

Impact case study (REF3b)

<p>Institution: Edge Hill University</p>
<p>Unit of Assessment: 3 - Allied Health Professions, Dentistry, Nursing and Pharmacy.</p>
<p>Title of case study: Using the Patients' Concerns Inventory (PCI) for patients who have head and neck (H&N) cancer in order to improve their experiences of clinic consultations, help in development of quality indicators and improve professional out-patient practice.</p>
<p>1. Summary of the impact The PCI is a carefully designed Head & Neck (H&N) cancer pre-clinic consultation checklist and comprises aspects of care and outcomes that patients might wish to raise with the multi-professional healthcare team. The PCI is an innovative and effective tool whose development has been optimised for touch screen devices. (Full details on use of the PCI is given at http://www.patient-concerns-inventory.co.uk/PCI/Home.html.) The PCI has improved patient experiences of clinic consultations, helped development of quality indicators and improved professional practice. The impact of the programme of work has led to its wider implementation nationally as exemplified by its adoption by the British Association of Head and Neck Oncologists (BAHNO), its inclusion in the National H&N Cancer dataset, its emerging use internationally, and its development in other chronic conditions.</p>
<p>2. Underpinning research Work on the PCI started at the EPRC in 2007 by Rogers (a H&N surgeon seconded to the EPRC in a professorial capacity to undertake research within his specialist field) and Lowe (EPRC visiting professor). Rogers continues this work within the EPRC to the present date. References to selected outputs of this work are given in Section 3, and cross-referenced in the notes below.</p> <p>The basis for the development of the PCI stemmed from the international reputation of Rogers and Lowe in the field of health related quality of life (HRQOL) in H&N cancer and the limitations that HRQOL questionnaires have in contributing to improvements in patient care. Previous work by Rogers in quality of life issues indicated that there was poor patient satisfaction with patients' needs unmet in out-patient consultations. It was also found that little research has been done on development and use of inventory checklists such as the PCI. The work of Brennan (2011) on the 'distress thermometer' was one of the few examples found. However, this instrument has been subsequently critiqued for not being very effective as it is not as condition-specific as is the PCI.</p> <p>Initial development of the PCI was through a systematic review of the literature of items contained in H&N HRQOL questionnaires. A series of patient and carer focus groups also helped to generate items for the PCI. The systematic review and focus groups generated 45 questionnaire findings. Further refinements to inclusion of the PCI items were made following a peer group Delphi-type study and pilot study work¹. Patients were highly involved in development of the PCI with those participating in the development work suggesting an additional seven items bringing the total of items included in the final version of PCI to 52. The finding of the pilot study also showed that the majority of the patients valued use of the PCI and saw it as a welcome opportunity to make the health team aware of their concerns and anxieties.</p> <p>The first iteration of the PCI was evaluated in out-patient clinics at Aintree University Hospital (AUH) and has been used in over 1000 consultations at the H&N Regional Centre based at AUH. The PCI has also been evaluated across the Merseyside and Cheshire network in 8 other clinical units and the locality support services. The research undertaken by Rogers et al demonstrated the utility of the PCI in a busy out-patient clinical setting and that this was coupled with high levels of improved patient satisfaction¹.</p> <p>Later studies have found that use of the PCI helps identification of various patient concerns such as fear of recurrence. The seriousness of this for patients and the contribution that the PCI can make to elicit this concern was an unexpected finding and is now a focus of on-going research². Other examples of patient concerns include mood and anxiety problems and worries about appearance⁶. Issues concerning speech, swallowing and pain were also identified³. The PCI</p>

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identifies both issues that are common and those that are different across the H&N cancer tumour sites and stages⁴.

Further studies undertaken by Rogers and team resulted in the publication of an additional 22 papers. These papers, largely published in high impact journals, have focused on research that has investigated the PCI and its validation and underpinning concepts, methodological considerations, its impact on clinical practice, patient fears of recurrence, international collaboration and development in other conditions. Generally these studies have demonstrated that the PCI provides opportunities for more holistic consultations, without significantly increasing clinic time^{1,5}.

3. References to the research

Research concerning development of the PCI is of 2/3* quality is evidenced by such things as the impact values (IF) of the journals the PCI studies have been published in and adoption of the PCI by other reputable researchers and research units. (Full reference list is available at www.edgehill.ac.uk/eprc.)

1. Journal Article: Rogers SN, El-Sheikha J, Lowe D. The development of a Patient's Concerns Inventory to help reveal patients concerns in the head and neck clinic. *Oral Oncol.* 2009; 45(7): 555-61. DOI: 10.1016/j.oraloncology.2008.09.004 (IF: 2.695, 5 Year IF 3.278)).

2. Journal Article: Ghazali N, Cadwallader E, Lowe D, Humphries G, Ozakinci G, Rogers SN. Fear of recurrence among head and neck cancer survivors: longitudinal trends. *Psychooncology.* 2013 Apr; 22(4): 807-13 DOI: 10.1002/pon.3069. (IF: 3.506). ISI Journal Citation Reports © Ranking: 2012: 3/36 (Social Sciences Biomedical); 12/126 (Psychology Multidisciplinary); 14/75 (Psychology); 67/197 (Oncology).

