The Rollout and Evaluation of the Head and Neck Cancer Patient Concerns Inventory Across the Merseyside and Cheshire Network

Final Report

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Contents

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3. Background

The Patient Concerns Inventory (PCI) is a carefully designed head and neck cancer pre-clinic consultation checklist (PCI-H&N). It is comprised of 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 .[1]

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 [2], concept [3-7], methodological aspects [8-10] , impact on clinic [11-13], validation [14-20], fear of recurrence [21, 22], international collaborations [23], and other disease states [24-26]. 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 [27]. The PCI allows for better patient-healthcare communication, easier identification of needs and concerns, and early signposting for additional support and intervention.

The imperative for wider evaluation is set in the context of the PCI-H&N being under consideration as a key quality indicator in the mandatory national audit of all H&N cancer units undertaken by DAHNO (Data for Head and Neck Oncologists DAHNO) on behalf of the DoH. Although development work at Aintree University Hospital was very positive, the merit of the PCI as a tool across the network had not been evaluated, and it was unclear whether there would be barriers to its wider adoption. Hence, the aim of this project was to set up, trial and evaluate the PCI-H&N across the Merseyside and Cheshire Cancer Network (MCCN).

The evaluation included feedback from patients, clinic nurse specialist and consultants. It provided a valuable opportunity to refine the PCI before considering this approach as a standard of care in H&N cancer survivorship in this region.

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 allowed reflection on the level of support that is available in their local hospital.

4. Method

The first stage of this study involved raising awareness of the PCI-H&N across the MCCN. Resource material to support the rollout was developed and made available on the PCI specific website: http://www.patient-concerns-inventory.co.uk.

The relevant H&N oncology follow-up clinics across the network were identified and engagement made with locality teams (clinician and specialist nurse). A workshop for these teams was held in November 2012 to further reinforce the online education resources.

Review head and neck oncology clinics were identified at Arrowe Park Aintree University Hospital (AUH), Chester (held at the 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 participate at that time. CCO were invited to evaluate the PCI in 12 patients at the end of their radiotherapy but declined. Ethical approval followed by individual site specific approval was obtained. 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.

Purposeful sampling of consecutive clinics was carried out in order to identify suitable patients using the inclusion and exclusion criteria below:

Inclusion

- Squamous cell carcinoma of the larynx, oropharynx or oral cavity.
- 4 patients with oral cancer (2 early – stage 1 or 2 and 2 late – stage 3 or 4) , 4 patients with orpharyngeal cancer early – stage 1 or 2 and 2 late – stage 3 or 4), 4 patients with laryngeal cancer early – stage 1 or 2 and 2 late – stage 3 or 4)
- Patients treated with curative intent.
- Diagnosis between 6 to 24 months.
- No evidence of recurrence / ongoing disease.
- On 6 to 8 week out-patient follow-up clinics.
- Able to communicate satisfactorily for a telephone survey.

Exclusion

- Previous head and neck cancer / with treatment failure recurrence.
- Inability to give fully informed consent (cognitive impairment, psychiatric diagnoses).
- Ability to communicate adequately without needing a translator.
- Other head and neck sites

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 patients with early stage and two with late stage oral cancer, two with yearly stage and two with late stage oropharyngeal cancer, and two with early stage and two with late stage laryngeal cancer.

Much of the recruitment 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 delays in site R&D approvals. 289 patients were screened from the clinic template at AUH. Of those approached only 13 patients declined. Twenty-one initially agreed to the study at the time of the clinic visit but later declined. There were 81 patients recruited, 15 of whom subsequently withdraw.

It proved very difficult to identify sufficient numbers of larynx cancer sites. This sub-site was less frequently seen than oral and oropharyngeal. Also, most oropharyngeal cancers have advanced presentation so that early oropharynx is less common. The table below shows that more patients than originally intended were recruited in certain groups to make up the total numbers within the recruitment timeframe, those being early stage oral cavity and later stage oropharynx.

