# Health Needs Assessment within Hull CCG: Development & Trial of the Medical Elderly Patient Concerns Inventory (ME-PCI) in the Context of Supporting Health Commissioning

# Abstract

## 1. Aims and Objectives

This study aimed to develop and pilot three versions of a Medical Elderly Patient Concerns Inventory (ME-PCI) patient questionnaire to assess its potential as a tool for health needs assessment and as an aid to improving the quality of the clinical consultation by easing communication between patient and consultant.

## 2. Methods

For each clinical group (collapse, gastroenterology and neuropsychiatric), the research team completed a literature review to identify potential areas of concern to patients, amended by an iterative Delphi panel approach of clinical professionals, researchers and patients. These initial lists were grouped into themes to reduce duplication and improve clarity. They were then presented and discussed within a patient focus group, and fed back to the Delphi panel to finalise a draft version of the PCI. Each of the three PCIs was piloted in 20 patients, with summary data being recorded on identified need and usability via patient and consultant questionnaires. The project was completed at Hull and East Yorkshire NHS Trust between 2014 and 2015 and was led by Professor Rogers working with Dr Harman, Dr Richards and Dr Saharia.

## 3. Findings

Patients attended outpatient medical elderly clinics. The average age was 84, and two thirds of patients were female. Patients across the 3 groups identified an average of 8.6 items for discussion. 60% of patients requested a referral, which acted as one of the sources for clinical discussion. Half of all patients had an onward referral made, with most referrals coming from the collapse and neuropsychiatry patient groups. The average consultation time was 31 minutes ranging from 10 to 90 minutes across the three groups. While additional services were not identified in this process, the data produced indicated that several services could be usefully provided in parallel to these clinics. An average of 75% of patients across the three groups indicated that their overall satisfaction with the consultation was outstanding/excellent. When asked how easy it was to include the PCI in the consultation, the consultants answered very easy/easy in 92% of cases. Only on two occasions did the consultants answer *difficult*. The consultants considered that *all/most* of the PCI ticked items were discussed in the consultation in 95% of cases and that the PCI made the consultation much better/better in 88% of cases. In 95% of cases the consultants felt that the PCI definitely or maybe helped the patient communicate with them. In 60% of the cases, the consultants felt that the PCI had *definitely* or *maybe* triggered additional support.

# 4. Conclusion

This study found that the PCI approach was usable for this patient group, despite their more complex and varied needs. The PCI could be used as a health needs assessment tool, and did identify required services, including those which could be delivered in parallel to the clinics. The PCI was an effective aid to patient communication, being welcomed by patients and consultants, and being readily embedded within clinical practice. The use of the PCI could be extended to include nursing, AHP or other staff, which may further simplify communication in the clinical setting.

# Full Report

# 1. Aims and Objectives

The aims of this project were to:

- Establish the use of the Patient Concerns Inventory (PCI) as a health needs assessment tool in order to support effective commissioning.
- Explore its ability to improve the quality of clinical consultations for the patient.

The objectives of this project were to:

- Establish and validate PCI questionnaires in three areas within the medical elderly specialty: neuropsychiatric; gastroenterology; and collapse.
- Pilot each of these three PCIs in a clinical setting on a total of 60 patients.
- Collect patient requirement (demand) and clinical referral or signposting (supply) data.
- Collect satisfaction data from these patients and the opinions of the consultants concerned.
- Aggregate the data from these PCIs to identify common themes and requirements in order to assess the extent of unmet need.

# 2. Background and Rationale

The Patient Concerns Inventory (PCI) is a relatively short, bespoke questionnaire, comprising a list of potential concerns from which patients identify items that they would like to discuss in their consultation. The PCI is one of many similar approaches to aiding patient communication in the clinical setting. These differ from Patient Related Outcomes Measures (PROMs), Health Related Quality of Life Questionnaires and most forms of Holistic Needs Assessments in that the design is tightly focused on screening patients for issues or concerns to support and inform communication and patient care in the clinical setting. In practice, the appropriate PCI is completed by the patient before the outpatient appointment, passed to the clinical professional, and used to focus that consultation on the patients concerns and the management of these.

The purpose of the PCI is to assist clinicians in addressing the issues most relevant to the individual patient while acting as a discussion trigger, and thus improve the efficiency of the clinical consultation and improve patient satisfaction (Rogers S *et al*, 2011). PCIs can be particularly useful for patients who are fragile, vulnerable, have low self-esteem, find the clinical setting intimidating, or are less articulate.

The original Head and Neck Cancer PCI was developed by Professor Simon Rogers (Millsopp L *et al*, 2006) at Edge Hill University and Aintree University Hospitals NHS Trust. Since patients concerns will vary according to their condition, several bespoke versions have been developed by clinical groups to support their clinical consultations, reflecting the particular needs of those patients (Ghazali N and Rogers S 2011; Flexen J. *et al*, 2011). Examples include head and neck cancer, neuro-oncology, breast cancer, and rheumatology.

Published work indicates that both patients and clinicians benefit from being able to effectively structure the clinical consultation around patient needs (Ghazali N. *et al*, 2011;

Kanatas A, *et al*, 2012; Moots RJ and Rogers S, 2011). In some cases, PCIs also allow patients to choose who they wish to see or be referred to from a range of multidisciplinary team members or other non-medical professionals.

While PCIs are clearly useful for individual patients and clinicians, cumulatively they could potentially provide information about the wider needs of particular patient groups. The elderly make extensive use of community, health and social care services. These services are complex and expensive to manage. Successive governments have sought cost effective means of coordinating services in order to best maintain the health and independence of this population.

Recently, the DoH has encouraged the use of patient focussed approaches to support commissioners in undertaking health needs assessment (DoH, 2012). Hull PCT saw the experimental potential in using the PCI approach as a tool for health needs assessment, to support the true identification of patient need, and thereby potentially support service design and delivery for medical elderly patients. This report describes the results of the research study that Hull PCT funded.

# 3. Design and Methodology

The team was led by Professor Simon Rogers, the Chief Investigator based at Edge Hill University. The Principal Investigators at Hull and East Yorkshire NHS Trust were Dr Harman, Dr Saharia and Dr Richards, supported by a research nurse within the department. External review and additional support was provided by a Trial Steering Committee that included Professor Leslie Walker as an independent Chair. Hull and East Yorkshire acted as the trial sponsor, and REC approval was granted by the East Midlands NRES Committee on 30<sup>th</sup> September 2013.

