

## **The rollout and evaluation of the Head and Neck Cancer Patient Concerns Inventory across the Merseyside and Cheshire Network**

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2. NHS North West Sharing & Learning Awards (Innovation@northwest.nhs.uk) funded £5,000 to develop information material to support roll out allowing professional advice around the content, format, design and production of patient information leaflet, creation of an instruction manual for healthcare professionals, and a DVD available online.
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### **Ethics**

REC reference: 12/NW/0743

### **Conflict of interest**

There is the potential for conflict of interest as Professor Rogers has been an integral person in the development of the PCI, however this evaluation was undertaken by a study specific researcher, Mrs Shirley Cooper, (independently appointed by Aintree R&D for this project ). Data has been collected anonymously. In the writing of the report every effort has been made to draw valid and balanced conclusions.

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## Executive summary

### Introduction

The Patient Concerns Inventory (PCI-H&N) is a carefully designed 57 item checklist specific for use in head and neck cancer follow-up. Although development work at one hospital has been very positive, the merit of the PCI-H&N as a tool across a wider network had not been evaluated. The imperative for wider evaluation is set within the context of the PCI-H&N having been included as a key quality indicator in the NHS national mandatory audit of all H&N cancer units (Data for Head and Neck Oncologists DAHNO). The PCI-H&N has now been formally adopted by DAHNO, starting in 2014 with the inclusion of “use of the PCI” into the 10th collection year requirements as it continues the trend of including measures that reflect patient experience.

### Aim

The aims of this project were to set-up and evaluate the PCI-H&N across the Merseyside and Cheshire Cancer Network.

### Method

Patients were included from across the Merseyside and Chester Cancer Network with review clinics at Aintree University Hospital (AUH), Arrowe Park, Leighton, Royal Liverpool Hospital (RLUH), and St Helens. Purposeful sampling recruited 12 patients with early and 4 with late stage laryngeal cancer, 19 patients with early and 10 with late stage oral cancer, 10 patients with early and 26 with late stage oropharyngeal cancer. Of these 81 patients, 15 withdrew before the end of the study. A total of 66 patients, 8 doctors and 6 nurse specialists were part of the complete evaluation process.

### Results

Almost all the patients found the PCI-H&N easy or very easy to complete. They felt that PCI-H&N caused no notable problems with the running of appointments. Two-thirds felt that all or most of their PCI-H&N items were talked about in the consultations. Half felt the PCI-H&N made a positive difference to their appointment. No patient felt the PCI-H&N made the consultation worse or much worse. Two-thirds of patients felt the PCI had helped them communicate with the doctor and there was also a minority who felt their communication with the doctor and team was already excellent and could not be improved. One-quarter felt the PCI had triggered additional support they would otherwise not have had, and a quarter would maybe/definitely have liked to have been referred to other people. Although the PCI-H&N tended to raise patients expectations around the consultation only a small minority (12%) felt it maybe/definitely led to disappointment through unmet needs. Most patients would definitely like to continue using the PCI-H&N and only 5% definitely not. The

majority of the doctors and Clinical Nurse Specialists involved in the evaluation saw the potential benefit of the PCI-H&N in clinical practice. However, there are practical, administrative and educational aspects that need to be addressed before effective wider roll out is possible. Most (52%) of those having used both paper and computer versions of the PCI-H&N preferred the computer version, though the majority of all patients (54%) felt that completing the PCI-H&N at home via the internet would not be useful to them. Patients did not see the use of an internet based PCI concerns check list approach as a way to reduce the frequency of clinic attendances as most preferred to have the face to face interaction and physical screening afforded by attending a clinic.

## Discussion

The wider adoption of the PCI-H&N across the Network is supported by this study. Patients value the PCI approach in consultations, in particular the under 70 age group, 63% of whom definitely wanted to continue with the PCI, and also those with advanced stage disease (Stage 3 and 4) and those with oropharyngeal and laryngeal sites. The feasibility of integrating its use into routine care needs further evaluation. It is likely that each clinic and locality will develop their own solutions as to how best to incorporate it. Patients need to be given a choice as to whether they wish to use the PCI-H&N and for those using the PCI whether it is completed on a computer or paper

## Introduction

The Patient Concerns Inventory (PCI) is a carefully designed head and neck cancer pre-clinic consultation checklist (PCI-H&N). It comprises 57 issues that patients might wish to raise in their consultation and provides the opportunity for patients to indicate that they wish to see other members of the multi-professional healthcare team. More information is available on the PCI website <http://www.patient-concerns-inventory.co.uk/><sup>1</sup>.

The PCI-H&N has been established in one clinical setting at the H&N surgery regional centre (University Hospital Aintree). Its evaluation has led to several papers addressing initial assessment<sup>2</sup>, concept<sup>3-7</sup>, methodological aspects<sup>8-10</sup>, impact on clinic<sup>11-13</sup>, validation<sup>14-20</sup>, fear of recurrence<sup>21,22</sup>, international collaborations<sup>23</sup>, and other disease states<sup>24-26</sup>. These studies have demonstrated that the PCI provides opportunities for more holistic consultations, without significantly increasing clinic consultation times.

Further data on the influence on clinic consultations, doctor-patient communication and patient satisfaction will be forthcoming from work completed by Ghazali as part of her MD submission<sup>27</sup>. The PCI allows for better patient-healthcare communication, easier identification of needs and concerns, and early signposting for additional support and intervention.

Although development work at Aintree University Hospital has been very positive, the merit of the PCI as a tool across the network has not been evaluated. Despite its benefits in clinical care there are potential barriers to wider adoption. Hence, the aim of this project was to set up, tryout and evaluate the PCI-H&N across the Merseyside and Cheshire Cancer Network (MCCN) before considering this approach as a standard of care in H&N cancer survivorship in this region. The evaluation included feedback from patients, Clinic Nurse Specialists and consultants.

The imperative for wider evaluation is set in the context of the PCI-H&N having been included as a key quality indicator in the NHS national mandatory audit of all H&N cancer units (Data for Head and Neck Oncologists DAHNO). DAHNO will ask that all H&N units across England and Wales submit evidence that patients have conducted the PCI as a holistic needs assessment and in future years request that individual PCI items selected by patients also be included in their submission. The value the PCI-H&N has in providing a holistic patients' need assessment and how this can improve professional practice is substantiated by the support given by the British Association of H&N Oncology Nurses (BAHNON) and the National Association of Laryngectomee Clubs. These associations have endorsed use of the PCI as a 'helpful and specific H&N holistic needs assessment'.

Development work at Aintree University Hospital has resulted in the PCI computer-based platform being upgraded to a web-based facility. It is now possible for the PCI tool to be readily used by patients, clinicians and multi-disciplinary team members (MDT) across the MCCN.

This one-year evaluation project involved aspects of service innovation, health improvement, and patient empowerment/engagement. Key steps were required before commencing the evaluation: establishing clinical and IT contacts at each of the H&N departments across the network; information material for patients and staff; basic instruction on how to use the PCI in clinical practice for the clinical teams (web-based resource and DVD); ethics site-specific approval; formulation of the semi-structured patient evaluation; and appointment of a Project Manager.

The PCI-H&N evaluation is consistent with the Cancer Improvement Programme which aims to transform, deliver and build sustainable improvements across the entire pathway of cancer care. Head and neck cancer patients can have complex needs following radical surgery at Aintree University Hospital (AUH), and radiotherapy / chemoradiotherapy at Clatterbridge Centre for Oncology (CCO). Patients have review clinics at Arrowe Park, AUH, Chester (held at Clatterbridge site), Isle of Man (IOM), Leighton, Royal Liverpool Hospital (RLUH), and St Helens. The PCI evaluation should allow reflection on the level of support that is available in their locality (peripheral hospital).

## **Methods**

The project had two main components, firstly the setting-up of the PCI for use in clinics and secondly an evaluation.

### ***Set-up***

**The set-up phase of the project comprised the following steps:**

1. Resource material to support the rollout was developed and was made available on the PCI specific website: <http://www.patient-concerns-inventory.co.uk/>

The website contained:

- i) The PCI
- ii) Instructional video for the computer system and the interpretation of the PCI
- iii) Instructional video to demonstrate the use of the PCI in clinic
- iv) Patient information leaflet
- v) Other background material

2. Identify the H&N oncology follow-up clinics across the network and engage with locality teams (clinician and specialist nurse)

3. Proof test the PCI computer application for use in the roll-out

4. Print three 'carbon' copy versions of the PCI for use in clinics where IT facilities were not available (three sheets with the top copy retained by the patient, second copy sent to patients GP, and third copy retained in the patients notes).

5. Workshop held in November 2012 to help raise awareness and inform the staff.

### ***B. Evaluation***

The evaluation phase of the project comprised the following steps:

1. Ethical approval followed by individual site specific approval. Gaining R&D approval at each Trust is a time consuming process for any project. The sites where approval was granted were Southport and Ormskirk, Chester, Aintree University Hospital (AUH), St Helens, Arrowe-Park, Royal Liverpool Hospital (RLUH), and Leighton.

2. Identification of clinics

Review head and neck oncology clinics were identified at Arrowe Park Aintree University Hospital (AUH), Chester (held at Clatterbridge site), Isle of Man (IOM), Leighton, Royal Liverpool Hospital (RLUH), and St Helens. There were no follow-up clinics at Clatterbridge (CCO), Ormskirk & Southport (patients followed up at AUH), or Warrington (patients followed up at St Helens). Most Isle of Man patients were reviewed at AUH and the clinical team at IOM declined to recruit patients. CCO were invited to evaluate the PCI in 12 patients at the end of their radiotherapy but declined.



### 3. Patient selection

Purposeful sampling of consecutive clinics was carried out in order to identify suitable patients by site of referral, stage, tumour site (larynx, oral cavity, oropharyngeal), between 6 months and 2 years on from treatment with curative intent, disease free and between the ages of 18-80 years. Patients were to be excluded if there was cognitive impairment, psychiatric disorder, palliative intent, tumour recurrence or if beyond 2 years since diagnosis / completion of treatment. The rationale for purposeful sampling was to try to avoid an over representation of early oral and late oropharyngeal cancers. Early oral cancers tend to predominate in review Maxillofacial clinics at AUH whilst oropharyngeal cancers tend to be late presentation and be reviewed by both ENT and MFU. From each hospital the intention was to recruit two early stage and two late stage oral cancer patients, two early stage and two late stage oropharyngeal cancer patients, and two early stage and two late stage laryngeal cancer patients.

Much of the recruitment of patients took place at AUH because of the number of patients routinely followed up at Aintree. A total of 15 clinic lists were screened between 22nd January and 1st May 2013 with recruitment starting in January 2013 and finishing in June 2013. The number of clinics and period of recruitment was much shorter at the spoke clinics due to the delays in getting individual Trust site specific and R&D approval. 289 patients were screened from the clinic template at AUH. Precise details on the numbers not eligible or missed is lacking but of those approached only 13 refused to take part in the project. Twenty-one initially consented to the study at the time of the clinic visit but then changed their minds and withdrew. There were 81 patients recruited of whom 15 subsequently dropped out.

Recruitment by referring hospital and location of the review clinic- most patients overall are followed up at Aintree

	Review clinic					Total
	AUH	Arrowe Park	Leighton	RLUH	St Helens	
Referring Hospital						
Arrowe Park	5	5				10
AUH	16					Regional centre (clinic at CCO site)
Chester	5					no clinic
IOM	5					8
Leighton	4		4			13
RLUH	5			8		no clinic
Ormskirk & Southport	9					10
St Helens & Knowsley	3				7	no clinic
Warrington	5					81
Total	57					

#### Recruitment by site and stage

	Early stage	Late stage
Larynx	12	4
Oral cavity	19	10
Oropharynx	10	26

It proved very difficult to identify sufficient numbers of patients with late stage laryngeal cancer. It was also difficult to recruit those with early oropharyngeal tumours since most oropharyngeal cancer patients present late. As can be seen in the above table, ultimately more patients than originally intended were recruited in certain groups to make up the total numbers within the recruitment timeframe, these being early stage oral cavity and late stage oropharynx.

#### 5. PCI completion

Recruited patients were asked to complete the PCI<sup>1</sup> when they came to clinic. The expectation was that they would routinely have 6 weekly outpatient appointments and the study would take place over three consecutive appointments, about 4 months. After the third clinic appointment, the Project Manager would contact them to agree a mutually convenient time for the post-study telephone survey. Prior to this they were to be sent the evaluation pack that included a copy of the PCI, the Holistic Needs Assessment tool, and a copy of the questions used in the semi-structured telephone survey.

#### 6. Interviews

The evaluation material and semi-structured telephone interview were piloted in six patients from the Head and Neck Research Forum, following which minor changes were made. For patients or clinical staff having difficulty with a telephone survey, a response on a paper questionnaire was allowed. See appendix 1 for the questions asked. All the telephone interviews were taped to allow the Project Manager to check back on the notes made during the interview and to enable responses to be transcribed verbatim.

#### 7. Statistical analysis

Statistical analysis largely comprised descriptive methods. The characteristics of the whole patient group interviewed are described along with results from their first completed PCI and clinical profile. Quantitative results from the interview are combined with qualitative free text. All patient identifiers and any clinician specific references were removed. Chi-squared, Fishers exact and Mann-Whitney tests of significance were used as appropriate to compare clinical and demographic characteristics of those who initially consented and then participated with those who initially consented and then did not participate. Chi-squared and Fishers exact test were also used to test for associations with whether patients would definitely like to continue using the PCI type approach in clinic consultations.

## Results

All 81 initial recruits completed at least one PCI questionnaire at clinic and data from 77 of these were available at the time of analysis. Of the 81 recruits, 2 subsequently asked to be withdrawn from the interview process, 3 were withdrawn because their cancer returned and were receiving palliative care, 2 responded too late to be included in analysis and despite repeated attempts another 8 did not participate in the interview process. Data from telephone interviews were obtained from 59 patients whilst 7 sent in their responses by post using a paper questionnaire form of the interview. These 66 were compared to the 15 not participating in the interview process in respect of clinical characteristics (Table 1) and initial PCI data (Tables 2 & 3). Non-participants were 6 years younger on average but had a similar clinical profile as participants in regard to tumour site, clinical staging and primary treatment and there was a similar gender split. Fewer had completed their first PCI questionnaire at Aintree University Hospital and they were more recently diagnosed with a shorter time lag between diagnosis and first PCI questionnaire. The first PCI questionnaire profiles of the two groups were very similar in terms of the number of items selected by domain and for the majority of individual items. The only notable difference was in regard to the concern 'speech/voice/being understood' which was higher in the group that subsequently did not participate in the interview process. The remainder of the analysis focuses on the 66 subsequent participants.

The clinical characteristics of the 66 are summarised in Table 1. Mean (SD) age at recruitment was 63 (9) years and two-thirds (68%) were male. Tumour site was oral (36%), oropharyngeal (45%) or laryngeal (18%) with late overall clinical 3-4 staging at diagnosis for 45%. Most (59%) were primarily treated with surgery alone, with others treated by surgery and adjuvant radiotherapy (17%) or by primary chemotherapy, radiotherapy or both (24%). The referral site was Aintree University Hospital (14), Royal Liverpool University Hospital (10), Arrowe Park Hospital (9), Leighton Hospital Crewe (8), Southport/Ormskirk Hospitals (7), St Helen's/Knowsley Hospitals (6), Warrington Hospital (4), Countess of Chester Hospital (4) and from the Isle of Man (4). Only 21% (14) completed three PCI before the interview with half of the others completing two PCI and half only the one PCI.

The time from diagnosis to first completion of the PCI questionnaire was <12 months (24%), 12-23 months (55%), ≥24 months (21%). The first PCIs were completed between 20<sup>th</sup> February and 4<sup>th</sup> September 2013 (median 1<sup>st</sup> May), mainly (74%, n=49) at Aintree University Hospital, other locations being Royal Liverpool University Hospital (8), St Helens (7), Arrowe Park (5) and Leighton (4). Patients selected a median (IQR) of 5 (2-8) concerns on their initial PCI to discuss during the clinic consultation (Table 2) and 87% selected at least one item, predominantly from the physical and functional well-being and psychological, emotional and spiritual well-being domains. One-quarter (24%) selected one or more health professionals to see. The 10 most selected concerns (Table 3) were fear of recurrence (49%), dry mouth (44%), chewing/eating (35%), salivation (30%), fatigue/tiredness (29%), dental health/teeth (24%), mucus production (24%), taste (24%), swallowing (22%) and coughing (21%). The most selected health professionals (Table 3) were dental hygienist (10%), dentist (10%), and speech & language therapist (6%).

The median (IQR) time from diagnosis to interview questions was 22 (15-27) months and the questions were answered between 3<sup>rd</sup> July and 2<sup>nd</sup> October 2013 (median 9<sup>th</sup> September).