Recruitment by Site and Stage

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

The consented patients went on to complete a PCI-H&N in up to three consecutive clinic appointments. Patients completed the PCI-H&N, either online, on paper or both, before their clinic appointment and the completed PCI-H&N was then used in the clinic consultation. Patients later completed a taped telephone survey asking them about their experience of the PCI-H&N. Before this survey, they were sent a blank copy of the PCI-H&N and a blank copy of the Patient Concern Checklist (PCC) in order for comparisons to be made. For those patients who had problems with a telephone survey, a paper version of the questionnaire was made available. Comments and opinions on the use of the PCI-H&N were also collected from a total of 8 consultants and 5 clinical nurse specialists who were involved in the study.

The results were analysed using largely descriptive methods. 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.

5. Results

Data from telephone interviews were obtained from 59 patients and a further seven via a paper questionnaire form of the interview. These 66 were compared to the 15 patients who did not participate in the interview process in respect of demographic and clinical characteristics. There were no significant differences between the two groups which would cause any concern for this analysis. 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 (p = 0.03). However, this concern was only ticked by 4 four of the 15 subsequent non-responders and so, if significant, it is only a partial explanation for nonresponse. The remainder of the analysis focuses on the 66 subsequent participants.

The clinical and demographic characteristics of the 66 patients who took part in the evaluation stage are summarised in Table 1, below:

Table 1: Characteristics of patients (n=66)

Sex	Male	68% (45)
	Female	32% (21)
Age	Mean (SD)	63 (9)
	Median (IQR)	63 (58-68)
	<60 years	33% (22)
	60-69 years	47% (31)
	70+ years	20% (13)
Tumour site	Oral	36% (24)
	Oro-pharyngeal	45% (30)
	Laryngeal	18% (12)
Clinical stage	Early12	55% (36)
Clinical stage	Late34	45% (30)
Primary	Surgery only	59% (39)
Treatment	Surgery + RT	17% (11)
	RT/CRT only	24% (16)
First PCI	Aintree Univ Hosp	74% (49)
Completed	Elsewhere	26% (17)

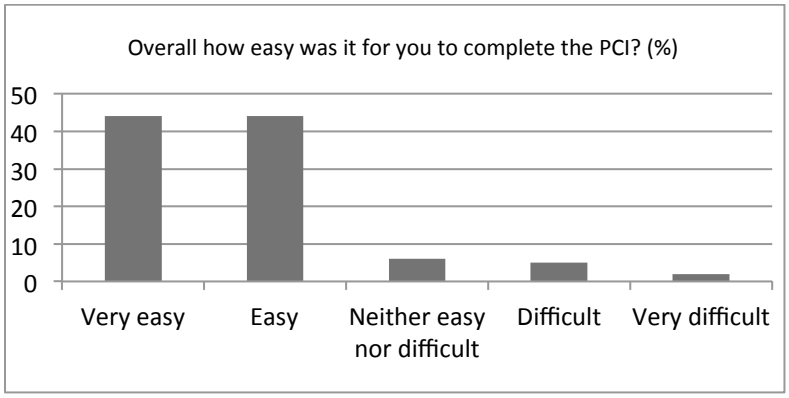
Patients selected between two and eight (median = 5, IQR = 2 - 8) concerns on their initial PCI to discuss during the clinic consultation and 87% selected at least one item, predominantly from the physical and functional well-being and psychological, emotional and spiritual well-being domains. One-quarter (24%) selected one or more health professionals to see. See Table 2, below. The 10 most selected concerns 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 were *dental hygienist* (10%), *dentist* (10%), and *speech & language therapist* (6%).