This research project focused on three clinically defined groups within the medical elderly specialty: neuropsychiatric including dementia, depression and delirium; gastroenterology, including weight loss, swallowing problems, anaemia and bowel pattern disturbance; and collapse including explained and unexplained falls, collapse, syncope, and cardiac presentations.

The project was composed of two main stages. First, development of three PCIs for use with elderly patients being treated for neuropsychiatric diseases, gastroenterological diseases, or collapse, using the standard PCI methodology as developed by Professor Rogers. Second, testing of these three PCIs with 20 patients within each group as a prospective, single centre, nonrandomised, pilot study. Data collection consisted of the PCIs themselves, and patient and consultant satisfaction questionnaires.

A literature review provided an initial list of items which might be included in each of the three bespoke PCIs. This was subsequently reviewed by a Delphi panel composed of a range of clinical staff and patient representatives. It was then assessed by a focus group of patients suffering from symptoms related to Collapse, Gastroenterology or Neurology who were recruited from general care of the elderly clinics. These focus groups enabled similar terms to be grouped into terms readily understood by elderly people in Hull, and identified duplicative or confusing items. Data from all focus groups were used to develop the common components of the PCIs that would be used to support potentially common issues experienced by all three patient groups, while specific patient groups concentrated on issues related to the three conditions, for inclusion within those specific PCIs. As a final step, the three PCIs were reassessed by the Delphi panel. Professor Simon Rogers led this process and followed the established standard (Rogers S, *et al*, 2009; Flexen J, *et al*, 2011).

The resulting three PCIs (Appendix 1) were piloted with consenting patients presenting to Medical Elderly Clinics in Hull and East Yorkshire NHS Trust, led by a group of Care of the Elderly Consultants working with a senior research nurse within the department. Patients were selected sequentially within relevant clinics. Interested patients were consented prior to their clinic appointment, and then completed a PCI specific to their main treatment condition. The PCIs were paper based, rather than using a tablet or other medium, to make them more accessible for this age group. After consultation, the patients completed an 11 item standard RCGP patient satisfaction questionnaire. The consultants were asked to make a note of any onward referrals which they made for each patient and to note the start and finish time of the consultation. To ensure timely capture of their opinions on the usefulness of the PCI, the consultants completed a questionnaire immediately after the consultation.

The main focus of this study was to assess which services patients required access to, and the volume of services patients were referred to, with the aim of assessing whether this approach can be used to identify clinical needs and the services that should be used to address these. A secondary aim was to assess the value of the PCI in terms of patient satisfaction, and usefulness to consultants. Due to the small patient numbers, only descriptive summary statistics were used, and data were managed through Edge Hill University.

# 4. Results and Commentary

## 4.1 Patient Profile

A total of 61 patients were recruited into the trial, one of whom did not ultimately attend clinic. All remaining participants successfully completed the trial with 20 patients in each clinical group. Across all three groups patients' ages ranged from 71-96 years old, with 63% being over 80 years old. 67% of all patients were female. See Figure 1. Neuropsychiatry patients tended to be older than those in the other two clinical groups. 75% of those in the neuropsychiatry group were over the age of 80 in comparison to 60% in the collapse group and 55% in the Gastroenterology group. Figure 2 shows the gender and age profile of the patients recruited into each clinical group. This being a pilot study, no attempt at randomisation of the sample was made with the selection of patients being made on a sequential basis within each clinic. Anecdotal evidence suggests that the resulting age and gender profile is generally representative of the three clinics.

# 4.2 Main Presenting Conditions

Patients within the Collapse group had a small number of clearly defined presenting criteria, having either had a fall (55%), suffered dizziness (35%), or having poor mobility (10%). Gastroenterology and Neurology patients presented with a wider range of symptoms and conditions. Common presenting symptoms for Gastroenterology were Low HB/Anaemia (45%) and Weight Loss (20%), and for Neurology TLOC/STML (20%), Memory Loss (15%), Parkinson's Disease (15%), and Dizziness (15%). See Table 1.

Clear symptom based clinics, such as Collapse, are more amenable to having services built around them, since most patients will likely have similar needs. Providing services for Neurology and Gastroenterology groups may be more difficult, since patients have a greater range of symptoms.

# 4.3 Types of Patient Concerns

Each of the three PCIs were composed of five sections. 'Your Health and Treatment' related to issues that were common and specific to that particular patient group (Collapse, Gastroenterology, Neuropsychiatry). The other four sections were common issues that were

considered to affect all of these groups, and potentially elderly people in general. 'Coping with Everyday Life' addressed functional ability, such as Walking, Using Stairs, Dressing Yourself etc. 'Care and Support in Your Home' addresses the home and living situation, including 'Manging your Home', 'Money and Benefits', 'Caring for Others' etc. 'How You Feel Within Yourself' addresses psychological and social issues, such as 'Anxious', 'Loss of Confidence', 'Lonely' etc. The final section seeks to trigger requests that the patient feels they need, by asking the question 'Would you like to be able to talk to or be referred to any of the following?'. This mainly included common services, such as 'Social Services', 'Mental Health Teams', but may include specialist services appropriate to particular conditions, such as 'Alzheimer's Society'.

# 4.3.1 Your Health and Treatment

Common across all three patient groups was a keenness for patients to discuss their 'Health and Treatment', which consisted of items related to their diagnosis, symptoms, and direct clinical problems. All patients ticked at least one item in this group (Table 2.1), with patients indicating an average of five to six items each (Tables 2.2 -2.5). Although some items were rarely used, such as 'Treatment Side Effects', 'Other Illnesses', 'End of Life Care', 'Bladder Problems' and 'Bleeding', and these could potentially be removed, a large range of diverse issues was identified in this section, which appeared to trigger additional discussions during consultations. "Diagnosis", was selected by 78% of patients across the three groups and was perhaps too indiscriminate an item. Later iterations of the ME-PCI could explore how this item could be reworded. Figures 3.1 - 3.3 illustrate patients' concerns by clinical group. It can be seen that patients identified a broad range of multiple concerns within this well used section.

