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DETERMIN Study Management Group

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Patient preference for commonly-used, head and neck cancer-specific quality of life questionnaires in the follow-up setting (Determin): A multi-centre randomised controlled trial and mixed methods study

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Abstract

Background: Quality of life (QoL) assessment forms an integral part of modern cancer care and research. The aim of this study is to determine patients' preferences and willingness to complete commonly used head-and-neck cancer (HNC) QoL questionnaires (QLQs) in routine follow-up clinics.

Methods: This is a randomised control trial of 583 subjects from 17 centres during follow-up after treatment for oral, oropharyngeal or laryngeal cancer. Subjects completed three structured validated questionnaires: EORTC QLQ-HN35; FACT-HN and UW-QOL, and an unstructured patient-generated list. The order of questionnaire presentation was randomised, and subjects were stratified by disease site and stage. Patients self-rated the questionnaires they found most helpful to communicate their health concerns to their clinicians.

Results: Of the 558 respondents, 82% (457) found QLQs useful to communicate their health concerns to their clinician (OR = 15.76; 95% CI 10.83–22.94). Patients preferred the structured disease-specific instruments (OR 8.79; 95% CI 5.99–12.91), while the open list was the most disliked (OR = 4.25; 95% CI 3.04–5.94). There was no difference in preference by treatment modality. More women preferred the FACT-HN (OR = 3.01, 95% CI 1.05–8.62), and patients under 70 preferred EORTC QLQ-HN35 (OR = 3.14, 95% CI 1.3–7.59). However, only 55% of patients expressed preference to complete questionnaires routinely at the clinic.

Conclusions: Most patients found QLQs helpful during their follow-up and 55% supported routine questionnaires in follow-up clinics. Males and people over 70 years old were the least willing to complete the routine questionnaires and preferred shorter questionnaires (e.g., UW-QOL). Women preferred FACT-HN, and younger

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patients preferred EORTC QLQ-HN35. Reasons for the reluctance to complete questionnaires require elucidation.

KEYWORDS

EORTC QLQ-HN35, FACT-HN, head and neck cancer, patient concerns list, quality of life, UW-QOL

1 | INTRODUCTION

Quality of life (QoL) assessment is an integral part of research in cancer, especially in the evaluation of efficacy and outcomes of new treatments. Regular assessment of QoL and functional disability during clinical consultations has been shown to facilitate clinician-to-patient communication, improve clinicians' awareness of patients' QoL issues and improve the emotional functioning of patients.^{1,2} Consequently, various professional bodies have recommended evaluation of QoL as an integral part of clinical care.³

Many of the validated QoL questionnaires (QLQs) in HNC patients have shown the ability to differentiate well between patients with tumours at different sub-sites, disease stages, and different treatment modalities.^{4–6} They have also shown responsiveness over time, and even the ability to predict future QoL and survival.⁷ However, there are a plethora of published QLQs for head and neck cancer (HNC) patients.^{8,9} While the majority of clinicians indicate they find some QLQs useful, many clinicians are unsure which questionnaire to use, which limits the routine use of QLQs in HNC clinics.^{8–11}

Two of the most commonly-used questionnaires (EORTC QLQ-HN35 and FACT-HN) have demonstrated similar score characteristics, reliability, sensitivity and construct validity, but they appear to measure somewhat different aspects of health-related QoL.¹² That emphasises the importance of QLQ selection for the required setting and context. The preferences of patient sub-groups may therefore be an important factor to determine the QoL instruments to be used in clinical practice.

However, this potentially important determinant of QLQ choice has rarely been explored before. We systematically searched MEDLINE and EMBASE databases for studies examining HNC patients' preference for QLQs, using a comprehensive search strategy with no language or publication date restrictions (search updated on 17 September 2022). A total of 730 articles were screened and only one relevant article by Mehanna and Morton¹³ identified, which was a pilot study for this current trial.