The median (IQR) time from first PCI completion to the interview questions being answered was 3.8 (2.9-4.7) months. The duration of the telephone interview was recorded for 56 of the 59, with median (IQR) duration of 13.2 (11.0-16.0) minutes, range 3.0 – 24.0 minutes. The interview questionnaire comprised a mix of closed and open-ended questions, and responses to the former are shown in Table 4.

Just over half (53%) had completed a PCI at clinic using a computer and three-quarters (74%) had completed one on paper. Those who had used both were asked for their preference: 12 said computer, 5 paper, 6 either. Almost all (88%) found the PCI easy or very easy to complete with only 6% finding it difficult or very difficult. Only 11% said there were specific PCI items that gave them problems. The PCI caused no notable problems (94% 'not at all') with the running of appointments. Two-thirds (67%) felt that all or most of their PCI items were talked about in the consultations. Half (47%) felt the PCI made a positive difference to their appointment and half (53%) felt it had made no difference or were unsure. Only 11% said that they maybe/definitely did not tick items of concern because the clinic appointment was either not the right time or place to discuss them. Four-fifths (79%) had seen a consultant surgeon, one-fifth (20%) a consultant oncologist, 11% another doctor and 3% were unsure. Half (50%) felt the PCI had been of use to the doctor, with only 5% feeling it not to have been of use. Two-thirds (66%) felt the PCI had helped them communicate with the doctor, but 11% felt it had not. One-quarter (27%) felt the PCI had triggered additional support they would otherwise not have had, whilst one-quarter (26%) were not sure and nearly half (47%) said not so. A quarter (25%) would maybe/definitely have liked to have been referred to other people, but 54% said definitely not. Nearly half (45%) felt the PCI had maybe/definitely raised expectations, one quarter (25%) definitely not so. A minority (12%) felt raised expectations had maybe/definitely led to disappointment through unmet needs, but nearly three-quarters (71%) definitely did not think so. Over half (58%) would definitely like to continue using the PCI, another 17% maybe so, and only 5% definitely not. Over one-third (37%) were positive about using the PCI at home via the internet but for half (46%) this would definitely not be useful to them. One-quarter (23%) overall (and 24% of the subset positive about using the PCI at home via the internet) felt the PCI web-based approach could reduce the number of clinic appointments, whilst one-third (32%) thought it would definitely not do so. Whereas one-quarter (29%) felt that a reduction in clinic frequency could help them, one half (50%) felt it could be unhelpful. Fewer visits would lead to notable financial savings for one-quarter (28%) but would have no effect at all for 37%. On a more general note 17% indicated ways in which their clinic experience could have been made better for them.

Further analyses were done to see if any of the clinical and demographic factors were associated with patients having a definite preference to continue using the PCI type approach in clinic consultations (Table 5 – 7). These suggest that elderly patients, female patients, patients with oral tumours and patients presenting with early tumours are less likely to definitely want to continue with the PCI (Table 5). Initial PCI results (Tables 6 & 7) do not suggest any PCI factors associated with continuance.

Patients were asked to explain the reasons for some of their answers, as per the interview questionnaire. A wide selection of verbatim responses is listed in Appendix 2.

Staff interviews were conducted with 9 members of staff, comprising 3 consultant doctors and 5 clinical specialist nurses who participated directly in the study, and 1 other nurse (Macmillan support & information manager) not personally involved. The interview comprised a mix of closed open-ended questions, with one of the consultants submitting responses by post. In addition a shortened version of the interview questionnaire was emailed to 9 consultant doctors with 5 responses received. The staff responses were collated and are reflected in Appendix 3. All staff responders had some familiarity with the PCI and all but one had used it in Clinic. Just over half (7/12) found it easy to include in consultation, with 2/12 finding it difficult. Only one doctor had significant problems running the PCI in clinic and all doctors felt that some, most or all PCI items ticked by patients were discussed. A majority of responders (8/14) felt the PCI made a positive difference to the consultation, none a negative difference. All felt that the PCI was something the patient found useful. Most (10/13) would like to continue using the PCI type approach in consultations, including 6/8 of doctors.

In regard to the comparison between the Patient Concerns Inventory (PCI) and the Patient Concerns Checklist (PCC) 57 patients were sure they had received blank versions of both in readiness for the interview questionnaire and 44 that they had completed both in readiness. Of these 44 one-third (33%) preferred the PCI, one-quarter (24%) the PCC whilst for the rest there was either little difference or they weren't sure.

## Discussion

Previous publications<sup>1-26</sup> have shown the potential benefit of the PCI-H&N in out-patient review appointments. It has been integrated into routine practice in one clinic but the potential benefits, barriers, and acceptability had not been evaluated across a wider clinical network. This step is essential if more general adoption of the PCI in head and neck cancer care is to be considered.

The study has merit as most of the sample of Clinical Nurse Specialists and Consultants had little or no previous experience of the PCI. The setting was in busy routine out-patient clinics. The local network had a reasonable representation with five of six hospital out-patient clinics contributing to the study. Anonymous patient and clinical feedback via the project manager encouraged honest and frank feedback. The use of semi-structured interviews allowed for a richness of comment from the verbatim responses to help qualify what was good or bad about aspects of the PCI process. The project delivered within 18 months from funding being awarded, and this included final study design, ethical submission, patients and staff information material, recruitment, evaluation, analysis, report writing and dissemination at a Patient Concerns Workshop in November 2013. Delays in getting site-specific approval in the time window for recruitment hampered the use of the PCI with nearly half of patients overall only being able to use the PCI once in clinic. Most data came from patients reviewed in clinic at the AUH. This in part mirrors the review structure with most oral cancers being reviewed at AUH as well as patients from the IOM, Southport and Ormskirk. Although a better representation for other spoke clinics would have been preferred, the comments from patients and in particular the Clinical Nurse Specialists and Consultants give valuable insight as to the issues involved in rolling out the PCI across the Network. There was an under representation of patients with laryngeal cancer and given the communication difficulties these patients might have, further evaluation in this group would be helpful.

This project has demonstrated that most patients appreciated the use of the PCI in their clinic appointment. Seeing the consultant gave them reassurance particularly around the physical examination to confirm there was no recurrence of the cancer. The PCI helped to give patients the opportunity to raise issues they wanted to discuss. Its inclusion seemed to enhance the consultation. In this cohort the issue that patients wished to discuss most was fear of recurrence, and this has been a consistent finding with the other papers published on the PCI-H&N. The importance that patients place on dental health / teeth perhaps reflects difficulties accessing services, as evidenced by the dental hygienist and dentist being the most selected health professionals that patients also wished to see or be referred to.

In general the PCI-H&N was very acceptable and appreciated by patients. Almost all found the PCI-H&N easy or very easy to complete (88%) and that it caused no notable problems with the running of appointments (94%). Two-thirds felt that all or most of their PCI-H&N items were talked about in the consultations and half felt the PCI-H&N made a positive difference to their appointment. No patient felt that the impact was negative.

Two-thirds felt that the PCI had helped them communicate with the doctor while 11% felt that it had not though some of these patients already regarded their communication with the doctor and team as excellent and could not be improved. One-quarter felt the PCI had triggered additional support they would otherwise not have had, and a quarter would maybe/definitely have liked to have been referred to other people,

Although the PCI-H&N tended to raise patients expectations around the consultation only a minority felt it maybe/definitely led to disappointment through unmet needs. Patients liked the opportunity to talk about issues they wished to raise but in doing so gained benefit from the discussion rather than expecting the clinicians to come up with new solutions to complex and chronic problems.

Most patients would definitely like to continue using the PCI, H&N and only 5% definitely not. Most of the doctors and Clinical Nurse Specialist involved in the evaluation see the potential benefit of the PCI-H&N in clinical practice; however from their comments there are practical, administrative and educational aspects that need to be addressed before effective wider roll out is possible.

The use of the PCI-H&N by computers or on the Internet at home polarised the patients with about a third positive about this approach; however around half felt it would be unrealistic and a significant barrier. Some patients will have a clear preference on how they would wish to complete the PCI-H&N and so both computer and paper versions should be available.

Patients did not really see the use of the PCI concerns check list approach as a way to reduce the frequency of clinic attendances as they prefer to have face to face interaction and physical screening. They get considerable reassurance from physical examination to exclude the possibility of recurrence. The high level of emotional concern when attending clinic review means that any strategy of stratified clinics with reduced frequency based on high, medium and low risks of recurrence requires patient education, information, open access to review and enhanced emotional support.

The PCI-H&N appears feasible as a head and neck specific HNA across the Network and patients seem to really value this approach. There is a need to develop and evaluate the education of clinical teams (clinicians and nursing staff) as how 'best' to use the PCI-H&N in practice. There is also a need to evaluate the health economic benefit of this approach, not only in terms of reduced frequency of clinics if patients perceive the need, but also quicker recovery through better access to support services. There could be fewer requests for additional screening investigations and clinic appointments if patients were managed better in regard to their primary PCI concern of fear of recurrence.

Development work at Aintree University Hospital has resulted in the PCI computer-based platform being upgraded to a web-based facility. It is now possible for the PCI tool to be readily used by patients, clinicians and multi-disciplinary team members (MDT) across the MCCN. We need to be more clear though as to the added benefit of a PCI computerised system compared to the use of the PCI on paper. The Aintree system integrates both the PCI and a H&N cancer specific health related quality of life questionnaire into a complementary

package. The computer system is able to analyse the quality of life data and have problem areas identified at the outset of the consultation alongside the PCI concerns selected. Realistically a paper version would only be able to accommodate the PCI alone as any real-time analysis of the quality of life information within the confines of the consultation is impractical. If the IT problems experienced in this project are typical of what to expect in any general roll-out then both forms of the PCI-H&N need to be available. The computer system has added benefits but the paper version may well provide the initial impetus into a new location.

The benefits of using the PCI-H&N within a computer system are that it is quick to complete, requires no filing away or scanning into patient records, could be paperless, there are no missing data, enables email prompts to relevant MDT members, can link between clinics and thus provide longitudinal data, facilitates continuous audit as records are available (so long as all patients use the computer rather than a pick and mix hybrid involving paper), can readily identify patients scoring badly across a wide range of health related quality of life domains, and has the ability to add other items of local interest e.g. lifestyle advice / solutions. Potential barriers to having a computer version are that some patients are uncomfortable using a computer and that these patients need a volunteer to support their PCI completion, a separate room is required for computer entry and patients might be concerned about missing their place in the clinic order. Finally, there is always the possibility of an IT failure that could prevent the use of the computer version of the PCI and in such situations a paper version would be the reserve option though any subsequent updating of records to maintain completeness would require manual input.

The findings of this study support the wider adoption of the PCI-H&N into clinics as most patients prefer this approach to the traditional approach and would like to continue using it. Further evaluation is needed to explore if an iPad format that allows patients to complete the PCI while in the clinic waiting area would be both workable and acceptable to patients. There needs to be clarity on how to promote patient choice to either use or not use the PCI, complete it on paper or use a computer. Should the PCI-H&N not be regarded as a suitable tool for integration into routine clinics there needs to be discussion with the Clinical Nurse Specialists and doctors as to when to use the PCI selectively, e.g. at certain time points in the cancer journey or with certain groups of patients. Wider dialogue around the use of the PCI in patient care with other agencies providing care in the community such as GPs is needed. What this project has indicated is that patient expectations are likely to be raised if the PCI is used and if a site opts to use it, in whatever way, it is important to make direct reference during the consultation to the PCI items selected as otherwise patients may feel as if their contributions were somehow being ignored and leave dissatisfied.

As a result of the successful use of the PCI-H&N across networks and the general demonstration of its usability by and acceptability to patients and clinicians, the PCI-H&N has now been formally adopted by DAHNO, starting in 2014 with the inclusion of "use of the PCI" into the 10th collection year requirements as it continues the trend of including measures that reflect patient experience. As the familiarity of the PCI across England and Wales expands then the audit will seek to collect more in-depth aspects of the PCI. These audit data will be used, in conjunction with the Healthcare Quality Improvement Partnership (HQIP), to achieve quality improvements that benefit patients and their care.



An electronic version of the PCI-H&N was the 2010 E-Health Insider winner for 'Best use of IT in patient and citizen involvement in healthcare'. Subsequently, versions of the PCI have been adapted for iPad use in the University of Dundee, and touchscreen tablets at the University of Ulster and Ulster Hospital. There is also an initiative to support national roll-out through collaboration with Macmillan by forming a head and neck specific holistic needs assessment tool by amalgamating the E-HNA and the PCI-H&N.

There is also growing momentum to extend the concept of the PCI into new clinical areas with additional functionality being built into these new versions through regional, national and international collaborations. Most recently this involves a fully funded project examining the usefulness of the PCI as a health needs assessment tool when used with elderly patients across three clinical areas. This study is being carried out in collaboration with Edge Hill University and Hull and East Yorkshire Hospital Trust. Electronic adaptations of the PCI-H&N have been developed. The PCI has been adopted for use in Neuro-Oncology (the Edinburgh Centre for Neuro-Oncology), Breast Cancer (the Cancer Research UK Centre and St James's Institute of Oncology, Leeds), Rheumatology (University of Liverpool), Stroke (Aintree University Hospital), and internationally for head and neck cancer and restorative dentistry in Brazil, Canada, Malaysia and the USA, and has been translated into 7 languages including Chinese, Arabic Urdu and French.

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Table 1. Measured clinical & demographic characteristics of initial recruits (n=81) by whether they subsequently participated in the interview process.

		Participated		P value*
		Yes (n=66)	No (N=15)	
Sex	Male	68% (45)	73% (11)	0.77
	Female	32% (21)	27% (4)	
Age	Mean (SD)	63 (9)	57 (8)	0.05
	Median (IQR)	63 (58-68)	57 (50-65)	
	<60 years	33% (22)	73% (11)	0.12
	60-69 years	47% (31)	27% (4)	
70+ years	20% (13)	-		
Tumour site	Oral	36% (24)	33% (5)	0.76
	Oro-pharyngeal	45% (30)	40% (6)	
	Laryngeal	18% (12)	27% (4)	
Clinical stage**	Early12	55% (36)	53% (8)	>0.99
	Late34	45% (30)	47% (7)	
Primary Treatment	Surgery only	59% (39)	67% (10)	0.86
	Surgery + RT	17% (11)	13% (2)	
	RT/CRT only	24% (16)	20% (3)	
First PCI Completed	Aintree Univ Hosp	74% (49)	53% (8)	0.13
	Elsewhere	26% (17)	47% (7)	
Year of diagnosis	2010-2011	58% (38)	20% (3)	0.01
	2012-2013	42% (28)	80% (12)	
Months from diagnosis to first PCI	Median (IQR)	18 (12-24)	11 (7-15)	0.02
	< 12 months	24% (15)	60% (9)	0.02
	12-23 months	55% (34)	20% (3)	
	24+ months	21% (13)	20% (3)	
	Not known	(4)	-	

\*Fishers exact test or chi-squared comparing groups for categorical data as appropriate; Mann-Whitney test between 'Yes' and 'No' for age in years and months from diagnosis to first PCI.

\*\* three ('Yes':1, 'No':2) with late staging for quota sampling recruitment purposes were later reclassified as being early staging.

Table 2. Initial PCI results (number of items selected by domain) of initial recruits (n=81) by whether they subsequently participated in the interview process.

	Participated?						P value*	All initial PCI (n=77/81)		
	Yes (N=63/66)			No (n=14/15)				%1 or more	Mean	Median (IQR)
	%1 or more	Mean	Median (IQR)	%1 or more	Mean	Median (IQR)				
Physical and functional well-being	83% (52)	4.51	4 (1-7)	79% (11)	4.50	3 (1-8)	0.48	82% (63)	4.51	4 (1-7)
Treatment related	22% (14)	0.24	0 (0-0)	14% (2)	0.21	0 (0-0)	0.59	21% (16)	0.23	0 (0-0)
Social care and social well-being	16% (10)	0.29	0 (0-0)	29% (4)	0.71	0 (0-1)	0.25	18% (14)	0.36	0 (0-0)
Psychological emotional and spiritual well-being	62% (39)	1.17	1 (0-2)	50% (7)	1.36	1 (0-2)	0.54	60% (46)	1.21	1 (0-2)
Total number of PCI items selected for discussion during consultation	87% (55)	6.21	5 (2-8)	93% (13)	6.79	3 (2-9)	0.42	88% (68)	6.31	5 (2-8)
Total number of PCI health professionals selected to see or be referred on to	24% (15)	0.43	0 (0-0)	29% (4)	1.14	0 (0-1)	0.58	25% (19)	0.56	0 (0-1)

\*Mann-Whitney test

Table 3. Initial PCI results (individual items selected) of initial recruits by whether they subsequently participated in the interview process.

