Institution: Edge Hill University		
Unit of Assessment: A3 - Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Patient Concerns Inventory (Head and Neck) - focussing clinical consultations on what matters to patients		
Period when the underpinning research was undertaken: 2014-2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Simon Rogers	Professor (0.2FTE) Research Associate (0.2FTE) Professor (Seconded to undertake research in unit)	Nov 2006 – April 2012 Oct 2013 – Nov 2013 (Secondments since 2013)
Mary O'Brien	Professor	2003-present
Period when the claimed impact occurred: 2014-2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact

The **Patient Concerns Inventory** Head and Neck (PCI-HN), developed by Rogers, is a low-cost prompt-list completed by Head and Neck (HN) cancer patients before outpatient encounters to focus these on patients' primary concerns and facilitate patient-centred care. Developed with patients, PCI-HN is underpinned by 14 years of research establishing patient benefits, culminating in a recently reported NIHR-funded trial. Rogers has driven PCI-HN uptake into cancer services; inclusion in national guidance and professional audit and championed PCI development in other languages and conditions. Macmillan Cancer Support, following Rogers' collaboration, has now successfully embedded PCI-HN specific items into their national Holistic Needs Assessment tool.

2. Underpinning research

The PCI-HN is a prompt-list, consisting of 56 Head and Neck cancer items, from which HN cancer patients can choose concerns they wish to discuss with their clinician during an outpatient appointment. It can be completed on paper, tablet or wipe-board either self-administered or with support and is passed to the clinician to facilitate patient-centred care planning. The PCI-HN was developed by Rogers, whose research activity has been situated in the Faculty Health, Social Care and Medicine at Edge Hill since 2006. As a HN cancer surgeon and clinical researcher, Rogers observed that quality-of-life measures were practically limited in the elicitation of HN cancer patients' key concerns, which were frequently left unexplored during clinical consultations.

Early work, in collaboration with patient groups, and outlined in the previously submitted impact case study, was concerned with the underpinning concepts, methodological considerations and validation of the PCI-HN. Since 2014, Rogers has published over 25 research papers on the PCI approach.

The benefits of PCI-HN in routine practice

Early studies within Rogers' own centre were replicated within a regional network with the majority of 66 patients and 14 clinicians appreciating the value of the PCI-HN (Output 1). Rogers confirmed the PCI-HN uncovers a range of unmet needs such as sexual intimacy and dental concerns, and that it is accessible across socioeconomic, age and HN cancer subtype groups. Rogers showed the PCI-HN's clinical utility in ongoing follow-up of HN cancer patients, with evidence that identified concerns are associated with worse quality-of-life, particularly, within social-emotional functioning. Thus, suggesting it could lead to improvements in patient's quality-of-life. This work culminated in a pragmatic cluster preference trial, funded by the National Institute of Health Research, involving 15 consultants. The recently published trial results have shown clinically meaningful improvement in the social–emotional aspect of cancer recovery in

those that received the PCI-HN, without evidence of substantial increase in consultation time (Outputs 2 and 3).

The relevance of the PCI in other settings and conditions

As well as evidence that PCI-HN is relevant across the UK, it has been cross-culturally validated. Rogers maintains an ongoing international research collaboration and a recent study across 19 centres in 16 countries confirmed the relationship of PCI concerns with quality-of-life, but also differences in concerns between countries (Output 4). Rogers has also been involved in supporting other research groups to develop PCI in other diseases; there are publications in rheumatology (O'Brien) (output 5), burns (Spencer), breast cancer and brain cancer.

Further research on unexplored concerns in Head and Neck cancer patients

Following up on the finding of greater anxiety and depression among patients with fear of recurrence on the PCI-HN, Rogers found that these patients feel reluctant to raise these concerns because they feel this may damage relationships with their clinician (Output 6). Observations that PCI-generated concerns differ across socioeconomic groups led to studies which showed that doctors spent less time with more deprived patients, who took a more passive role and engaged in fewer relational discussions suggesting potential health inequalities.

3. References to the research

Output 1. **Rogers SN**, Lowe D. An evaluation of the Head and Neck Cancer Patient Concerns Inventory across the Merseyside and Cheshire Network. Br J Oral Maxillofac Surg. 2014 Sep;52(7):615-23. doi: 10.1016/j.bjoms.2014.04.011. Epub 2014 Jun 11. PMID: 24927654.

Output 2. **Rogers, S.N**., Allmark, C., Bekiroglu, F. et al. Improving quality of life through the routine use of the patient concerns inventory for head and neck cancer patients: main results of a cluster preference randomised controlled trial. Eur Arch Otorhinolaryngol (2020). https://doi.org/10.1007/s00405-020-06533-3

Output 3. **Rogers SN**, Semple C, Humphris GM, Lowe D, Kanatas A. Using a patient prompt list to raise concerns in oncology clinics does not necessarily lead to longer consultations. Br J Oral Maxillofac Surg. 2020 Nov;58(9):1164-1171. doi: 10.1016/j.bjoms.2020.08.035. Epub 2020 Aug 19.

