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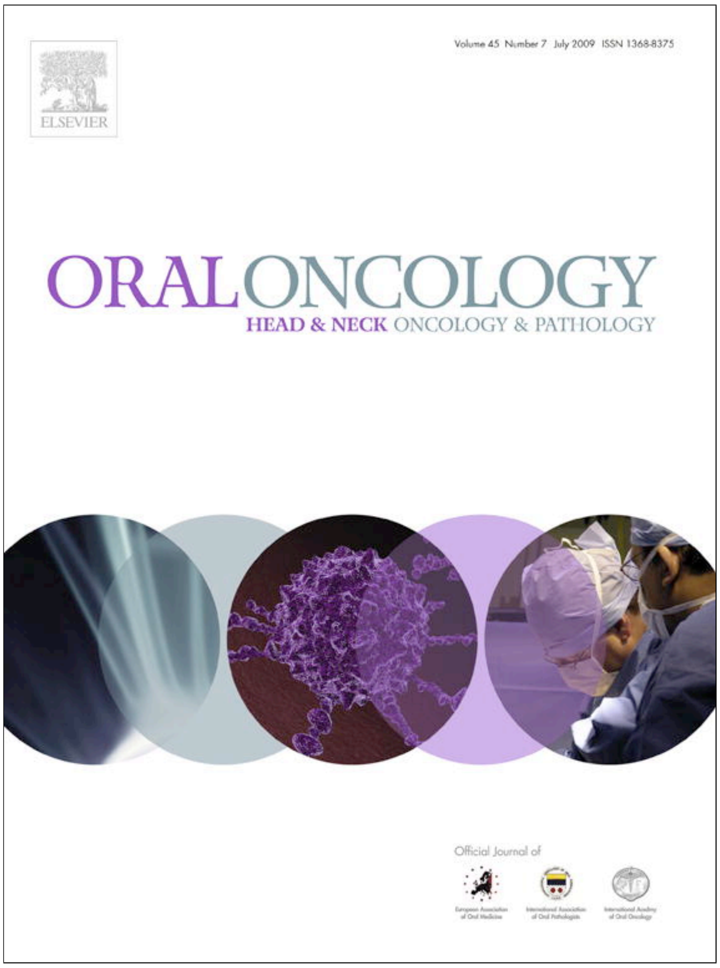

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# The development of a Patients Concerns Inventory (PCI) to help reveal patients concerns in the head and neck clinic

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## SUMMARY

The purpose of the Patients Concerns Inventory (PCI) is to identify the concerns that patients would like to discuss during their consultation. The PCI covers a range of issues including hearing, intimacy, fatigue, financial/benefits, PEG tube, relationships, regret, support for family, and wound healing. It also lists MDT members that patients would like to see or be referred on to.

The PCI is completed using a touch-screen computer (TST) immediately before consultation. Responses are networked into the consultation room. A 28 weeks pilot for one consultant ran from August 2007 with 123 (of maximum 150) patients. The median time to complete the TST was 8 min.

Patients most frequently selected fear of recurrence (37%), dental health/teeth (27%), chewing (24%), pain in head/neck (20%), fatigue/tiredness (19%), saliva (18%) and swallowing (18%). The two MDT members they wished to see were dentist (19%) and speech/language therapist (10%). The vast majority felt the PCI made a difference (quite a bit/very much) to their consultation as it made it 'a bit more personal', 'reminds them of the points they want discussed', 'allows the consultation to get straight to the point'. Although the PCI can raise many issues it did not noticeably prolong the consultation (median 8 min with PCI, 7 min without PCI).

The Patients Concerns Inventory (PCI) helps focus the consultation onto patient needs and promotes multidisciplinary care. Following this very successful pilot the PCI is being rolled out to other consultants in the H & N clinic.

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## Introduction

The impact of head and neck cancer and its treatment affects patients and carers in a variety of ways.[1] Some issues relate to the stage of disease, site of cancer and treatment whilst other issues are less predicable and more individual.[2] As there is a range of issues affected, it can be very difficult to identify patients with problems when they attend clinic. This is made more problematic by the busy nature of out-patient clinics where often there are considerable time pressures. Another hurdle is that some patients tend to have low-self esteem and are reluctant to complain.[3] Patients can have particular problems in communicating their problems verbally. They can be unsure about what is appropriate to ask during their consultant and are conscious of taking up valuable consultant time. Many patients do not wish to be a burden. Hence it seems inevitable to a certain extent that patient problems will be under recognised.[4]