Aiming to facilitate the routine use of QoL instruments in clinical practice, this study determined patients' preference and willingness to use four different QLQ in routine follow-up clinics.

2 | METHODOLOGY

2.1 | Study design

This was a multi-centre, cross-sectional, blinded randomised controlled trial (RCT), with an additional qualitative analysis. It was undertaken in 17 HNC secondary care clinics between 2008 and 2011

Key points

- This is the first randomised controlled trial to systematically examine head and neck cancer (HNC) patients' preferences for commonly used quality of life questionnaires (QLQs).
- Most HNC patients find QLQs of benefit in communicating with their clinicians.
- Patients overwhelmingly favour structured questionnaires over non-structured patient-generated lists.
- Only over half of HNC patients favour using the QLQs routinely at the clinic. Women and younger patients favoured FACT-HN and EORTC QLQ-HN35, respectively.
- Men and patients older than 70 were the least willing, and favoured short questionnaires. Reasons for this warrant further exploration.

(Table S1). The study followed CONSORT reporting guidelines.¹⁴ The study was given ethics approval by the Coventry and Warwickshire National Ethics Committee (06/Q2802/101).

2.2 | Participants

Patients attending for their HNC follow-up at the participating centres were assessed for eligibility. We included patients who had curative treatment for oral, oropharyngeal or laryngeal cancer, and were undergoing follow-up at least 1 month, and no more than 5 years, post-treatment. Patients with confirmed or suspected recurrence were excluded.

2.3 | Procedures

Study instrument and information leaflets were posted to patients before their clinic appointment. On attendance to the clinic, if willing to participate, patients gave written informed consent, and were asked to complete the questionnaires before meeting the clinician. The study instrument consisted of four HNC-specific QLQs, and a previously-piloted survey¹³ that prompted patients to compare the questionnaires, Figure S1.

2.3.1 | Selection of study questionnaires

The four QLQs included in the study were: the Functional Assessment of Cancer Therapy Head and Neck questionnaire (FACT-HN) version

4¹⁵; the European Organisation of Research into the Treatment of Cancer Quality of Life Questionnaire—Head and Neck-35 version 1.0 (EORTC QLQ-HN35),¹⁶ the University of Washington Quality of Life Questionnaire version 4 (UW-QOL)¹⁷ and patient concerns list (PCL).¹⁸

The FACT-HN, EORTC QLQ-HN35 and the UW-QOL were selected because they are the QLQs most widely used by HNC clinicians at the time of the study. The EORTC QLQ-HN35 has since been updated to EORTC QLQ-HN43.¹⁹ FACT-HN comprised of 27 generic questions, and 12 Additional Concerns for Head and Neck questions. The UW-QOL comprised of 10 head- and neck-specific questions with 3 global health-related QoL questions, and one free-text question. Due to its length, we used the EORTC QLQ-HN35 alone, and added only two global QoL questions from EORTC QLQ-C30. The PCL questionnaire is an unstructured unvalidated questionnaire, that asked patients to list up to 10 health concerns in their own language on a blank sheet, and rank them in order of priority. For further details of instrument characteristics, see Table S2.

2.4 | Randomisation and masking

All patients received all four QLQs to complete, but the order of questionnaire presentation was randomised in equal ratio to avoid habituation and tiredness bias. Study packs were collated centrally according to one of 24 randomised combinations, using a computer generated random-permuted block algorithm design. Consecutive patients received sequentially numbered, sealed opaque envelopes, according to their stratification by disease site (oral or oropharyngeal versus laryngeal) and stage (Stage I, II vs. Stage III, IV). The randomisation allocation sequence was concealed from the patients and local researchers.

2.5 | Outcomes

The primary outcome was to determine the most helpful QLQ in describing the patients' health problems (Figure S1). Secondary outcomes included: odds ratio (OR) for willingness to complete a questionnaire in the clinic; OR for the least helpful instrument in describing their health problems; the reasons for patients' preferences; and patients' preferences for the characteristics of an ideal instrument for routine use in the clinic.