# 4.3.2 Coping with Everyday Life

This section addresses concerns related to mobility and self-care, such as 'Walking', 'Using Stairs', Washing yourself', 'Using the toilet' etc. Overall some 60% of patients ticked at least one item from this group, and one - two items on average (see Table 2.1). Common concerns were 'Falling' (25% of all patients), 'Walking' (20%),' 'Incontinence' (17%), 'Using Stairs' (17%), 'Using the Toilet' (12%), 'Washing Yourself' (7%) and 'Bath & Showering' (8%). Less popular issues included 'Dressing Yourself' (3%), 'Getting In and Out of Car' (3%), 'Driving' (3%), and 'Getting Exercise' (2%).

Two thirds of the Collapse group indicated an item in this section (Table 2.2), with concerns being concentrated in the areas of 'Walking' (25% of all Collapse patients), 'Falling' (20%), 'Incontinence' (20%), 'Using Stairs' (15%) and 'Washing Yourself' (10%). See Figure 3.1. Just under half of the Gastroenterology group indicated at least one item in this section (Table 2.3), and these concerns were focussed on 'Walking' (25%), 'Falling' (15%) and 'Using Stairs' (10%), with individuals having an equal spread of other issues. See Figure 3.2.

Just over two thirds of the Neuropsychiatry group indicated at least one item in this section (Table 2.4), signalling concerns with 'Falling' (40%), 'Using Stairs' (25%), 'Using the Toilet' (25%), 'Incontinence' (25%), 'Bath/Showering' (15%), and 'Walking' (10%). This group had a slightly broader range of issues than those reported by the other two groups. See Figure 3.3.

These findings suggest that some two thirds of patients across all groups have concerns regarding personal mobility and personal care. Whether these issues can be addressed by physical modification to their homes and personal mobility, such as handrails, walkers, stairlifts, elevated toilets etc, or require direct personal care, is unknown. However, it does indicate the need for a more integrated approach between health and social care focused on specific functional issues.

## 4.3.3 Care and Support in Your Home

This section sought to address issues relating to the patient and their home life, while offering a route for patients to address more significant problems. Approximately a third of patients completed at least one item in this section. More common concerns were 'Money and Benefits' (15%), 'Seeing Your Family' (13%), 'Caring for Others' (10%), 'Carers' (10%), and 'Meals' (10%). Less common were areas of 'Managing Your Home' (7%), and 'Loss of Independence' (3%). See Table 2.1.

Just under half (45%) of Collapse patients identified concerns in this section (Table 2.2), with the most common item being 'Money and Benefits' (30%). See Figure 3.1. Interestingly, no patients indicated a concern about 'Loss of Independence'. By contrast, only a quarter of Gastroenterology patients identified any concerns in this section (Table 2.3). This group's commonest concern was 'Caring for Others' (15%). See Figure 3.2. Some 40% of the Neuropsychiatry group of patients identified concerns in this section (Table 2.4), with the most common concern being 'Seeing Your Family' (25%). See Figure 3.3.

Overall it appears that well over a third of patients had concerns in this area, and that these were pragmatic concerns, relating to income, family contact and carer responsibilities. These are not necessarily issues that would otherwise be easily and spontaneously identified in clinics.

## 4.3.4 How You Feel Within Yourself

This section aimed to allow patients to communicate their wider psychological and social concerns. Some two thirds of patients indicated at least one item in this section, with patients indicating one - two items on average. Common concerns were 'Low Mood' (37%), 'Anxiety' (33%), 'Loss of Motivation' (18%), 'Depression' (13%), 'Lonely' (12%), and 'Loss of Confidence' (12%). Less common concerns were 'Communication' (5%), 'Loss of Dignity' (2%), 'Nervous' (2%), 'Isolated' (2%). No patients indicated 'Religious Needs' or 'Alcohol Problems'. See Table 2.1.

Some 70% of Collapse patients identified concerns in this section (Table 2.2), most commonly, 'Low Mood' (50%), being 'Anxious' (35%), 'Loss of Confidence' (20%), and 'Loss of Motivation' (20%). See Figure 3.1. Half of Gastroenterology patients identified concerns in this section (Table 2.3), reporting 'Low Mood' (25%), 'Depressed' (20%), and 'Loss of Motivation' (20%). See Figure 3.2. In the Neuropsychiatry group, 70% of patients identified concerns in this section (Table 2.4), and the most common items indicated were 'Anxiety' (50%) and 'Low Mood' (35%). See Figure 3.3.

It is clear from these results that psychological concerns are common in these groups of patients, particularly low mood and anxiety. Interestingly few patients identified concerns regarding 'Loss of Dignity' (2% across all patients). The high number of concerns which were indicated in this section highlights the need for psychological/social support across this group of patients.

## 4.3.5 Would you like to be able to talk to or be referred to any of the following?

In order to elicit additional concerns and discussions, patients were invited to indicate potential referrals they considered necessary. The aim of this section was to enable focused discussions on patient identified need, and also trigger issues that may not have been already addressed. Overall some 42% of patients indicated at least one need within this section, with an average of one - two items each. The most common were Age UK (13%), Social Services (12%), the Mental Health Team (12%), and 'Occupational Therapy' (10%). Less common were 'Dietician' (5%), 'Chiropodist' (5%), 'Continence Service' (3%),

'Physiotherapy' (2%) and 'Palliative Services' (2%). No patients requested 'Community Nursing' or 'Chaplain' services (Table 3).

Figure 4 details the referral requests made by patients in each clinical group. Half of Collapse patients made requests in this section, with the most common requests being for 'Age UK' (25%), 'Social Services' (20%) and 'Mental Health Team' (15%). Some 40% of Gastroenterology patients made requests, with the most common being 'Mental Health Team' (15%), 'Occupational Therapy' (10%), 'Age UK' (10%) and 'Dietician' (10%). Just over a third of Neuropsychiatry patients made requests in this section, requesting help from 'Social Services' (10%), 'Occupational Therapist' (10%), and 'Chiropodist' (10%).

Overall, under half of patients requested a specific onward referral, and although these were mainly for Age UK, social services, the mental health team, or occupational therapy, it can be seen that there existed a wide spread of referral requests with some patients requesting more than one. These requests formed the basis for contextual discussions with patients, and actual referral patterns are discussed below in section 4.4.