Computer-assisted technology (touch-screen – TST) has been shown to be a useful way of gaining insight into the patient perspective. Taenzer and colleagues[5] reported on the feasibility and reliability of computerized quality of life screening for patients attending out-patient breast cancer clinics. Potential benefits to patients included productive use of waiting room time, greater efficiency in the assessment process, and an improved likelihood that nurses and physicians recognise and attend to quality of life deficits. Health-related quality of life (HR-QOL) data can potentially help identify unmet needs[6] and can be useful in consultations.[7,8] Its use in routine assessment of cancer patients' HR-QOL had a positive impact on physician–patient communication and resulted in better HR-QOL and emotional functioning for some patients. Health-related quality of life data collection is feasible using TST in patients with head and neck cancer.[9] Patients are willing to complete the questionnaire on a touch-screen and find the equipment easy to use. Compliance could be improved by instructing clinicians and nurses and having better alert systems for when to use the touch-screen.[10]

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The concept of a patients concern inventory (PCI) is wider than that of HR-QOL as it allows patients to formulate an individualized record of their concerns, needs and priorities that can be used as a structure to help guide out-patient consultations and promote multidisciplinary care. The use of head and neck HR-QOL questionnaires for this purpose is limited as the number and range of items is restricted. Their structure is selective and not amenable to change due to the careful psychometric development required to establish a validated questionnaire for multi-centre longitudinal comparison. A PCI can cover a wider range of issues. The Liverpool pilot PCI lists 45 issues and asks patients to select those issues they would like to discuss in their consultation or whilst at clinic. It also lists 8 professionals and asks patients to select those who they wished to talk with either in clinic or by referral. Identification of individual patients concerns allows multidisciplinary team members to better target their sometimes limited resources towards those most at need or missed on any established protocol of referral.

In its current form the PCI derives itself from a synthesis of issues covered in other HR-QOL questionnaires, and in discussion with various groups such as locally; the laryngectomy support group, head and neck support group, patient research forum, hospital volunteers, ward and out-patient staff and the multidisciplinary head and neck team. Regionally it has been presented to the Merseyside and Chester Cancer Network and the Cancer Network Partnership Group (MCCN). Nationally it has been discussed in several forums such as the National Association of Laryngectomee (NALC) committee and the Survivorship group of the Head and Neck National Cancer Research Institute (NCRI) Clinical Studies Group.

The aim of this study was to pilot the head and neck PCI using TST with patients attending a routine out-patient clinic. More specifically, to assess the frequency of issues and professionals, the times to fill-in the TST, length of consultation, the relation of PCI to patient characteristics and HR-QOL, longitudinal evaluation in patients completing the PCI more than once, overall patient feedback and overall feasibility and logistics.

## Method

The study population comprised the head and neck cancer patients of one consultant (SNR) attending weekly clinics between 1st August 2007 and 30th April 2008 inclusive. Patients were included if they were on the Liverpool oncology database, were disease free and under routine follow-up at least 6 weeks following completion of treatment. Patients were excluded on each visit if before treatment, palliative, attending dressing clinic for post-operative wound management or part of another outcomes study in clinic.

The TST comprised of the UW-QOLv4,[11] additional questions about each item of the UW-QOL and if these were stable, getting worse, or getting better, the 45 PCI issues and the PCI list of 8 professionals. The 45 PCI issues are listed as part of the results (Fig. 1) as are the members of the multi-professional team (Fig. 2). Patients were invited to complete the TST by a hospital volunteer. A standard touch-screen computer was used and the programme was in Microsoft Access. The data from the TST was placed directly on to the hospital drive and through the normal password protection arrangement was retrieved by the clinician in another room in clinic immediately preceding the patient consultation.

The UW-QOL was analysed for this study in terms of its two composite scores, 'physical function' and 'social–emotional function'. Physical function is the simple average of the swallowing, chewing, speech, saliva, taste and appearance domain scores whilst social–emotional function is the simple average of the activity, recreation, pain, mood, anxiety and shoulder domains. Non-cancer reference data for the UW-QOL was from 372 patients attending ten general dental practices.[12]

Statistical testing involving patient characteristics used first available PCI data only. Due to many analyses performed statistically significance was set as $p < 0.01$. Spearman coefficients measured association of UW-QOL scores with age, time from diagnosis and of UW-QOL scores with number of PCI issues/professionals selected by patients. Association between patient characteristics and number selected were assessed with the Mann–Whitney (2 categories) or Kruskal–Wallis (>2 categories) test. Association of specific issues/professionals selected with UW-QOL scores was also assessed by Mann–Whitney, with patient characteristics by either Fishers exact (2 categories) or Chi-squared (>2 categories) test. For patients with two or more sets of PCI data, Wilcoxon matched pairs test assessed change in number of issues/professionals selected, in time to complete TST and in length of consultation.

## Results

The touch-screen computer was operational at the clinic for 28 out of a possible 40 calendar weeks. It was not used during 12 weeks when the clinic was cancelled for SNR annual leave and study leave, annual leave of the volunteer, and hospital audit days. During these 28 weeks there were 285 patient clinic consultations involving 150 patients known to have head and neck cancer. Of the patients asked only 3 patients refused (4 consultations) refused to complete the PCI. In all the touch-screen technology (TST) was used to gather information for 182 consultations from 123 patients (range 1–5 clinics per patient). The response rate was 123 of 150 patients (82%). Of those missed the reasons were because there was a problem with the setting up of the PCI at the start of clinic, occasionally the system crashed for part of the clinic, and some patients were taken to participate in another outcomes study and hence missed the PCI.