2.6 | Statistical analysis

To detect a 50:25:25 true division of preferences, at 90% power and 5% significance, a total of 126 patients who expressed a preference were required in each stratum. To account for incomplete reporting and missing data, the total sample size was increased by 10% to 560 patients.

Descriptive methods were used to summarise the patient characteristics and instrument preference. Outcomes were analysed using

logistic regression models with and without multivariate analysis fitted to generate the OR of patients' preference of each instrument.

Thematic analysis of the questionnaire responses was undertaken. Coding theory was used to explore the qualitative data from the unordered list to identify themes of concerns most important to patients. Using the NVIVO software, coding was independently conducted by Ben Carter, who had no knowledge of the content of the QLQs and was naïve of any likely codes. Common Terminology Criteria for Adverse Events (CTCAE) version 4.0 was used to provide definitions for medical concerns and aid coding of the data.²⁰ Codes were developed into themes through multiple discussions between both coders and a clinical author Hisham Mehanna.

3 | RESULTS

3.1 | Patient characteristics

Between October 2008 and May 2011, 797 subjects were consented and randomised in 17 centres in the UK. 583 (73.2%) returned their questionnaires, with 558 answering the primary outcome measure (Table 1, Figure S2 CONSORT¹⁴ Flow Diagram). The analysed patient sample had an overall mean age of 65.7 years \pm 11 SD, and was predominantly male (74.4%). The median time from treatment completion to recruitment into the study was 406 days, with 260 subjects (46.6%) recruited within a year of treatment end (Table 1). There was some variation in the distribution of female subjects across the type and stage of cancer: 15.3% of subjects with early laryngeal cancer, 17.6% of advanced laryngeal; 39% of early oral/oropharyngeal and 27.3% of advanced oral/oropharyngeal subjects (Table S3). There were fewer flap reconstructions in the laryngeal cancer group (4.5%, 12/261), compared to oral cancer group (40.1%, 122/304), reflecting expected clinical practice (Table 1, Table S3).

3.2 | Primary outcome: Questionnaire preference

Overall, most subjects (82%, 457/558) considered that one or any of the questionnaires were helpful in describing their health problems to their clinician, compared to none of the instruments being helpful (OR = 15.76; 95% CI 10.83–22.94; p -value <.001) (Table 2). Thirty percent (167/558) of subjects felt that any questionnaire would be helpful, and did not have a preference for a specific questionnaire. Amongst the 52% (290/558) subjects who indicated preference for a specific questionnaire, the EORTC QLQ-HN35 was the most favoured (98/290; OR = 3.38; 95% CI 2.23–5.11; p < .001), followed by FACT-HN (92/290; OR 3.17; 95% CI 2.09–4.82; p < .001) then UW-QOL (65/290; OR 2.24; 95% CI 1.45–3.47; p < .001). PCL received the lowest number of preferences (35/290), Figure 1 and Table 2. Even when instrument preference was adjusted for statistically significant covariates (age and gender), subjects still overwhelmingly indicated a preference for questionnaires over no questionnaires (OR 9.23; 95% CI 5.10–16.7, p < .001).

TABLE 1 Patient baseline characteristics, by instrument preference.

