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Using a patient prompt list to raise concerns in oncology clinics does not necessarily lead to longer consultations

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Abstract:	Head and Neck oncology post-treatment consultations form a critical component of care in terms of support and surveillance. They occur frequently in the first few years and can place substantial demands on health care resources. However, they provide useful opportunities for patients to raise issues and receive tailored information and support. The aim of this paper is to assess whether the use of a 56 item patient prompt list (PCI), completed immediately prior to the consultation significantly increases its duration. This was a pragmatic cluster preference randomised control trial of 288 patients with 15 consultant clusters from two sites either 'using' (n=8) or 'not using' (n=7) the PCI. Consultation times were known for 283 patients (136 PCI, 147 non-PCI) who attended their first post-treatment trial consultation, a median (IQR) 103 (70-160) days after the end of treatment. Consultations lasted a median (IQR) of 10 (7-13) minutes, mean 11.1 in non-PCI patients and a median (IQR) of 11 (8-15) minutes, mean 12.0 in PCI patients (p=0.07). After adjustment for patient clustering and significant case-mix the 95% confidence interval for the mean difference was from 1.45 minutes shorter with PCI to 2.98 minutes longer, p=0.50. There was significant variation in duration by consultant, tumour stage, treatment mode, overall QOL, distress (all p<0.001). In those completing the PCI, duration increased with the total number of PCI items selected (p<0.001). In conclusion, the inclusion of a prompt list to help facilitate the conversation with patients did not make a substantial difference to consultation times.

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Using a patient prompt list to raise concerns in oncology clinics does not necessarily lead to longer consultations

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Professor K. Shakib PhD, FRCS(OMFS), MRCS(Eng), FDSRCS(Eng), MBBS, BDS

Editor of the British Journal of Oral and Maxillofacial Surgery

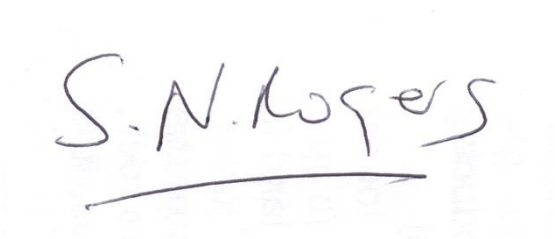
6th April 2020

Dear Kaveh,

Please find attached a submission **'Using a patient prompt list to raise concerns in oncology clinics does not necessarily lead to longer consultations'.**

As we all realise on a day to day basis there are considerable demands on head and neck cancer (HNC) clinics. In part, the flow of the clinic rests with the length of consultations. It is surprising how little is published on this topic. The Patient Concerns Inventory randomised trial as afforded us the opportunity to air this issue.
BJOMS is our favoured first journal and if you would kindly consider the submission we would be most grateful. We are very slightly over the word limit and would look to reduce this if possible when addressing the reviewers comments.

Yours sincerely



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Manuscript with title (excluding any author details including names and affiliations)

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'Using a patient prompt list to raise concerns in oncology clinics does not necessarily lead to longer consultations'

Abstract

Head and Neck oncology post-treatment consultations form a critical component of care in terms of support and surveillance. They occur frequently in the first few years and can place substantial demands on health care resources. However, they provide useful opportunities for patients to raise issues and receive tailored information and support. The aim of this paper is to assess whether the use of a 56 item patient prompt list (PCI), completed immediately prior to the consultation significantly increases its duration. This was a pragmatic cluster preference randomised control trial of 288 patients with 15 consultant clusters from two sites either 'using' (n=8) or 'not using' (n=7) the PCI. Consultation times were known for 283 patients (136 PCI, 147 non-PCI) who attended their first post-treatment trial consultation, a median (IQR) 103 (70-160) days after the end of treatment. Consultations lasted a median (IQR) of 10 (7-13) minutes, mean 11.1 in non-PCI patients and a median (IQR) of 11 (8-15) minutes, mean 12.0 in PCI patients (p=0.07). After adjustment for patient clustering and significant case-mix the 95% confidence interval for the mean difference was from 1.45 minutes shorter with PCI to 2.98 minutes longer, p=0.50. There was significant variation in duration by consultant, tumour stage, treatment mode, overall QOL, distress (all p<0.001). In those completing the PCI, duration increased with the total number of PCI items selected (p<0.001). In conclusion, the inclusion of a prompt list to help facilitate the conversation with patients did not make a substantial difference to consultation times.