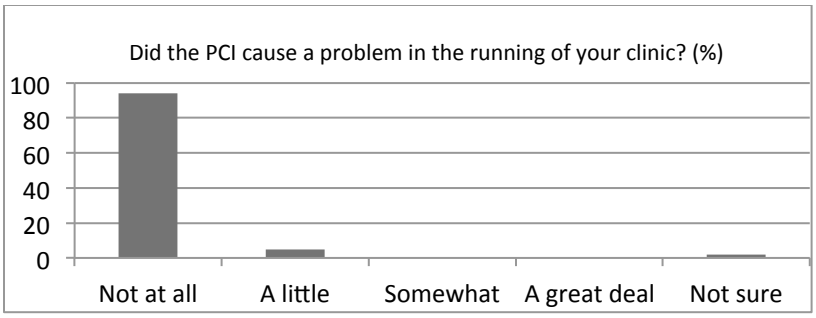
Table 2: Items Selected by Domain: % selecting 1 or more item (n= 63)

Physical and functional well-being domain	83% (52)
Treatment related domain	22% (14)
Social care and social well-being domain	16% (10)
Psychological emotional and spiritual well-being domain	62% (39)
PCI items selected for discussion during consultation – across all domains	87% (55)
PCI health professionals selected to see or be referred on to	24% (15)

The interview questionnaire comprised a mix of closed and open-ended questions, and responses to the former are presented in full in Appendix 1. Almost all (88%) found the PCI easy or very easy to complete with only 6% finding it difficult or very difficult (see below). One patient who found it difficult commented: *Well some of the things you're asking…don't relate to my cancer but I do feel* [I have] *those problems.* Another who found it very difficult noted: [it] *brings back memories.*



Nearly all (94%) felt that the PCI-H&N had caused no problems with the running of their clinic appointment with only 5% reporting that it had caused *a little* problem (see below).

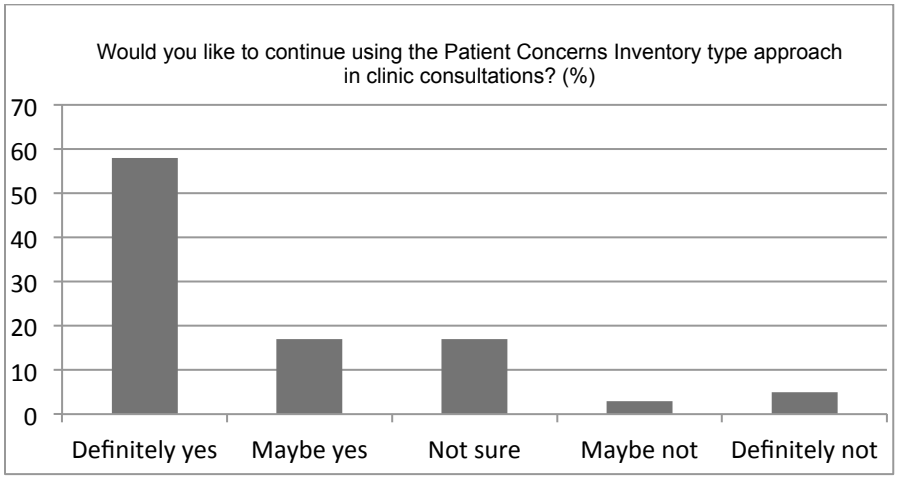


The response from the study patients was very positive with 75% reporting that they would like to continue using the PCI-H&N in clinic consultations (see below) and 66% feeling that the use of the PCI-H&N had helped them communicate with their consultant.

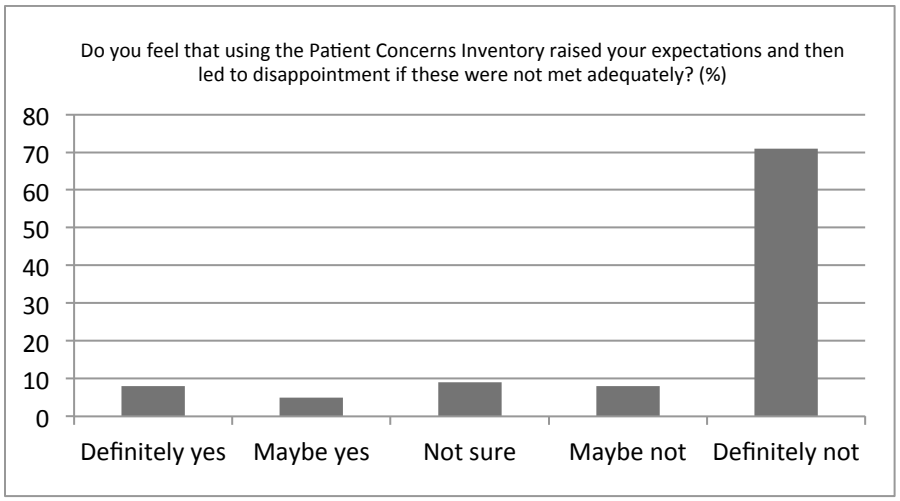
Comments from those who would like to continue using the PCI-H&N include: *Just very helpful gives you confidence and you go in relaxed; Ticking a box is easy… to find the right time to speak up isn't always. You just don't want to interrupt him, so he is the expert he is and you're just the patient. It's finding the right time to introduce it without being rude; 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* [the PCI].