There were 70 males and 53 females with TST data. At their first clinic using TST their mean (SD) age was 63 (11) years. Most (86%, 106/123) had a diagnosis of squamous cell carcinoma, with others having: adenoid cystic carcinoma (3), mucoepidermoid carcinoma (3), malignant ameloblastoma (2), low grade polymorphous adenocarcinoma (2), lymphoma (2), verrucous carcinoma (2), adenocarcinoma (1), histiocytosis (1) and undifferentiated carcinoma NOS (1). Most (72%, 89) had oral tumours, with 21% (26) oropharyngeal, 3% (4) salivary and 3% (4) others. One-quarter (24%, 29) had advanced T3-T4 tumours and 20% (25) were clinically N positive. Half (51%, 63) had free-flap surgery and 43% (53) radiotherapy, 8 being primary radiotherapy.

At the time of clinic 34% (62/182) of TST patients were within 12 months of diagnosis, 31% (56) were within 12–35 months and 35% were 36 or more months after diagnosis. Mean (SD) scores of 72 (22) were recorded for UW-QOL physical function and 75 (19) for UW-QOL social–emotional function. Reference data from general dental practice non-cancer patients (REF) gave mean (SD) scores of 95 (10) for physical function and 83 (19) for social–emotional function and no notable age–sex variations. Relative to a non-cancer population the physical deficits for these cancer patients were more pronounced than deficits in social–emotional functioning. In terms of UW overall QOL, 33% (60) felt 'good', 34% (62) 'very good' and 7% (13) 'outstanding'. Overall UW-QOL correlated more strongly with social–emotional function (Spearman 0.63) than with physical function (Spearman 0.40).

From the 45-item PCI the most frequently selected issues that patients wanted to discuss in their consultation or whilst at clinic (Fig. 1) were: fear of recurrence (37%), dental health/teeth (27%),

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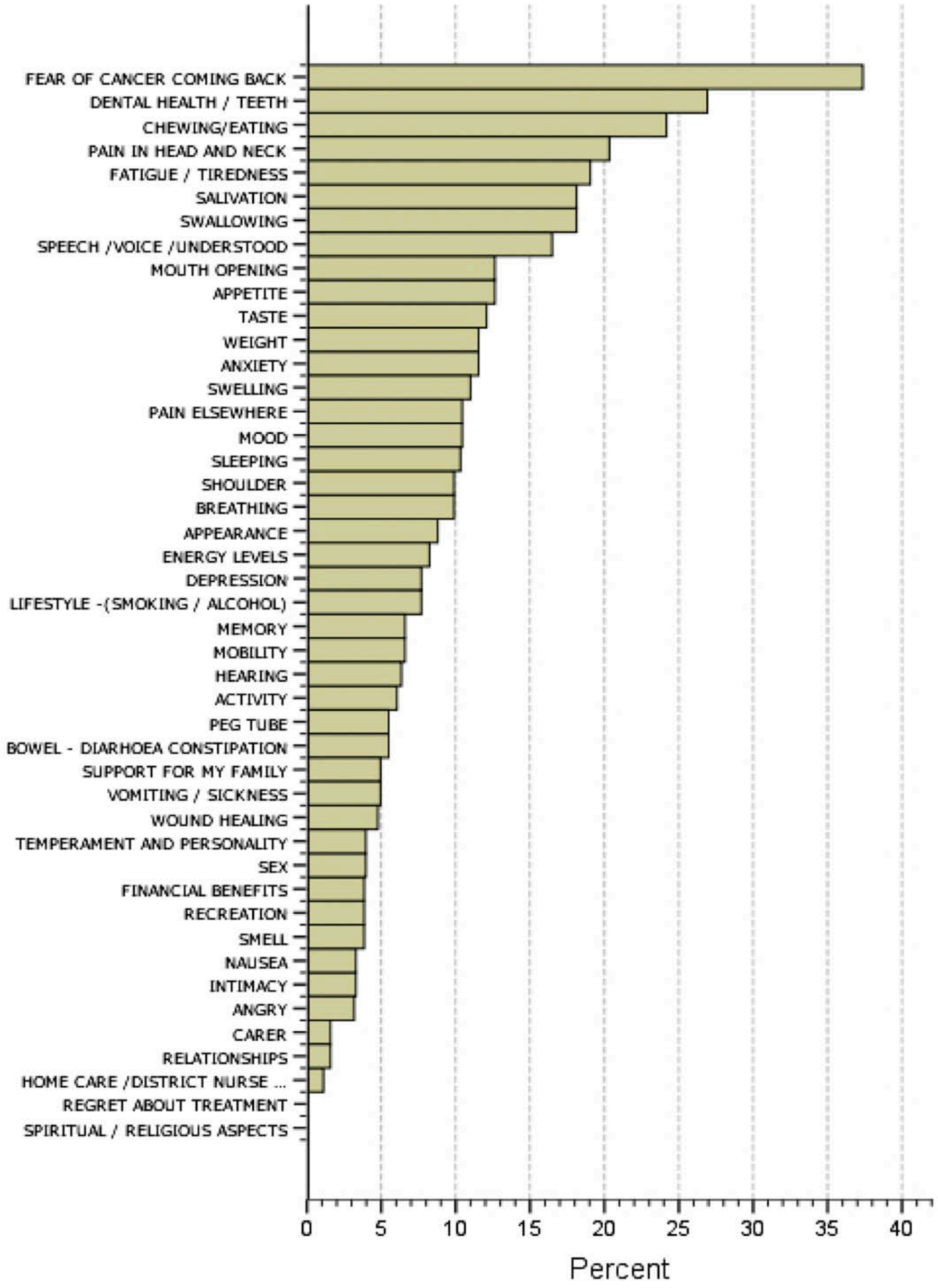