	Participated?		All initial PCI (n=77/81)
	Yes (N=63/66)	No (n=14/15)	
<b>Physical and functional well-being</b>			
Activity	8% (5)	-	6% (5)
Appetite	14% (9)	14% (2)	14% (11)
Bowel habit (diarrhoea or constipation)	5% (3)	7% (1)	5% (4)
Breathing	5% (3)	14% (2)	6% (5)
Chewing/eating	35% (22)	21% (3)	32% (25)
Coughing	21% (13)	21% (3)	21% (16)
Dental health/teeth	24% (15)	21% (3)	23% (18)
Dry mouth	44% (28)	43% (6)	44% (34)
Energy levels	14% (9)	21% (3)	16% (12)
Fatigue/tiredness	29% (18)	50% (7)	32% (25)
Hearing	19% (12)	7% (1)	17% (13)
Indigestion	8% (5)	7% (1)	8% (6)
Mobility	6% (4)	14% (2)	8% (6)
Mouth opening	13% (8)	14% (2)	13% (10)
Mucus production	24% (15)	21% (3)	23% (18)
Nausea	3% (2)	-	3% (2)
Pain in head and neck	15% (10)	21% (3)	17% (13)
Pain elsewhere	6% (4)	7% (1)	6% (5)
Regurgitation	3% (2)	-	3% (2)
Salivation	30% (19)	7% (1)	26% (20)
Shoulder	22% (14)	21% (3)	22% (17)
Sleeping	17% (11)	14% (2)	17% (13)
Smell	6% (4)	-	5% (4)
Sore mouth	19% (12)	14% (2)	18% (14)
Swallowing	22% (14)	36% (5)	25% (19)
Swelling	5% (3)	21% (3)	8% (6)
Taste	24% (15)	14% (2)	22% (17)
Vomiting/sickness	5% (3)	7% (1)	5% (4)
Weight	3% (2)	7% (1)	4% (3)
<b>Treatment related</b>			
Cancer treatment	16% (10)	14% (2)	16% (12)
Regret about treatment	2% (1)	-	1% (1)
PEG tube	2% (1)	-	1% (1)
Wound healing	5% (3)	7% (1)	5% (4)
<b>Social care and social well-being</b>			
Carer	-	7% (1)	1% (1)
Dependants/children	-	-	-
Financial / benefits	8% (5)	7% (1)	8% (6)
Home care/district nurse support	-	-	-
Lifestyle issues (smoking/alcohol)	5% (3)	7% (1)	5% (4)
Recreation	3% (2)	-	3% (2)
Relationships	3% (2)	7% (1)	4% (3)
Speech/voice/being understood	6% (4)	29% (4)	10% (8)
Support for my family	3% (2)	14% (2)	5% (4)

<b>Psychological emotional and spiritual well-being</b>			
Appearance	8% (5)	14% (2)	9% (7)
Angry	3% (2)	7% (1)	4% (3)
Anxiety	13% (8)	14% (2)	13% (10)
Coping	6% (4)	14% (2)	8% (6)
Depression	11% (7)	14% (2)	12% (9)
Fear of the cancer coming back	49% (31)	43% (6)	48% (37)
Fear of adverse events	3% (2)	-	3% (2)
Intimacy	6% (4)	-	5% (4)
Memory	3% (2)	7% (1)	4% (3)
Mood	10% (6)	7% (1)	9% (7)
Self-esteem	2% (1)	14% (2)	4% (3)
Sexuality	-	-	-
Spiritual /religious aspects	-	-	-
Temperament and personality	3% (2)	-	3% (2)
Anything else*	3% (2)	7% (1)	4% (3)
<b>Health professionals selected</b>			
Audiologist	-	-	-
Chaplain	-	-	-
Clinical nurse specialist	2% (1)	-	1% (1)
Dental hygienist	10% (6)	21% (3)	12% (9)
Dentist	10% (6)	14% (2)	10% (8)
Dietician	2% (1)	-	1% (1)
Nursing staff	-	7% (1)	1% (1)
Occupational therapist	-	7% (1)	1% (1)
Oral rehabilitation team	2% (1)	7% (1)	3% (2)
Physiotherapist	2% (1)	-	1% (1)
Radiotherapist/oncologist	3% (2)	7% (1)	4% (3)
Speech and language therapist	6% (4)	21% (3)	9% (7)
Social worker	-	7% (1)	1% (1)
Surgeon	3% (2)	14% (2)	5% (4)
Family doctor	3% (2)	-	3% (2)
Clinical psychologist	-	-	-
Emotional support therapist	-	7% (1)	1% (1)
Financial advisor	2% (1)	-	1% (1)
Anyone else	-	-	-

\*Yes: muscle aching, cardio rehab. 'No': Haemoglobin Levels

Fishers Exact test: p=0.03 (Speech/voice/being understood), p=0.07 (Swelling), p=0.08 (Self-esteem), otherwise p>0.10 for all other items.



Table 4. Response to closed interview questions (n=66)

1. In readiness for telephone survey have you received blank versions of both the Head & Neck-Patient Concerns Inventory and the Patient Concerns Checklist?	Yes: 89% (59)	No: 3% (2)	Not sure: 8% (5)		
2. Were you able to find time to complete both the blank Patient Concerns Inventory and Patient Concerns Checklist before this interview?	Yes: 67% (44)	No: 32% (21)	Not sure: 2% (1)		
3. How many times did you complete the Patient Concerns Inventory as part of the clinic review?	Once: 21% (14)	Twice: 27% (18)	Three or more: 39% (26)	Can't remember: 12% (8)	
4. Did you complete the Patient Concerns Inventory either on computer, on paper, or both?	Computer: 18% (12)	Paper: 39% (26)	Both: 35% (23)	Can't remember: 8% (5)	
5. Overall how easy was it for you to complete the Patient Concerns Inventory?	Very easy: 44% (29)	Easy: 44% (29)	Neither easy nor difficult: 6% (4)	Difficult: 5% (3)	Very difficult: 2% (1)
6. Were there any specific items on the Patients Concerns Inventory that gave you problems when completing it?	Yes: 11% (7)	No: 85% (56)	Not sure: 5% (3)		
7. Did the Patient Concerns Inventory cause a problem in the running of your appointment?	Not at all: 94% (61)	A little: 5% (3)	Somewhat: 0% (0)	A great deal: 0% (0)	Not sure: 2% (1)
8. Do you feel that the Patient Concerns Inventory items you ticked were talked about and included in your consultations?	All: 30% (19)	Most: 38% (24)	Some: 9% (6) Few: 3% (2)	None: 14% (9)	Not sure: 6% (4)
9. How much of a difference do you think the Patient Concerns Inventory made to your clinic appointment?	Much better: 9% (6)	Better: 38% (25)	No difference: 43% (28)	Worse/Much worse: 0% (0)	Not sure: 9% (6)
10. Were there some issues that you wanted to tick or did tick but the clinic appointment was not the right time or place to talk about the issue(s)?	Definitely yes: 5% (3)	Maybe yes: 6% (4)	Not sure: 22% (14)	Maybe not: 12% (8)	Definitely not: 55% (36)
11. At your Patient Concerns Inventory consultation which doctor did you tend to see? (note multiple answers possible)	Consultant oncologist: 20% (13)	Consultant surgeon: 79% (52)	Other doctor: 11% (7)	Not sure: 3% (2)	
12. Do you feel that the Patient Concerns Inventory was something the doctor found useful?	Definitely yes: 25% (16)	Maybe yes: 25% (16)	Not sure: 46% (30)	Maybe not: 2% (1)	Definitely not: 3% (2)
13. Do you feel that the Patient Concerns Inventory helped you communicate with the doctor?	Definitely yes: 45% (29)	Maybe yes: 22% (14)	Not sure: 23% (15)	Maybe not: 3% (2)	Definitely not: 8% (5)
14. Do you feel that the Patient Concerns Inventory items triggered any additional support that you otherwise would not have got?	Definitely yes: 20% (13)	Maybe yes: 8% (5)	Not sure: 26% (17)	Maybe not: 14% (9)	Definitely not: 33% (22)
15. Would you have liked to have been seen by or have been referred on to any other people?	Definitely yes: 22% (14)	Maybe yes: 3% (2)	Not sure: 15% (10)	Maybe not: 6% (4)	Definitely not: 54% (35)
16. Would this be in addition to your surgeon, oncologist, other doctor? (N=16 denominator of those responding 'definitely yes' or 'maybe yes' to question 15)	Definitely yes: 9/16	Maybe yes: 1/16	Not sure: 2/16	Maybe not: 0/16 Definitely not: 0/16	No answer given: 4/16
17. Do you feel that using the Patient Concerns Inventory raised your expectations around what to expect from the clinic and consultation?	Definitely yes: 25% (16)	Maybe yes: 22% (14)	Not sure: 22% (14)	Maybe not: 8% (5)	Definitely not: 25% (16)
18. Do you feel that using the Patient Concerns Inventory raised your expectations and then led to disappointment if these were not met adequately?	Definitely yes: 8% (5)	Maybe yes: 5% (3)	Not sure: 9% (6)	Maybe not: 8% (5)	Definitely not: 71% (47)

19. Would you like to continue using the Patient Concerns Inventory type approach in clinic consultations?	Definitely yes: 58% (38)	Maybe yes: 17% (11)	Not sure: 17% (11)	Maybe not: 3% (2)	Definitely not: 5% (3)
20. Would you find it useful to fill in the Patient Concerns Inventory at home via the internet?	Definitely yes: 28% (18)	Maybe yes: 9% (6)	Not sure: 9% (6)	Maybe not: 8% (5)	Definitely not: 46% (30)
21. Do you feel that the Patient Concerns Inventory web-based type of approach could reduce the number and frequency of clinic appointments?	Definitely yes: 9% (6)	Maybe yes: 14% (9)	Not sure: 33% (22)	Maybe not: 12% (8)	Definitely not: 32% (21)
22. If the frequency of clinics was reduced by using something like the Patient Concerns Inventory for you would that be a helpful or unhelpful for you?	Definitely helpful: 15% (10)	Maybe Helpful: 14% (9)	Not sure: 21% (14)	Maybe Unhelpful: 20% (13)	Definitely Unhelpful: 30% (20)
23. If the Patient Concerns Inventory type approach leads to fewer visits to the hospital and more support locally how much of a difference would this make to you in terms of the financial cost to you during cancer follow-up?	A great deal: 18% (12)	Somewhat: 9% (6)	A little: 25% (16)	None at all: 37% (24)	Not sure: 11% (7)
24. How does the Patient Concerns Inventory (PCI) compare to the Patient Concerns Checklist (PCC)?  Q24 responses for those where Q1=Yes, i.e 59 patients sure they had received blank versions of both PCI and PCC in readiness for the interview  Q24 responses for those where Q2= Yes, i.e 44 patients who had found time to complete both the PCI and PCC before the interview	PCI much better: 16% (10)  PCI much better: 16% (9)  PCI much better: 17% (7)	PCI better: 13% (8)  PCI better: 14% (8)  PCI better: 17% (7)	Little difference: 21% (13) Not sure: 27% (17) Little difference: 23% (13) Not sure: 23% (13) Little difference: 19% (8) Not sure: 24% (10)	PCC better: 16% (10)  PCC better: 18% (10)  PCC better: 17% (7)	PCC Much better: 8% (5)  PCC Much better: 7% (4)  PCC Much better: 7% (3)
26. On a more general note are there any ways that the clinic experience could have been made any better for you?	Yes: 17% (11)	No: 83% (55)			

Very occasionally there was no response given or the question was not applicable – these have not been included in the table and the row totals reflect this.

Table 5. Would patients definitely like to continue using the PCI type approach in clinic consultations?

		Would definitely like to continue using the PCI	P value*
Sex	Male	68% (30/44)	0.03
	Female	38% (8/21)	
	<60 years	57% (12/21)	0.007
	60-69 years	74% (23/31)	
70+ years	23% (3/13)		
Tumour site	Oral	38% (9/24)	0.03
	Oro-pharyngeal	72% (21/29)	
	Laryngeal	67% (8/12)	
Clinical stage**	Early <sup>12</sup>	47% (17/36)	0.05
	Late <sup>34</sup>	72% (21/29)	
Primary Treatment	Surgery only	58% (22/38)	0.86
	Surgery + RT	55% (6/11)	
	RT/CRT only	63% (10/16)	
First PCI Completed	Aintree Univ Hosp	56% (27/48)	0.58
	Elsewhere	65% (11/17)	
Year of diagnosis	2010-2011	54% (20/37)	0.45
	2012-2013	64% (18/28)	
Months from diagnosis to first PCI	< 12 months	60% (9/15)	0.91
	12-23 months	61% (20/33)	
	24+ months	54% (7/13)	

\*Fishers exact test or chi-squared comparing groups for categorical data as appropriate.

Table 6. Initial PCI results (any item selected by domain) by whether patients would definitely like to continue using the PCI type approach in clinic consultations

<b>1 or more item selected from the following:</b>		Would definitely like to continue using the PCI	P value*
Physical and functional well-being domain	Yes	61% (31/51)	0.74
	No	55% (6/11)	
Treatment related domain	Yes	79% (11/14)	0.13
	No	54% (26/48)	
Social care and social well-being domain	Yes	80% (8/10)	0.18
	No	56% (29/52)	
Psychological emotional and spiritual well-being domain	Yes	55% (21/38)	0.43
	No	67% (16/24)	
Total number of concern items selected (range 0-57)	0	63% (5/8)	0.24
	1-4	59% (10/17)	
	5-9	48% (12/25)	
	≥10	83% (10/12)	
Health professionals to see or be referred on to	Yes	73% (11/15)	0.25
	No	55% (26/47)	

\*Fishers exact test, apart from chi-squared test for total number of concern items selected

Table 7. Initial PCI results (10 most frequent items selected) by whether patients would definitely like to continue using the PCI type approach in clinic consultations

	Item selected	Would definitely like to continue using the PCI	P value*
Fear of recurrence	No	59% (19/32)	0.99
	Yes	60% (18/30)	
Dry mouth	No	57% (20/35)	0.80
	Yes	63% (17/27)	
Chewing / eating	No	60% (24/40)	0.99
	Yes	59% (13/22)	
Salivation	No	58% (25/43)	0.78
	Yes	63% (12/19)	
Fatigue / tiredness	No	53% (24/45)	0.15
	Yes	76% (13/17)	
Dental health / teeth	No	60% (28/47)	0.99
	Yes	60% (9/15)	
Mucus production	No	62% (29/47)	0.76
	Yes	53% (8/15)	
Taste	No	60% (28/47)	0.99
	Yes	60% (9/15)	
Swallowing	No	60% (29/48)	0.99
	Yes	57% (8/14)	
Coughing	No	65% (32/49)	0.11
	Yes	39% (5/13)	

\*Fishers exact test

## Appendix 1 The patient and staff interview questionnaires

### A. Patient survey

These are the questions I will be asking during the telephone interview if you could please read over them before hand it would be helpful.

1. In readiness for telephone survey have you received a blank versions of both the Head & Neck-Patient Concerns Inventory and the Patient Concerns Checklist?

Yes  No  Not Sure

2. Were you able to find time to complete both the blank Patient Concerns Inventory and Patient Concerns Checklist before this interview?

Yes  No  Not Sure

3. How many times did you complete the Patient Concerns Inventory as part of the clinic review?

0  1  2  3  more than 3  Can't remember

4. Did you complete the Patient Concerns Inventory either on computer, on paper, or both?

Computer only  Paper only  Both  Can't remember

If both which did you prefer and why

5. Overall how easy was it for you to complete the Patient Concerns Inventory?

Very easy  Easy  Neither easy nor difficult  Difficult  Very difficult

If difficult or very difficult why was that?

6. Were there any specific items on the Patients Concerns Inventory that gave you problems when completing it?

Yes  No  Not Sure

Why was that?

7. Did the Patient Concerns Inventory cause a problem in the running of your appointment?

Not at all  A little  Somewhat  A great deal  Not Sure

If somewhat or a great deal why was that?

8. Do you feel that the Patient Concerns Inventory items you ticked were talked about and included in your consultations?

All  Most  Some  A few  None  Not sure

If a some, a few or none why do you think that was?

9. How much of a difference do you think the Patient Concerns Inventory made to your clinic appointment?

Much better  Better  No difference  Worse  Much worse  Not sure

If better or much better why was please give a reason for your response

If worse or much worse why was please give a reason for your response

10. Were there some issues that you wanted to tick or did tick but the clinic appointment was not the right time or place to talk about the issue(s)?

Definitely yes  Maybe yes  Not sure  Maybe not  Definitely not

If definitely yes or Maybe yes why that was?

11. At your Patient Concerns Inventory consultation which doctor did you tend to see?

Consultant oncologist  Consultant surgeon  Other doctor  Not sure

12. Do you feel that the Patient Concerns Inventory was something the doctor found useful?

Definitely yes  Maybe yes  Maybe not  Definitely not  Not sure

If definitely yes or Maybe yes why that please give a reason for your response

If Maybe not or definitely not why was please give a reason for your response

13. Do you feel that the Patient Concerns Inventory helped you communicate with the doctor?

Definitely yes  Maybe yes  Maybe not  Definitely not  Not sure

If definitely yes or Maybe yes please give a reason for your response

If Maybe not or definitely not please give a reason for your response

14. Do you feel that the Patient Concerns Inventory items triggered any additional support that you otherwise would not have got?