Among those who felt it had helped with communication were the following comments*: It seemed to make me feel more at ease; It sort of makes you feel better; It takes a bit of the pressure off you; I think* [the PCI] *opens the door for you …some people can be reticent about coming forward.*

Typical of the comments from those who answered negatively to this question was this response: *I don't feel there is any problem communicating with the consultant because of his manner and approach.*



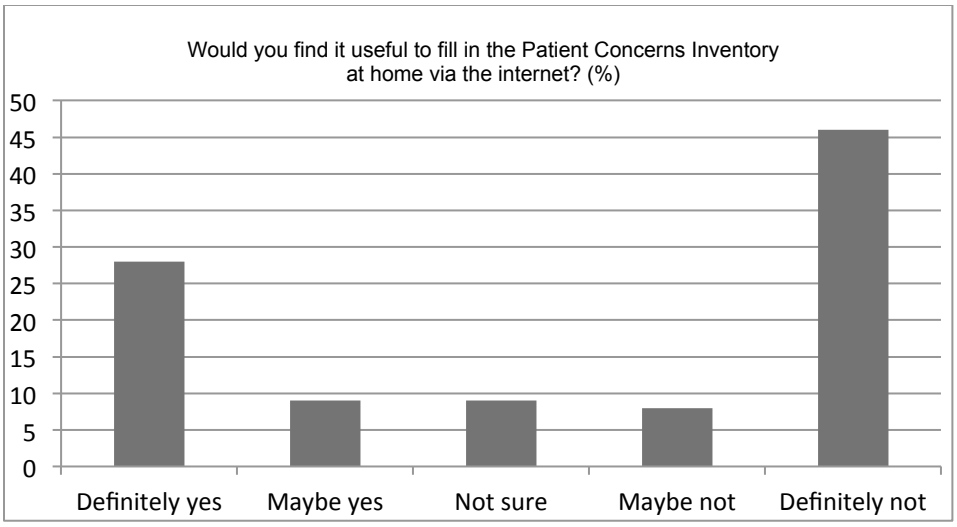
Although 46% reported that use of the PCI-H&N had raised patients' expectations of the consultation, only 12% felt that this subsequently led to disappointment with these expectations not being adequately met (see below). One such disappointed responder noted: *Maybe yes because I still haven't seen a dentist even though it was talked about, nothing has been arranged for me to see a dentist.*



27% of patients felt that the use of the PCI-H&N had resulted in them receiving additional support which they otherwise would not have received. Comments from these 27% include*: The same day as my check-up I had a hearing test followed by a further appointment for hearing aids; …there were other people in the* [consulting] *room and the minute I came out they came out and spoke to me. We discuss something like my teeth and how to get in touch with the dentist; …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 …*

Although 33% felt that the PCI-H&N had definitely not triggered additional support, it was clear from the comments that many of these responders did not feel that they required additional support or, as one patient put it: *Because I didn't ask and I won't because "I am an independent old sod!"*

Most (52%) preferred a paper version of the PCI-H&N with the majority of patients (54%) being unhappy about the idea of completing the PCI-H&N at home via the internet (see below). Typical comments included*: No I am not confident enough on the computer; I am too old for computers*…And, interestingly: *I would rather do it as per appointment as an honest evaluation of how I was feeling on that day.*