**Figure 1** Issues from the 45-item PCI that patients specifically wanted to talk about in their consultation or whilst at clinic.

chewing/eating (24%), pain in head and neck (20%), fatigue/tiredness (19%), saliva (18%), swallowing (18%) and speech/voice/being understood (16%). The median (IQR) number of issues selected was 3 (1–6), range 0–21 with 82% (149) selecting at least 1 issue. The three professionals they most wished to talk with either in clinic or by referral (Fig. 2) were: dentist (19%), surgeon (10%) and speech and language therapist (10%). The median (IQR) number of professionals selected was 0 (0–1), range 0–8 with 42% (77) selecting at least one.

Physical and social–emotional functioning at the time of first completing the PCI was associated with the number of issues selected (Spearman −0.38 and −0.46, respectively, both $p < 0.001$) and the number of professionals selected (−0.31 and −0.29, both $p = 0.001$). None of the other patient characteristics was associated at $p < 0.01$ (Table 1). Significant associations at $p < 0.01$ with specific issues and professionals selected by the patients are shown in Table 2. Physical function scores were largely predictive of issues specific to oral function (chewing/eating, mouth opening, PEG tube, speech/voice/being understood, swallowing, taste) whereas social–emotional function scores were largely predictive of issues related to emotion and social activity (depression, mood, energy, fatigue/tiredness, recreation, and family support) as were UW overall QOL scores (results not shown). Both function scores were predictive of wanting to see a dentist. Of patients aged under

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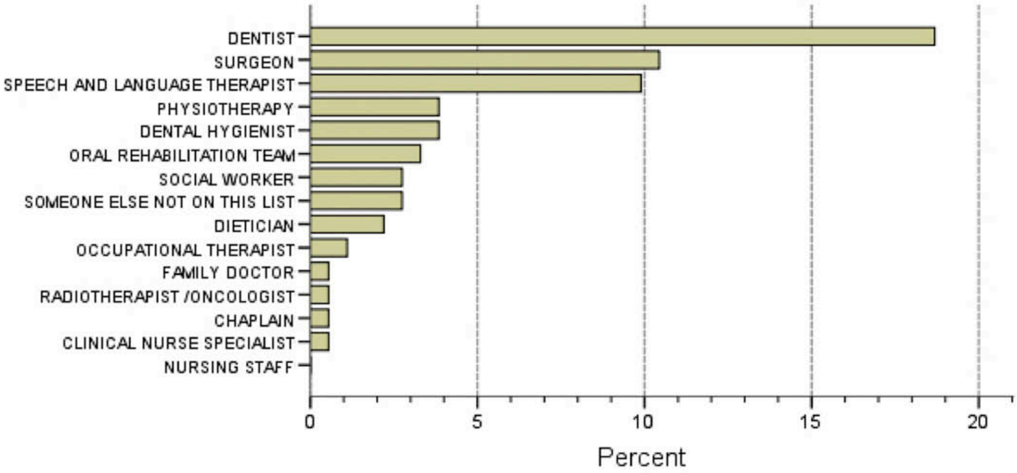

**Figure 2** Health professionals that patients specifically wished to talk with either in clinic or by referral.

**Table 1**
Patient characteristics and the number of issues and professionals selected from first time use of the PCI ($n = 123$).