Definitely yes  Maybe yes  Maybe not  Definitely not  Not sure

If definitely yes or Maybe yes please explain what this was?

If Maybe not or definitely not why was additional support not triggered do you think?

15. Would you have liked to have been seen by or have been referred on to any other people?

Definitely yes  Maybe yes  Maybe not  Definitely not  Not sure

If yes or maybe yes please explain who this might be?

16. Would this be in addition to your surgeon/oncologist/other doctor?

Definitely yes  Maybe yes  Maybe not  Definitely not  Not sure

17. Do you feel that using the Patient Concerns Inventory raised your expectations around what to expect from the clinic and consultation?

Definitely yes  Maybe yes  Maybe not  Definitely not  Not sure

If yes please explain why this might be?

18. Do you feel that using the Patient Concerns Inventory raised your expectations and then led to disappointment if these were not met adequately?

Definitely yes  Maybe yes  Maybe not  Definitely not  Not sure

If yes or not sure please explain why this might be?

19. Would you like to continue using the Patient Concerns Inventory type approach in clinic consultations?

Definitely yes  Maybe yes  Maybe not  Definitely not  Not sure

If definitely yes or Maybe yes why that can you give a reason for your answer

If Maybe not or definitely not why that can you give a reason for your answer?

20. Would you find it useful to fill in the Patient Concerns Inventory at home via the internet?

Definitely yes  Maybe yes  Maybe not  Definitely not  Not sure

If definitely yes or Maybe yes can you give a reason for your answer

If Maybe not or definitely not can you give a reason for your answer

21. Do you feel that the Patient Concerns Inventory web-based type of approach could reduce the number and frequency of clinic appointments?

Definitely yes  Maybe yes  Maybe not  Definitely not  Not sure

If definitely yes or Maybe yes why is that?

If Maybe not or definitely not why is that?

22. If the frequency of clinics was reduced by using something like the Patient Concerns Inventory for you would that be a helpful or unhelpful for you?

Definitely helpful  Maybe helpful  Maybe unhelpful  Definitely unhelpful  Not sure

If definitely helpful or Maybe helpful why that is?

If Maybe unhelpful or definitely unhelpful why is that?

23. If the Patient Concerns Inventory type approach leads to fewer visits to the hospital and more support locally how much of a difference would this make to you in terms of the financial cost to you during cancer follow-up?

A great deal  Somewhat  A little  None at all  Not sure

If none at all or a great deal why can you give a reason for your answer

24. How does the Patient Concerns Inventory compare to the Patient Concerns Checklist?

Patient Concerns Inventory much better  Patient Concerns Inventory better

Patient Concerns Checklist better  Patient Concerns Checklist much better  Little difference  Not sure

If Patient Concerns Inventory much better or better why is that?

If Patient Concerns Checklist much better or better why is that?

25. Do you have any other comments about your experience with the Patient Concerns Inventory?

26. On a more general note are there any ways that the clinic experience could have been made any better for you?

Yes  No

If yes please expand

Thank you for your help with this questionnaire.

Is there anything I have missed that you would like to ask me.

## ***B. Staff survey***

1. In readiness for this survey have you received a blank versions of both the H&N-PCI and the Patient Concerns Checklist (Merseyside and Cheshire)?

Yes  No  Not sure

2. Were you able to find time to read and consider both the blank PCI and PCC before this interview?

Yes  No  Not sure

3. How familiar would you say you are with the PCI?

A great deal  A little  Somewhat  Not at all  Not sure

If not at all why was that?

4. Have you used the PCI in clinic?

A great deal  A little  Somewhat  Not at all  Not sure

If not at all why was that?



5. Do you feel that you had enough background / training about the PCI?  
 Definitely yes  Maybe yes  May be not  Definitely not  Not sure   
 If definitely yes or may be yes can you give a reason for your answer  
 If many be not or definitely not can you give a reason for your answer
6. Have patients completed the PCI on computer only, paper, both?  
 Computer only  Paper only  Both  Can't remember   
 If both which did you prefer and why
7. How easy was it for you to include the PCI in the consultation?  
 Very easy  Easy  Neither easy nor difficult  Difficult  Very difficult  Not sure   
 If difficult or very difficult can you give a reason for your answer
8. Did the PCI cause a problem in the running of your clinic?  
 Not at all  A little  Somewhat  A great deal  Not sure   
 If somewhat or a great deal can you give a reason for your answer
9. Do you feel that the PCI items ticked by the patient were discussed/included in the consultations?  
 All  Most  Some  A few  None  Not sure   
 If a few or none why do you think that was?
10. How much of a difference do you think the PCI made to the consultation?  
 Much better  Better  No difference  Worse  Much worse  Not sure   
 If better or much better can you give a reason for your answer  
 If worse or much worse can you give a reason for your answer
11. Were there some issues that you felt that patients should not be encouraged to tick at your clinic appointment ?  
 Definitely yes  Maybe yes  May be not  Definitely not  Not sure   
 If definitely yes or may be yes which ones were these and why?
12. Do you feel that the PCI was something the patient found useful?  
 Definitely yes  Maybe yes  May be not  Definitely not  Not sure   
 If definitely yes or may be yes can you give a reason for your answer  
 If many be not or definitely not can you give a reason for your answer
13. Do you feel that the PCI helped the patient communicate with you?  
 Definitely yes  Maybe yes  May be not  Definitely not  Not sure   
 If definitely yes or maybe yes please explain what this was?  
 If may be not or definitely not please explain what this was?
14. Do you feel that the PCI items triggered any additional support that might otherwise had been missed?  
 Definitely yes  Maybe yes  May be not  Definitely not  Not sure   
 If definitely yes or maybe yes please explain what this was?  
 If many be not or definitely not why was additional support not triggered do you think?
15. Would you like to continue using the PCI type approach in clinic consultations?  
 Definitely yes  Maybe yes  May be not  Definitely not  Not sure   
 If definitely yes or may be yes can you give a reason for your answer  
 If many be not or definitely not can you give a reason for your answer

16. With advances in the internet etc do you think patients would find it useful to fill in the PCI at home via the internet?

Definitely yes  Maybe yes  May be not  Definitely not  Not sure

If definitely yes or may be yes can you give a reason for your answer

If many be not or definitely not can you give a reason for your answer

17. Do you feel that the PCI web-based type of approach could reduce the number and frequency of clinic appointments?

Definitely yes  Maybe yes  May be not  Definitely not  Not sure

If definitely yes or may be yes can you give a reason for your answer

If many be not or definitely not can you give a reason for your answer

18. If the frequency of clinics was reduced by using something like the Patient Concerns Inventory for you would that be a helpful or unhelpful for you?

Definitely helpful  Maybe helpful  Maybe unhelpful  Definitely unhelpful  Not sure

If definitely helpful or Maybe helpful can you give a reason for your answer

If Maybe unhelpful or definitely unhelpful can you give a reason for your answer

19. How does the PCI compare to the Patient Concerns Checklist?

PCI much better  PCI better  PCC better  PCC much better  Little difference  Not sure

If PCI much better or better why is that?

If PCI much better or better why is that?

20. What barriers do you feel there are to the introduction of the PCI?

21. Any other comments about the your experience with the PCI?

Thank you for your help with this questionnaire.

### ***C. Shortened email staff survey***

This comprised questions 3,4,7,8,9,10 and 15 of the above staff interview along with one additional question: "If we are to roll the PCI out across the network as a H&N cancer holistic needs assessment what issues need to be addressed to make this a success? "

## Appendix 2 Patient responses to interview questions

### Q4. Did you complete the Patient Concerns Inventory either on computer, on paper, or both?

Computer: 18% (12)	Paper: 39% (26)	Both: 35% (23)	Can't remember: 8% (5)
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#### If both which did you prefer and why

##### No difference

- I was quite happy to do either and both were as easy as the other to complete.
- To be honest didn't make much difference
- No preference
- both were fine
- Doesn't matter to me but I just can't use a computer. It's alright if the volunteer does it for me, I'll answer to questions to it.
- Doesn't make much difference.

##### Computer

- Computer just its easier you can take your time and let the question sink in. I would rather done it on the laptop.
- Computer one because it was quicker
- Computer was good cause the volunteer was behind me and he does it all just, press this button.
- Computers that's what I work with To be honest with you its probably easier on computer but I don't think the answers you are given to tick box, I don't think there are enough options.

##### Paper

- I find the paper one is easier because my computer runs slow.
- Paper seemed to be easier
- Paper easier to follow
- I prefer the paper one because I could ask the questions while I was doing it.
- Paper think about the questions more

**Q5. Overall how easy was it for you to complete the Patient Concerns Inventory?**

Very easy: 44% (29)	Easy: 44% (29)	Neither easy nor difficult: 6% (4)	Difficult: 5% (3)	Very difficult: 2% (1)
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**5A If difficult or very difficult why was that?**

Difficult	Very difficult
<ul style="list-style-type: none"> <li>• Well some of the things you're asking it doesn't relate to my cancer but I do feel those problems. Talked about another issue that is affecting life - they look after an elderly mother with dementia.</li> <li>• I thought it was quite difficult because the section I wanted to complete wasn't there my concern are anxiety and there's no boxes to tick on that problem I had</li> <li>• Ticking some boxes in case was related to cancer treatment eg I had a back pain I raised it and he said no just take some ibuprofen in two weeks go and see your GP. I was sitting in the waiting area should I bring it up or shouldn't I? But I have got a pain in my back that wasn't there it's reared its head I am thinking could it be connected?</li> </ul>	<ul style="list-style-type: none"> <li>• Brings back memories.</li> </ul>

Other responses given to this question:

- (Easy): I would say because there aren't answers there that you want sometimes. You got to sort of read over it and try to fit yourself into a category.
- (Easy): but there was one or two on the back page that were a bit awkward to fill in.

**Q6. Were there any specific items on the Patients Concerns Inventory that gave you problems when completing it?**

Yes: 11% (7)	No: 85% (56)	Not sure: 5% (3)
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**Why was that?**

- Some of the similarities of the questions. Needing in between bit.
- Different things you can find with these questions, like sore or dry mouth. My mouth is sore at times but it's not sore all the time. It's uncomfortable. When I am eating now it's uncomfortable because I have a tumour taken out of my throat. But not all the time some days are better than others. My tongue lies on me teeth if I chomp down when I am asleep its very sore and raw in the morning. Things like that it's hard to put it all down.
- I put yes because not enough choice in the answers I think. Some of them for instance a sore mouth, sometimes it's not really sore it's more like burning all the time. There is nothing on here can you my particular problem down.
- Yes it was only because I didn't know what it was asking for sometimes.
- Some I didn't want to answer.
- I thought they were confusing because a lot of the symptoms related to may be just after my operation that's the question said. Sometime down the line I don't think they were affecting me. I had different concerns.
- Because there weren't enough options and answers to the questions given

**Q7. Did the Patient Concerns Inventory cause a problem in the running of your appointment?**

Not at all: 94% (61)	A little: 5% (3)	Somewhat: 0% (0)	A great deal: 0% (0)	Not sure: 2% (1)
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**If somewhat or a great deal why was that? – no relevant patients**

Other responses given to this question:

- (A little) One of those got be around when they make the appointment
- (Missing data) Not until this week when I said to you my daughter picking us up and she obviously in work. When someone else is bringing you and going back there is a concern.

**Q8. Do you feel that the Patient Concerns Inventory items you ticked were talked about and included in your consultations?**

All: 30% (19)	Most:38% (24)	Some: 9% (6) Few: 3% (2)	None: 14% (9)	Not sure: 6% (4)
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**if a some, a few or none why do you think that was?**

Some	A few	None
<ul style="list-style-type: none"> <li>Felt that some points were brought up but not all.</li> <li>I am not sure the people have the sheet I filled in.</li> <li>Because certain things I filled in the form have been mentioned during my consultation.</li> <li>I don't to be honest. He talked about a few.</li> <li>I think that the consultant has got his own agenda</li> </ul>	<ul style="list-style-type: none"> <li>I filled in 2 forms at two clinics. One the first thing the doctor said was you filled in an inventory and talk about this it was frank and straight away. I thought that is the right result. Since then it has now escalated I now have a hearing aid. My other option was to go to my GP. The second one I filled in my appointment was about to finish and I told my consultant I said we haven't discussed this and he went 'ah'. It was clipped to the front of my file but he hadn't looked. As it happened there was nothing I really wanted to discuss but he hadn't mentioned it at all and he hadn't looked at it , he wasn't aware of it.</li> <li>Did not have many concerns</li> </ul>	<ul style="list-style-type: none"> <li>Seem to remember putting specific things on it I didn't know whether it was up to me to bring those concerns up but they didn't come up from the consultants mouth</li> <li>Well at this present moment in time I don't think I have any concerns</li> <li>My doctor just wanted to check my throat that was all. The doctor got the questionnaire there had but they didn't seem interested in that, I have got disability sore skin sore and dry mouth, I got all of that.</li> <li>I don't know I mentioned things in the consulting room but they weren't really answered to be honest with you.</li> <li>None because my doctor puts these goggles on looks in the back of my mouth feels the back of my neck and says everything is good and I love that when she says that.</li> </ul>

Other responses given to this question:

- (Most) Most where whatever I asked about or ticked on the paper I was spoken to about.
- (Most)The doctor has what he has to do and then he says has anything been bothering you and you just tell him what you've been thinking. Most of the time if you write it down. Sometimes you think I was going to ask him that and you haven't written it down you've forgotten most it's great.
- (Most)The second time he never mentioned nothing but the first time he did Yeah it was all fine.

**Q9. How much of a difference do you think the Patient Concerns Inventory made to your clinic appointment?**

Much better: 9% (6)	Better: 38% (25)	No difference: 43% (28)	Worse/Much worse: 0% (0)	Not sure: 9% (6)
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**If better or much better why was please give a reason for your response / If worse or much worse why was please give a reason for your response**

<b>Much Better</b>	<b>Better</b>
<ul style="list-style-type: none"> <li>• It was much better because the items were discussed otherwise they wouldn't have been.</li> <li>• Bring able to talk to you about it and fill the forms out that made me think more you know.</li> <li>• I think it was normally you're going in and your mind is not on your think about not what maybe concerning you. Having filled that out your concentration on those points they are immediately to mind</li> <li>• I think everything runs more smoothly, you get a quick consultation. You know the doctors aware of any problems or concerns you may have before you go in.</li> <li>• I think it was much better because the doctor knew what you wanted to talk about before you went in.</li> </ul>	<ul style="list-style-type: none"> <li>• It's helpful for me because it means the consultant is forewarned sort of thing.</li> <li>• He got to know my feelings</li> <li>• Cause it sort of reminds you to bring things up.</li> <li>• Certainly helps its better that you have one of them cause then you know and they know what you want to ask about.</li> <li>• Because it's good to be able to talk about things that concern you. Is it going to come back, has it all gone? If you don't ask the doctor they presume that you know, because they are so busy.</li> <li>• Cause it takes more time off the doctor and take a bit of the weight off the doctor.</li> <li>• It saves time for the consultant and the patient didn't it. I thought it a very good idea myself.</li> <li>• It made it easier</li> <li>• Couple of question I could bring up</li> <li>• put my mind at rest on some concerns</li> <li>• Because it saves time I felt</li> <li>• helped to remind me and focus on important areas to discuss</li> <li>• Doctor knew in advance what I wanted to say.</li> <li>• Help me remember some of the question I wanted to ask to be honest.</li> <li>• Highlighted areas of concern and areas of note for me personally</li> <li>• When I went into the appointment the clinician was aware of what I wanted to talk about and my concerns.</li> </ul>

Other responses given to this question:

- (not sure) We don't talk about it. Just checks me over.
- (not sure) It's hard to evaluate because I didn't have that many issues.
- (no difference) I would go in armed with my note book and my list of questions, I already noted in my questions anyway.
- (no difference) My consultant has always been very thorough if I ask a question he gives me the answer. Not left wondering.
- (no difference) In my experience haven't had any problems.