Baseline patient characteristics	Overall	Preferred instrument						
		UW-QOL	FACT-HN	EORTC QLQ-HN35	PCL	Any	None	Not sure
N (%)	558 (100%)	65 (11.6%)	92 (16.5%)	98 (17.6%)	35 (6.3%)	167 (29.9%)	29 (5.2%)	72 (12.9%)
Gender, N (%)								
Female	143 (25.6%)	22 (15.4%)	36 (25.2%)	23 (16.1%)	7 (4.9%)	35 (24.5%)	5 (3.5%)	15 (10.5%)
Male	415 (74.4%)	43 (10.6%)	56 (13.5%)	75 (18.1%)	28 (6.7%)	132 (31.8%)	24 (5.8%)	57 (13.7%)
Age, mean (SD)	65.7 (11.0)	65.5 (12.9)	63.8 (12.2)	62.8 (9.2)	63.9 (10.0)	66.9 (10.5)	68.7 (8.9)	67.3 (10.8)
Age, N (%)								
Younger than 60	54 (19–58) ^a	20 (11.5%)	32 (18.4%)	39 (22.4%)	12 (6.9%)	45 (25.9%)	7 (4%)	19 (10.9%)
60–70	63 (59–66) ^a	22 (10.3%)	36 (16.8%)	39 (18.2%)	14 (6.5%)	65 (30.4%)	9 (4.2%)	29 (13.6%)
70–80	70 (67–73) ^a	18 (13.5%)	17 (12.8%)	19 (14.3%)	8 (6%)	44 (33.1%)	11 (8.3%)	16 (12%)
Older than 80	78 (74–113) ^a	5 (13.5%)	7 (18.9%)	1 (2.7%)	1 (2.7%)	13 (35.1%)	2 (5.4%)	8 (21.6%)
Number of days since procedure	406 (197–900)	495 (224–812)	425 (202–846)	345 (195–956)	360 (162–954)	446 (193–908)	436 (217–791)	384 (169–1039)
Median (IQR)								
Time since procedure								
Less than 1 year	260 (46.6%)	25 (9.6%)	42 (16.2%)	52 (20.0%)	18 (6.9%)	74 (28.5%)	14 (5.4%)	35 (13.5%)
1–2 years	123 (22.1%)	22 (17.9%)	20 (16.3%)	15 (12.2%)	6 (4.9%)	39 (31.7%)	6 (4.9%)	15 (12.2%)
More than 2 years	174 (31.2%)	18 (10.3%)	29 (16.7%)	31 (17.8%)	11 (6.3%)	54 (31.0%)	9 (5.2%)	22 (12.6%)
Stage								
Early ^b	287 (51.6%)	31 (10.8%)	55 (19.2%)	47 (16.4%)	16 (5.6%)	82 (28.6%)	17 (5.9%)	39 (13.6%)
Advanced ^c	269 (48.4%)	34 (12.6%)	36 (13.4%)	50 (18.6%)	19 (7.1%)	85 (31.6%)	12 (4.5%)	33 (12.3%)
Site (specific question)								
Oral	157 (28.1%)	19 (12.1%)	35 (22.3%)	22 (14.0%)	10 (6.4%)	42 (26.8%)	7 (4.5%)	22 (14.0%)
Oropharynx	129 (23.1%)	15 (11.6%)	19 (14.7%)	35 (27.1%)	13 (10.1%)	32 (24.8%)	6 (4.7%)	9 (7.0%)
Larynx	272 (48.8%)	31 (11.4%)	38 (14.0%)	41 (15.1%)	12 (4.4%)	93 (34.2%)	16 (5.9%)	41 (15.1%)
Modality								
Surgery	139 (24.9%)	16 (11.5%)	33 (23.7%)	16 (11.5%)	6 (4.3%)	41 (29.5%)	8 (5.8%)	19 (13.7%)
RT/CT	251 (45.0%)	28 (11.2%)	31 (12.4%)	50 (19.9%)	22 (8.8%)	72 (28.7%)	15 (6%)	33 (13.1%)
Surgery and RT/CT	164 (29.4%)	21 (12.8%)	26 (15.9%)	31 (18.9%)	7 (4.3%)	54 (32.9%)	5 (3%)	20 (12.2%)

Abbreviations: CT, chemotherapy; IQR, interquartile range; RT, radiotherapy.

^aMedian (range).^bStage I and II.^cStage III and IV.

TABLE 2 Primary outcome—the odds ratio (OR) of preference for the instrument that patients thought would be most helpful to describe their health problems to their doctor.