| | | | N of issues to discuss in consultation or whilst in clinic | | | | N of professionals to talk with in clinic or be referred to | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | 5+ items | | | | 2+ people | |
| | | N | Median | IQR | % | N | Median | IQR | % | N |
| Age | <55 | 32 | 3 | 1–6 | 34 | 11 | 1 | 0–1 | 16 | 5 |
| | 55–64 | 45 | 4 | 1–6 | 44 | 20 | 0 | 0–1 | 13 | 6 |
| | 65+ | 46 | 3 | 1–5 | 26 | 12 | 0 | 0–1 | 11 | 5 |
| Sex | Male | 70 | 4 | 1–6 | 36 | 25 | 0 | 0–1 | 20 | 14 |
| | Female | 53 | 2 | 1–6 | 34 | 18 | 0 | 0–1 | 4 | 2 |
| Site | Oral | 89 | 3 | 1–5 | 33 | 29 | 0 | 0–1 | 13 | 12 |
| | Oropharyngeal | 26 | 4 | 2–7 | 42 | 11 | 1 | 0–1 | 12 | 3 |
| | Salivary/other | 8 | 3 | – | 38 | 3 | 1 | – | 13 | 1 |
| Time from diagnosis | < 12 months | 41 | 4 | 1–6 | 41 | 17 | 1 | 0–2 | 27 | 11 |
| | 12–35 months | 34 | 3 | 2–6 | 29 | 10 | 0 | 0–1 | 12 | 4 |
| | 36+ months | 48 | 2 | 1–6 | 33 | 16 | 0 | 0–1 | 2 | 1 |
| Clinical T | T1–2 | 94 | 3 | 1–6 | 36 | 34 | 0 | 0–1 | 13 | 12 |
| | T3–4 | 29 | 3 | 2–6 | 31 | 9 | 0 | 0–1 | 14 | 4 |
| Clinical N | N0 | 98 | 3 | 1–6 | 33 | 32 | 0 | 0–1 | 12 | 12 |
| | N1 | 15 | 4 | 2–10 | 47 | 7 | 0 | 0–1 | 13 | 2 |
| | N2 | 10 | 3 | 2–9 | 40 | 4 | 0 | 0–1 | 20 | 2 |
| Surgery | Free-flap | 60 | 4 | 2–7 | 43 | 26 | 1 | 0–1 | 18 | 11 |
| | No free-flap | 63 | 3 | 1–5 | 27 | 17 | 0 | 0–1 | 8 | 5 |
| Radiotherapy (RT) | RT | 53 | 4 | 2–6 | 40 | 21 | 1 | 0–1 | 13 | 7 |
| | No RT | 70 | 3 | 1–5 | 31 | 22 | 0 | 0–1 | 13 | 9 |
| Treatment | Primary RT | 8 | 4 | – | 25 | 2 | 0 | – | 0 | 0 |
| | Surgery, No RT | 70 | 3 | 1–5 | 31 | 22 | 0 | 0–1 | 13 | 9 |
| | Surgery & RT | 45 | 3 | 2–6 | 42 | 19 | 1 | 0–1 | 16 | 7 |
| Physical function (UW-QOL) * | < 50 | 14 | 8 | 2–14 | 64 | 9 | 1 | 0–2 | 43 | 6 |
| | 50–74 | 47 | 4 | 1–6 | 45 | 21 | 1 | 0–1 | 11 | 5 |
| | 75–89 | 19 | 4 | 2–5 | 32 | 6 | 0 | 0–1 | 11 | 2 |
| | 90+ | 43 | 2 | 0–3 | 16 | 7 | 0 | 0–1 | 7 | 3 |
| Social–emotional function (UW-QOL) * | < 50 | 11 | 9 | 5–16 | 82 | 9 | 1 | 1–2 | 36 | 4 |
| | 50–74 | 33 | 4 | 2–8 | 45 | 15 | 0 | 0–1 | 18 | 6 |
| | 75–89 | 43 | 3 | 1–5 | 33 | 14 | 0 | 0–1 | 9 | 4 |
| | 90+ | 36 | 1 | 0–3 | 14 | 5 | 0 | 0–1 | 6 | 2 |

* Spearman $P < 0.001$ with N of issues, $p < 0.01$ with N of professionals. None of the other patient characteristics were associated at $p < 0.01$ with N of issues or N of professions either from Spearman correlation (age, time from diagnosis), Mann–Whitney test (sex, clinical T, surgery, radiotherapy) or Kruskal–Wallis test (site, clinical N, treatment).

55 years 22% wanted to discuss appearance and 22% wished to see a speech and language therapist, whilst 15% of those with oropharyngeal tumours wanted to discuss PEG tubes. Activity (15%) and anxiety (27%) issues were selected within 12 months of diagnosis, 30% with free-flap surgery wanted to discuss speech/voice/being understood and 18% wanted to talk with a speech and language therapist. One third (34%) of those having radiotherapy wanted to discuss speech/voice/being understood and 30% wanted to discuss swallowing.