A web based PCI-H&N was not viewed as a way of reducing clinic visits with only 23% of the study patients feeling this was appropriate and only 9% seeing any method to reduce the frequency of clinic visits as being *definitely* and 14% as *maybe* helpful. Many (33%) were unsure how to answer this question but 44% viewed fewer clinic visits as *maybe* or *definitely not* helpful. The reasons expressed in the comments centred on the reassurance which the clinic visit afforded them*: 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; Because I wouldn't get that reassurance of him physically examining me; It gives me a lot of reassurance to be seen in clinic that everything is still on track.*

The majority of the consultants and clinical nurse specialists involved in the evaluation saw the benefit of the PCI-H&N in clinical practice and wanted to continue using it in their clinics. There was recognition of some practical issues involving the use of computer based version of the PCI-H&N and other logistical hurdles that required local solutions.

All but one responder felt that they had received adequate training in the use of the PCI-H&N and it was clear from the comments that the workshop had been particularly useful. For example*: It was attending the half-day session at Aintree that* [put] *the PCI in context which was really useful; Its all the literature you sent previously and study days…that really helped.*

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 (62%) felt the PCI-H&N made a positive difference to the consultation, and none a negative difference. All felt that the PCI-H&N was something the patient found useful. Most doctors (78%) would like to continue using the PCI type approach in consultations, as would most nurse (80%).

Typical positive comments regarding the use of the PCI-H&N included this from a Consultant: *I think* [the PCI] *focuses patients on to things that we may not necessarily cover, we may not have the answer to them but at least we point them in the right direction.* Negative comments centred on the difficulties encountered in the administration of the PCI-H&N in the busy clinical environment: *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 brining it in that kind of set up would be fine.*

When asked whether a PCI web-based type of approach could reduce the number and frequency of clinic appointments only one responder, a doctor, answered *maybe yes,* commenting that: *Could triage patients and send them to relevant intermediate clinics rather that all to medic.* The remainder of the respondents were very cognisant of the importance of the reassurance which the clinics brought to patients and the protocol driven nature of these clinics: *No for the H&N clinic because essentially we are looking for physical recurrence; I think the patients want that regular face to face follow up with the clinician; Frequency of follow up clinics are protocol driven and not patient driven.*

The final part of the evaluation asked patients and staff to comment on the use of the PCI-H&N format in comparison to the Patient Concerns Checklist (PCC). 34% of patients preferred the PCI-H&N compared to 24% who expressed a preference for the PCC. Those who preferred the PCI-H&N commented on its ease of use and relevance to them: *Easier to follow lay out better; 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.* Those that preferred the PCC appreciated its brevity: *Because you're just looking at one page; the only thing I would say is the patient concerns checklist would be a big saving on paper.*

The staff that expressed an opinion on this comparison preferred the PCI-H&N: [PCC] *is a research tool and not patient focused. It is confusing and not helpful in a clinic situation; I think the PCC is more general whereas the PCI is more targeted to head and neck problems; once you start ranking things* [as on the PCC] *I find personally it all gets confusing. It's one thing putting "do you have a problem with that?" … but when you say "which is the most important?" how do you compare passing urine with finances?*

6. Discussion

The wider adoption of the PCI-H&N across Networks is supported by this study. Patients, consultants and clinical nurse specialists value the PCI approach in consultations. The patients who placed less value on its use tended to be those who were already satisfied with the level of support received and the communication with their consultant. Most patients found the PCI-H&N easy to use. Although the PCI-H&N tended to raise patients expectations around the consultation only a minority felt it led to disappointment through unmet needs. Patients liked the opportunity to discuss their issues and benefitted from a balanced discussion with the clinician. 28% of patients felt they received additional support as a result of using the PCI-H&N.