Output 4. **Rogers SN**, Alvear A, Anesi A, Babin E, Balik A, et al. Variations in concerns reported on the patient concerns inventory in patients with head and neck cancer from different health settings across the world. Head Neck. 2020 Mar;42(3):498-512. doi: 10.1002/hed.26027.

Output 5. Ahmed AE, Lowe D, Kirton JA, **O'Brien MR**, Mediana A, Frankland H, Bruce H, Kennedy T, **Rogers SN**, Moots RJ. Development of a Rheumatology-specific Patient Concerns Inventory and Its Use in the Rheumatology Outpatient Clinic Setting. J Rheumatol. 2016 Apr;43(4):779-87. doi: 10.3899/jrheum.150068. Epub 2016 Feb 15

Output 6. Ozakinci G, Swash B, Humphris G, **Rogers SN,** Hulbert-Williams NJ. Fear of cancer recurrence in oral and oropharyngeal cancer patients: An investigation of the clinical encounter. Eur J Cancer Care (Engl). 2018 Jan;27(1). doi: 10.1111/ecc.12785. Epub 2017 Oct 12

Outputs 1-6 are published in rigorously peer-reviewed journals of international standing. Outputs 2 and 3 are as a result of rigorously peer-reviewed research funding awarded by National Institute of Health Research.

4. Details of the impact

As the research evidence about the utility, acceptability and feasibility of the PCI-HN has grown during the current REF cycle, Rogers has driven PCI implementation into routine practice. Consequently, PCI-HN has been recognised by senior policymakers [source 1], national cancer bodies [source 2] and cancer patient groups [source 3] as an effective way of ensuring that HN cancer patients' concerns are met across the patient pathway.

Embedding PCI-HN

There is evidence of national embedding of PCI-HN. Recognising the importance of the PCI-HN in patient care, the 2014 British Association of Head and Neck Oncologists included a question about the use of the PCI within Cancer Centres in their annual audit [source 4]. However, uptake across England was patchy with only 11% of patients completing the PCI-HN. Despite further monitoring through inclusion of a data item within the Somerset Cancer Register, a data collection system used by Cancer Centres across the country, national uptake of the PCI-HN remained low. Rogers recognised that more widespread implementation required a national IT infrastructure to enhance accessibility. Macmillan Cancer Support had incorporated a generic concerns checklist within their Holistic Needs Assessment package for people living with and beyond cancer, available nationally through an electronic portal (eHNA). Rogers worked with Macmillan to embed 13 items from the PCI-HN into the eHNA [source 5a]. This was the first time that Macmillan included items relating to a specific cancer and was based on the recognition of the robustness of the evidence underpinning the PCI-HN [source 2]. The PCI-HN items were included in October 2018 and a recent analysis has shown that the items are now well-embedded [source 5b]. There has been a year-on-year increase in the number of HN cancer patients completing the PCI-version; in 2020, 2575 HN cancer patients completed the eHNA, of whom 67% completed items from the PCI-HN. The PCI-HN items add value: four of the top 15 concerns raised were PCI-HN specific and patients rated 12 of the 13 PCI-HN items above 5 out of 10 in severity. Inclusion of PCI-HN items has increased its accessibility as the 56 organisations regularly using the PCI-HN version include primary and secondary care, social care, community teams, and private healthcare providers, not just Cancer Centres. As the factual statement from Macmillan attests: 'the insight that we gain from this additional data helps Macmillan to build a clearer picture of the concerns identified by this group of cancer patients, helping to identify areas for service development and improvement' [source 5a]. The Macmillan cancer support medical director further explains that integration of PCI items into the eHNA allow not only for improved care for individual patients but provides a national dataset on unmet needs, noting 'this will be enormously valuable in service planning'. [source 2].

Clinical experience [source 6] in addition to policy and professional body endorsement [sources: 1, 4 and 7] further attests to the benefits for patients of the implementation of the HN-PCI. A consultant clinical oncologist at the Beatson West of Scotland cancer centre and clinical lead for the Scottish Sarcoma network states that the PCI is 'transforming clinical consultations into person centred' benefitting both clinical teams and patients. As a result of a positive experience with the PCI-HN, the Scottish Sarcoma Network are developing a PCI for sarcoma patients on follow up [source 6]. The success of PCI-HN has also helped shape and crystallise NHS England's patient reported outcome measure (PROM) programme. The former Head of Insight at NHS England has confirmed that the PCI-HN played a significant role in their thinking on patient reported outcome measures (PROMS) due to 'its focus on what mattered to patients rather than what the clinician thought was of importance' [source 1].