Introduction

There are considerable demands on head and neck cancer (HNC) clinic capacity which are already under pressure to meet the two-week suspected cancer pathway, provide time to discuss the diagnosis and treatment options for new patients and to review patients after treatment. The burden is likely to grow due to increasing rates of HNC and more patients under follow-up for late effects. Although practices vary there is a higher frequency of follow-up in the first two years post treatment. In the first year this is between one to three months, and in the second year two to four months. [1] The schedule of review visits can be stratified by risk of loco-regional recurrence, with high risk patients being seen more frequently. [2,3] However, the follow-up consultation is valuable for several reasons. These include the assessment of treatment response, the identification of recurrence or new primary

tumours, the monitoring and management of complications, the checking for physical and psychosocial consequences, the opportunity to address unmet needs and provide support to patients and their families, and a chance to deliver life-style advice (the 'teachable moment'). [3-5]

There are many issues that patients might wish to raise for discussion at their post treatment consultations. [6] Patients value the opportunity to raise concerns,[7] however report barriers to expressing these. [8] Clinicians behaviour is the most dominant barrier, notably patients not being explicitly invited by the clinician to express concerns, and this is made worse in a setting of perceived lack of time. [8] It is feasible to suggest that a prompt list approach, such as the Patient Concerns Inventory (PCI) might help reduce barriers. [9,10] The PCI is a 56-item prompt list [11] and following a systematic review of various tools, it was recommended in the HNC setting due to excellent content validity. [12] Specialist HNC nurses and allied health professional when surveyed reported that of various tools available to assist in follow-up, holistic needs assessment and survivorship care, they felt a HNC specific tool such as the PCI was more appropriate. [13]

When considering the added benefit of using the PCI in routine review consultations, clinicians might conversely be apprehensive about the additional time it might take when patients are afforded the opportunity to raise numerous issues. The PCI could significantly add to the length of the consultation and introduce delay in an already busy outpatient clinic. Hence, the main aim of this paper is to assess whether the use of the PCI completed immediately prior to the consultation significantly increases its duration. A secondary aim is to document other associations with duration of consultation, with particular focus on the number and nature of the items selected by patients using the PCI.

Methods

The data come from a pragmatic cluster-controlled trial conducted at two UK Cancer Centres, namely Aintree and Leeds. Consultants (the clustering factor) were randomised to 'using' or 'not using' an intervention incorporating the PCI prompt list at all their trial clinics. The methods have been described previously. [14] Eligible patients were treated curatively for primary or secondary HNC, and all sites, stage of disease and treatments were included. Palliation and recurrence were exclusion criteria as were cognitive impairment,

psychoses or dementia. The PCI consists of 56 clinical items [11] which patients select from before their appointment, to help guide the outpatient consultation through the symptoms and problems experienced following treatment for HNC. Patients were first discussed at MDT meetings between January 2017 and December 2018, with clinics between April 2017 and October 2019. The first post-treatment trial consultation with consultant surgeon is the focus of this paper.