Instrument preference	(N)	Unadjusted univariable analysis			Adjusted multivariable analysis (adjusted for age and gender)				
		OR	95% confidence interval		OR	95% confidence interval		p-value	
			Lower	Upper	p-value		Lower	Upper	p-value
None	29	1.00—Reference category-				1.00—Reference category-			
Not sure	72	2.48	1.61	3.82	<.001	1.78	0.88	3.58	.11
Overall preference for one or any questionnaires	457	15.76	10.83	22.94	<.001	9.23	5.10	16.70	<.001
Preference for Any questionnaire	167	5.76	3.88	8.54	<.001	5.29	2.29	8.01	.001
Preference for a specific questionnaire									
UW-QOL	65	2.24	1.45	3.47	<.001	1.44	0.70	2.95	.32
FACT-HN	92	3.17	2.09	4.82	<.001	1.40	0.68	2.85	.36
EORTC	98	3.38	2.23	5.11	<.001	1.44	0.70	2.97	.32
PCL	35	1.21	0.74	1.97	.454	0.67	0.28	1.62	.38
Preference for any structured questionnaire ^a	255	8.79	5.99	12.91	<.001	4.32	2.32	8.04	<.001

^aThis is calculated by combining the preferences of the three structured validated questionnaires-UW-QOL, FACT-HN and EORTC.

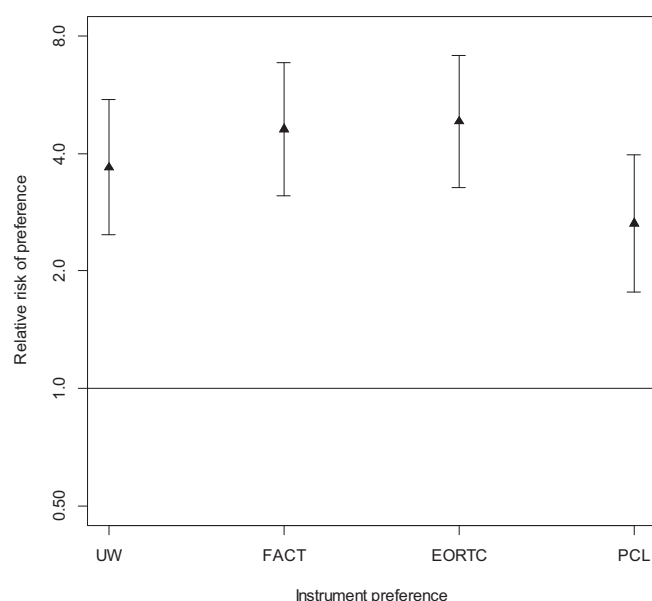


FIGURE 1 Relative risk (RR) of patient preference for a HNC-specific QoL instrument (with 95% confidence interval), compared to not wanting to complete a questionnaire*. *Patients who answered 'Any questionnaire' have been weighted equally between the four instruments.

3.3 | Most disliked questionnaire

In response to the question 'which questionnaire did you most dislike?', subjects indicated that the PCL was the most disliked instrument (OR = 5.52; 95% CI 3.60–8.45), followed by FACT-HN (OR = 1.80, 95% CI 1.10–2.93, $p = .02$). There was no appreciable difference

between the 'disliked' ratings for EORTC QLQ-HN35 and UW-QOL (OR = 1.16; 95% CI =0.68–1.98, $p = .69$). On multivariate analysis, none of the potential confounders of age, gender, stage, modality, time of treatment or order of presentation of questionnaire were found to be associated with being the most disliked questionnaire.

3.4 | Factors affecting patient preferences for which questionnaire to use?