Those selecting more issues and professionals took longer to complete the TST and were longer in discussion with the consultant (Table 3). The overall median time for completing the TST was 8 min (Inter-quartile range 6–11, range 3–27). The length of the consultation between TST patients and consultant was known

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**Table 2**
Patient characteristics and specific issues and professionals selected from first time use of the PCI ($n = 123$). The table shows only those associations significant at $p < 0.01$.

| Patient characteristic | | Specific issue or professional selected | Results to illustrate the association of patient characteristic with specific issue or professional selected | | | |
|---|---|---|---|---|---|---|
| Age$^{*}$ | Years | Appearance | < 55: 22%, 7/32 | 55–64: 9%, 4/45 | 65+: 2%, 1/46 | |
| | | Speech & language therapist | < 55: 22%, 7/32 | 55–64: 9%, 4/45 | 65+: 2%, 1/46 | |
| Sex | Male, Female | – | | | | |
| Site | Oral, oropharyngeal | PEG tube | Oral: 1%, 1/89 | Oropharyngeal: 15%, 4/26 | | |
| Time from diagnosis$^{*}$ | Months | Activity | < 12 m: 15%, 6/41 | 12–35 m: 3%, 1/34 | 36+m: 2%, 1/48 | |
| | | Anxiety | < 12 m: 27%, 11/41 | 12–35 m: 9%, 3/34 | 36+m: 6%, 3/48 | |
| Clinical T | T1–2, T3–4 | – | | | | |
| Clinical N$^{**}$ | N0, N1, N2 | – | | | | |
| Free-flap surgery | Yes, No | Speech/voice/understood | Yes: 30%, 18/60 | No: 8%, 5/63 | | |
| | | Speech & language therapist | Yes: 18%, 11/60 | No: 2%, 1/63 | | |
| Radiotherapy | Yes, No | PEG tube | Yes: 9%, 5/53 | No: 0%, 0/70 | | |
| | | Speech/voice/understood$^{++}$ | Yes: 34%, 18/53 | No: 7%, 5/70 | | |
| | | Swallowing | Yes: 30%, 16/53 | No: 7%, 5/70 | | |
| Treatment$^{**}$ | Primary RT, surgery no RT, surgery & RT | Speech/voice/understood$^{++}$ | Primary: 0%, 0/8 | Surgery, No RT: 7%, 5/70 | Surgery & RT: 40%, 18/45 | |
| | | Swallowing | Primary: 38%, 3/8 | Surgery, No RT: 7%, 5/70 | Surgery & RT: 29%, 13/45 | |
| UW-QOL physical function$^{*}$ | 0–100 scale | Appearance | < 50: 21%, 3/14 | 50–74: 13%, 6/47 | 75–89: 11%, 2/19 | 90+: 2%, 1/43 |
| | | Chewing/eating | < 50: 29%, 4/14 | 50–74: 34%, 16/47 | 75–89: 37%, 7/19 | 90+: 7%, 3/43 |
| | | Mouth opening$^{++}$ | < 50: 43%, 6/14 | 50–74: 17%, 8/47 | 75–89: 5%, 1/19 | 90+: 2%, 1/43 |
| | | PEG tube | < 50: 29%, 4/14 | 50–74: 2%, 1/47 | 75–89: 0%, 0/19 | 90+: 0%, 0/43 |
| | | Speech/voice/understood$^{++}$ | < 50: 36%, 5/14 | 50–74: 28%, 13/47 | 75–89: 16%, 3/19 | 90+: 5%, 2/43 |
| | | Swallowing$^{++}$ | < 50: 36%, 5/14 | 50–74: 28%, 13/47 | 75–89: 11%, 2/19 | 90+: 2%, 1/43 |
| | | Taste | < 50: 43%, 6/14 | 50–74: 15%, 7/47 | 75–89: 11%, 2/19 | 90+: 5%, 2/43 |
| | | Dentist$^{++}$ | < 50: 64%, 9/14 | 50–74: 26%, 12/47 | 75–89: 16%, 3/19 | 90+: 12%, 5/43 |
| UW-QOL social–emotional function$^{*}$ | 0–100 scale | Depression$^{++}$ | < 50: 64%, 7/11 | 50–74: 9%, 3/33 | 75–89: 5%, 2/43 | 90+: 0%, 0/36 |
| | | Energy | < 50: 45%, 5/11 | 50–74: 9%, 3/33 | 75–89: 0%, 0/43 | 90+: 3%, 1/36 |
| | | Mood$^{++}$ | < 50: 64%, 7/11 | 50–74: 12%, 4/33 | 75–89: 7%, 3/43 | 90+: 0%, 0/36 |
| | | Mouth opening | < 50: 36%, 4/14 | 50–74: 21%, 7/33 | 75–89: 7%, 3/43 | 90+: 6%, 2/36 |
| | | Pain in head and neck | < 50: 45%, 5/11 | 50–74: 33%, 11/33 | 75–89: 19%, 8/43 | 90+: 11%, 4/36 |
| | | Recreation | < 50: 9%, 1/11 | 50–74: 12%, 4/33 | 75–89: 0%, 0/43 | 90+: 0%, 0/36 |
| | | Shoulder | < 50: 27%, 3/11 | 50–74: 15%, 5/33 | 75–89: 7%, 3/43 | 90+: 3%, 1/36 |
| | | Support for my family | < 50: 9%, 1/11 | 50–74: 9%, 3/33 | 75–89: 0%, 0/43 | 90+: 0%, 0/36 |
| | | Fatigue/tiredness | < 50: 71%, 5/7 | 50–74: 25%, 4/16 | 75–89: 11%, 3/28 | 90+: 5%, 1/19 |
| | | Dentist$^{++}$ | < 50: 55%, 6/11 | 50–74: 33%, 11/33 | 75–89: 23%, 10/43 | 90+: 6%, 2/36 |

Fatigue/tiredness used since October 2007.
$^{*}$ Mann–Whitney test.
$^{**}$ Chi-squared test. Otherwise Fishers Exact test.
$^{++}$ $p < 0.001$, otherwise $0.001 < p < 0.01$.