Researchers at the Cancer Centres collected clinical and demographic data which matched those included in the head and neck 5000 project. [18] HRQOL data were completed electronically (desktop, tablet, iPAD) apart from one non-PCI consultant who used paper-based. HRQOL data included UW-QOLv4, [15] Distress thermometer [19] and EQ-5D-5L. [20] The UW-QOLv4 questionnaire consists of 12 single question domains, these having between 3 and 5 response options that are scaled evenly from 0 (worst) to 100 (best) according to the hierarchy of response. [15] In regard to overall QOL, patients are asked to consider not only physical and mental health, but also many other factors, such as family, friends, spirituality or personal leisure activities that were important to their enjoyment of life. Subsequent analysis has led to the development of subscale composite scores [16] and domain algorithms to screen for significant problems/dysfunction. [17]

Numerical data were summarised using the mean, median and Inter-quartile range (IQR). Boxplots showed variation in consultation times with boxplot and bar width scaled according to sample size. Asterisks represent values >3 box lengths from the edge of the box, with circles 1.5-3 box lengths away. Consultation times were compared using the Mann-Whitney (2 groups) or Kruskal-Wallis test (>2 groups). Spearman's correlation coefficient (r_s) was used to assess association between consultation time and other numerical/ordinal variables. Linear regression (STATA regress procedure) was used to estimate the unadjusted difference between PCI and non-PCI group mean consultation times and random effects linear regression (STATA xtreg procedure) was used to adjust for case-mix variables as independent predictors and for consultant clustering. To address skewness in the consultation times, standard errors (SEs) were estimated by a cluster bootstrap (5000 replications) that resampled with replacement over consultant clusters (rather than over individual observations). Statistical significance was regarded as $p<0.05$. SPSS v25 and Stata v13 were used for the analyses.

The PCI trial has ethical approval from North West - Liverpool Central Research Ethics Committee REC reference: IRAS 16/NW/0465, Project ID: 189554. It also has approval from the Health Research Authority (HRA). The Research and Development Department at Aintree University Hospital NHS Trust (AUH) is coordinating the trial and AUH is the sponsor for the trial.

Results

Consultation times were known for 283 (Aintree 175, Leeds 108) of 288 attending their first post-treatment clinic, median (IQR) 193 (122-245) days after diagnosis and 103 (71-160) days after end of treatment. Fifteen consultants participated, seeing a median (IQR) of 16 (13-26) patients, range 5-48. Median (IQR) patient age was 62 (55-69) years and 69% (195) were male. Other patient characteristics are shown in Table 1.

Consultations lasted a median (IQR) 10 (8-14) minutes, mean 11.5, range 2 to 41. Aintree consultations took a median (IQR) of 10 (7-12) minutes, mean 10.1, compared with 12 (9-17), 13.9 at Leeds ($p<0.001$). For PCI group patients they took a median (IQR) of 11 (8-15) minutes, mean 12.0, compared with 10 (7-13), 11.1 for Non-PCI patients ($p=0.07$). The median time was longer for PCI patients by 1 minute at Aintree and 2 minutes at Leeds (Figure 1), with means of 10.5 (PCI) and 9.7 (Non-PCI) minutes at Aintree and 14.0 (PCI) and 13.9 (Non-PCI) minutes at Leeds. Individual consultants varied considerably (Figure 2), with means ranging from 7.0 to 16.4 minutes, medians from 7 to 15 minutes ($p<0.001$).

Patients with advanced tumours, patients with treatments involving radiotherapy and/or chemotherapy and surgical patients having free-flap transfer had longer consultations (Table 1), as did patients living with others rather than living alone. Similar findings were seen for each centre (results not shown). There was no evidence of association between consultation time and days from the end of treatment to the clinic, $r_s=0.04$, $p=0.46$. Consultation time was weakly associated with the six-point overall QOL scale ($r_s=0.23$, $p<0.001$, Figure 3) and with the distress thermometer 0-10 scale ($r_s=0.21$, $p<0.001$, Figure 4), indicating longer consultation times with worse overall QOL and with greater distress. There were weak associations also with the UW-QOL physical function ($r_s=-0.21$, $p<0.001$) and social-emotional ($r_s=-0.23$, $p<0.001$) subscale scores and with the EQ-5D visual analog scale ($r_s=-0.16$, $p=0.008$), these indicating longer consultations with worse scale scores. Similar trends were noted for other HRQOL measures, with slightly longer consultation times for those

registering UW-QOL domain dysfunction and shorter times for those giving the best UW-QOL domain response, as well as longer times for patients having moderate or more severe problems on each of the EQ-5D domains (results not shown).

