

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

## Executive Summary

### 1. Background

The Patient Concerns Inventory - Head and Neck Cancer (PCI-H&N) is a carefully designed 57 item checklist specific for use in the follow up of patients with head and neck cancer. While 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 occurred in the context of the PCI-H&N being considered as a key quality indicator within the mandatory national NHS audit, 'Data for Head and Neck Oncologists' (DHANO).

The aim of this one year project was to roll out and evaluate the PCI-H&N across the Merseyside and Cheshire Cancer Network (MCCN) and in doing so, further develop the approach and refine the implementation process, so that national network adoption is possible.

### 2. Method

Having identified the relevant head and neck follow up clinics across the network and engaged with the key personnel at these centres, MDT members and the local support teams were trained in the use the PCI. This was completed using online resources and a workshop held in November 2012.

Eligible patients were recruited from across the MCCN with review clinics at Aintree University Hospital (AUH), Arrowe Park, Leighton, Royal Liverpool Hospital (RLUH), and St Helens. Purposeful sampling resulted in a total of 81 patients, 66 of whom remained in the study until completion.

Study 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. Study patients later completed a telephone survey about their experience of the PCI-H&N. 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.

### 3. Results

87% of patients ticked at least one concern, with the most frequently ticked item being *fear of cancer coming back*. 24% indicated that that they wished to be referred to another professional for help and advice. Most frequently this was to a dentist, dental hygienist, or speech and language therapist.

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 and 67% feeling that the use of the PCI-H&N had helped them communicate with their consultant. Although it was reported that use of the PCI-H&N had raised patients' expectations of the consultation, only 13% felt that this subsequently led to disappointment with these expectations not being adequately met. 28% felt that the use of the PCI-H&N had resulted in them receiving additional support which they otherwise would not have received.

Most respondents found the PCI-H&N easy to use with only 7% reporting any difficulty. Nearly all felt that the PCI-H&N had caused no problems with the running of their clinic appointment with 5% reporting that it had caused *a little* problem. Most 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. 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 29% seeing any method to reduce the frequency of clinic visits as being *definitely* or *maybe helpful*.

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.

#### **4. Discussion**

Patients, consultants and clinical nurse specialists value the PCI approach in consultations. 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 wider adoption of the PCI-H&N across the Network is supported by this study. 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 for those patients preferring this method. It is now possible for the PCI tool to be readily used by patients, clinicians and multi-disciplinary team members (MDT) across the MCCN. Some further work is required concerning the method of completion for the PCI-H&N but currently it is agreed that patients should be given the choice to complete either a paper or online version.

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 DoH. Starting in 2014 DAHNO will ask that all H&N units across England and Wales submit evidence that patients have completed the PCI as a holistic needs assessment and in future years request that the individual PCI items selected by patients also be included in their submission. Several different clinical groups are developing PCIs in other clinical areas, and research trials are ongoing in using the PCI for a complex group of gerontology patients. The project team are eager to extend the use of the PCI into new areas, particularly in view of the success achieved by this project, and the benefits arising from the gerontology project.

Of particular interest is the extension of the H&N PCI to include multi-agency social services, and thereby become a tool for the development of an Integrated Health and Social Care Integrated Care Plan, in accordance with the aims of the governments upcoming 'Care and Support Bill'.