## 4.4 Referrals Made

The consultants were asked to take note of any onward referrals which they made for the patient. 50% of all patients were referred on (see Table 4). Common referrals were for Physiotherapy (10%), Occupational Therapy (8%), Dieticians (7%), and Social Services (5%), followed by a range of other professions, including several acute services. Collapse and Neuropsychiatry patients had the highest onward referral rates (60% and 65% respectively) and the most diverse range of referral destinations, indicating that multi-disciplinary team approaches were more commonly needed for these groups of patients.

In the Collapse patient group, 60% of patients were referred onwards to a range of nine professional groups. Some 10-15% of patients were referred to Social Services, Age UK, Occupational Therapy or Continence Services. A similar pattern was found in Neuropsychiatry, where 65% of patients were referred to ten groups, most commonly Physiotherapy (25%), Neurology & Occupational Therapy (both 10%). The Gastroenterology group had a much smaller referral range of only four specialties, concentrating on Dieticians (15%).

It is clear that this patient group, particularly those in the Collapse and Neuropsychiatry sub groups, have a wide range of varied needs, and frequently require multi-disciplinary team management. Common professional groups referred to were Physiotherapy, Occupational Therapy, Dieticians, and Social Services. In view of these findings, parallel provision of some services may be appropriate for specific clinics. For example, Social Services, Occupational Therapy, Age UK and Continence Services might be appropriate for Collapse Clinics, while Dieticians may be appropriate for Gastroenterology Clinics, and Physiotherapy, Occupational Therapy and possibly Dieticians may be of benefit with Neuropsychiatry clinics.

## 4.5 Utilisation of PCI and Consultation Times

Comparable data on this topic were not collected but anecdotal evidence from the consultants themselves suggests that the use of the PCI did not lengthen the consultation. Consultations times ranged from 10 minutes to 90 minutes. Table 5 shows the average length of the consultations by clinical group. Figures 5.1 - 5.3 provide a graphical representation of how the number of items selected on an individual PCI may have impacted upon the length of the consultation. Prima facie there would seem to be no relationship between the two. This may be explained in that the PCI increases the range of issues discussed, but accelerates that discussion by easing communication, so that the overall impact is balanced, although individual consultations may be shorter or longer than normal.

# 4.6 Patient Satisfaction with the Clinical Consultation

For this pilot study no comparison was made with existing clinics that did not use the PCI. However, it does seem clear that the PCI had no negative effects on patients, with many expressing high degrees of satisfaction across several dimensions. The patient satisfaction questionnaire demonstrates that patients were happy with the quality of the clinical consultation in terms of feeling at ease and being engaged in the consultation. The aggregated results by each clinical group are presented in Figure 6. These data show that 98% of patients answered Very Good/Excellent/Outstanding over the full range of questions.

## 4.7 Consultant Satisfaction with the PCI within the Clinical Consultation

Figures 7.1 – 7.3 detail the results of the consultant questionnaire by clinical group and Table 6 presents aggregated data for all patients. Overall consultants found the PCI easy to integrate into the consultation (92%), felt that all or most of the items ticked by the patient were discussed (95%), that the PCI improved the consultation (88%), that the patient found the PCI useful (85%), and that it aided communication (95%). However, there was less agreement as to whether the PCI triggered any additional support that might have otherwise been missed, with 60% indicating definitely or maybe yes, 20% being unsure, and 18% believing not.

Within each sub-group, these patterns were broadly reflected. In the Collapse group 75% indicated that the PCI triggered support that otherwise may have been missed. There were lower but still substantial rates in the Gastroenterology group (55%) and the Neuropsychiatry group (50%). Appendices 2-4 presents the free text comments which the consultants were invited to make on the questionnaire. These comments are very positive with many consultants noting how the PCI aided communication between the patient and themselves.

## 5. Discussion

This study developed and trialled three PCIs for use in groups of the medical elderly (see section 4) defined by their primary condition or need (neuropsychiatric, gastroenterology and collapse, see section 4.2), given that elderly patients have complex and often interlocking conditions (see sections 4.3.1) that frequently require management by a multi-disciplinary team (see section 4.4) drawing on different clinical professionals, along with social services and voluntary agencies such as Age UK (see sections 4.3.5 and 4.4). Data was collected on patient requirements (demand), clinical referral or signposting (supply), patient satisfaction, and consultant opinion. The aim of the project was to (1) establish whether the PCI could be used in this more complex patient group, particularly as a health needs assessment tool in order to support effective commissioning, and (2) ascertain its ability to improve the quality of clinical consultations for the patient.

With regard to how patients used the PCI, across all groups they indicated an average of approximately eight to ten items with the majority of patient concerns being centred around their health and treatment. Also of note was the large number of concerns in relation to low mood, anxiety and depression (see section 4.4). Whilst the PCI did not identify new referral areas, it did help to identify which services could potentially be usefully delivered in parallel, and services for which there is higher demand.

In terms of the quality of the subsequent clinical consultation, patients showed a clear appreciation for the PCI (see section 4.6). To what degree this can be attributed to the PCI itself is hard to determine in this pilot study, since it would require a larger sample with comparative arms. However, consultants generally found the PCI of benefit, particularly for Collapse patients, in helping to clearly identify their issues and aiding communication (see

section 4.7). There was slightly less certainty with regard to whether the PCI triggered additional areas of concern, particularly for the Gastroenterology and Neuropsychiatry clinics. This may be a reflection of the patient group and the clinic format. Collapse patients are more likely to have suffered a recent incident that has created a number of new concerns that need addressing. By contrast, Gastroenterology Clinics may be addressing a more longstanding issue that has had a less immediately profound effect on the patient. Similarly, Neuropsychiatry clinics are likely to already address a broader range of issues, so may benefit less from the PCI. Average consultation time, which is typically approximately 30 – 60 minutes for these patients, did not seem to be adversely effected by the use of the PCI. Consultants comments indicate that where the PCI did generate additional discussion, this could usually be addressed relatively quickly and that the PCI streamlined the identification and communication of issues (see section 4.5).