**Table 3**
Number of issues and professionals selected from the PCI, the time taken to complete the TST and the duration of consultation ($N = 182$).

| | | N of issues selected | | | N of professionals selected | | |
|---|---|---|---|---|---|---|---|
| | | 0–1 | 2–4 | 5+ | 0 | 1 | 2+ |
| TST completion (min) | Median (IQR) | 6 (5–9) | 10 (6–11) | 9 (6–11) | 7 (5–10) | 9 (6–12) | 10 (6–15) |
| | Mean | 7.1 | 9.3 | 9.9 | 7.9 | 9.6 | 11.1 |
| | N | 47 | 42 | 49 | 79 | 44 | 15 |
| Consultation duration (min) | Median (IQR) | 7 (5–8) | 10 (7–14) | 10 (7–12) | 8 (6–10) | 10 (6–14) | 9 (7–14) |
| | Mean | 6.9 | 10.9 | 10.3 | 8.6 | 10.3 | 10.6 |
| | N | 59 | 54 | 64 | 102 | 55 | 20 |

for 138, the median (IQR) being 8 (5–10) min. Consultation times for 131 without the TST were also known – median (IQR) 7 (4–14) min. There were 41 without TST who actually did complete the TST on another occasion – without TST their median (IQR) was 8 (5–16) min.

There were 43 patients using the PCI on more than one occasion and for these 43 the median (IQR) number of issues to discuss on the first and second occasions was 4 (2–6) and 4 (0–7), respectively, (Wilcoxon, $p = 0.20$). The median (IQR) number of professionals selected to talk was 1 (0–1) and 0 (0–1), respectively, (Wilcoxon, $p = 0.05$). The median (IQR) time taken to complete the TST fell from 10 (8–14) minutes to 7 (5–9) minutes (Wilcoxon, $p < 0.001$) whilst the median (IQR) consultation time fell from 10 (6–10) min to 7 (5–10) min (Wilcoxon, $p = 0.04$).

Only in 4 instances was it ‘quite a bit (2)’ or ‘very much (2)’ difficult for the volunteer to get the patient to agree to complete the touch-screen. On 17% (31/182) of occasions volunteers said that patients encountered ‘quite a bit (9)’ or ‘very much (22)’ of a problem in completing the touch-screen. Some description of the ‘problem’ was given for 13 of these 31. Six were related to sight and patient/carer not having reading glasses, 2 were described as being ‘physically unable’, one ‘took a long time’ whilst for four it was known that the volunteer had pressed the buttons. Volunteers also stated that for 17% (32/182) of occasions the carer had had ‘quite a bit (16)’ or ‘very much (16)’ of an input in completing the questions.

Those completing the TST for the first time were asked how much difference it had made to their consultation. Half (62/123)

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felt it had made 'quite a bit (28)' or 'very much (34)' of a difference, 11% (14) 'a little' difference, 28% (34) 'no' difference, not known for 11% (13). Typical comments were that it made it 'a bit more personal', 'reminds them of the points they want discussed', 'allows the consultation to get straight to the point'. When asked if the information from the PCI would be helpful to their GP 52% (64/123) felt it would make 'quite a bit (27)' or 'very much (37)' of a difference, 13% (16) 'a little' difference, 24% (29) 'no' difference, not known for 11% (14).

## Discussion

This is the first time a PCI has been published specific to head and neck cancer patients. Previously, others have reported on HR-QOL data collected by TST.[10] A PCI has potential to improve patient outcome and provide a better use of out-patient clinic time. It can allow a targeted consultation on issues the patient wishes to discuss, and promote more appropriate access to members of the MDT. The pilot has included a reasonable number of patients with the majority participating. The PCI has face and content validity. As well as the wide consultation process in developing the PCI items, there has been an iterative process of interaction between consultant and patient. Other items not on the PCI were raised in 10 consultations. In two this was ticked in error and two were issues already identified in the PCI for which the patient wanted to add clarification. For the remaining six the issues were; other medical problems, mother with cancer, lymphoedema, hyperbaric oxygen, stress, and pain elsewhere in body. The fact that so few patients felt it necessary to add other items supports the detailed widespread collaboration that took place when formulating the PCI list. Depending on the clinical setting it is possible in the future to make minor refinements to the PCI list. There are various head and neck specific HR-QOL questionnaires[13–15] but the PCI is a different concept. It is something that can be used in conjunction with HR-QOL data collection in those departments where routine HR-QOL collection is part of clinical practice.