**Q10. Were there some issues that you wanted to tick or did tick but the clinic appointment was not the right time or place to talk about the issue(s)?**

Definitely yes: 5% (3)	Maybe yes: 6% (4)	Not sure: 22% (14)	Maybe not: 12% (8)	Definitely not: 55% (36)
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**If definitely yes or Maybe yes why that was?**

<b>Definitely yes</b>	<b>Maybe yes</b>
<ul style="list-style-type: none"> <li>• There is one thing is one thing Definitely one thing (unable to understand the word) check list</li> <li>• I thought it was the right time to talk about the problem</li> </ul>	<ul style="list-style-type: none"> <li>• Should treat myself and see GP.</li> <li>• It was the right time and place the right people weren't always necessarily available but the clinic was still the right place to raise the questions.</li> <li>• Well I didn't know what the survey would be about really</li> </ul>

Other responses given to this question:

- (Not sure) Not at this point I might of done early on but not at this point.
- (Not sure) It's one of the questions where I don't really know who to talk to about. I don't know if it's my own doctor in a way I don't know if concerns about the cancer or it could be the transplant basically.
- (Maybe not) Last week I didn't want to do the form because I was too anxious. It was a difficult appointment. Because any concerns I have had I have told my doctor and he can always answer them.
- (Maybe not) But there were one or two things I would like to have discussed but sometimes it asking how is your shoulder well my shoulder has never been touched at all it was my tummy that was my biggest problem because during the operation a muscle was taken from my tummy and bone from my hip. I have explained this but there is nothing can be done to relieve this so that's the issue there really.
- (Missing data) I don't think it's the right place or time to asked about pretty much straight away in some cases anyway because I don't think the consultant is actually specialised on all the areas that are discussed on your sheets.



**Q12. Do you feel that the Patient Concerns Inventory was something the doctor found useful?**

Definitely yes: 25% (16)	Maybe yes: 25% (16)	Not sure: 46% (30)	Maybe not: 2% (1)	Definitely not: 3% (2)
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**If definitely yes or Maybe yes why that please give a reason for your response /If Maybe not or definitely not why was please give a reason for your response**

Definitely yes	Maybe yes	Maybe not	Definitely not
<ul style="list-style-type: none"> <li>Because he knew more about the patient</li> <li>Because he knowing concerns before I went into see him so it saved time.</li> <li>It helping the patients to bring something forward he wants to information on. It helps the doctor as well as the patient.</li> <li>Well he should know how I feel. He must of found it useful because he knew what to ask me about.</li> <li>As I say when you enter the room the consultant whoever it is forewarned about your particular concerns so that why I think it's useful.</li> <li>The more they find out about the patient the better for the hospital and the better for me.</li> </ul>	<ul style="list-style-type: none"> <li>It highlighted straight problem I was having and could discuss it was escalated straight away. Once dismissed and twice ignored, speaks for itself.</li> <li>He certainly referred to it and used it asked me questions based on it so I would say yes.</li> <li>It helped to get the point I thought</li> <li>Everything was covered that we talked about.</li> <li>I think so as doctor knows how I feel now</li> <li>Easier for him to sort of narrow down the areas we need to discuss S: That is good.</li> <li>When I went into my appointment he did refer to it immediately</li> <li>He knew what was bothering me, the anxiety and that he talked about it then. May helped them as well, I don't know.</li> <li>He gets a better picture of the patients mental and physical state and the doctor can see it if there were other concerns that may not been in mind at the time.</li> </ul>	<ul style="list-style-type: none"> <li>You guys told me that he wanted me to do it.</li> </ul>	<ul style="list-style-type: none"> <li>Definitely not to be honest with you he didn't mention it. it wasn't mentioned at all.</li> <li>Not sure really what's he thinking. I did think the doctor ignored it.</li> </ul>

Other ('not sure') responses given to this question :

- He is the only one who can answer that. You need to speak to doctor to answer.
- Not sure about that because it was never discussed with the consultant at all I don't even know if he had the paper work in front of him.
- Well I don't know because I don't know what the doctors attitude is to it so I was going to put maybe yes but I altered it to not sure.

**Q13. Do you feel that the Patient Concerns Inventory helped you communicate with the doctor?**

Definitely yes: 45% (29)	Maybe yes: 22% (14)	Not sure: 23% (15)	Maybe not: 3% (2)	Definitely not: 8% (5)
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**If definitely yes or Maybe yes please give a reason for your response**

Definitely yes	Maybe yes
<ul style="list-style-type: none"> <li>• Because it brought up questions I wanted to ask that's it</li> <li>• It seemed to make me feel more at ease with them as I said before it helped me remember.</li> <li>• Yes it gave me a list well the questionnaire listed everything you could possibly think of and gave you a chance to highlight certain question I did want to ask. Like feeding dry mouth and all other things. It was like a memory tick list to ask the doctor.</li> <li>• I found him very helpful and easy to understand</li> <li>• Oh yes most definitely I find you have time to look through the document and tick off what you what to talk about then they've got in front of them in black and white so you both know what your talking about.</li> <li>• It puts things in your mind and helps you think of things I was going to mention and I was going to mention before I get caught up with the flow and then walk out afterwards thinking I wish I had mentioned.</li> <li>• Highlighted concerns or areas concerning to me</li> <li>• Because he talked about other things apart from what I was seeing them for.</li> <li>• Because you were clear in the problems that were affecting you and you talk about them.</li> <li>• Its sort of makes you feel better. It takes a bit of the pressure off you</li> <li>• I think they open the door for you some people can be reticent about coming forward so think it's helpful yes.</li> <li>• Yeah again the same thing he knew what your concerns where and he could address them without beating round the bush about anything else.</li> <li>• Because I knew what were going to discuss in advance and I already knew what I was going to ask.</li> </ul>	<ul style="list-style-type: none"> <li>• At least I had idea of what he was talking about.</li> <li>• Yes I don't think I had any issues to ask but it would if I had any issues</li> <li>• Well it's a question you ask yourself anyway. It worries you you'd ask him wouldn't you.</li> <li>• May have helped focus</li> <li>• Because I think he knew what I was concerned about and he talked to me about it</li> <li>• It helps to clarify the situation, allows you line up questions you should be asking that's the same for him I don't know.</li> <li>• Well the time allowed is short at each appointment and it helps to make the most of the time available that's what I have written down here.</li> <li>• Because you do think about things and sometimes you think well that's a bit silly and you wouldn't want to bring it up. If it was in the inventory it was good to see it there so you can respond to it. Another words you don't want to be over fussy.</li> <li>• Well I have been seeing for quite a while now so we have built up a relationship so I feel free to talk to him.</li> <li>• Know more about it more about the cancer and know more about what goes on.</li> <li>• Possible it makes yourself a bit more confident going into him because you made yourself more aware of what questions you wanted to ask. Prompted yourself about your concerns.</li> </ul>

**If Maybe not or definitely not please give a reason for your response**

<b>Maybe not</b>	<b>Definitely not</b>
<ul style="list-style-type: none"> <li>I don't feel there is any problem communicating with the consultant because of his manner and approach.</li> </ul>	<ul style="list-style-type: none"> <li>I put definitely not because wasn't aware of him doing that but it would do if I was aware of exactly what I was doing it would be definite help in the future and especially as you were starting off just going there because there is so much going on in your head and so many problems that I have had I could of actually done with that two years ago when I started out.</li> <li>Because when go in to see my doctor I sit down and they ask me how I am doing ,I say I am not too bad. The doctor puts the goggles on looks inside my mouth and moves my tongue a bit looks at the operation they did in my mouth feels the back of my neck and then goes everything is looking good. I have only seen one other consultants once but I don't really like that. I like to see my doctor because they are the one who did it all. They put my mind at ease when they say everything is great.</li> <li>Because I would of done it anyway. I was prepared with my questions. I knew what I wanted to say and I was quite happy to ask the questions.</li> <li>Definitely not but that's not to denigrate that particular item. i have always got on very well with my doctor and our communication always been absolutely brilliant so I don't think whatever anybody introduced could enhance that anyway.</li> <li>My doctor knew nothing about it. The doctor had never seen one and didn't know what was what. There is no communication at all.</li> </ul>

Other ('not sure') responses given to this question:

- I don't know what to give so I have ticked not sure. Basically I don't know what the doctors attitude is. They might find it helpful that I am ticking these forms. I feel that because I have never been a member of St Johns ambulance Brigade or a member of the Red Cross organisation, so therefore I am completely clueless medically or surgically and fortunately I have enjoyed good health.
- They never mentioned anything to me. I am not sure really
- I have always been able to communicate with my consultant they are very easy to talk to.
- Told me it had never been discussed and I explained what was supposed to happen. He told me it hasn't happened that way.
- it didn't help me, did nothing, not sure really. It was at the back of my mind but didn't really help.

**Q14. Do you feel that the Patient Concerns Inventory items triggered any additional support that you otherwise would not have got?**

Definitely yes: 20% (13)	Maybe yes: 8% (5)	Not sure: 26% (17)	Maybe not: 14% (9)	Definitely not: 33% (22)
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**If definitely yes or Maybe yes please explain what this was?**

Definitely yes	Maybe yes
<ul style="list-style-type: none"> <li>• Emotional counselling</li> <li>• Helped me with my weight.</li> <li>• Yes it was like a memory tick box. It listed everything you could possibly think of things that didn't affect me but jogged my memory for things that did.</li> <li>• The same day as my check-up I had a hearing test followed by a further appointment for hearing aids.</li> <li>• There were other people in the room and the minute I came out of the room they came out and spoke to me. We discuss something like my teeth and how to get in touch with the dentist.</li> <li>• In my case I think they would have created other support but I didn't need any if you understand.</li> <li>• Well you know you can sort of go to other people and say instead of talking to the doctor talk to you and sort of working with another type of thing.</li> <li>• To a fashion I would say yes because of the forms I filled in I was sent to see the audiology department because I suffer from deafness and chronic tinnitus and I was also sent to see the speech therapist as I struggle to eat and have a lot of scar tissue on the left hand side which prevents me opening my mouth.</li> <li>• When we were talking I was saying my shoulder has been sore and stiff and he sent me for physio. After the physio we discussed it again. It hasn't really done anything but what he said was because of the scar tissue and it's a big area that been traumatised it going to take a few more years to settle down that's all you need to know. You say fine then. Its information that helps you get on with life.</li> </ul>	<ul style="list-style-type: none"> <li>• Emotional counselling</li> <li>• Yes I think an issue cropped up and I thought oh good I had thought of mentioning that. I cannot remember now it all seems a long time ago.</li> <li>• On the last but one occasion the lady who was the support nurse came out afterwards and had asked me about fatigue which is something I had mentioned on the form but I don't think I had mentioned in the interview so I think it was being read and I think it was being followed up.</li> <li>• Seeing the consultant I have done this inventory and marked the things that are bothering me I felt I was being very well supported.</li> </ul>

**If Maybe not or definitely not why was additional support not triggered do you think?**

Maybe not	Definitely not
<ul style="list-style-type: none"> <li>• I don't think when I fill these forms out and had them back to you I am not sure where they went from there. Do they go to the doctor. Do they go to his secretary. I am not sure of the process I fill a form in give it back to you where does it go then?. I have notice no difference in the doctors treatment of me at all. I see another doctor I have not complaints what so ever he's informative, he's polite, he very very nice and caring doctor. The other doctor I don't think there is any connection between me and him. I am there he sees me and I go out of the door, I think my file goes back into the pack and you know there is no connection.</li> <li>• Highlight things. Memory stuff</li> <li>• Specialist nurse go between, she is good. Being able to call the specialist nurse for support.</li> <li>• Well I didn't need any additional support really.</li> <li>• Because I have had illness for a long time and I am over the worst of it now I think.</li> <li>• All my concerns have bee discussed already before hand</li> <li>• Cause to be honest with you I didn't need any additional support I thought I was getting everything I needed at the clinical consultation.</li> </ul>	<ul style="list-style-type: none"> <li>• No definitely not I have not heard from anybody else or seen anybody else only the specialist nurse who I do see when I go the consultant. I don't think it helped in that way.</li> <li>• Nothing different form when I started. It been all the same just a check over and see you in 4 months or come back in.</li> <li>• I don't feel I need additional support</li> <li>• I have had any additional support</li> <li>• I think I got everything I needed from my appointment</li> <li>• The doctor wanted to see the dentist</li> <li>• My consultant didn't seem bothered when I mentioned those things.</li> <li>• Because I didn't ask and I won't because "I am an independent old sod!"</li> <li>• No I personally did not need any additional support but I am sure if I had done it would have ben helpful.</li> <li>• I hadn't a clue of what was available and when I look at all this I think oh cricky it might of been something I could of used then.</li> <li>• It wasn't triggered by the PCI, it would have happened anyway because I would have asked the questions and looked for the support.</li> </ul>

Other ('not sure') responses given to this question:

- Because I honestly don't know.
- All do is be myself. I don't take anything else into consideration so I am not sure how that works for me.
- I have had all the support I need. I don't know by filling one of these in whether it's given me any different. Support and help I have had has been good all along.
- Not sure really because they are fine.
- I don't really need any other support from what I ask about and I am quite happy with the way I am going along. I have had not real other issues to ask about.
- I could of asked or said what was wrong hopefully he would have referred me to someone else.

**Q15. Would you have liked to have been seen by or have been referred on to any other people?**

Definitely yes: 22% (14)	Maybe yes: 3% (2)	Not sure: 15% (10)	Maybe not: 6% (4)	Definitely not: 54% (35)
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**If yes or maybe yes please explain who this might be?**

<b>Definitely yes</b>	<b>Maybe yes</b>
<ul style="list-style-type: none"> <li>• I haven't seen the Clatterbridge, can't remember seeing the doctor at Clatterbridge after the radiotherapy finished</li> <li>• Would like to see the dentist</li> <li>• Early on in the treatment but not at this stage.</li> <li>• Dentist? Dry mouth. Somebody who can help with a dry mouth syndrome taste swallowing, someone who could advise or give me information that would improve it.</li> <li>• I have been</li> <li>• But that was dentals but I have done that all myself anyway</li> <li>• Already had session with a psychologist</li> <li>• I would like to have seen the dentist more</li> <li>• Speech Therapist and Audiologist</li> <li>• They sent me to Speech Therapist prior to radiotherapy. As I was having treatment I saw them and they checked me out. I would say definitely yes because when things change when you go through your treatment.</li> </ul>	<ul style="list-style-type: none"> <li>• Consultant or surgeon</li> <li>• Consultant arranged appointments and help sort out various appointments</li> </ul>

**Q17. Do you feel that using the Patient Concerns Inventory raised your expectations around what to expect from the clinic and consultation?**

Definitely yes: 25% (16)	Maybe yes: 22% (14)	Not sure: 22% (14)	Maybe not: 8% (5)	Definitely not: 25% (16)
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**If yes please explain why this might be?**

Definitely yes	Maybe yes
<ul style="list-style-type: none"> <li>• Because basically it brought up questions that I could ask and as the patient it makes me feel better with having gone through a life threatening illness</li> <li>• Know more about it what to expect</li> <li>• Yes it made it seem as if people cared a bit more of what was going on.</li> <li>• You feel part of the procedure not just the patient if you understand, you are aware of what's happening and why. The more information you get the better it make you understand what's happening.</li> <li>• Again it's there in black and white for myself as a patient the doctors and any third party pen pushers. It's good for everyone to see in black and white.</li> <li>• It's just common sense. It's very easy to forget to ask something that at the back of your mind you get the form which empty your memory and the doctors are pretty good and they will response. It's a positive thing.</li> <li>• I don't know I just felt better because I could talk to them about it.</li> <li>• I'd come to the hospital and talk about what questions I would ask on route or just as we left the house. By the time you get into your consultant I forget them. So having the paper work in front of me, knowing what I said and know he got the same questions that I want to ask it helps an awful lot.</li> <li>• Everything just runs smoother its quicker you can ask for help if you need any. I just think everything is just smoother.</li> <li>• It makes you think clear and makes you thank about your concerns and problems.</li> </ul>	<ul style="list-style-type: none"> <li>• Expected to discuss my concerns but it didn't always happen.</li> <li>• Well when you go to the doctor you talk about things anyway so not really sure it would have been that beneficial so maybe yes.</li> <li>• Didn't know all these services where available and part of regular treatment.</li> <li>• Filling in the questionnaire in prior to entering into consultation I don't know why but myself I feel more positive about the consultation because my consultant has been forewarned about your concerns.</li> <li>• The fact that everybody is there and they are asking about you and your concerns because someone is looking after your welfare.</li> <li>• A direct example is I did raise the issue of fatigue, I was advised to go for blood test but off the back of that proved all clear but that lead to something else being found none serious but that lead to that being cleared up as well.</li> <li>• Because it gives me time to think about things you can mark what you need to ask your consultant about before you go into see him so think its good preparation really.</li> <li>• I would say maybe yes as the information goes to the GP, it's for him to action or ignore or just pass it to someone else I don't know.</li> <li>• Never had an appointment without a PCI</li> </ul>

**Q18. Do you feel that using the Patient Concerns Inventory raised your expectations and then led to disappointment if these were not met adequately?**

Definitely yes: 8% (5)	Maybe yes: 5% (3)	Not sure: 9% (6)	Maybe not: 8% (5)	Definitely not: 71% (47)
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**If yes or not sure please explain why this might be?**