In PCI group patients the median (IQR) number of PCI items selected was 5 (2-9), range 0-28, n=136. The top ten issues patients selected were dry mouth (50%, 68), dental health (35%, 48), chewing/eating (34%, 46), fear of recurrence (34%, 46), salivation (34%, 46), fatigue/tiredness (29%, 39), swallowing (29%, 39), taste (27%, 37), sore mouth (24%, 33) and mucus (24%, 33). Only two items were not selected: 'regret about treatment' and sexuality. Length of consultation increased with the total number of PCI items selected (r_s=0.35, p<0.001), this being driven by the numbers of items selected in the physical & functional, treatment-related and psychological / emotional / spiritual domains (Table 2). For 44 of the 56 PCI items both mean and median times were increased if that item was selected. Some of these increases were statistically significant (Table 2).

Linear regression (STATA regress) estimated the unadjusted difference between PCI and non-PCI group mean consultation times as 0.85 minutes longer in the PCI group (95% CI: 2.25 longer to 0.55 shorter), p=0.23. After adjustment for consultant clustering using random effects linear regression (STATA xtreg) and for case-mix factors of treatment, overall clinical stage, hospital site and living status (categories as per Table 1) as independent predictors, this became 0.54 minutes longer (95% CI: 2.75 longer to 1.66 minutes shorter), p=0.63. After further adjustment for overall QOL, distress thermometer, and physical and social-emotional composite scores (as per Table 1) it was 0.76 minutes longer (95% CI: 2.98 longer to 1.45 minutes shorter), p=0.50. The intracluster correlation (ICC) value estimate was 0.13.

Discussion

This paper spotlights the length of individual HNC patient clinic review consultations. It is appropriate to consider the frequency of follow-up consultations [2] and also how to make this more time efficient without losing overall efficacy. This study is the first to detail duration of review consultations and the impact of including the PCI. The study has strengths, notably having 15 different consultants across two centres and a comparison of PCI use using the rigour of a RCT. However, the study is limited by the absence of other factors that could alter consultation length, such as consultant style and personality, number of carers in the consultation, timing of the consultation within the clinic schedule (beginning or end), and late

running of consultations. Also, no record was made of the discussions that took place and how long it took to discuss specific issues. The PCI results need to be interpreted with caution data because items identified more commonly are more likely to reach statistical significance and these are not necessarily those with the biggest observed time differences. The study focuses on one clinic window around three months after treatment and as yet there is no data on how consultation lengths might vary over time. The study only included consultants and the length of consultations for surgeons in training was not assessed. The eight PCI consultants received one training session on using the PCI, either as a group presentation and discussion taking an hour or by individual training taking about 20 minutes. Anecdotally they reported how straightforward it was to include it as part of their usual practice but no attempt was made to evaluate this.

In this study, the addition of the PCI only led to a small increase in consultation length. This finding is supported by observation of clinicians in primary care, with patients having the opportunity to raise major concerns during the consultation, with no effect on visit length. [21] The PCI enables patients to raise concerns that might otherwise be missed [9, 10] and this can result in better patient satisfaction, improved communication and psychological wellbeing. In this current study, most PCI issues related to physical function, such as dry mouth, dental related concerns, and fatigue/tiredness, these forming a major component of clinic conversations. A common psychological issue is fear of recurrence. It was not known how long was spent addressing each issue; nevertheless, it is important to recognise the content as this helps to shape service delivery and policy making, as often the reality is that patients can wait a long time to access restorative dentistry and emotional support services. [22] Perhaps, with further patient and clinician training and additional multi-professional support material, consultation times could be reduced without diminishing the therapeutic benefit. However, consultations are actually quite short and rather than focus solely on time efficiency the focus should perhaps be on reconfiguring services to address unmet need, enhancing HRQOL and the 'teachable moment' of doctor-patient interaction.

