# NATIONAL BOWEL CANCER AUDIT

## The feasibility of using the Cancer Patient Experience Survey for comparative performance monitoring as part of a national colorectal cancer audit

**NBOCA: Feasibility Study**

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# 1. Executive Summary

Patient reported experience measures (PREMs) for cancer patients have been collected by NHS England via the Cancer Patient Experience Survey (CPES) since 2010. The aim of this short report was to explore the feasibility of reporting PREMs at hospital trust level in a cohort of newly diagnosed colorectal cancer patients admitted to hospital in England for initial treatment of their cancer through unique linkage of CPES responses to the National Bowel Cancer Audit (NBOCA).

Particular subgroups were under-represented within CPES responders including males, those at the extremes of ages, more deprived patients and those with more advanced disease. There was also significant variation in response rate according to diagnosing hospital.

Overall, CPES responses within colorectal cancer patients appeared positive and demonstrated good accuracy and clinical validity when compared with NBOCA data. A selection of CPES questions were evaluated as potential comparative performance indicators but lacked between-hospital variation negating their use for this purpose. The patient’s overall care score has scope to be used as a performance indicator but, due to small volumes, it is recommend that data are pooled over 3 years to give adequate statistical power. Further work is needed to understand the impact of differential non-response rates between hospital trusts on performance monitoring.

CPES can be linked to a relevant NBOCA cohort to provide national-level results in an annual report setting and monitor overall trends in responses. However, prior to this, methodological work to address bias from under-representation of certain patient groups needs to be addressed.

# 2. Introduction

Patient reported experience measures (PREMs) are essential measures of quality of care. The first Cancer Patient Experience Survey (CPES) was undertaken in England in 2010.[1] This national patient experience survey is commissioned annually by NHS England and forms an integral part of the NHS Cancer Programme and NHS Long Term Plan.[2] The survey has been designed to enable patients to provide their views on the care they have received through their entire cancer journey including primary and secondary care visits.[3]

Each year, unadjusted and case-mix adjusted results are provided at Clinical Commissioning Group (CCG) and NHS hospital trust level with separate analyses by tumour group. Case-mix adjustment accounts for gender, age, ethnic group, socioeconomic status and tumour group. These results are used to facilitate targeted future improvements, as well as enabling national comparative performance monitoring.[3]

The surveys are carried out in a snapshot of patients admitted to hospital for their cancer during a 3-month window. There is therefore wide heterogeneity in where patients may be in their care trajectory from initial neo-adjuvant treatment and major resection, all the way through to stoma reversal and end of life care. Results for colorectal cancer (CRC) patients are reported under the umbrella heading of ‘Lower GI’ tumours and include patients with small intestine and anal cancers. Additionally, the survey results are provided in isolation without any detailed patient, tumour or treatment data to guide their interpretation.

The aim of this report was to link the CPES responses to the National Bowel Cancer Audit (NBOCA) data to establish the feasibility of reporting PREMs as part of a national clinical audit. Specifically, to explore the reporting of these measures in a more homogeneous group of patients admitted to hospital for initial treatment of their primary CRC. In order to do this, an eligible cohort of newly diagnosed patients in NBOCA admitted for initial treatment of their cancer was used. In this cohort, the characteristics of CPES responders compared to non-responders was evaluated, as well as hospital trust variation in CPES response rate, and the clinical validity and accuracy of CPES responses in comparison to NBOCA data.

The potential for the development of new performance indicators for NBOCA using CPES responses was also investigated. Performance indicators are used to describe clinical performance and are helpful in identifying variation in practice and therefore facilitating quality improvement and benchmarking, informing policy-making and enabling more informed patient choice. Previous work has described four key considerations for the development and evaluation of performance indicators including assessment of validity, statistical power, technical specification and fairness.[4] Potential new performance indicators were appraised using this structured approach.

# 3. Methods

### 3.1 Cancer Patient Experience Survey (CPES)

This report utilises results from the 2015 iteration of the CPES survey which was designed, implemented and managed by Quality Health.[5] This wave of the survey was chosen as significant adjustments were made to the content of the surveys from this point forwards. This allowed us to assess the feasibility of a survey comparable to those from which data is going to be collected in the future.