<b>Definitely yes</b>	<b>Maybe yes</b>	<b>Not sure</b>
<ul style="list-style-type: none"> <li>I was expecting a bit more because it was something new something being trailed you'd think people would embrace it and drive it forward but there was nothing. It was if filling a bit of paper and you were just putting it in the bin.</li> <li>Form lost or not interested.</li> <li>No I thought everything was fine .I didn't feel disappointed nor let down.</li> <li>It gives me more information of the journey I am on that's basically it.</li> </ul>	<ul style="list-style-type: none"> <li>Because as I said it could make you a bit more confident going into the consultation because it prompted you and reminded you of the questions you wanted to ask but if you don't have confidence then to bring them up in the consultation leave it up to the consultant to so the obviously that's a disappointment. I have never had any great concerns things I am not really bothered about bringing up anyway.</li> <li>Again I go back to the factg that my Doctor is a surgeon I don't' know if it falls within his criteria to address my problems or to pass them onto someone else. In on instance my doctor wasn't available and I saw another doctor who listened to what I was saying understood I had problems with my mouth and he prescribed medication for my mouth and medication for the scarring which helped. But as I say my Doctor seems to be focussed on surgical aspect of my treatment and not the after care. He's done his job and just makes sure it worked out as he expected and that's it.</li> <li>Maybe yes because I still haven't seen a dentist even though it was talked about, nothing has been arranged for me to see a dentist</li> </ul>	<ul style="list-style-type: none"> <li>Because I saw my consultant that was all and my consultant is only concerned about my throat. When I say I get very breathless and I can't walk very far and I have got this good cough they are not concerned.</li> </ul>



**Q19. Would you like to continue using the Patient Concerns Inventory type approach in clinic consultations?**

Definitely yes: 58% (38)	Maybe yes: 17% (11)	Not sure: 17% (11)	Maybe not: 3% (2)	Definitely not: 5% (3)
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**If definitely yes or Maybe yes why that can you give a reason for your answer?**

Definitely yes	Maybe yes
<ul style="list-style-type: none"> <li>• I feel it helps to answer questions you tend to forget. It's a reminder of what you want to ask mostly. I felt it was very good</li> <li>• Save time for both parties doesn't it. I thought so anyway.</li> <li>• I think it's good to consult with people on how your feeling at the time</li> <li>• I think it was a very good idea. We all have worries and that my not be nothing worrying about and if your told no its ok you must expect this.</li> <li>• It gives me an opportunity if I have any problems to make sure they are actually addressed when I go into see the consultant or doctor.</li> <li>• I am sure if it hasn't helped me it must be able to help other people</li> <li>• You give it into the doctor and issues are sort of seen to straight away.</li> <li>• Not a problem to fill out and if it can help then that's fine.</li> <li>• It doesn't impede anything and it helps you think about things before you go in that's honestly what it does for me.</li> <li>• Never had an appointment without one so I don't know what its like not to have a PCI</li> <li>• Just very helpful gives you confidence and you go in relaxed.</li> <li>• I just get muddled up and the questions I want to ask I can't think of straight away at the time, I come out and I should have asked him that. It's too late then because it's gone. That's why it's a definite yes to that.</li> <li>• Again in the doctors more aware before you go in of what concerns you might have and address them quicker.</li> <li>• I think it's a very good medium for both the patient and doctor.</li> <li>• Helps you to speak to different people for help.</li> <li>• Ticking a box is easy to find the right time to speak up isn't always. You just don't want to interrupt him, so he is the expert he is and you're just the patient. It's finding the right time to introduce it without being rude.</li> </ul>	<ul style="list-style-type: none"> <li>• It reminds me what to aske when you get there and when you come out you think meant to ask such a thing.</li> <li>• It just depends on how long it all goes on and how much time it takes on the day of my appointment</li> <li>• Yes I didn't have it when I was first at the clinic and I think it would have been very useful then. Now my condition is stable it's of far much less use.</li> <li>• Only had one consultation using the PCI so I am not sure.</li> <li>• I have had nothing to complain about</li> <li>• I suppose it does help to clarify you line up your thoughts more so maybe yes.</li> <li>• So everybody knows what is available.</li> <li>• Not inconvenient at all and potentially helpful</li> <li>• Because it should make more satisfactory appointment. I think sometimes you go into a consultation and you have these questions running around in your head before you go in and when you go in you forget all about them and I think if there was something prompting you and something structured there then it should really help both people in the consultation.</li> </ul>

**If Maybe not or definitely not why that can you give a reason for your answer?**

Maybe not	Definitely not
<ul style="list-style-type: none"> <li>• Can speak to surgeon or his receptionist any time if I have any concerns</li> <li>• Because I have covered most things with my consultant and am only going now for six months appointments so everything seems to be in order.</li> </ul>	<ul style="list-style-type: none"> <li>• I don't think its doing me much good.</li> <li>• I didn't make any difference to me what so ever it hasn't for me up to now let's put it that way.</li> <li>• Definitely not in my case. It hasn't made any difference to me because I know what I am going to ask and he has given me the answers. I don't know if it has been helpful to the consultant.</li> <li>•</li> </ul>

Other ('not sure') responses given to this question:

- I think it's good. It would be good I think there are certain things that the consultants got his job, he is a consultant. He is a specialist in that one particular massive massive area and I think if you were taken off to one side with a head and neck whatever kinda of nurse and sat down and given the opportunity to go through things, I think that would give you better support from day one. It would give you better support and it would give you them contacts that you need to keep you mentally stable you could say because you just feel like you're on your own. There are groups out there and there are specialist out there that I found out 18 months up the line when I came to see you. Why on earth that wasn't given to me initially and you know I got a card saying if you got any problems or you want to talk about anything just give me a call. You don't want that because you go home you know you want something on a 2 monthly or 4 weekly ever frequently you're going to see your consultant. It would be nice to click a button and someone to give you airing and say I believe you want to speak to me about tis or I need to speak to you about that something in private because you're sitting in front of the consultant your nervous and all you want to do is have a laugh and a joke, him to say it's not grown back and you get off home. whereas if you can get into a room click a couple of buttons and the people actually respond to you then I think going forward that would be a good idea.
- It is helpful to highlight concerns but then discussed the appointments are quite rushed. If they worked and were actually talked about, yes, but they weren't talked about. I saw three different doctors and it was never mentioned.
- I am not sure because I don't feel like I get a lot out of it. As I say I would have asked those questions I ticked off on the inventory. I would have asked them because I had them written down on piece of paper. I write things down as I think about them things I want to ask. So I don't it's helped me to be honest.
- I am not sure I don't know how it all works what's behind it all I suppose it to help.

**Q20. Would you find it useful to fill in the Patient Concerns Inventory at home via the internet?**

Definitely yes: 28% (18)	Maybe yes: 9% (6)	Not sure: 9% (6)	Maybe not: 8% (5)	Definitely not: 46% (30)
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**If definitely yes or Maybe yes can you give a reason for your answer/If Maybe not or definitely not can you give a reason for your answer**

<b>Definitely yes</b>	<b>Maybe yes</b>	<b>Maybe not</b>	<b>Definitely not</b>
<ul style="list-style-type: none"> <li>• Yes probably I would do it on the computer.</li> <li>• It saves what we are doing now you could a lot more direct time availability and cost is nothing.</li> <li>• Just easier I can do it without thinking I need to be here or there. I can do it in my own time.</li> <li>• Particular if I get a reminder by email or something, it probably I am more likely to do if left to do it on paper particularly if I have to find the bits of paper in the first place. It's just a little more convenient because I am on line everyday anyway so just makes it a little more accessible.</li> <li>• It would save time at the appointment. I don't see any reason why you would have to do it there if you can do it at home</li> <li>• It's easier. I would do it at home</li> <li>• To me it would be useful. The internet is a pass time for me.</li> <li>• More time to think about the questions and how you really feel about the answer</li> </ul>	<ul style="list-style-type: none"> <li>• My computer is slow</li> <li>• It easier to do it at home rather than having somebody, a member of staff, looking over your shoulder while you're doing it. It's just a more relaxed way of doing it.</li> <li>• If I was to spend a bit more time at the hospital whether I do at the hospital or home doesn't make much difference.</li> <li>• no answer given</li> <li>• Sit down with my daughter and talk to her about it.</li> <li>• If you had sent to me it would have been a problem. But I suppose not everyone especially older people wouldn't have the internet would they?</li> </ul>	<ul style="list-style-type: none"> <li>• If it was on the internet I don't think I'd get round to doing it because I'd think I'll do it later. Laziness on my part I would forget where as if it comes through the post or is in clinic you'd remember</li> <li>• Happy to try it and see whether it was better</li> <li>• I am not very good with the net. I am a total beginner</li> <li>• Maybe I would rather do it as per appointment as an honest evaluation of how I was feeling on that day.</li> </ul>	<ul style="list-style-type: none"> <li>• No not really it can sometimes be a little bit confusing and there are not always the answers you need on the screen</li> <li>• I don't know how to use the internet.</li> <li>• I can't use computer.</li> <li>• No I haven't got the internet.</li> <li>• I am too old for computers</li> <li>• No I am not confident enough on the computer.</li> <li>• I am not on the internet.</li> <li>• The issues rather than fill it in at home it's better to speak to someone before you go in to see the surgeon.</li> </ul>

**Q21. Do you feel that the Patient Concerns Inventory web-based type of approach could reduce the number and frequency of clinic appointments?**

Definitely yes: 9% (6)	Maybe yes: 14% (9)	Not sure: 33% (22)	Maybe not: 12% (8)	Definitely not: 32% (21)
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**If definitely yes or Maybe yes why is that?/If Maybe not or definitely not why is that?**

<b>Definitely yes</b>	<b>Maybe yes</b>	<b>Maybe not</b>	<b>Definitely not</b>
<ul style="list-style-type: none"> <li>• Speeds up appointments</li> <li>• If I could it would be definitely yes. Save jumping on buses or getting lifts or whatever and you can do it in your own time and you're not tied down to certain time are you?</li> <li>• I do find it a pain in the backside trekking all out to Aintree every 3 months it nice when I have been there and been told not concerns and see you in another three months' time but wouldn't it be good if I didn't need to go and see somebody to be told that. That would save me a lot of time, money and give me a way of concentrating on carrying on with my professional life.</li> <li>• I am ticking a box saying I am concerned about the scar</li> </ul>	<ul style="list-style-type: none"> <li>• See my consultant when I have any problems</li> <li>• Because I think it does help to have things sorted before you go in to see your consultant.</li> <li>• I would think so yes Time will tell I suppose time will tell</li> <li>• Possibly, if it means can get in touch with the hospital again and any problems might be he can deal with them there and then.</li> <li>• People on internet may be more helpful for them to do it in the house than travel to hospital.</li> <li>• If they weren't happy they could be seen sooner instead of waiting 6 months and worrying about it.</li> <li>• The doctor or consultant would know if there was a big problem and call the patient in.</li> </ul>	<ul style="list-style-type: none"> <li>• I can't see using a computer would make any difference.</li> <li>• Again lack of home access and I do like face to face access.</li> <li>• Although I have been clear for a couple of years I personally need the assurance of someone physically look at me so I would want to continue.</li> <li>• It gives me a lot of confidence to know they still keep an eye on me.</li> <li>• I feel the doctor will know how many appointments I need and making an inventory won't change his mind.</li> <li>• Apart from the fact your being treated there is some form of 1-1 reassurance when you go</li> </ul>	<ul style="list-style-type: none"> <li>• I feel a lot happier after the consultant runs his hand over my neck looks into my throat and tells me it's all clear.</li> <li>• Because of the situation I am in I still have to visit the consultant.</li> <li>• I have a camera down me nose so really no.</li> <li>• No I don't think so because I like to see the doctor. Not talk to a machine.</li> <li>• I don't agree with that one at all because I feel that going to lose contact with people and I am all against computers internet websites and robots. I don't want a locally based clinic to go to I am quite happy to travel 40 minutes to here.</li> <li>• Consultations are important for advice reassurance, information.</li> <li>• I like to see the doctor. I go to see the consultant for a reason</li> </ul>

<p>on my neck and I could get the appropriate appointment with the appropriate people for me to see.</p>			
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**Q22. If the frequency of clinics was reduced by using something like the Patient Concerns Inventory for you would that be a helpful or unhelpful for you?**

Definitely helpful: 15% (10)	Maybe Helpful: 14% (9)	Not sure: 21% (14)	Maybe Unhelpful: 20% (13)	Definitely Unhelpful: 30% (20)
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**If definitely helpful or Maybe helpful why that is? /If Maybe unhelpful or definitely unhelpful why is that?**

Definitely helpful	Maybe helpful	Maybe unhelpful	Definitely unhelpful
<ul style="list-style-type: none"> <li>• Less time spent in hospital wouldn't it.</li> <li>• If saving the doctors time as well as yourself and giving them time for other patients.</li> <li>• Because I would have to come so often.</li> <li>• Exceedingly helpful because its expensive inconvenient time consuming to go there.</li> <li>• As my treatment is going on and the better I am getting yes I would see it as very helpful. Again because I am getting better I tend to try and go out a bit more and my family. Tied to an appointment means can't always do this, say a trip comes up with my grandkids school.</li> </ul>	<ul style="list-style-type: none"> <li>• I think it may be helpful or not sure. I suppose</li> <li>• You should be able to go to the clinic when you need to go</li> <li>• It would be helpful if it was reduced and I was still working so for younger people ideally it disrupt their working life.</li> <li>• Difficult to answer in relation to my condition I need to be seen by a specialist</li> <li>• I don't have a problem going once every 2 months. It's not inconvenient to go to the hospital although at the hospital parking is a bit of an issue at time like. I don't know what to say to that to be fair.</li> </ul>	<ul style="list-style-type: none"> <li>• Already on reduced visits</li> <li>• For me I would rather go to the clinic because then I am assured of what goes on by the doctor or oncologist</li> <li>• Probably unhelpful. I don't want my clinic appointments reduced. I want my clinic appointments to be what they said are supposed to be.</li> <li>• Basically because I like to see people and for them to check that I am ok.</li> <li>• Running in conjunction being examined I think it would work well.</li> <li>• Because I would soon talk face to face or of fill forms in sooner see the Doctor.</li> <li>• Ok about it we don't need to see you. That type of approach would work a</li> </ul>	<ul style="list-style-type: none"> <li>• Oh it would be very unhelpful I like to see my doctors face to face</li> <li>• I feel it wouldn't be helpful to me at all because I have a constant worry the cancer may return so would not wish to see less of the doctor</li> <li>• Because I wouldn't get that reassurance of him physically examining me.</li> <li>• No I'd like to come to clinic as much as they want me</li> <li>• Contact with consultants is of prime importance</li> <li>• Because I would rather see face to face and they could explain it if I don't understand.</li> <li>• It gives me a lot of reassurance to be seen in clinic that everything is still on track</li> <li>• Because you still going to have the same</li> </ul>

		<p>little further down the line.</p> <ul style="list-style-type: none"><li>• Depends on the frequency of the concerns inventory</li></ul>	<p>problems cropping up no matter how many times you go.</p>
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**Q23. If the Patient Concerns Inventory type approach leads to fewer visits to the hospital and more support locally how much of a difference would this make to you in terms of the financial cost to you during cancer follow-up?**

A great deal: 18% (12)	Somewhat: 9% (6)	A little: 25% (16)	None at all: 37% (24)	Not sure: 11% (7)
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**If none at all or a great deal why can you give a reason for your answer**

A great deal	None at all
<ul style="list-style-type: none"> <li>• As things stand at the moment it doesn't make any difference but if I was driving a car it would be very expensive. Locally we have a local hospital. But you know if you're going to see the people you want to see.</li> <li>• Flying over to Liverpool all the time. If I could be seen locally it would greatly reduce the cost on the NHS.</li> <li>• I have had to take a lot of time off work. I have missed an awful lot of work where I have only been in and out in 10 minutes-15minutes yet its cost me a full days work.</li> <li>• 100 mile trip not cheap who would be locally. If work more cost because I would lose money from work.</li> <li>• it would be just more convenient</li> <li>• I have to pay for all my travel expenses and time consuming</li> <li>• It would make a great deal actually coming to Aintree from St Helens.</li> <li>• A great deal just as I said its expensive in terms of fuel in the car lost work opportunities, parking costs etc Anything that can be brought into play that reduces the amount of travelling</li> <li>• It would make a great deal because of the illness I had one of children would have to take time off work to take me or they wanted to because the didn't think I was fit enough. So if you get local support you have less time to travel and less time for them to take off work.</li> </ul>	<ul style="list-style-type: none"> <li>• My daughter brings me</li> <li>• 5 min drive to hospital and back I don't think it's much.</li> <li>• No it wouldn't have it all because the lovely people, I am picked up at home and dropped off at home, its lovely.</li> <li>• I work part time and my appointment is always on my day off. So I don't have to take anytime off work. The only cost is my petrol coming to and from the hospital. Not great cost to me in coming to the appointments.</li> <li>• The peace of mind given by clinic appointment far outweighs the cost of a visit. Clinics give me peace of mind.</li> <li>• Well I am seeing one to one person and for what it costs me to come and do that I don't pay for car parking charges and for the little bit of petrol that I use it won't make any difference to me. Financially I would just say that.</li> <li>• The reason being that I am semi retired and it's not a problem</li> <li>• Support local, I am local anyway.</li> <li>• I just get the bus</li> <li>• Most costs covered by DSS</li> <li>• There is no financial cost because I only live over the road.</li> <li>• Live near Hospital</li> <li>• You wait around have your appointment and by the time you get home at night you're absolutely exhausted. So sometimes we will stay and have a couple of days in Chester. If I feel up to it and that's much better and we pay for that.</li> <li>• I am financially ok.</li> <li>• I am in walking distance to the hospital it's not a financial burden.</li> </ul>