Overall, the study found that it was possible to develop PCIs for use with sub-groups of the medical elderly. Interestingly, the needs of elderly patients are not primarily defined by their age, but by their conditions (see sections 4.2 and 4.3.1) and their individual socio-economic and socio-psychological settings (see sections 4.3.2 - 4.3.4). This supports the approach taken in this study that it would not be possible to produce a single 'elderly PCI'.

While the PCI could be used as a patient-centred means of health needs assessment, other similar techniques, such as a patient and consultant sampled checklists, could provide equally useful data, since patient and consultant requests showed a small range of variation. However, both patient and consultant reported outcomes strongly indicated that the PCI improved the quality of the clinical consultation for the patient, and this appears to have limited impact on the average duration of consultations. Quantifying this impact would need a comparative trial, but these findings do accord with previous work using the PCI. The PCI aids patient communication in this group, and can be used as a method for health needs assessment.

This project gives some guidance as to how the PCI could be used in practice. First, the PCI appears more useful in clear symptom based clinics, particularly those dealing with an acute or sudden change in circumstances with wide ranging impacts, where a range of needs may be present, and where understanding and communicating those needs may be more difficult. The Collapse Clinics were a good example of this.

Second, since there may have been some reticence on the part of patients to identify wider social need to consultants, it may be that the PCI approach could be shared between consultants, nursing staff or AHPs. This may further ease communication in a cost effective manner, and allow the PCI to be readily integrated into nursing care.

Third, while clinical issues dominated most patient concerns, many of the elderly had difficulties with commonly identifiable issues, such as personal care and mobility, income and benefits, and family and carer responsibilities. These issues were largely pragmatic, and could be managed by appropriate referrals to specific public services or voluntary or commercial agencies. For example, handrails, walkers, stair-lifts, managed carer provision and respite support etc. Many patients had psychological and social needs, mainly relating to low mood and anxiety, and it can be argued that provision of mental health services, although less directly functional in nature, are similarly pragmatic approaches that could be integrated into routine services, probably at a fairly low level of intensity.

Fourth, some clinics, particularly those identified above, could benefit from parallel provision of a mixture of specific clinical and social services to address areas such as benefits, building modifications etc., and voluntary or commercial organisations to address more subtle needs, such as respite, mental health support etc. For example, Social Services, Occupational Therapy, Age UK and Continence Services would appear to be useful for new patients in Collapse Clinics, since it is likely they would be fully utilised, and therefore cost effective. Social and voluntary provision could be built into these clinics – for example, mental health care using voluntary or commercial organisations. Gastroenterology Clinics would benefit from Dietician support, and Neuropsychiatry clinics may gain from Physiotherapy and Occupational Therapy provision. Other clinics would have different potential configurations, and by assessing these, it is likely that some common sets of collective provision could be usefully delivered in parallel for many services dealing with these clinical groups.

## 6. Conclusion

The PCI approach, which has previously been used in cancer, can be developed and used in elderly patients with chronic and complex conditions. In this single centre pilot study, the PCI was well received by both patients and consultants. The use of the PCI reportedly resulted in better communication in the clinical setting, making it easier to identify and address issues of concern to the patient. The PCI did not appear to extend the length of average consultation.

With regard to the quality of patient consultations, the PCI was an effective aid to patient communication, being welcomed by patients and consultants, and being readily embedded within clinical practice. The use of the PCI could be extended to include nursing, AHP or other staff, which may ease the identification of issues, supporting more rapid and cost effective care.

While the PCI can be used as a health needs assessment tool, and indeed has demonstrated defined needs for specific clinics, other approaches to this can be taken. In this study, onward referrals were required for 50% of patients. In terms of designing elderly service provision, it appears that (a) clinics seeing patients referred to elderly medicine with collapse would benefit from support from Social Services, Age UK, Occupational Therapy and Continence Services, (b) clinics seeing patients referred to elderly medicine with gastrointestinal symptoms would benefit from support from dieticians, and (c) clinics seeing patients referred to elderly medicine with neuropsychiatry issues would benefit from Neurology, Psychiatry, Occupational Therapy and Physiotherapy services. General Clinics, where patients were intermingled, would benefit from Physiotherapy, Occupational Therapy, Dieticians and Social Services. It may be possible that some Social Service support could be routed via Age UK or vice versa, thereby defraying costs.

With regard to cost effectiveness, a future trial could assess the degree to which PCI need identification, and the delivery of that need, was preventative in nature, and quantify the potential for cost savings related to this.

#### **Bibliography**

DoH, National Cancer Action Team, Holistic Needs Assessment for People with Cancer: A Practical Guide for Health Care Professionals', DoH, London, 2012

Flexen J, Ghazali N, Lowe D, Rogers SN. Identifying appearance-related concerns in routine follow-up clinics following treatment for oral and oropharyngeal cancer. Br J Oral Maxillofac Surg. 2011 Jun 14.

Ghazali N and Rogers SN. The Head and Neck Cancer Patient Concerns Inventory (PCI): A Practical Holistic Assessment Tool in Outpatient Setting. PRO Newsletter #45 (Spring 2011)

Ghazali N and Rogers SN. The Head and Neck Cancer Patient Concerns Inventory (PCI): A Practical Holistic Assessment Tool in Outpatient Setting. PRO Newsletter #45 (Spring 2011)

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 Nov;19(11):1879-86.

Kanatas A, Ghazali N, Lowe D, Rogers SN. The identification of mood and anxiety concerns using the patients concerns inventory following head and neck cancer. Int J Oral Maxillofac Surg. 2012 Jan 18.

Millsopp L, Frackleton S, Lowe D, Rogers SN. A feasibility study of computer-assisted health-related quality of life data collection in patients with oral and oropharyngeal cancer.. Int J Oral Maxillofac Surg. 2006 Aug;35(8):761-4.

Moots RJ, Rogers SN. Rheumatology today and in the future. Rheumatology (Oxford). 2011 Dec;50(12):2149-50.

Rogers SN, El-Sheikha J, Lowe D. The development of a Patients Concerns Inventory (PCI) to help reveal patients concerns in the head and neck clinic. Oral Oncology 2009; 45: 555–561

Rogers SN. Clifford N, Lowe D. Patient and carer unmet needs: a Survey of the British Association of Head and Neck Oncology Nurses. .BJOMS 2011; 49: 343-348.