The following inclusion criteria were used for the 2015 survey[6]:

- Aged 16 years and over on the date of discharge
- Alive at the time at which the survey was first distributed
- Confirmed primary diagnosis of cancer pertaining to the relevant ICD-10 codes in the first diagnosis field of their patient records
- All cancer patients; not just restricted to those newly diagnosed
- Discharged from an English NHS Trust following an inpatient episode or day case attendance for *cancer-related* treatment (elective or emergency) between 01 April 2015 and 30 June 2015

The collection of information for this survey was mandatory for all acute and specialist English NHS trusts which provide adult cancer services. Trusts were responsible for compiling a list of patients whom they deemed eligible from PAS (patient administration system) hospital records. This list was sent to Quality Health who distributed the survey accordingly with three separate deceased checks.[6]

The survey was not completed by patients until between October 2015 and March 2016. The 2015 survey was the first to use mixed mode methodology. Surveys were distributed by post and followed up with two reminders as required. Patients were able to complete the survey online or via a telephone service with translation facilities if required.

The eligible sample size for this wave of the survey across all cancers was 108,272 patients. The overall response rate was 66%, although the eligible cohort comprised only a minority of all patients with cancer because the inclusion criteria included a hospital admission with a discharge date in a 3-month window. This response rate is relatively high compared to other patient experience surveys which have response rates between 30-50%.[7] There were 8,696 responses recorded for the lower GI group but this includes small intestine and anal cancers which are not routinely captured by NBOCA.[6]

The 2015 survey included 69 questions about the care and treatment received by cancer patients and a final free text box for additional comments.[5] The questions broadly covered each part of the care pathway from diagnosis to treatment:

- *Care prior to and including diagnosis* – including diagnostic tests, seeing a General Practitioner and being informed of the diagnosis
- *Care during cancer treatment* – including deciding which treatment is best, Clinical Nurse Specialist input, general support provided, hospital care as either an inpatient, day patient or outpatient, and General Practitioner care
- *Basic information about the cancer diagnosis* – including time since first treatment, presence of metastatic disease at diagnosis and whether treatment was curative
- *Basic patient demographics* – including gender, longstanding conditions and ethnicity

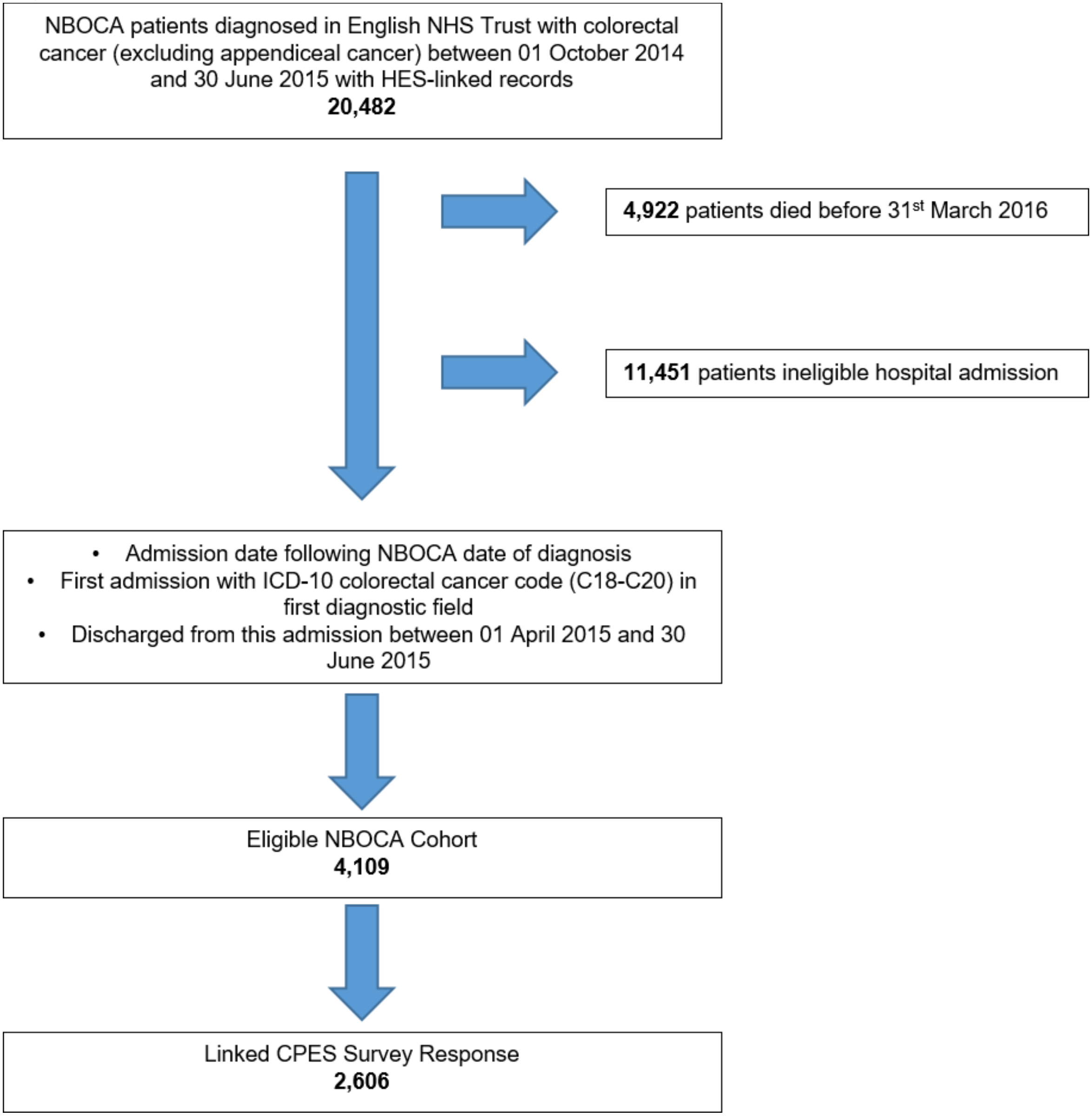
### ***3.2 Linkage to National Bowel Cancer Audit data***