3.4.1 | Patient characteristics and treatment modality

There were no differences in preference across the treatment modalities. After fitting a multivariable model, only gender and age were deemed to influence preference (Table S4). More women than men preferred FACT-HN (OR = 3.01, 95% CI 1.05–8.62, $p = .04$). After adjustment for gender, a higher proportion of patients under 70 years preferred EORTC QLQ-HN35 compared to over 70 (OR = 3.14, 95% CI 1.3–7.59, $p = .01$).

When subjects indicated a preference for a specific instrument, it was because it was relevant to their problems (48.7%, 284/583), easy to understand (43%, 251/583) and helped them describe their health problems (35.5%, 207/583).

3.4.2 | Structured instruments versus open unstructured lists

Even after adjustment for covariates, patients still overwhelmingly preferred a validated structured questionnaire (OR 8.79; 95% CI

TABLE 3 Qualitative thematic analysis: patient-reported importance of the FACT-HN, UW-QOL and EORTC QLQ-HN35 domains in terms of their ability to discriminate between the major and minor themes.

EORTC QLQ-HN35																				
Qualitative theme	Pain	Swallowing	Senses	Speech	Social eating	Social contact	Red libido	Teeth	Opening mouth	Dry mouth	Sticky saliva	Coughing	Feel ill	Pain killers	Nutritional supplement	Feeding tube	Weight loss	Weight gain	Composite	
Major theme	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Minor theme																				
Voice	✓																			
Dysphagia	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Cough	✓																			
Sore Throat	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Shoulder Pains	✓																			
Mood	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Dyspnoea	✓																			
Neck Pain	✓																			
Periodontal																				
Bowels	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Dysgeusia	✓																			
FACT-HN														UW-QOL						
Qualitative theme	Physical well-being	Social well-being	Emotional well-being	Functional well-being	Composite	Pain	Appearance	Activity	Recreation	Swallowing	Chewing	Speech	Shoulder	Taste	Saliva	Composite				
Major theme	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Minor theme																				
Pain	✓																			
Dry Mouth	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Fatigue	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Anxiety	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Function	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Minor theme																				
Voice	✓																			
Dysphagia	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Cough	✓																			
Sore Throat	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Shoulder Pains	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Mood	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Dyspnoea	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			
Neck Pain	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓			

TABLE 3 (Continued)

Qualitative theme	FACT-HN				UW-QOL												
	Physical well-being	Social well-being	Emotional well-being	Functional well-being	Composite	Pain	Appearance	Activity	Recreation	Swallowing	Chewing	Speech	Shoulder	Taste	Saliva	Composite	
Periodontal																	
Bowels	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓		✓			
Dysgeusia														✓	✓		✓

5.99–12.91, $p < .001$), as opposed to the open unstructured PCL, (OR 1.21; 95% CI 0.74–1.97, $p = .45$; Table 2).

3.4.3 | Head- and neck- specific versus combined general and specific questionnaires

After adjustment for variables (Table 2), the most common preference was for any structured questionnaire, that is, no specific preference for a particular one (OR 5.3, 95% CI 2.3–8.0, $p = .001$). Amongst those who expressed a specific preference, the three validated questionnaires were equally preferred, with no statistically significant differences, suggesting that the two head and neck-specific questionnaires (EORTC QLQ-HN35 and UW-QOL) were as good as the combined general and specific questionnaire (FACT-HN).

3.4.4 | Thematic qualitative analysis

Sixteen themes were reported by patients in the open unstructured list of concerns (Table 3). Of these themes, the EORTC QLQ-HN35 did not identify two head and neck specific complaints: periodontal complaints and dysgeusia. UW-QOL and FACT-HN, in addition to these, also did not cover cough complaints, and the latter also did not include dry mouth.

3.5 | Willingness to complete QoL instruments routinely at the follow-up clinic

Fifty-five percent (294/534) of subjects felt that it would be helpful to complete an instrument routinely at the clinic. This varied by: gender, 64% of women compared to 52% of men; age, 66% of under 60 year olds, compared to 57% of 60–70 year olds, and 42% of over 70 year olds; cancer stage, 52% with early disease, compared to 59% with advanced disease; tumour site, 61% of oral and oropharyngeal subjects, compared to 49% laryngeal; treatment modality, 53% of subjects who had surgery alone, 57% who had radiotherapy or chemoradiotherapy without surgery, and 55% who had surgery ± chemoradiotherapy.