3. Journal Article: Ghazali N, Lowe D, Rogers SN. Enhanced patient reported outcome measurement suitable for head and neck cancer follow-up clinics. *Head Neck Onco.* 2012, 4:32 (IF: 3.08). Available on request.

4. Journal Article: Kanatas A, Ghazali N, Lowe D, Udberg M, Heseltine J, O'Mahony E, Rogers SN. Issues patients would like to discuss at their review consultation: variation by early and late stage oral, oropharyngeal and laryngeal sub-sites. *Eur Arch Otorhinolaryngol.* 2013 Mar; 270(3): 1067-74. DOI: 10.1007/s00405-012-2092-6. Epub 2012 Jun 29. (IF: 1.458)

5. Journal Article: Ghazali N, Kanatas A, Langley DJ, Scott B, Lowe D, Rogers SN. Treatment referral before and after the introduction of the Liverpool Patients' Concerns Inventory (PCI) into routine head and neck oncology outpatient clinics. *Support Care Cancer.* 2011; 19(11):1879-86. DOI: 10.1007/s00520-011-1222-9 (IF: 2.597)

6. Journal Article: Flexen J, Ghazali N, Lowe D, and Rogers SN. Identifying appearance-related concerns in routine follow-up clinics following treatment for oral and oropharyngeal cancer. *Br J Oral Maxillofac Surg*, 2012, 50 (4) 314-20. DOI: 10.1016/j.bjoms.2011.05.005 (IF: 2.717) Eigenfactor 0.01892, ranking 2nd out of 82 journals in the category 'Dentistry, Oral Surgery & Medicine'.

4. Details of the impact

Impact of use of the PCI is interim and emerging. However, it is increasingly being used across a variety of different clinical settings, conditions and countries. For example, the PCI has been adopted for use in the formulation of the PCI-neuro-oncology (the Edinburgh Centre for Neuro-Oncology) PCI-breast cancer (the Cancer Research UK Centre and St James's Institute of Oncology, Leeds), PCI-Rheumatology (University of Liverpool), PCI-elderly medicine (NHS Hull Clinical Commissioning Group), PCI-stroke (AUH) and international clinical colleagues (more detail given later in this section). Also the substantive nature of on-going studies currently being undertaken and forging of new research partnerships means full impact will come to fruition over the next few years. Nevertheless there are a number of impacts that can be claimed between 1 January 2008 and 31st July 2013. These are:

Claim 1: PCI improves patients' experience of their H&N clinic consultations

The PCI supports the concept of personalised healthcare and follow-up at a time in the cancer journey which is most appropriate to the individual and within the financial constraints of the NHS

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(evidence of this was presented at a BPOS conference – Documentary Source 1). Also a pre and post evaluation study⁵ concerning introduction of use of the PCI in out-patient clinics showed that it allows patients to bring their own agenda to consultations without lengthening the consultation time (Factual Statement 1 given by Chairperson of H&N Support Group). Clinic assessment is also more holistic and allows a broader array of concerns to be raised with the consultant. For example, two thirds of patients who have experienced use of the PCI state that their consultation was greatly enhanced when compared to the usual procedures adopted when attending their out-patient appointments. Use of the PCI has also resulted in higher rates of appropriate referrals to other members of the multi-professional team for such things as emotional and clinical psychology support (Documentary Sources 1, 2, Factual Statement 1, and Ghazali's MD findings).

The PCI has also been piloted in other continents giving further evidence of impact concerning improvements to patients' experiences. For example, in Malaysia it has been established that 'the majority of oral cancer patients found the PCI helpful in identifying their concerns during consultations, thus favourably indicating its future use of patient management in routine clinical care' (Documentary Source 2). Endorsement of the PCI in contributing to patients' experiences is also demonstrated by the statement given by Macmillan in development of the national E-HNA Macmillan Cancer Support tool (Factual Statement 2).

The benefits of the PCI in engaging with patients and allowing their concerns to be heard was recognised by a national award, E-Health Insider EHI (the e-health community) awards 2010 winner 'Best use of IT in patient and citizen involvement in healthcare' (Documentary Source 3). In addition reach of the PCI is reflected in its development for iPad application (MiPCI) (Cancer Nursing Research and Practice NMAHP Research Unit, University of Stirling, Scotland) and touchscreen tablet (Macmillan CNS - Head and Neck Cancer, Cancer Services, and Ulster Hospital, Northern Ireland). Finally the PCI has been a driver for patient-relevant clinical research in several aspects of care most notably the fear of recurrence. For example, the St Andrews' research team have gained funding from the Innovation Research stream NHS Fife to conduct further investigations into use of the PCI. The St Andrews team describe how use of the PCI 'has supported a substantial stream of clinical research based on intervention to reduce undue recurrence anxieties' (Factual Statement 3).