The National Bowel Cancer Audit (NBOCA) is an audit of secondary care. It reports annually on patients *newly diagnosed* with CRC, assuming that the vast majority of patients should have an inpatient or daycase admission around the time of their diagnosis.

NBOCA data for patients diagnosed 01 October 2014 to 30 June 2015 was linked to Hospital Episode Statistics (HES) to provide information about all inpatient and daycase admissions to English NHS trusts. Patients who died prior to distribution of the survey were excluded. The first hospital admission following date of diagnosis with a first diagnostic field containing an ICD-10 code for CRC (C18-C20) was identified from HES.

A relevant cohort of 4,109 patients within NBOCA with a CRC-related hospital admission soon after diagnosis (median 24 days, IQR 0-42) was identified, who would be expected to have been surveyed according to the CPES eligibility criteria.[6] These patients are representative of the newly diagnosed patients who NBOCA would expect to report on within the audit setting (Figure 1). Of these, 2,606 patients (63%) had linked CPES survey responses.

**Figure 1 –** Flow diagram of study inclusion and data linkage



### *3.3 Feasibility analyses*

#### i) Characteristics of responders compared to non-responders

Patient, tumour and treatment characteristics of the 2,606 patients with linked CPES responses were compared to those of the 1,503 NBOCA patients identified as eligible for survey completion but without a linked CPES response.

#### ii) Hospital trust variation in response rate

National variation in the proportion of NBOCA patients with a linked CPES response out of those identified as eligible for CPES completion was explored according to NBOCA diagnosing trust. Annual volumes of patients per trust were low and therefore, as a sensitivity analysis, response rates were pooled for the 2013-2015 CPES waves.

### iii) Clinical validity and accuracy of responses

The correlation between survey responses and relevant patient, tumour and treatment characteristics from NBOCA data was used to assess the clinical validity of CPES responses. For example, the CPES response for the number of primary care attendances prior to hospital referral was correlated with initial TNM staging.

CPES responses were compared to NBOCA data in order to evaluate accuracy. For example, responses as to whether patients reported that they had undergone surgery were correlated with if they had received chemotherapy or radiotherapy.

### iv) Use of CPES measures as performance indicators

A selection of CPES responses were evaluated as performance indicators according to four previously described criteria: validity; fairness; statistical power and technical specification.[4] The clinical validity of the CPES questions was assessed in the previous sub-section. The fairness of CPES responses involves ensuring appropriate risk-adjustment can be performed, and assessing variation in response rate between providers (described above). NBOCA data linked to Hospital Episode Statistics provides rich information on the important patient and tumour characteristics needed for risk-adjustment, including demographics, cancer staging, performance status and comorbidities.

The technical specification of the CPES responses was assessed using questions which gave clinically meaningful information and measured aspects of care which were likely to be relevant to patients. Four questions previously reported by other national clinical audits were selected.[8] [9] Following evaluation of the distribution of responses for each question, it was determined that there was not enough variation to make hospital trust-level comparative monitoring purposeful in three of these.