It is recognised that in this pilot the PCI has been tested in only one consultant's clinic. Also most patients attending clinic were familiar with being involved in outcomes research and might be more willing to be involved than those in other clinical settings. The cohort was predominately oral cavity (three quarters) and just under one quarter oropharynx. Patient experience of the PCI is yet to be tested in laryngeal, hyopharyngeal, base of skull and other head and neck cancer sites. Also in our group there were few patients treated by primary radiotherapy and relatively few had advanced disease. The inclusion of these types of patients might potentially change the percentage of items raised and the MDT member(s) they wish to see/be referred to.

All but two of the 45 issues in the PCI were selected by patients in the pilot. The commonest issue was fear of recurrence mentioned by over one third of patients. When asked about this during the consultation most were not unduly distressed by this thought but a few needed referrals on to the emotional support therapist and clinical psychologist. Chewing/eating were frequent issues and it was the dentist who the patients most frequently want to be referred to. This reflects the cohort in the pilot, which were predominantly oral cancers. Even for issues never raised (e.g. regret about treatment) or seldom flagged, we feel it is important to keep them in the PCI. The PCI is easy for patients to complete and takes little time. Although certain items might not be raised very often it does not diminish their importance. Also for a patient with none or few issues the clinician has the reassurance that the patient has had the opportunity to mention things. There might be other items that need to be added and the PCI will evolve in individual clinic settings because of the iterative nature of discussing items of concern between patient and consultant and MDT members in clinic. We are adding a further 5 items, those of indigestion, coughing, mucus production, regurgitation, and discussion about cancer treatment.

Even though there is a large range of issues it is inevitable that some patients will choose not to raise them in the consultation. This might be because they feel guilty or embarrassed about the issue such as alcohol, intimacy or financial problems. Also in the clinic situation there may be issues the patient will choose not to talk about because they feel it an inappropriate forum or inappropriate person. Although the PCI gives patients 'permission' to raise aspects in consultation more work is required in implementing the PCI to ensure that patients unmet needs are recognised even if this means using resources outside of the out-patient setting. Also there needs to be awareness that if issues are raised by the patient that these are addressed. The clinician and MDT colleagues should be in a position to give advice and where necessary onward referral. It is also possible that by reminding patients of issues their distress levels could rise particularly if issues are not adequately addressed.

Forty-three patients completed the PCI more than once. On each occasion they raised a similar number of issues. It took significantly less time to complete the TST process. With a larger group we intend to explore the change in selection of PCI items over time. It might be that patients choose not to select certain PCI items if it has previously been discussed and either a solution was found or more worryingly if no solution was forth coming. However, there is evidence that patients just value recognising and talking through problems and that this is appreciated and therapeutic. Patients could keep raising specific issues for reassurance and this should not be passed over. There might be differences between patients, family and physicians as to which issues are most appropriately discussed.[16] Although both patients and oncologists seem willing to discuss a wide range of HRQL issues, Detmar and co-workers felt that communication regarding psychosocial issues might be hampered by competing expectations as to who should take the lead in initiating such discussions. It is hoped that the PCI will facilitate an open collaborative agenda between patient, family and healthcare professionals.

The PCI has been used in combination with the UW-QOLv4. Because the TST makes questionnaire completion less of a burden to patients it is possible to use other questionnaires in combination with the PCI to get a better indication of patient subjective outcome and identify those with dysfunction.[6] The time taken to fill-in the TST was relatively short at 8 min. This included the UW-QOLv4, other additional non-validated questions and the PCI. The time taken to compete, the process was quicker for those who were repeating it at a subsequent consultation.

Nearly one fifth of patients encountered 'quite a bit' or 'very much' of a problem in completing the touch-screen. The main reason was that they had not brought their reading glasses. We have changed the clinic appointment invitation to specifically request patients to bring their glasses; however, sometime not having glasses is a surrogate for not being confident with computers or concerns about their reading level. The volunteer can help these patients complete the PCI as their data is important as they are often most vulnerable and disadvantaged. The volunteer had no previous experience of head and neck cancer and as part of the volunteer scheme was trained to act as an impartial facilitator.

The next step in evaluating the PCI in routine clinical practice is to roll out in to other consultants clinic and use it in other head and neck cancer sites. Given the goals of the instrument, an important element of its further evaluation is to assess the number of referrals to other members of the health care team and the subsequent health outcomes themselves. We are exploring the possibility of evaluating the impact of the PCI using a RCT design, to ascertain its impact on HR-QOL, content of consultation, MDT referrals/intervention, and patient experience.

Author's personal copy

In conclusion patients seem to genuinely appreciate the PCI. It seems to be a practical tool appropriate to a busy out-patient clinic. The PCI helps to focus the consultation on an individual basis to make it cover the key issues for the patient without undue delay to the consultation.

## Conflict of interest statement

None declared.

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