Claim 2: The PCI has impacted on development of quality indicators in H&N cancer services

The PCI has been included as a key quality indicator in the NHS national mandatory audit of all H&N cancer units (Data for H&N Oncologists). The PCI was adopted for the first time in 2012/13, by the British Association of H&N Oncologists (BAHNO), This network represents all the H&N units in England and Wales. The PCI is being used to show as evidence that units are conducting holistic needs assessments. From 2013/14 onwards units will be required to return summaries of responses to the various PCI items to BAHNO (Documentary Source 4). The significance of these auditing processes is demonstrated by the 2012 annual report that included 8272 patients across 30 Networks representing England and Wales (Health and Social Care Information Centre, National Head and Neck Cancer Audit 2013). The potential that clinical audits have to improve patient experiences is described by the Healthcare Quality Improvement Partnership (HQIP) when outlining how audit data can be translated into quality improvements that benefit patients and their care.

Claim 3: The PCI has improved professional practice in H&N out-patient clinics

An area of care that the PCI has directly impacted is the provision of holistic care in out-patient clinical practice. Much of the aforementioned research of Rogers identifies that patients feel that use of the PCI permits them to raise a wider range of issues than they may have done in their previous out-patients appointments^{1, 4, 5}. For example, using touch screen format the PCI allows a comprehensive list of patient concerns to be shared with the healthcare team prior to them meeting together. The value the PCI has in providing a holistic patients' need assessment and how this can improve professional practice is substantiated by the British Association of H&N Oncology Nurses (BAHNON) and the National Association of Laryngectomy Clubs. These associations have endorsed the use of the PCI (Factual Statement 4). A further area of professional practice to which the PCI contributes is the understanding and appreciation of patients' perspectives. Central to use of the PCI is that the patient voice is heard. Patient involvement in developing the

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PCI and satisfaction with its subsequent use is illustrated by a recent Radio Merseyside interview (July 22nd, 2013) with Rogers and a H&N cancer patient. The patient was asked about development and effectiveness of the PCI when used at their out-patient appointments. Positive comments predominated from the patient (<http://www.patient-concerns-inventory.co.uk/PCI/Home.html>)

In recognition of the patient-focused nature of the PCI and its value in contributing to the provision of out-patient care various H&N clinical units abroad have adapted the PCI for use in different healthcare settings. For example, the patient-focused nature of the PCI is verified in Factual Statement 5 given by the Director Head and Neck Surgery Department at the Hospital do Cancer AC Camargo, São Paulo, Brazil. The PCI has also been adapted for use in the restorative dental services, University of Florida USA and the Lawson Health Research Institute, London, Canada. The PCI is being used, for example, as an outcome measure in research being conducted by the Canadian team whereas in Brazil researchers are using the PCI to explore patient expectations of cancer care. The PCI has also been translated into seven different languages including Chinese, Arabic, Urdu and French.

Finally the judgements of funders in awarding grants for further investigations also is evidence of the perceived significance that use of the PCI can make to improving professional practice. Grants awarded by the various local and national funding bodies including the British Association of Oral and Maxillofacial Surgeons (BAOMS) demonstrate a degree of confidence in the value use of the PCI has in improving professional practice and also the grant capture perhaps most notably in elderly medicine where a grant of £102K funds a current evaluation study. These are some of several grants that have been awarded to evaluate and further develop use of the PCI in clinical practice including the North Yorkshire and Humber Commissioning Support Unit (Documentary Source 5).

5. Sources to corroborate the impact

Factual Statements

1. Chairperson, University Hospital Aintree, H&N Support Group. (Patient statement) – addresses impact claim 1.
2. Chief Executive, Macmillan Cancer Support – addresses impact claim 1, specifically influence on development of eHNA tool.
3. Professor of Health Psychology, University of St Andrews – addresses impact claim 1.
4. Chairperson, British Association of Head and Neck Oncology Nurses – addresses impact claim 3.
5. Director, Head and Neck Surgery and Otorhinolaryngology, Hospital do Cancer AC Camargo, São Paulo, Brazil – addresses impact claim 3, an example of use in professional practice overseas.

Documentary Sources

1. British Psychosocial Oncology Society presentation (Chester, December 2/3rd 2010). Items of Concerns of Head and Neck Cancer Survivors in Routine Oncology Follow up Clinics. Ghazali N et al. found at <http://www.bpos.org/>
2. Hatta J et al. The feasibility of using patients' concerns inventory (PCI) in managing Malaysian oral cancer patients. International Journal of Oral and Maxillofacial Surgery. DOI, IJOMS-D-12-00976R1 (IF: 1.521)
3. E-Health Insider EHI (the e-health community) awards 2010 found at <http://www.ehealthawards.com/>
4. BAHNO, Newsletter found at www.bahno.org.uk
5. Minutes of the Hull Clinical Commissioning Group Board (26/6/13) Quality and Safety Report, page 27. <http://www.hullccg.nhs.uk/data/uploads/committee-meetings/26-06-13/agenda-item-5.1-annual-quality-patient-safety-report-july-2013-.pdf>