Further evaluation was therefore focussed on the CPES question ‘Overall how would you rate your care?’ for which a response was marked on a Likert scale of 0 to 10. The main consideration with this response was determining which score cut-off to use (≥7, 8, 9 or 10). Statistical power was calculated based on a 10% absolute reduction in the proportion of patients rating their overall care above each of the different score thresholds. The validity of the indicator was also evaluated for each score threshold, by assessing its association with each of the following likely correlated: sex, age, mode of presentation, length of stay, unplanned readmission and unplanned return to theatre.

The amount of between-hospital variation in responses according to different score thresholds was also determined using funnel plot methodology and intra-class correlation co-efficients (ICCs). ICCs for each threshold were obtained using random effects logistic regression models with a random intercept modelled for each hospital to account for clustering within each hospital. This facilitated evaluation of the trade-off between statistical power, the validity of the different score thresholds (assessed as the association with likely correlates), and the amount of between-hospital variation.

# 4. Results

## i) Characteristics of responders compared to non-responders

The characteristics of eligible NBOCA patients with and without CPES responses are shown in Table 1. Patients with completed CPES surveys were more likely to be female and aged 65-84 years old. A significant difference according to socioeconomic status was identified with more deprived patients less likely to have a completed CPES survey.

In addition, patients with a CPES response tended to be fitter according to performance status, have colonic tumours, less advanced disease and have been admitted with their bowel cancer electively. Patients without a CPES survey were more likely to have undergone alternative treatments to major resection or have no recorded procedure. Generally, patients without a CPES response had more missing NBOCA data.

Some characteristics found to be associated with response rate were also found to be associated with ratings of care. For example, 42.5% of patients in the most deprived quintile gave their overall cancer care score as 10 compared to 34.0% in the least deprived quintile.

**Table 1 –** Characteristics of patients according to CPES survey response or no response

| | **CPES Non-responders n=1,503** | | **CPES Responders n=2,606** | | **Total** | | **p value** |
|---|---|---|---|---|---|---|---|
| | No. | % | No. | % | No. | % | |
| **Sex** | | | | | | | **0.049** |
| Male | 888 | 59.1 | 1,457 | 55.9 | 2,345 | 57.1 | |
| Female | 615 | 40.9 | 1,148 | 44.1 | 1,763 | 42.9 | |
| Total | 1,503 | 100.0 | 2,605 | 100.0 | 4,108 | 100.0 | |
| Missing | 0 | 0 | 1 | 0 | 1 | 0 | |
| **Age Group** | | | | | | | **<0.001** |
| 0-64 | 581 | 38.7 | 802 | 30.8 | 1,383 | 33.7 | |
| 65-74 | 458 | 30.5 | 882 | 33.8 | 1,340 | 32.6 | |
| 75-84 | 356 | 23.7 | 762 | 29.2 | 1,118 | 27.2 | |
| >=85 | 108 | 7.2 | 160 | 6.1 | 268 | 6.5 | |
| Total | 1,503 | 100.0 | 2,606 | 100.0 | 4,109 | 100.0 | |
| **Socioeconomic status** | | | | | | | **<0.001** |
| 1 (most deprived) | 283 | 18.9 | 334 | 12.9 | 617 | 15.1 | |
| 2 | 297 | 19.8 | 460 | 17.7 | 757 | 18.5 | |
| 3 | 354 | 23.6 | 572 | 22 | 926 | 22.6 | |
| 4 | 283 | 18.9 | 597 | 23 | 880 | 21.5 | |
| 5 (least deprived) | 282 | 18.8 | 635 | 24.4 | 917 | 22.4 | |
| Total | 1,499 | 100.0 | 2,598 | 100.0 | 4,097 | 100.0 | |
| Missing | 4 | 0.3 | 8 | 0.3 | 12 | 0.3 | |
| **Audit Year** | | | | | | | **0.952** |
| 2015 | 539 | 35.9 | 937 | 36 | 1,476 | 35.9 | |
| 2016 | 964 | 64.1 | 1,669 | 64 | 2,633 | 64.1 | |