Rogers SN. How developments in Maxillofacial Surgery have contributed to improved quality of life for patients. ENT & Audiology News 2011; 20: 46-48.





Age Range of all Patients: 71 - 96 Years



**Gender: All Patients** 



■ 70 - 80 years ■ > 80 years





# Figure 2: Gender and Age Profiles by PCI Clinical Group





Your Health & Treatment



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# Care & Support in your Home



Figure 3.2: Types of Concerns: Gastroenterology





**Care & Support in Your Home** 



Figure 3.3: Types of Concerns: Neuropsychiatry

**Coping With Everyday Life** 







**Care & Support in Your Home** 







Figure 5.1: Collapse: Length of Consultation and Total Number of Items Ticked on the PCI

Fig 5.2: Gastroenterology: Length of Consultation and Total Number of Items Ticked on the PCI





Figure 5.3: Neuropsychiatry: Length of Consultation and Total Number of Items Ticked the PCI



# Figure 6: Aggregated Data from Patient Satisfaction Questionnaires Collapse



# Figure 7.1: Consultant Questionnaire: Collapse



# Figure 7.2: Consultant Questionnaire: Gastroenterology



# Figure 7.3: Consultant Questionnaire: Neuropsychiatry

Condition	Collapse %	Gastroenterology %	Neuropsychiatry %	Total %
	(n=20)	(n=20)	(n=20)	(n=60)
Dizziness	35		15	17
Fall	55			18
Poor Mobility	10			3
Abdominal Pain		10		3
Anaemia		15		5
Chronic Bowel		5		2
Diarrhoea		5		2
Low HB		30		10
Nausea		5		2
Reflux		5		2
Upper GI Bleed		5		2
Weight Loss		20		7
Confusion			10	3
CVA			5	2
Dementia			10	3
Headaches			5	2
Memory Loss			15	5
Parkinson's Disease			15	5
TLOC/STML			20	7
Tremor			5	2
Total	100	100	100	100

# Table 1: Patients Main Presenting Conditions: %

Your Health &	%	Coping With Everyday	%	Care & Support in Your	%	How You Feel Within	%
Treatment	n=60	Life	n=60	Home	n=60	Yourself	n=60
Diagnosis	78	Walking	20	Managing your home	7	Anxious	33
Bleeding	8	Using stairs	17	Money and benefits	15	Loss of confidence	12
Appetite	18	Falling	25	Caring for others	10	Depressed	13
End of Life Care	1	Getting exercise	2	Your carers	10	Low mood	37
Eye Sight	17	Getting in & out of car	3	Meals	10	Loss of dignity	2
Hearing	15	Driving	3	Seeing your family	13	Nervous	2
Medication	38	Dressing yourself	3	Loss of independence	3	Lonely	12
		Washing yourself	7	Neglect	0	Loss of motivation	18
		Bath / showering	8	Abuse	0	Isolated	2
		Using the toilet	12			Religious needs	0
		Incontinence	17			Alcohol problems	0
						Communication	5
% ticking at least one item in the section	100		60		37		63

 Table 2.1: Types of Concerns: Common Categories For All Patients: %

Table 2.2	Items of	Concern:	Collapse
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Section	Items Indicated (Rounded Average <sup>1</sup> )	% ticking at least one item in the section
Your Health & Treatment	6	100%
Coping With Everyday Life	1	65%
Care & Support in Your Home	1	45%
How You Feel Within Yourself	2	70%
Would You Like to be Able to Talk to or be Referred to Any of the Following	1	50%
Total Items	10	

# Table 2.3: Items of Concern: Gastroenterology

Section	Items Indicated (Rounded Average)	% ticking at least one item in the section
Your Health & Treatment	5	100%
Coping With Everyday Life	1	45%
Care & Support in Your Home	1	25%
How You Feel Within Yourself	1	50%
Would You Like to be Able to Talk to or be Referred to Any of the Following	1	40%
Total Items	8	

<sup>&</sup>lt;sup>1</sup> Total items ticked in the category within the patient group, divided by the number of patients in that group.

Table 2.4: Items of Concern: Neur	ops	sychiatry
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Section	Items Indicated Rounded Average	% ticking at least one item in the section
Your Health & Treatment	5	100%
Coping With Everyday Life	2	70%
Care & Support in Your Home	1	40%
How You Feel Within Yourself	2	70%
Would You Like to be Able to Talk to or be Referred to Any of the Following	1	35%
Total Items	9	

Would you like to be able to talk to or be referred to any of the following?	% n=60
	10
Social Services	12
Mental Health Team	12
Physiotherapy	2
Occupational Therapy	10
Chiropodist	5
Age UK	13
Community Nursing	0
Continence service	3
Palliative Care	2
Dietician	5
Chaplain	0
total % patients requesting a referral	42

# Table 3: Common Referral Requests For All Patients: %

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Referral Type	Collapse % n=20	Gastroenterology% n=20	Neuropsychiatry% n=20	Total % n=60
Social Services	15	0	5	5
Mental Health Team	0	5	5	3
Physiotherapy	5		25	10
Occupational Therapy	10	5	10	8
Chiropodist	5		5	3
Age UK	15	0	0	3
Community Nursing				0
Continence service	10	0		3
Palliative Care	0			0
Dietician		15	5	7
Chaplain				0
Alzheimer's Society			0	0
OTHER SERVICES				
Admiral Nurses	5		5	3
ENT	5			2
Upper GI MDT		5		2
Psychology			5	2
Psychiatry			5	2
Neurology			10	3
Ophthalmology	5			2
Patients Indicating Referral	60%	25%	65%	50%

# Table 4: Onward Referrals Made For All Patients: %

# Table 5: Average Duration of Clinical Appointment by Clinic Type

Average Consultation Time (mins)				
Collapse Gastroenterology Neuropsychiatr				
34	28	31		

	% n=60	% n=60	% n=60
	Very Easy/Easy	Neither Easy Nor Difficult	Difficult/Very Difficult
How easy was it for you to include the PCI in the consultation?	92	5	3
	All/Most	Some	A Few/None
Do you feel that the PCI items ticked by the patient were discussed/included in the consultation?	95	2	3
	Much Better/Better	No Difference	Worse/Much Worse
Do you think the PCI made a difference to the consultation?	88	12	0
	Definitely Yes/Maybe Yes	Not Sure	Maybe Not/Definitely Not
Do you feel that the PCI was something this patient found useful?	85	15	0
	Definitely Yes/Maybe Yes	Not Sure	Maybe Not/Definitely Not
Do you feel that the PCI helped the patient communicate with you?	95	5	0
	Definitely Yes/Maybe Yes	Not Sure	Maybe Not/Definitely Not
Do you feel that the PCI items triggered any additional support that might otherwise have been missed?	60	20	18

# Table 6 Consultant Satisfaction Questionnaire: Aggregated Data For All Patients: %

Appendix 1: ME-PCI Patient Questionnaires Collapse, Gastroenterology, and Neuropsychiatric

# **Collapse Patient Concerns Inventory**

Please tick any of the items below which are of concern to you and which you would like to talk about during your consultation in clinic today. You can choose more than one concern. You are also asked to tick any of the services to which you may wish to be referred. This form will then be given to the doctor who is seeing today.