## Q24. How does the Patient Concerns Inventory (PCI) compare to the Patient Concerns Checklist (PCC)?

Restricted to patients who had found time to complete both the PCI and PCC before the interview

PCI much better: 17% (7)	PCI better: 17% (7)	Little difference: 19% (8) Not sure: 24% (10)	PCC better: 17% (7)	PCC Much better: 7% (3)
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**If Patient Concerns Inventory much better or better why is that?/ If Patient Concerns Checklist much better or better why is that?**

PCI much better	PCI better	PCC better	PCC much better
<ul style="list-style-type: none"> <li>• More itemised concerns on it.</li> <li>• If patients concerns inventory much better because it highlights problems more in depth.</li> <li>• More detail</li> <li>• Easier to get through you have to look up and down if you've got short term memory loss like me you'd be going back all the time. I just like thing to be easy to fill in like the PCI</li> <li>• It looks more involved</li> <li>• The above view look in depth more at the subject under concern the checklist whilst being somewhat simplistic is easily understood but does not encourage comments on why or when the concerns occur.</li> <li>• I find it pretty</li> </ul>	<ul style="list-style-type: none"> <li>• It's easier to go down and tick and tick.</li> <li>• Easier to complete</li> <li>• Easier to follow lay out better</li> <li>• Just better with I feel more at ease.</li> <li>• Well with the PCI one I was able to go through it fine but the one with the thermometer some of the questions on that I thought what's that got do with me? PCI is much easier to follow well laid out.</li> <li>• I don't really know it just shows how you're coping or know how you're feeling personally.</li> <li>• But I liked the thermometer on the other one because they give you degrees of how distressed you are or not distressed. There is a level you can tick. I thought that</li> </ul>	<ul style="list-style-type: none"> <li>• Opportunity to express degree of concern or feeling</li> <li>• Because you're just looking at one page. It's just nearly all the basic. Whereas the other one is stretched out. I would say the PCC is more easier to fill in than the other one is.</li> <li>• On the thermometer one I can say it worse or its better.</li> <li>• It seems easier to look at its well set out.</li> <li>• It explains a bit more on the other one seems to an awful lot of things to tick. This is more refined is that the word for it.</li> <li>• It's more explanatory more informative.</li> <li>• The one with the thermometer hits the points very well. It's gives you a</li> </ul>	<ul style="list-style-type: none"> <li>• Because I can say how bad I am. There's only one or two things that concern me really everything is alright.</li> <li>• I don't really find any difference. The only thing I would say is the patient concerns checklist would be a big saving on paper: I would prefer the check list because I'll help save the rain forest you see.</li> <li>• Well the thermometer one was easy to understand the ratings were easy to give you know.</li> <li>• It appears to be much easier to work through</li> </ul>

<p>easy to fill in straight to the point of what it is you want to talk about.</p>	<p>was slightly better.</p> <ul style="list-style-type: none"><li>• Just seemed to be laid out better</li></ul>	<p>quick visual aid straight away that will be an aid to the doctor and patient.</p> <ul style="list-style-type: none"><li>• It just makes it easy doesn't it and it gives you levels what you think.</li></ul>	
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### Appendix 3. Staff responses to interview questions

**KEY : D=Consultant Doctor, N=Specialist Nurse**

All staff interviewed received a blank versions of both the H&N-PCI and the Patient Concerns Checklist (Merseyside and Cheshire) in readiness for the survey. All found time to read and consider both the blank PCI and PCC before this interview.

#### Q3. How familiar would you say you are with the PCI?

A great deal	Somewhat	A Little	Not at all	Not sure
6	2	6	0	0
D:3, N:3	D:1, N:1	D:4, N:2		

#### Q4. Have you used the PCI in clinic?

A great deal	Somewhat	A Little	Not at all	Not sure
3	1	9	1	0
D:2, N:1	N:1	D:5, N:4	N:1	

#### Q5. Do you feel that you had enough background / training about the PCI?

Definitely yes	Maybe yes	Not sure	Maybe not	Definitely not
6	1	0	1	1
D:1, N:5	D:1		D:1	N:1

If definitely yes or may be yes can you give a reason for your answer:

- (D) Oh I have a very good specialist nurse who made sure I was well trained in terms of bringing up concerns
- (D) I was happy with it. Obviously seen it before. I looked it over and I have seen it a few times in Clinic. I am very happy to use it.
- (N) That's because I have information from the team.
- (N) Its all the literature you sent previously and study days and because it's used in the directorate. I feel like I was very familiar with the PCI. What was on it and what the purpose of it was.
- (N) I have been involved with changes over the years with the PCI as well so you get to know it and sort of using either the electronic or paper version as well for patients.
- (N) It was attending the half-day session at Aintree that the PCI in context which was really useful. Then again I attended the quality of life conference and there was a lot of referencing to the PCI. So I was able to and that compounded the learning that had taken place in the half day session and I was also able to discuss it with other people who were using at the conference.
- (N) It was just sent out you came out you explain it all you sent all the paper work so it wasn't a case of your doing this here you go. You'd gone through it and given me

the paper work and things so it was as if. I had the opportunity to ask questions if I didn't understand.

If maybe not or definitely not can you give a reason for your answer:

no comments made

**Q6. Have patients completed the PCI on computer only, paper, both?**

Computer only	Paper only	Both	Can't remember
0	6 D:2, N:4	2 D:1, N:1	0

If both which did you prefer and why

- (N) From a practical point of view to keep the clinic running smoothly the paper. We have had some problems with the electronic version can delay the patient consultation and actually at times the patients are seen. In clinic and that for a lot of patients that's fine but some patients get distressed because they actually feel like they will miss their slot to see the doctor.

**Q7. How easy was it for you to include the PCI in the consultation?**

Very Easy	Easy	Neither easy nor difficult	Difficult	Very difficult
0	7 D:5, N:2	3 D:2, N:1	2 D:1, N:1	0

If difficult or very difficult can you give a reason for your answer:

- (D) Patients using PCI are sometimes drawn away from main clinic waiting area causing them to miss appointment times frustrating!!
- (N) The reason it's difficult is it depends on how many doctors, who those doctors are in clinic, the size of the clinics. Which impacts on the availability of space to have that discussion with the patient.
- (N) At the spoke because it was new on consultant refused to use it, the other consultant did. Getting patients for the study was hard because I was trying to do my role as CNS and doing that part that was difficult. Once it was up and running and I knew the patients it wasn't difficult at all because I could identify the patients on the list. Sometimes I missed them if my previous clinic ran late and that's happened on 2 occasions but other than that once it go up and running I found it not difficult at all.

**Q8. Did the PCI cause a problem in the running of your clinic?**

A great deal	Somewhat	A Little	Not at all	Not sure
0	1 D:1	4 D:3 N:1	6 D:4 N:2	4 D:1 N:3

If somewhat or a great deal can you give a reason for your answer:

- (D) Patients using PCI are sometimes drawn away from main clinic waiting area causing them to miss appointment times frustrating!!

Other comments:

- (D – ‘a little’) I would say it caused a problem but it meant that we probably discussed things we wouldn’t have discussed otherwise which meant time. I am not saying it’s not valuable but it does, the H & N clinic tend to be a "Cattle Market" (not meant in any Derogatory manner) there are huge numbers of patients coming through and obviously you want to address problems but you worry about spending time when maybe you’ve got lots of other patients to see so it’s a balance.
- (N - N/A) I think because it was me doing it obviously you helped me recruit the patients but for it to continue at the spoke it would need a similar system to Aintree that a volunteer would approach the patient because I find it more stressful for me that i am trying to look for patients are coming run out get them to fill it out and put into the notes making sure they go to the appropriate doctor because as I say the oncologist doesn’t want to participate in it so making sure the notes come into the consultant and registrar who are happy to participate in it. but its more the fact that it is becoming my job to do that and I would need to see someone volunteer.
- (N – N/A) I would say initially it did when we started it was mayhem really trying to co-ordinate between identifying those patients that were to go forward for PCI, then trying to get them logistically get them seen by the volunteer, get the information across and also make a timely manner so it didn't mean that would normally be 10-20 minutes clinic consultation was elongated too long for people because of other time commitments but also making sure people are seen as close to their appointment time. There have been a few and that because on those days it’s been short staffed. I know sometimes with some of the staff on the clinic it can be quite confusing they have more pressure on the clinic staff themselves to get the clinic running regularly especially the manager likes everything seam less fashion. Whereas I am sure if we explained to the patients that they maybe called in a different order and this is the reason why that would solve any problems.
- (N – N/A) I think it’s time consuming that’s peoples concern isn't it and I know the argument against that you focus on the things people want to talk about so it becomes more time effective. I thinks it’s about the clinicians want to get involved and look at the wider issues. Just the same as when we are trying to get the CNS to use the Patients Concerns Checklist People who feel that they do a good assessment and that is not necessary don't want to do it.

**Q9. Do you feel that the PCI items ticked by the patient were discussed/included in the consultations?**

All	Most	Some	A few / None	Not sure
4 D:3 N:1	2 D:2	3 D:3	0	4 N:4

If a few or none why do you think that was? – none applicable

Other comments:

- (D – ‘all’) Then the big worry is the patients will come in and tick everything but they didn't they were two or three items ticked.
- (N – ‘N/A’) Because the consultant would go through each one with them so they were all covered.
- (N – ‘N/A’) I think the doctors as in a different way but as what my colleague said there are certain things the doctor want to deal with and certain things they feel it's a team approach not just the doctor in the consultation. That's why they are joint cancer clinics. There are somethings they feel we can deal with and they leave them issues to us which is fine but in the spoke they didn't really tick who they wanted to see because they knew there is only me and the doctors there and speech therapist there is no one. Although you say who would you like to see the patient the to tick the people they know who would be in that clinic at that time. But no they were discussed and included because I think the doctors know it was part of research trail they wanted to help as much as possible, so they were quite keen to help.
- (N – blank for first part of Q9) I would say yes apart from one patient ticked everything I I think it depends on I guess if your looking at the PCI as a whole if your using in a medical consultation there are certain items that our medical colleagues are more comfortable dealing with. There are some items on the PCI they may not have particularly have ticked they want to see the nurse specialist or whatever they are definitely handed over especially around issues of intimacy and sex and things like that. Where the consultants don't feel, I had a gentleman who ticked it the other week obviously it was a big thing, sitting in the consultation he did try and bring it up with the consultant. But the consultant was just putting blocking tactics because I guess he didn't know how to do. We were able to talk about it later so I guess there are some things that some items that the patients will see as medical focussed or others they would ask the nurse specialist or dietician or sometimes it whoever is there that's going to listen.
- (N – ‘not sure’) I am not sure because the consultations where done by the consultant and not me but I do know that some of the patient spoke to me afterwards and things that had come out from looking what their answers where issues had been raised and addressed but that we but that was only third party.
- (N – ‘not sure’) because I wasn't necessarily in the room when they discussed it.

**Q10. How much of a difference do you think the PCI made to the consultation?**

Much Better	Better	No difference	Worse / Much worse	Not sure
3 D:1 N:2	5 D:4, N:1	3 D:3	0	3 N:3

If better or much better can you give a reason for your answer

- (D) Brings patient issues to attention of doctor and allows focus on Patient Concerns
- (D) I think it made a big difference to be honest, we tended to discuss things I wouldn't have asked about otherwise.
- (N) From the patients perspective they had the opportunity to address issue they may not addressed had they not completed the PCI, and from my point of view they would have opportunity to discuss any issues.
- (N) Particularly in the spoke clinic it's so busy and patients want to come in and let the doctor see them to say the cancer has gone that they are ok. They sort of want to know they are cancer free, it sort of like a prompt because when you go into a doctor sometimes you get a bit frustrated or you forget what you want to ask. So there important to them obviously they want to know the cancer has gone but they also want these issues that are concerning them before they walk in so it's a holistic consultation everything has been discussed.
- (N) I personally think its much better overall once you forget the logistics and you look at if for what it's all about empowering the patient really to take ownership in the consultation. I think it really does make a difference and whether its just makes a difference for that day for them and they feel like they have been listen to I think with cancer especially you lose so much control so many aspect of life so actually help the patients maybe reintroduce that control to them is part of their rehabilitation in a way I found it seems to help them. I think it's reduced the number of doorway consultations so they will see the doctor they will walk out with them to make an appointment they will come out with a few things that have obviously been worrying them but they have not felt they could talk about them because they are the lift for the PCI empowers them.

If worse or much worse can you give a reason for your answer – none applicable

Other comments:

- (N – 'not sure') Because I wasn't in the consultation.
- (N – 'not sure') Not sure from my point of view but speaking to my consultant colleagues who had used it had said they like it because it was like I have got this problem that problem the other problem. From one I spoke to he liked it so form my point of view I don't know.

**Q11. Were there some issues that you felt that patients should not be encouraged to tick at your clinic appointment ?**

Definitely yes	Maybe yes	Not sure	May be not	Definitely not
0	2 D:1, N:1	1 D:1	0	5 D:1, N:4

If definitely yes or maybe yes which ones were these and why?

- (D) Psychological reasons
- (N) I know the consultants hope they wouldn't tick sexual bits because we are H&N may not be necessarily something you have time to sit and discuss in a follow up clinic when your main concern is that they haven't got recurrence I suppose that's the one they thought if they tick that one I am going to skirt round the issue.

Other comments:

- (D – 'definitely not') I may not be able to help them but there is no reason they shouldn't ask.
- (N – 'definitely not') I think sometimes they may tick something and want you to deal with it and you have to be honest and say there are things you can't deal with and then but part of our role especially as nurse specialists is dealing with what we can and maybe sign posting to others so you not saying you've got all the skills to deal with everything but you can certainly refer on.
- (N – 'definitely not') I don't think we should encourage them not to tick them I think all domains are relevant.
- (N- N/A) Absolutely not I think they should be the things being looked at.



**Q12. Do you feel that the PCI was something the patient found useful?**

Definitely yes	Maybe yes	Not sure	May be not	Definitely not
5 D:2, N:3	3 D:1, N:2	0	0	0

If definitely yes or maybe yes which ones were these and why?

- Patient concerns that not normally addressed in clinic were addressed.
- I am thinking of a particular patient I saw twice with it and they raise questions that they were clearly concerned about which we probably wouldn't have covered otherwise because the consultation are very much aimed at looking for recurrence not about the feel good factor. There isn't that sort of time for it so it's very much quick in and out sort of thing and everything is ok and no sign of recurrence etc so it very much based on the physical thing rather than the emotional thing and the patient obviously had concerns but I don't think they would have been addressed otherwise so I think it was very valuable.
- Some patients would express themselves adequately others fear they may lead to nil replies but on questioning were they happy with everything.
- From the feedback patients have given.
- There some patients that weren't interested but patient they were included definitely useful. When a patient comes in they have waited that long at the spoke they just want to get in and get out but I suppose things that were worrying them before they came in they couldn't get and get out because the doc would address their concerns in the consultation. Whereas if it's busy they don't want to bother the doctor or rush to doctor. I felt it gave a bit of tick that prompted the doctor to ask them questions when they come in. So they wouldn't be forgotten about.
- It's a real aid memoir for the patients and carers too. It's like I said before its passing the baton to them and giving them control in areas their life again and you can't really under estimate that.
- I think maybe yes from the brief discussion I had with a very small number of patients following their consultation.
- Speaking to the ones who had done it possible yes for a couple possibly no for a couple so half and half some were I don't know what to tick and I said if they haven't got any problems you don't need to tick anything. You haven't got to find something and you've not got to tick something in the box.

Other comment:

- (N) I have seen letters when obviously the PCI has been used in clinic. So you get a really nice letter summarising the concerns someone has raised.

**Q13. Do you feel that the PCI helped the patient communicate with you?**

Definitely yes	Maybe yes	Not sure	May be not	Definitely not
5 D:2, N:3	0	2 D:1, N:1	1 N:1	0

If definitely yes or maybe yes which ones were these and why?

