – 1.32)	0.27
G	67	41	0.75 (0.43 – 1.32)	0.32	0.81 (0.45 – 1.74)	0.49
H	67	39	0.79 (0.45 – 1.39)	0.41	0.89 (0.49 – 1.62)	0.69
I	27	28	0.44 (0.23 – 0.86)	0.02	0.49 (0.24 – 1.00)	0.05

\* The multivariable model was adjusted for HRQoL (Global subscale of the EORTC QLQ-C30) age at time of the questionnaire, time since diagnosis, sex, education, occupation, partnership, location of tumour, type of tumour and comorbidity