### YOUR HEALTH AND TREATMENT

- □ Diagnosis
- □ Arthritis
- □ Tremours
- □ Weakness
- □ Chest pain
- □ Medications
- □ Appetite
- □ Weight loss or gain
- □ Faint or dizzy
- □ Hearing
- $\Box$  Eye sight
- □ Trouble sleeping
- □ Tiredness
- □ Treatment side effects
- □ Pain
- □ Swollen ankles
- □ Bleeding
- □ Other illnesses
- $\Box$  End of life care

## **COPING WITH EVERY** DAY LIFE

- □ Walking
- □ Using stairs
- □ Falling
- □ Getting exercise
- □ Getting in & out of car

- □ Driving
- □ Dressing yourself
- □ Washing yourself
- □ Bath / showering
- □ Using the toilet
- □ Incontinence

#### **CARE & SUPPORT IN** YOUR HOME

- □ Managing your home
- □ Money and benefits
- □ Caring for others
- □ Your carers
- □ Meals
- □ Seeing your family
- □ Loss of independence
- □ Neglect
- □ Abuse

#### **HOW YOU FEEL** WITHIN YOURSELF

- □ Anxious
- $\Box$  Loss of confidence
- Depressed
- □ Low mood
- $\Box$  Loss of dignity
- □ Nervous
- □ Lonely
- □ Loss of motivation

- □ Isolated
- □ Religious needs
- □ Alcohol problems
- □ Communication

## **OTHER CONCERNS**

#### WOULD YOU LIKE TO BE ABLE TO TALK TO OR BE **REFERRED TO ANY OF** THE FOLLOWING?

- □ Social Services
- □ Mental Health Team
- □ Physiotherapy
- □ Occupational Therapy
- □ Chiropodist
- □ Age UK
- Community Nursing
- □ Continence service
- □ Palliative Care
- Dietician
- □ Chaplain

## **OTHER SERVICES**

Thank you very much for your time in completing this PCI. We hope that you have found it a useful. All information is confidential

# **Gastroenterology Patient Concerns Inventory**

Please tick any of the items below which are of concern to you and which you would like to talk about during your consultation in clinic today. You can choose more than one concern. You are also asked to tick any of the services to which you may wish to be referred. This form will then be given to the doctor who is seeing today.

## YOUR HEALTH AND TREATMENT

- □ Diagnosis
- □ Medications
- □ Appetite
- □ Weight loss or gain
- □ Bowel problems
- □ Bladder problems
- Nausea
- □ Swallowing
- $\Box$  Cough
- □ Breathlessness
- □ Indigestion
- □ Heartburn
- □ Hearing
- □ Eye sight
- □ Trouble sleeping
- □ Tiredness
- □ Treatment side effects
- Pain
- □ Swollen ankles
- □ Bleeding
- □ Other illnesses
- □ End of life care

## COPING WITH EVERY DAY LIFE

- □ Walking
- □ Using stairs
- □ Falling

- □ Getting exercise
- $\Box$  Getting in & out of car
- □ Driving
- □ Dressing yourself
- □ Washing yourself
- □ Bath / showering
- □ Using the toilet
- □ Incontinence

## CARE & SUPPORT IN YOUR HOME

- □ Managing your home
- $\hfill\square$  Money and benefits
- □ Caring for others
- □ Your carers
- □ Meals
- □ Seeing your family
- □ Loss of independence
- □ Neglect
- □ Abuse

#### HOW YOU FEEL WITHIN YOURSELF

- □ Anxious
- $\Box$  Loss of confidence
- □ Depressed
- $\hfill\square$  Low mood
- $\hfill\square$  Loss of dignity
- □ Nervous
- $\Box$  Lonely

- □ Loss of motivation
- □ Isolated
- □ Religious needs
- □ Alcohol problems
- □ Communication

## **OTHER CONCERNS**

- WOULD YOU LIKE TO BE ABLE TO TALK TO OR BE REFERRED TO ANY OF THE FOLLOWING?
- □ Social Services
- Mental Health Team
- □ Physiotherapy
- Occupational Therapy
- □ Chiropodist
- □ Age UK
- □ Community Nursing
- Continence service
- Palliative Care
- Dietician
- □ Chaplain

## **OTHER SERVICES**

Thank you very much for your time in completing this PCI. We hope that you have found it a useful. All information is confidential

# **Neuropsychiatric Patient Concerns Inventory**

Please tick any of the items below which are of concern to you and which you would like to talk about during your consultation in clinic today. You can choose more than one concern. You are also asked to tick any of the services to which you may wish to be referred. This form will then be given to the doctor who is seeing today.