Advance tumour stage was associated with longer consultations, not surprising as these patients have more aspects of dysfunction to assess and discuss. Also, stage is associated with worse overall QOL, lower mood, and greater distress and these are associated with consultation duration. Furthermore, the total number of PCI items raised is associated with stage of cancer, [6] low mood and poorer HRQOL. [23] The data shows considerable variability

by individual consultant and this probably reflects distinct patterns of dialogue used in the doctor-patient communication. Given the complexity of HNC and its aftermath, and the reassurance of the physical examination, it is notable that most consultations were just over 10 minutes. This probably reflects time constraints inherent in busy out-patient clinics and the need to undertake reviews as time efficiently as possible. It is recognised that some consultations might need to be much longer to perform adequate review and address patient concerns. In light of this, there is an emergence and recognition of the extended role of CNSs and within many HNC outpatient clinics, follow-up care is supported or shared to promote holistic, personalised patient care.

In conclusion, the inclusion of a prompt list to help facilitate the conversation with patients does not seem to make a substantial difference to consultation times. As most patients really appreciate this holistic approach to their care, worries about its inclusion into routine consultations in respect to disrupting the flow of clinics is unfounded.

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Declaration of Competing interests

The 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.

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Table 1. Consultation times by case-mix factors

		Patients	Mean	Median (IQR)	P value*
	All patients	283	11.5	10 (8-14)	
Site	Aintree	175	10.1	10 (7-12)	<0.001
	Leeds	108	13.9	12 (9-17)	
Trial group	PCI	136	12.0	11 (8-15)	0.07
	Non-PCI	147	11.1	10 (7-13)	
Consultant experience	Before 2010	138	11.0	10 (8-12)	0.17
	Since 2010	145	12.0	11 (8-15)	
Gender	Female	88	11.6	10 (7-15)	0.72
	Male	195	11.5	10 (8-14)	
Age at clinic	<55	68	12.1	11 (9-15)	0.10
	55-64	115	11.0	10 (7-14)	
	65-74	67	12.5	11 (8-15)	
	≥75	33	10.3	9 (7-13)	
Tumour site:	Oral cavity	132	11.7	10 (7-15)	0.20
	Oropharynx	91	11.3	10 (8-14)	
	Larynx	38	10.9	9 (7-12)	
	Other	22	12.9	12 (9-16)	
Overall stage	Early 0-2	122	10.5	9 (7-12)	<0.001
	Advanced 3-4	161	12.3	11 (9-15)	
Primary treatment:	S only	93	9.3	9 (7-11)	
Surgery (S)	S only & FF	21	12.5	11 (7-15)	
RadioTherapy (RT)	RT or RT/CT only	57	12.1	10 (8-15)	<0.001
ChemoTherapy (CT)	S & (RT or RT/CT)	67	12.4	11 (9-15)	
Free Flap transfer (FF)	S & (RT or RT/CT) & FF	45	13.8	12 (8-19)	
WHO comorbidity	0	177	11.3	10 (8-13)	0.65
	1	65	12.3	10 (8-16)	
	2-4	41	11.5	10 (7-15)	
ACE27 comorbidity	None	135	11.4	10 (8-13)	0.60
	Mild	94	11.9	11 (8-15)	
	Moderate	47	11.1	10 (8-13)	
	Severe	7	13.6	14 (n/a)	
Living situation	Alone	65	9.9	9 (7-12)	0.01
In house/flat	With others	215	12.1	10 (8-15)	
Working	Yes	86	11.9	10 (8-14)	0.45
	No	189	11.5	10 (7-15)	
Financial benefits	Yes	105	11.6	10 (8-14)	0.44
	No	155	11.8	10 (8-15)	
Smoking habit	Current	37	10.8	9 (7-14)	0.15
	Former	158	11.6	10 (8-14)	
	Never	80	12.1	11 (8-15)	
Alcohol habit	Current	191	11.3	10 (7-14)	0.09
	Former	72	12.6	12 (8-15)	
	Never	13	10.6	10 (6-16)	
IMD 2019 quintile	1=least deprived	34	12.9	12 (9-15)	0.14
	2	55	12.2	11 (8-15)	
	3	48	11.3	10 (7-14)	
	4	39	11.9	11 (8-15)	
	5=most deprived	107	10.8	10 (7-12)	
Overall QOL**	Good, V good, Outstanding	195	10.8	10 (7-13)	0.004
	Fair, poor, V poor	88	13.2	11 (9-15)	
Social-emotional	<60	71	13.5	11 (9-17)	0.01
function score**	60-79	96	11.5	10 (8-14)	
	80-100	116	10.3	10 (7-13)	
Physical function	<60	89	13.1	11 (8-17)	0.001
Score**	60-79	107	11.5	11 (8-15)	
	80-100	87	10.0	9 (7-12)	
Distress	<4	157	10.9	10 (7-13)	0.01
Thermometer	≥4	126	12.3	11 (8-15)	