The issue that patients wished to discuss most was fear of recurrence, and this has been a consistent finding within papers published on the PCI-H&N. Patients report that they do not wish to see a reduction in the frequency of their follow-up clinics because they welcome the reassurance that the physical examination in clinic affords them. The importance that patients place on dental health / teeth both as a concern and as an onward referral choice perhaps reflects some difficulty accessing services. Quick access to these services can now be prioritised and coordinated across the Network.

The feasibility of integrating its use into routine care needs some further evaluation with local bespoke solutions being developed to ease its incorporation. The Network is continuing to develop the PCI-H&N, devising methods to ensure patient choice is promoted. 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. The benefits of using a computer based PCI and also the barriers to this approach are well documented[28] but locally these benefits need to be made clear if an IT rollout is to commence across the network.

Elsewhere, PCI technology continues to be exported in to other clinical areas and patient groups. 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 versions of the PCI-H&N have been developed. 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. Separately, Macmillan are seeking to adopt the PCI within their E-HNA Cancer Support Tool, and discussions are ongoing regarding the potential development of a generic PCI, separate from the PCI-H&N. 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), Elderly Medicine (Hull and East Yorkshire NHS Trust), 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.

7. Next Steps

As a result of the successful use of the PCI-H&N across networks and the demonstration of its usability by and acceptability to patients and clinicians, the PCI-H&N has now been formally adopted by the Department of Health (DoH), the British Association of Head and Neck Oncologists (BAHNO), the British Association of Head and Neck Oncology Nurses (BAHNON), and the National Association of Laryngectomee Clubs, which represents head and neck cancer patients.

Starting in 2014 the Data for Head and Neck Oncology (DAHNO) section of the Health and DoHs' Social Care Information Centre (HSCIC) will require all head and neck cancer unit across England and Wales to submit evidence that patients have completed the PCI as the holistic needs assessment component of the core data set, and in future years, with the support of BAHNO and BAHNON, request that the individual PCI items selected by patients also be included in these submissions. 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.

With the successful completion of this PCI-H&N project within the Merseyside and Cheshire Network, and the subsequent formal adoption of the PCI-H&N by the Department of Health, Professor Rogers and his team at Edge Hill University are keen to extend the use of the PCI into new clinical areas with additional functionality being built into these new versions.

A pilot project to this effect is currently being completed as a partnership between Edge Hill University, Hull and East Yorkshire NHS Trust, Aintree University Hospitals and Hull Clinical Commissioning Group. This project is developing a PCI for use with 3 specific groups of elderly patients (psycho-geriatric, gastroenterology and falls patients).

This single centre pilot has four aims:

- To develop an effective PCI that is usable by these vulnerable patient groups,
- To assess its effectiveness in identifying and addressing individual patient need,
- To identify the range of services that these patient groups typically require access to (population health needs assessment),
- To identify how existing NHS, local authority, voluntary or independent sector provision can be harnessed to address these needs, either within the clinic setting, or through referral or signposting to support networks

This project has received £102,000 funding from Hull Clinical Commissioning Group and is scheduled to complete early in 2014. The project is proceeding to target and within budget, and early results are promising.

Consequently, the project team wish to extend this project by

- Rolling it out across multiple hospitals within the North West Coast AHSN
- Embedding social services, the voluntary and independent sectors within the process, so that the PCI can
    - act as the basis for a Health and Social Care Integrated Care Plan, in accordance with the aims of the upcoming 'Care and Support Bill', which will create a patients right to a care and support plan to be prepared in consultation with the person and carer.
    - act as an integrated care tool to unite and coordinate care provision based on individual patient need, and
    - act as a mechanism for planning coordinated service provision across different sectors, for addressing the needs of these vulnerable populations, and supporting the work of the Health and Wellbeing Boards
    - act as a tool for inter-organisational development and cooperation, focused on real patient need
- Assessing impact from a health economic perspective, including patient satisfaction, and use of health and social care delivered across different organisations and sources
- Establish whether the PCI can be delivered, or managed, through an electronic format to simplify data management and sharing

It is anticipated that this project would support the development of a simple holistic needs assessment tool, being used for various applications, and which could similarly be adopted nationally after demonstration within networks.

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