### YOUR HEALTH AND TREATMENT

□ Driving

- □ Diagnosis
- □ Butterfly Scheme
- □ Hallucinations
- □ Memory
- □ Headaches
- □ Medications
- □ Appetite
- □ Weight loss or gain
- □ Hearing
- $\Box$  Eye sight
- □ Trouble sleeping
- $\Box$  Tiredness
- □ Treatment side effects
- □ Pain
- □ Swollen ankles
- □ Bleeding
- □ Other illnesses
- □ End of life care

## COPING WITH EVERY DAY LIFE

- □ Walking
- $\Box$  Using stairs
- □ Falling
- □ Getting exercise
- □ Getting in & out of car

- Dressing yourself
- □ Washing yourself
- $\Box$  Bath / showering
- □ Using the toilet
- □ Incontinence

## CARE & SUPPORT IN YOUR HOME

- □ Managing your home
- □ Money and benefits
- □ Caring for others
- □ Your carers
- □ Meals
- □ Seeing your family
- $\hfill\square$  Loss of independence
- □ Neglect
- □ Abuse

## HOW YOU FEEL WITHIN YOURSELF

- □ Anxious
- $\hfill\square$  Loss of confidence
- □ Depressed
- $\hfill\square$  Low mood
- □ Loss of dignity
- □ Nervous
- $\Box$  Lonely
- $\hfill\square$  Loss of motivation

- □ Isolated
- □ Religious needs
- □ Alcohol problems
- □ Communication

# **OTHER CONCERNS**

#### WOULD YOU LIKE TO BE ABLE TO TALK TO OR BE REFERRED TO ANY OF THE FOLLOWING?

- □ Social Services
- Mental Health Team
- □ Physiotherapy
- □ Occupational Therapy
- □ Chiropodist
- Age UK
- □ Community Nursing
- □ Continence service
- Palliative Care
- Dietician
- □ Chaplain
- □Alzheimer's Society

# **OTHER SERVICES**

Thank you very much for your time in completing this PCI. We hope that you have found it a useful. All information is confidential

# Appendix 2: Free Text Comments: Consultant Questionnaire: Collapse

How easy was it to include the PCI in the consultation?

Do you feel the PCI items ticked were discussed in the consultation?

Do you think the PCI made a difference to the consultation?

- Asked about mood
- Identified key areas that otherwise would have been missed
- More holistic
- Allowed her to cover concerns that I wouldn't have picked up
- More rounded consultation
- More holistic
- Diagnosed polymyalgiarhum. otherwise would not have covered symptoms as patient was follow up.
- Picked up continence issue

#### Do you feel that the PCI was something the patient found useful?

- Gave opportunity to discuss all concerns
- Identified 2\* drug side effects
- Allowed him to freely discuss his concerns
- Picked up depression and deteriorating sight
- Allowed him to cover his agenda
- Not Sure Think would have been covered as part of the consultation
- Holistic approach

#### Do you feel the PCI helped the patient communicate with you?

- Allowed patient to discuss end of life care
- Covered low mood and difficult in coping with wife's' dementia
- Hard of hearing. PCI allowed us to cover his concerns
- Allowed him to discuss freely his concerns
- Hard of hearing so allowed improved communication
- Hard of hearing. Helped patient put points across.

#### Do you feel the PCI triggered any additional support?

- Chiropody service
- Low mood, anxious
- OT and talk of end of life care
- Referral to social services
- Physio. Assess medications re low mood and consider CPA
- Had already self referred to social services. Had they not, PCI would have prompted that
- Continence service
- Refer to ophthalmology. Depression.
- OT input
- Continence

## Other comments

- Really provided insight into patients agenda
- Very happy post consultation and of time spent with him, explanations and changes made.
- Good. Useful
- Useful
- Age UK and finance were additional components covered as a result of the PCI

## Appendix 3: Free Text Comments: Consultant Questionnaire: Gastroenterology

How easy was it to include the PCI in the consultation?

Do you feel the PCI items ticked were discussed in the consultation?

- A Few - Cognitive impairment made this difficult

Do you think the PCI made a difference to the consultation?

- Covered areas otherwise left undisclosed
- Covered swollen ankles & stopped medications
- Holistic approach
- Clear concerns identified
- Focuses on concerns
- No Difference All points already covered
- No Difference As already covered
- Able to identify carer strain

#### Do you feel that the PCI was something patient found useful?

- Discussed care from the patients agenda
- Able to express her concern
- Allowed her to gather thoughts before consultation
- Gathered thoughts pre consult

#### Do you feel PCI helped patient communicate with you?

- Maybe yes as has short term memory loss helped gather thoughts
- Definitely yes to identify carer strain
- Not Sure but did help his daughter

#### Do you feel the PCI triggered any additional support?

- Review of medications
- Dietician, community clubs for social isolation
- Mood, anxiety
- Referral to mental health
- Social services

#### Other comments

- Useful guide to focus on
- Useful to address specific concerns
- Found it very useful
- Patient repeated all her concerns during consultation and they were addressed

# Appendix 4: Free Text Comments: Consultant Questionnaire: Neuropsychiatry

## How easy was it to include the PCI in the consultation?

- Difficult Cognitive impairment made it difficult to discuss in detail
- Easy although added 15 minutes to consult

Do you feel PCI items ticked were discussed in consultation?

Do you think the PCI made a difference to the consultation?

- Highlighted she wanted a referral to chiropody
- Explained social concerns lifeline
- Reassured that she could discuss all her concerns
- Allowed to discuss concerns e.g. coping
- Allowed more patient focused discussion
- Patient felt open to discussing areas of life otherwise not covered e.g. driving and anxiety
- More rounded approach
- Holistic approach
- Reduced medications as a result of this process
- Enabled a thorough assessment. Patient and relative felt listened to and issues addressed
- Son appreciated concerns being addressed
- Patient centred

## Do you feel that the PCI was something patient found useful?

- Picked up low mood otherwise missed
- Put patient at ease
- More involved
- Not Sure incorrectly completed
- Allowed to allay fears
- Not Sure although his daughter, main carer, did
- We discussed issues we would not previously have raised
- Allowed to discuss concerns re coping in the home
- Concerns were discussed, relatives felt reassured

## Do you feel PCI helped patient communicate with you?

- Has speech problem making consultation otherwise difficult
- Explained other symptoms
- Allowed a safety net and promoted open communication
- More relaxed
- Definitely yes due to cognitive impairment

## Do you feel the PCI triggered any additional support?

- Physio and alternative accommodation
- Explained other symptoms
- Social services and literature

- PT/OT and Falls at home
- Support to daughter
- PT
- Referred to mental health for depression. Would have triggered social services but already in progress.
- Neurology
- Already had a good care package. If physio had been available then maybe have been beneficial.
- Not sure seem to have relevant support

# Other comments

- It highlighted drug side effects nicely. Probably helps patent focus on concerns prior to consultation.
- Feel it's important. Part of a thorough assessment and allows patient centred care.