*Mann-Whitney test (2 comparison groups), Kruskal-Wallis (>2 comparison groups)

** From the UW-QOL v4

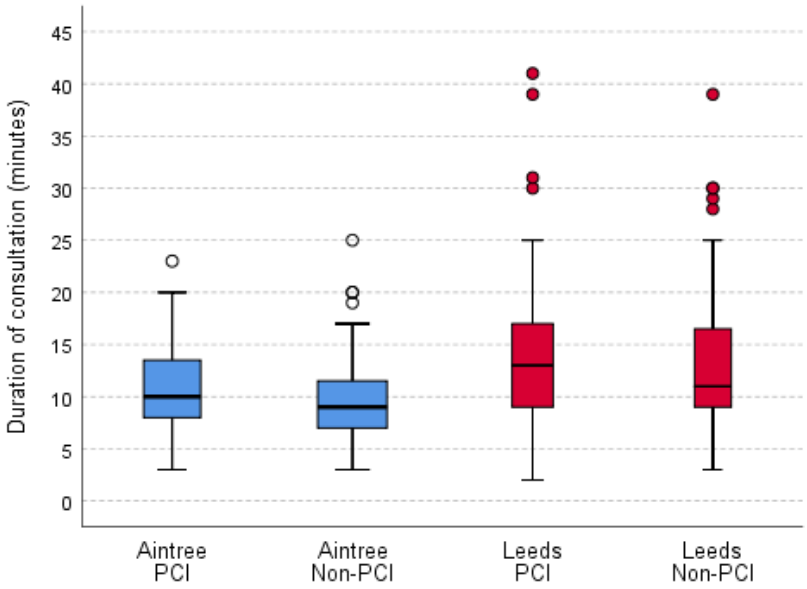
Table 2. Consultation times by the number of PCI items selected and by specific PCI items selected