- (D) The patient was able to talk through the form with me.
- (D) It made it easier for them to raise things that I don't think they would have done otherwise.
- (N) It as we said in the previous question, they sit in the waiting room they have all the worries of the world on their shoulder, sometimes they tick things. A lot of them when they come in and you say the cancer isn't there that fear of recurrence has been addressed so sometimes even the clinical examination address some of the problems on the PCI. But it's nice for the doctor to say oh I've noticed you have ticked this and they say that's ok because you just gone to through and I think it did help them and it helped the doctor to know there are other concerns.
- (N) As well as the patient communicating. It helps with doctor and patient relationships as well as them being able to express how they are feeling about things. It also encourages them to have the conversation with the doctor and breaks down any barriers. It's more holistic more of team approach and things are discussed that wouldn't necessarily deemed as important by either the patient or the doctor.
- (N) yes because sometimes they go into the consultation wound up anyway because they have come for a check-up is it going to be there or not and they sometimes forget problems they have got, they know they have the problems but once your faced with the doctor the doctor does his bit and that fine and they are ready to go out and get out and thing I never said my mouth is still dry or .. so having that I think it was a prompt if you like for the issues so they didn't get distracted.

If maybe not or definitely not can you give a reason for your answer

- (N) I don't think it made them communicate any better than without it. I don't think it changed the way they communicate, it gives them the opportunity to discuss something it gives the opportunity to communicate but they change the way they communicate.

**Q14. Do you feel that the PCI items triggered any additional support that might otherwise had been missed?**

Definitely yes	Maybe yes	Not sure	May be not	Definitely not
4 D:1, N:3	3 D:2, N:1	1 N:1	0	0

If definitely yes or maybe yes which ones were these and why?

- (D) It made it easier for them to raise things that I don't think they would have done otherwise.
- (D) Especially items of nutritional support.
- (N) I suppose on certain occasions yes it does. If there are certain questions they would approach the doctor with but they felt by ticking that piece of paper the question without them actually asking the doctor they feel its import to the doctor maybe because its being used so obviously doctor want to discuss these issues. Some people with intimacy and things they don't want to bother the doctor or they are too embarrassed to mention it in clinic room. but because it son the list it is ok to talk about it even we can't answer the question we know where to signpost them to.
- (N) I think there have been patients who have been using the PCI who may we have contacted the community services and one of the problems we have with some of the community services is that we send the referral out but it's not always acted on because we don't always get direct feedback on that. I have had a few occasions when a patient had found community services has been a problem at home and it's just been a prompt for me then to able to just look into and that might be high priority for them particularly when hey go into speak to the doctor because the minute they are in front of them it's all about the actual cancer and whether it's gone and what's next rather than the general wellbeing side so I think there has been more triggers to thing like that peripheral things rather that immediate.
- (N) I think it did especially with this one patient I am think of it brought to our attention something neither myself or consultant where aware of so we a least could be mindful of it. We hadn't realised this particular patient had a twin brother who had died from a similar disease about nine years ago and that was very much tied up in his fears of recurrence and that was identified through the consultation with the PCI.

If maybe not or definitely not can you give a reason for your answer : no comments

**Q15. Would you like to continue using the PCI type approach in clinic consultations?**

Definitely yes	Maybe yes	Not sure	May be not	Definitely not
4 D:3, N:1	6 D:3, N:3	0	2 D:2	1 N:1

If definitely yes or maybe yes which ones were these and why?

- (D) Because of all the positive answers I have given so far.
- (D) I would be very happy to. Well as I said before the same thing, I think focuses patients on to things that we may no necessarily cover, we may not have the answer to them but at least we point them in the right direction.
- (N) It's proved its worth in making a difference. Maybe more patient information at the beginning of the cancer journey so it becomes in bedded. Some clinics you go to you get weighed before and if it was embedded in that way it would make it easier.
- (N) I think maybe yes I can see the value of it in its present format I don't know but I would say yes.
- (N) Because listening to sort of the consultants say it did help channel the consultation but it's just getting the forms filled in attached and married up with the. It's the fact someone has to be in control of it and when you're doing other things in clinic its how do you keep in control of that as well. From a consultation point of view I would say yes it was a good thing because it has channelled what they have talked about to specific areas but it's getting a handle on it. When you've got other things to do in clinic.
- (N) I think it's because we are tied between PCI and McMillian with HNA.I don't know but some sort of tool is beneficial in clinic but which one I am not sure. I don't know if there is enough time to do the PCI in clinic setting. I think you couldn't address that in a medical clinic setting you would have to do it in a separate setting.

If maybe not or definitely not can you give a reason for your answer

- (N) It would be nice if there was a better set up with the spoke. I just don't think with the spoke as it is at the moment it wouldn't run well because it would be hit and miss and maybe whether you caught the patient. It would have be set up correctly where obviously the volunteer going through the list with the consultant at the beginning of clinic so he can identify which patients is appropriate and them approach them bringing it in that kind of set up would be fine.

**Q16. With advances in the internet etc do you think patients would find it useful to fill in the PCI at home via the internet?**

Definitely yes	Maybe yes	Not sure	May be not	Definitely not
2 D:2	4 N:4	1 N:1	0	1 D:1

If definitely yes or maybe yes which ones were these and why?

- (D) I am sure they would but it wouldn't be easy for us in clinic. We would have to have some way of printing it out because of we had it on the internet it would have been a nightmare but if they would do it at home that would be fine. I just thought you don't want them to have it too long because if they have it for months they will thing everything which is obviously a worry because you can't cover everything you want the most important things. Having said that I don't know maybe if they had it 24 hours in advance they would have more chance to think about it than suddenly be put on the spot.
- (N) If you're technological person then that would be a definite yes if you're not a technological person. It really does depend on the patients IT skills and I think looking at our group of patients it would be a very mixed. Elderly patients don't have internet access and some do probably find it's a maybe yes because it's very patient dependant.
- (N) Some would if they had a computer but even if you could do it or even patients who didn't you could send it out previously so when they are sitting at home they can come to clinic with them if they would remember to bring it with them it would be quite good.
- (N) Yeah if they were computer literate.

If maybe not or definitely not can you give a reason for your answer

- (D) H & N patients are rarely from the subsection of the population who use the internet.

Other comment

- (N) I think for some people yes but I will say to people do you have access to the internet and they will say my daughter will find that out for me or my son will do that for me. You don't want to be doing this that way for people who are internet savvy. Yes they might be willing to do it and some might really appreciate that but as long as that's not seen as the only option.

**Q17. Do you feel that the PCI web-based type of approach could reduce the number and frequency of clinic appointments?**

Definitely yes	Maybe yes	Not sure	May be not	Definitely not
0	1 D:1	3 N:3	1 N:1	4 D:2, N2

If definitely yes or maybe yes which ones were these and why?

- (D) Could triage patients and send them to relevant intermediate ( word hard to read) Rather that all to medic.

If maybe not or definitely not can you give a reason for your answer

- (D) Frequency of follow up OPD are protocol driven and not patient driven.
- (D) No for the H&N clinic because essentially we are looking for physical recurrence. This is more about how the patient feels rather than if they have a lump in their neck so I am not sure. I don't think it's a substitute, I think it's an addition but it's not a substitute.
- (N) I think the patients want that regular face to face follow up with the clinician. I know we looking at reducing follow up appointments somewhere down the line but patients would rather have more frequent appointments than less frequent. I think patients would probably come back for reassurance face to face with the clinician. It's a practical assessment isn't it they are most reliant on the physical assessment rather than anything else.
- (N) No not necessarily patients like to be seen because they like people to have a look. It's all good and well tick what their areas of concern are but they like to be looked at they don't like the camera up the nose because they've had a look and said it's alright so i don't think it will reduce the frequency
- (N) Whether it reduces the time spent and when for some patients long term out of diagnosis if they would feel happier seeing the doctor for a clinical thing immediately have a clinical examination but the doctor and then going into talk to say nurse specialist or somebody about the other things they ticked that might be but still taking to hem and we talked about nurse led follow up clinics the patients have said I would still want the doctor because it that contact they have from day one. That the reassuring and I think that's why we have patients who could be discharged after 5 years but still want to come back for a yearly follow-up because they want that reassurance.

Other comment:

- (N – 'not sure') I don't so because they have a strict criteria of how they follow patients with cancer. I think it helps with consultation. It may reduce the consultation time because it stream lining the consultation to the patients' needs but I don't think it would particularly reduce the amount of time they visit.

**Q18. If the frequency of clinics was reduced by using something like the Patient Concerns Inventory for you would that be a helpful or unhelpful for you?**

Definitely helpful	Maybe helpful	Not sure	Maybe unhelpful	Definitely unhelpful
0	4 N:4	2 D:1, N:1	0	2 D:2

If definitely helpful or Maybe helpful can you give a reason for your answer

- (N) It would be helpful for us but it might not be helpful for the patients they like to come back and know they have no cancer. So maybe helpful if it would reduce but as we said with the previous, it's the hands on. It's the hand on they want to hear there is no cancer here at this time and we will see you in three months times. All the patients say time and we will see you three months time. They walk out on clouds feeling like they can conquer the world afterwards. I think they got a reassurance in the fact they have got that quite regimented follow-up.
- (N) I think it may be helpful for the professionals lets us know where they are up in their cancer journey and if there are any targeted things we needed to offer for them outside and outside of the appointments. I know there was talk of the patients doing the PCI whenever patients felt there was need to discuss and email it through in some way.
- (N) It may be helpful because it will free me to do something else I suppose it may be helpful

If Maybe unhelpful or definitely unhelpful can you give a reason for your answer

- (D) I would say definitely unhelpful it would help me because I would see less patients. In terms of patients care I think it would be unhelpful. I think its different to physical examination you're looking at different things one is looking at patients wellbeing and concerns and the other is about what we find when we examine them.

Other comment:

- (N- 'unsure') I think using the PCI is helpful regardless of the frequency of the clinics because it gives them a chance to address their issues throughout their whole follow up. The issue they would identify on a PCI I think patients would see that separate to a consultation were they are physically examined. Even if you were to ask them to complete the PCI every 2 months I don't think they are going to be reassured that the disease hasn't returned.

**Q19. How does the PCI compare to the Patient Concerns Checklist?**

PCI much better	PCI better	No difference / Not sure	PCC better	PCC much better
2 D:1, N:1	2 D:1, N:1	2 D:1, N:1	0	0

If PCI much better or better why is that?

- (D) Check list is a research tool and not patient focused. It is confusing and not helpful in a clinic situation.
- (D) I prefer the one we have seen that maybe familiarity with inventory. The reason I say that is once you start ranking things I find personally it all gets confusing. It's one thing putting to sort of do you have a problem with that which is fine but when you say which is the most important how do you compare passing urine with finances. I find when you start ranking things I find it very artificial. But I thought the other one was very its easy it takes you through various things people tick if they you know. The PCI is easy straight forward, the PCC this gets kind off complicated.
- I think the PCC is more general were as the PCI is more targeted to head and neck problems. Head and neck patients could have the other one is too general it could because on a general ward for a medical patient, for any patient. Whereas I think the PCI is more streamlined for our patient's needs.
- It looks better

Other comment:

- (N – 'little difference') I think they are both very similar and from a patients perspective they are both very practical to use they have a very comprehensive list to read and with tick boxes and I think the patients like the tick boxes.
- (N – N/A) I have no idea because I have never used a PCC and I wasn't totally aware we were supposed to be comparing the two.
- (N – blank)I like the PCI because I have grown with it but I like the PCC in the fact that patients can rank the top four concerns that are most important.
- (N – N/a) In some bits it better and in some bits perhaps not as specific and I guess the challenge is for H & N patient you're doing one particular one and for everyone else a different one the risk is you might develop one for corectal cancer and something else. The other side of things is there is not much difference so I guess the issue is whether you want to start developing individual ones or whether you actually say H&N is different to all the rest and therefore they do need their own.



**Q20. What barriers do you feel there are to the introduction of the PCI?**

- (D) None on our unit.
- (D) I suppose there is the administrative side of it; someone is going to have to take over the paperwork take responsibility for the paperwork. Make sure the patient is given the forms. If you say it's going to be on the internet, patients have to have internet access so there is all that and there is the other thing is that..(Interrupted by a phone call) So there is the administrative side and the time, I think its important that the patient should voice their concerns and we tend to be very physical in the sense of are you eating and drinking? Is your weight steady. Any lumps in your neck? That sort of thing but there are lots of other things that patients have concerns about that we don't address. In a holistic sense we ought to hand we should. Now I may not have all the answers if someone asks me about benefits I can't answer that but at least we can point them in the right direction. You if those sorts of things are concerning them they should have the opportunity to raise them. I think it's a very good way of doing that.
- (N) Time to prepare and space to do it effectively.
- (N) At the spoke it's the way the clinic runs there is only myself and the consultant and registrar. There is just no man power if they could utilise it the way they do in AUH than I don't think there would be a barrier because the consultants happy to do it and the registrar. The oncologist isn't but ultimately that's a stumbling block because if the patients to see him it wouldn't get done. The patient may tick the form, basically one doctor may not be happy to do it and doesn't think it's got a place in the clic and the fact of man power to identify the patients and get them to fill out the form before they come in.
- (N) I think mainly its getting everybody embedded in it really. When it works well with a consultant who's on board it works really well and you can see the benefits of it. So it's just getting the other consultants to see where it is relevant for them in their practise and that the hard one really. That the tricky one. Also education the patients it is part of their consultation. So maybe empowering them if they have not asked to do it that they do it. There are some patients I know that have been under the care of other consultants and have known the PCI that are now coming through to XXXXXXXX and doing the PCI and they feel they have benefited and feel their consultation has more meaning that was the phrase they used "that consultation had more meaning and he felt actually part of the consultation. It's just the education isn't it? The belief and getting people to believe that it works. The gastro team they see the difference it makes and not that going to slow your consultation down but actually going to direct it and they are not expected to deal with everything that's ticked. The other worry is when you look at the forms on the back page where there is a list of who they want to see currently I'd say 9 times out of 10 that's not always completed and I don't know if they don't quite know enough about all these people how they can affect or they may as well tick the surgeon because he's the boss. I guess you will know yourself by looking at the results tends mainly to be the surgeon or dietician or audiologist but it's not the things like social worker even ourselves as nurse specialists. They are not quite sure where fit in, so they don't tend to tick those.
- (N) Any changes that are made to the way we work or the structure of what we do. I think you've got your usual issues with change management. I think initially people may see it as time consuming or another thing we have to do. It has a potential in it certainly in the early stages to slow down the clinics as staff get use to using it. I also think there is an element of patients may need support to be able to do this to fill it in

and as it stand at the moment there isn't any kind of support to help them if they've got any questions, in how to fill it out as it is at the moment they are given the PCI a paper copy and they take into the consultation with them. If they have had any difficulties or they are not sure what to do when they are filling it out there is nobody to support them to do that. I think that might be a barrier that there aren't any staff available to help them to do that.

- (N) Probably time and organisation somebody to make sure it gets given out and thing like that. That's the hardest thing I found. In that sort of identify the patients at the start was difficult but then when they were coming to clinic that was fine I'd get the forms and things but it was keeping a handle on it once I had pinned them to the notes then I was in clinic so i was relying on somebody else to make sure they got given to the patients when the patients come and then they got their copy and the other copy got put in their notes so I'd have to make sure they went to the doctors that had signed up for it. So I think it was that I found difficult was keeping a handle on that because I had my own job to do.
- (N) I think from a clinicians point of view either specialist nurse or doctor you asking them , in some ways you're not asking them to different to anything they should be doing anyway. That's one side of the argument and its the way they can actually do that. So because we are not using it and I have seen a direct outcome of it then it's difficult to say I think certainly form because I have been involved in the network rollout of the PCC I hear feedback. Most patients like this kind of thing because it's simple. It put down what they want to do you know and we are talking pedantic in a way what better here or there I think the important thing is doing something in a way rather than doing nothing. I know patients have expressed they actually deeply appreciate that someone's actually listening to them.

#### **Additional question added to the shortened email survey of consultant doctors**

**If we are to roll the PCI out across the network as a H&N cancer holistic needs assessment what issues need to be addressed to make this a success?**

- To specify in what ways it might improve, or facilitate more efficient care – eg. Ability to arrange alternate nurses led review clinics based on results of PCI being largely 'clear'. To specify what items are brought up in consultation that can be helpfully discussed and resolved (as opposed to issues that can't be treated). Also need to be clear how PCI might be used – eg. As a one off at the two year post-treatment point – presumably better to avoid repeatedly asking the patients the same questionnaire.
- Definitive evidence that it makes a difference to patient care.
- Allow more consultation time to explore the issues raised by the patient.
- The length of the form and lack of relevance of some of the questions makes it a little long winded. It does however help direct the line of questioning when dealing with follow-ups. I would tend to address issues such as these as part of my usual consultation, but for those with a less holistic approach it might help people tackle the more emotional issues in the consultation.
- Continued education of the medical team to get it established.

**Q21. Any other comments about the PCI?**

- I think there may be a perception that PCI is mainly a research tool rather than anything else. Also many patients and doctors may feel reasonably satisfied with the consultations they already have – i.e. PCI may solve a set of problems that don't exist.