Multivariate analysis demonstrated that only age and gender influenced willingness to complete a questionnaire at the clinic. Women were more likely to want to complete questionnaires than men (OR = 1.58; 95% CI 1.05–2.39; $p = .023$). Older participants (>70 years old) were less willing to complete an instrument in the clinic and preferred shorter questionnaires (Figure 2).

4 | DISCUSSION

This study provides new insights into patient preferences for HNC-specific QLQs, and their willingness to complete them routinely in the follow-up clinic. Most patients found QLQs helpful to communicate

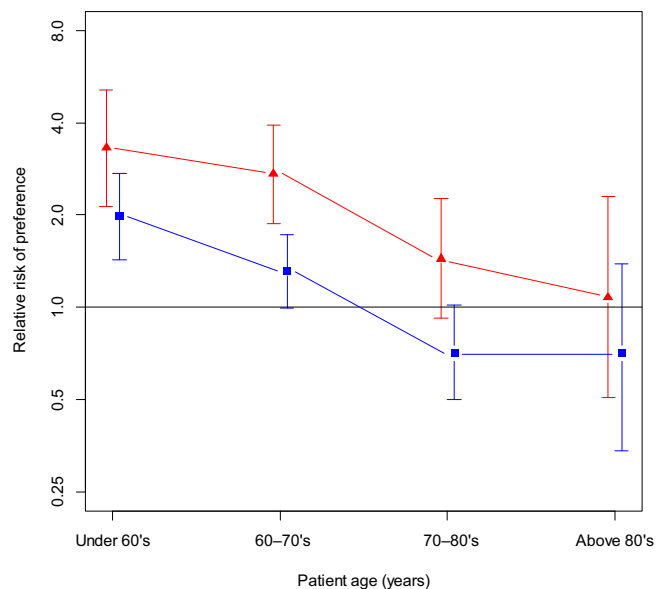


FIGURE 2 Relative risk and 95% confidence interval for patients wanting to complete the questionnaire at the clinic (red triangle); and patients reporting that longer questionnaires (≥ 21 questions) were most desirable (blue square).

their health concerns with their clinicians, which was also demonstrated in previous studies.^{1,2} Moreover, half of the patients preferred a specific questionnaire; with mainly structured ones preferred over unstructured PCLs. Yet despite this, when given a choice, only half of patients preferred to complete a questionnaire at their routine clinic consultations. Importantly, older patients and men were less likely to choose to complete a QLQ, and favoured them to be shorter. In contrast, women and younger patients were more likely to want to complete questionnaires in the clinic, and preferred FACT-HN and EORTC QLQs respectively. Reasons for these are unclear, and may be related to literacy rates in males and older patients, as well as in psychological and behavioural differences by gender and age. The simple unstructured listing of problems was consistently the least preferred instrument, justifying the use of the structured questionnaires, despite the additional resource required for that.

Use of a relatively long (35-item) head and neck specific module (QLQ-HN35) did not appear to affect its popularity, nor did use of the short (13-item) head neck specific UW-QOL questionnaire. This is possibly because the head and neck specific questionnaires (EORTC and UW-QOL) appeared to cover the largest number of patient complaints (themes), compared to the combined (general and specific) FACT-HN instrument.