		Patients	Mean	Median (IQR)	P
	All patients	136	12.0	11 (8-15)	value*
Number of items selected					
Total number	0-4	54	10.2	10 (7-12)	0.004
	5-9	49	12.5	11 (9-15)	
	10-14	20	13.8	15 (10-16)	
	≥15	13	14.4	15 (8-18)	
Physical & functional	0-4	72	10.2	10 (7-12)	<0.001
Wellbeing domain	5-9	42	14.1	14 (9-16)	
	≥10	22	13.7	12 (10-18)	
Treatment related	None	95	11.4	10 (8-14)	0.06
domain	≥1	41	13.2	12 (9-17)	
Social care and social	None	105	12.0	11 (8-15)	0.60
Wellbeing domain	≥1	31	12.0	11 (9-16)	
Psychological, emotional	None	64	10.6	10 (7-13)	0.02
& spiritual domain	One	42	12.6	12 (9-15)	
	≥2	30	14.1	12 (9-18)	
Specific items selected (p<0.05)**					
Depression	Yes	8	17.8	17 (n/a)	0.006
	No	128	11.6	11 (8-15)	
Mobility	Yes	10	17.1	15 (11-19)	0.01
	No	126	11.6	11 (8-15)	
Vomiting	Yes	5	16.6	18 (n/a)	0.01
	No	131	11.8	11 (8-15)	
Fatigue/tiredness	Yes	39	15.0	14 (11-18)	<0.001
	No	97	10.8	10 (8-14)	
Mucus	Yes	33	14.4	14 (9-19)	0.006
	No	103	11.2	10 (8-14)	
Dental health	Yes	48	13.8	14 (9-18)	0.01
	No	88	11.0	10 (8-13)	
Shoulder	Yes	30	14.0	12 (9-17)	0.03
	No	106	11.4	10 (8-14)	
Pain in head/neck	Yes	29	13.7	14 (10-16)	0.01
	No	107	11.5	10 (8-14)	
Fear of cancer returning	Yes	46	13.4	12 (9-16)	0.05
	No	90	11.3	10 (8-15)	
Salivation	Yes	46	13.1	12 (9-15)	0.01
	No	90	11.4	10 (8-14)	

*Mann-Whitney test (2 comparison groups), Kruskal-Wallis (>2 comparison groups)
** ordered according to the difference in mean times of when item selected and when not selected

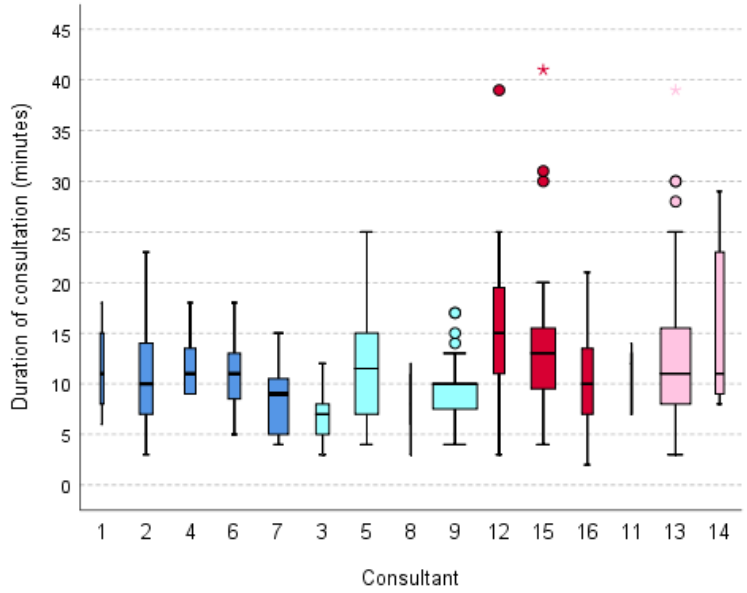
n/a: IQR only computed if n≥10

Figure 1. Consultation times for PCI and non-PCI patients at Aintree and Leeds



Note that the boxplot and bar width are scaled according to the number of patients. An asterisk represents a value more than 3 box lengths from the upper or lower edge of the box, while a circle marks a value between 1.5 and 3 box lengths away from the box.

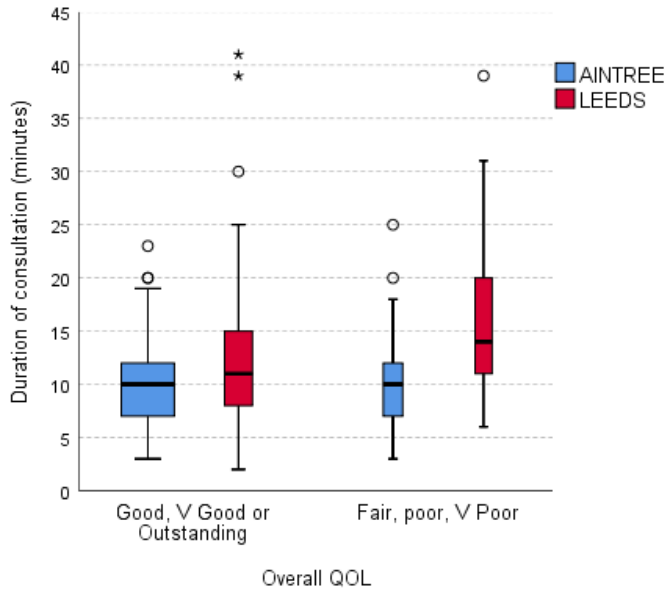
Figure 2. Consultation times by consultant