PCI-HN has been upheld internationally and independently as the best patient reported outcome measure (PROM) for revealing unmet need in HN cancer patients [source 8]. Rogers has recognised the importance of ensuring ongoing support and training of health professionals to promote the PCI-HN in practice: for example, UK HN Quality of Life conference workshop 2018 and online training for dental health professionals. A website provides access to the tool (PCI Head & Neck Cancer | HaNC Support).

Development of PCIs for other clinical areas

Rogers' dissemination about patient benefit has led to interest in this approach within other HN cancers [source 6] and disease areas. Other cancer PCIs have been developed and validated in breast and one in brain cancer [sources 9,10]. The Rheumatology PCI developed in collaboration with other Edge Hill University academics (O'Brien) is being implemented in practice [source 11; output 5]. A Rheumatology consultant at Aintree University hospital acted as an advocate for the development of 'a Rheumatology-specific Patient Concerns Inventory' and notes it has 'proven to be a positive addition to consultations in our clinical setting.' PCI use in the rheumatology clinic has helped to identify areas of patient's unmet needs that were previously not noticed [source 11]. A Burns PCI also developed in collaboration with other Edge Hill academics following focus groups hosted by The Katie Piper Foundation (a national burns charity) highlighting the disparity between burns patients' concerns and those of their health professionals [source 12].

Rogers' acknowledged expertise in this area has led to his appointment as chair of the NHS England Quality-of-Life metrics group, which includes steering the roll-out of a nationwide metric, and further opportunity to highlight PCI benefits.

There has been increasing international interest in the PCI; Rogers has undertaken international keynote talks (World ENT Conference 2017, World Congress of Oral Oncology, Brazil 2015) [source 13], leading to other language versions of the PCI-HN and an international research collaborative involving 19 units in 16 countries (output 6). It is anticipated that the recent publication of robust randomised controlled trial evidence of the patient benefits of the low-resource PCI-HN will further bolster implementation nationally and internationally (output 2). Future research will focus on developing PCI-HN for other stages in the patient journey, implementing PCI-HN in virtual consultations and through cloud-based IT systems and the implementation of PCI in other disease areas.

5. Sources to corroborate the impact

Source 1: Factual Statement - Former Head of Insight and Feedback NHS England
Source 2: Factual Statement – Macmillan Cancer Support Medical Director
Source 3: Factual Statement – Patient testimonial
Source 4: National Head and Neck Cancer Audit 2014. DAHNO 10th annual report. Published September 2015 Report 33: Has a Patient Concerns Inventory been completed? clin-audi-supp-prog-head-neck-dahn-13-14-rep33.pdf (digital.nhs.uk) Accessed 4/3/21 (also included as a PDF)
Source 5a: Factual Statement - eHNA Digital Product Owner Macmillan Cancer Support
Source 5b: Macmillan Cancer Support eHNA data extract Head and Neck cancer cases
Source 6: Factual Statement- Consultant Clinical Oncologist
Source 7: Eds Vinidh Paleri and Nick Roland: United Kingdom National Multidisciplinary Guidelines. The Journal of Laryngology & Otology (2016), 130 (Suppl. S2) - pages S49 to 52 and pages S212- 49
Source 8: Shunmugasundaram C, Rutherford C, Butow PN, Sundaresan P, Dhillon HM. Content comparison of unmet needs self-report measures used in patients with head and neck cancer: A systematic review. Psycho-oncology. 2019. https://doi.org.edgehill.idm.oclc.org/10.1002/pon.5257
Source 9: Kanatas, A., et al. The Breast Cancer Specific Patient Concerns Inventory [PCI] As a Means to Assist the Identification of Body Image Concerns in Routine Follow Up Clinics. (2014) J Cancer Oncol 1(1): 1-10.
Source 10: Rooney AG, Netten A, McNamara S, Erridge S, Peoples S, Whittle I, Hacking B, Grant R. Assessment of a brain-tumour-specific Patient Concerns Inventory in the neuro-oncology clinic.Support Care Cancer. 2014 Apr;22(4):1059-69. doi: 10.1007/s00520-013-2058-2. Epub 2013 Nov 29.
Source 11: Factual Statement: Rheumatology consultant
Source 12: Gibson JAG, Yarrow J, Brown L, Evans J, Rogers SN, Spencer S, Shokrollahi K Identifying patient concerns during consultations in tertiary burns services: development of the

Adult Burns Patient Concerns Inventory.BMJ Open. 2019 Dec 30;9(12).e032785. doi: 10.1136/bmjopen-2019-032785.PMID: 31892660
Source 13: Cancer world article: Meanings and Measures of Quality of Life in Head and Neck Cancer