This study is novel in that, to our knowledge, it is one of the few randomised studies in health-related QoL. It is also one of a very few studies that compares patient preferences for QLQs, using the three most widely used HNC-specific questionnaires, as well as a basic, unstructured patient-generated list. Our response rate of 75% is considered adequate for questionnaire studies.²¹

Our study does have limitations. We used the previous version of the EORTC QLQ-HN35, as it was the most up-to-date version at the

time. However, we believe most of the findings of the study remain applicable, despite the introduction of an updated 43 question version. We used the QLQ-HN35 alone, as we felt including the QLQ-C30 would have added significant burden on the patients, and may have further affected their preferences. We have only focused on patient preference and did not specifically address other aspects, such as performance characteristics and ability to predict prognosis, as these have been previously studied extensively.^{6,7,22,23}

Our findings suggest that the FACT-HN may be the instrument of choice for women, and the QLQ-HN35 for younger patients. Patients over 70 years of age expressed a clear wish for shorter instruments, and therefore UW-QOL may be the instrument of choice for them. Patients consistently reported the least preference for the unstructured patient-generated list.

The advent of computer tablets and smartphone technology may provide an opportunity to facilitate the individualization of patient QoL assessment.²⁴ However, minimal clinically-important differences and trigger thresholds for interventions need to be determined for the different questionnaires to derive the maximum benefit from them.²⁵ Research into all these factors would be important, and into the development of algorithms to 'translate' changes in scores between the different questionnaires, thereby allowing clearer and easier understanding of the clinical implications.

5 | CONCLUSIONS

We found that HNC patients value the use of QoL instruments to aid communicating their health needs to their doctors. They preferred structured disease-specific instruments, but a large proportion also found all the questionnaires useful. The simple patient-generated unstructured list was the least preferred. Only half of our patients expressed preference to complete QLQs routinely in the clinic, which is significantly influenced by their age and gender.

AUTHOR CONTRIBUTIONS

Hisham Mehanna: Conceptualization, Funding acquisition, Methodology, Investigation, Data curation, Formal analysis, Supervision, Project administration, Writing—original draft, Writing—review and editing. **Ben Carter:** Data curation, Formal analysis, Writing—original draft, Writing—review and editing. **Andrew Hartley:** Data curation, Formal analysis, Writing—review and editing. **Ahmad K. Abou-Foul:** Data curation, Formal analysis, Writing—review and editing. **Jill Brooks:** Writing—original draft, Writing—review and editing. **June Jones:** Investigation, Data curation, Data curation, Formal analysis, Writing—original draft, Writing—review and editing. **Lydia Fresco:** Data curation, Formal analysis, Writing—review and editing. **Laura Moss:** Data curation, Formal analysis, Writing—review and editing. **Terence M. Jones:** Data curation, Formal analysis, Writing—review and editing. **Simon N. Rogers:** Data curation, Formal analysis, Writing—review and editing. **Randall P. Morton:** Conceptualization, Methodology, Supervision, Writing—review and editing.

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CONFLICT OF INTEREST STATEMENT

Professor Hisham Mehanna is a National Institute for Health Research (NIHR) Senior Investigator. The views expressed in this article are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care. Professor Mehanna declares these interests: Employment disclosure: Warwickshire Head and Neck Clinic Ltd. Leadership disclosure: Director and wife director of Warwickshire Head and Neck Clinic Ltd. Stock or other ownership: Warwickshire Head and Neck Clinic Ltd. Honoraria: AstraZeneca. Speakers Bureau: MSD, Sanofi Pasteur, Merck. Research Funding: GSK Biologicals, MSD, Sanofi Pasteur, GSK Plc, AstraZeneca. Travel Accommodation Expenses: Sanofi, Pasteur, MSD, Merck. All other authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

PEER REVIEW

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/coa.14054>.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author, (Hisham Mehanna), upon reasonable request.

ETHICS STATEMENT

This study was performed in accordance with the Declaration of Helsinki. The study was given ethics approval by the Coventry and Warwickshire National Ethics Committee (06/Q2802/101).

PATIENT CONSENT STATEMENT

All of the participants gave written informed consent.

CLINICAL TRIAL REGISTRATION

The study is registered in the ISRCTN registry (ID Number 69567857).

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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