Aintree PCI: consultants 1, 2, 4, 6, 7
Aintree Non-PCI: consultants 3, 5, 8, 9
Leeds PCI: consultants 12, 15, 16
Leeds Non-PCI: consultants 11, 13, 14

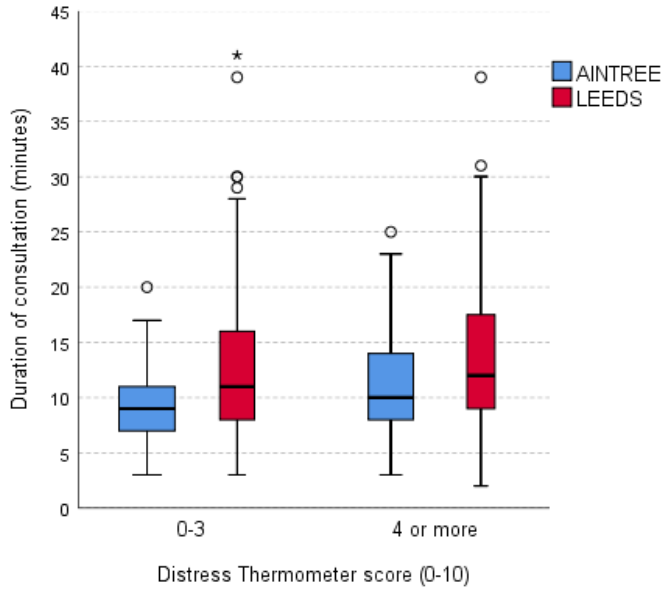
Note that the boxplot and bar width are scaled according to the number of patients. An asterisk represents a value more than 3 box lengths from the upper or lower edge of the box, while a circle marks a value between 1.5 and 3 box lengths away from the box.

Figure 3. Consultation times by overall QOL stated by patients on the UW-QOLv4 questionnaire



Note that the boxplot and bar width are scaled according to the number of patients. An asterisk represents a value more than 3 box lengths from the upper or lower edge of the box, while a circle marks a value between 1.5 and 3 box lengths away from the box.

Figure 4. Consultation times by the Distress thermometer scale



Note that the boxplot and bar width are scaled according to the number of patients. An asterisk represents a value more than 3 box lengths from the upper or lower edge of the box, while a circle marks a value between 1.5 and 3 box lengths away from the box.

Using a patient prompt list to raise concerns in oncology clinics does not necessarily lead to longer consultations.

Simon N Rogers, Cherith Semple, Gerald M Humphris, Derek Lowe, Anastasios Kanatas

Conflict of interest statement

We have no conflicts of interest.

Ethics statement/confirmation of patient's permission

The data, which had been collected as part of a service audit rather than for research, met the criteria of the local Clinical Governance Department for service evaluation.

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Author contribution

Manuscript Title Using a patient prompt list to raise concerns in oncology clinics does not necessarily lead to longer consultations

Please provide details in the table below of each author(s) contribution to the submitted manuscript

AUTHORS	Conception and design of study/review/case series	Acquisition of data: laboratory or clinical/literature search	Analysis and interpretation of data collected	Drafting of article and/or critical revision	Final approval and guarantor of manuscript
Rogers	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Semple				**Yes**	
Humphris				**Yes**	
Lowe		**Yes**	**Yes**	**Yes**	
Kanatas		**Yes**		**Yes**	

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