Table 1 Continued

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Total | 1,503 | 100.0 | 2,606 | 100.0 | 4,109 | 100.0 | |
| **Cancer Site** | | | | | | | **0.001** |
| Colon | 868 | 57.8 | 1,656 | 63.5 | 2,524 | 61.4 | |
| Rectosigmoid | 87 | 5.8 | 142 | 5.4 | 229 | 5.6 | |
| Rectal | 548 | 36.5 | 808 | 31.0 | 1,356 | 33.0 | |
| Total | 1,503 | 100.0 | 2,606 | 100.0 | 4,109 | 100.0 | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Performance Status** | | | | | | | **<0.001** |
| 0 | 631 | 49.6 | 1,190 | 53.0 | 1,821 | 51.7 | |
| 1 | 378 | 29.7 | 763 | 34.0 | 1,141 | 32.4 | |
| ≥2 | 264 | 20.7 | 293 | 13.0 | 557 | 15.8 | |
| Total | 1,273 | 100.0 | 2,246 | 100.0 | 3,519 | 100.0 | |
| Missing | 230 | 15.3 | 360 | 13.8 | 590 | 14.4 | |
| **Pre-treatment T-stage** | | | | | | | **<0.001** |
| T1 | 89 | 6.2 | 198 | 7.9 | 287 | 7.3 | |
| T2 | 275 | 19.2 | 597 | 23.7 | 872 | 22.1 | |
| T3 | 751 | 52.5 | 1,346 | 53.4 | 2,097 | 53.0 | |
| T4 | 316 | 22.1 | 381 | 15.1 | 697 | 17.6 | |
| Total | 1,431 | 100.0 | 2,522 | 100.0 | 3,953 | 100.0 | |
| Missing | 72 | 4.8 | 84 | 3.2 | 156 | 3.8 | |
| **Pre-treatment N-stage** | | | | | | | **0.021** |
| N0 | 667 | 46.7 | 1,291 | 51.2 | 1,958 | 49.6 | |
| N1 | 501 | 35.1 | 826 | 32.8 | 1,327 | 33.6 | |
| N2 | 259 | 18.1 | 403 | 16.0 | 662 | 16.8 | |
| Total | 1,427 | 100.0 | 2,520 | 100.0 | 3,947 | 100.0 | |
| Missing | 76 | 5.1 | 86 | 3.3 | 162 | 3.9 | |
| **Pre-treatment M-stage** | | | | | | | **0.005** |
| M0 | 1,131 | 84.2 | 2,096 | 87.5 | 3,227 | 86.3 | |
| M1 | 213 | 15.8 | 300 | 12.5 | 513 | 13.7 | |
| Total | 1,344 | 100.0 | 2,396 | 100.0 | 3,740 | 100.0 | |
| Missing | 159 | 10.6 | 210 | 8.1 | 369 | 9.0 | |
| **RCS Charlson Score** | | | | | | | **0.154** |
| 0 | 805 | 54 | 1,467 | 56.6 | 2,272 | 55.6 | |
| 1 | 458 | 30.7 | 778 | 30.0 | 1,236 | 30.3 | |
| 2 | 228 | 15.3 | 347 | 13.4 | 575 | 14.1 | |
| Total | 1,491 | 100.0 | 2,592 | 100.0 | 4,083 | 100.0 | |
| Missing | 12 | 0.8 | 14 | 0.5 | 26 | 0.6 | |
| **Emergency Admission** | | | | | | | **<0.001** |
| Yes | 208 | 14.0 | 222 | 8.6 | 430 | 10.5 | |
| No | 1,280 | 86.0 | 2,368 | 91.4 | 3,648 | 89.5 | |
| Total | 1,488 | 100.0 | 2,590 | 100.0 | 4,078 | 100.0 | |
| Missing | 15 | 1 | 16 | 0.6 | 31 | 0.8 | |

Table 1 Continued

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **Surgery Type** | | | | | | | **0.008** |
| Major Resection | 1,138 | 90.8 | 2,183 | 93 | 3,321 | 92.3 | |
| Local Excision | 46 | 3.7 | 79 | 3.4 | 125 | 3.5 | |
| Stoma | 32 | 2.6 | 35 | 1.5 | 67 | 1.9 | |
| Stent | 14 | 1.1 | 8 | 0.3 | 22 | 0.6 | |
| Other | 23 | 1.8 | 42 | 1.8 | 65 | 1.8 | |
| None recorded | 250 | 16.6 | 259 | 9.9 | 509 | 12.4 | |

### ii) Hospital trust variation in response rate

There were 139 English NHS hospital trusts with at least 10 eligible NBOCA patients for the 2015 CPES wave. There was significant variation in the proportion of patients with CPES responses according to hospital trust of diagnosis (Figure 2a). 17 hospital trusts lay outside the 95% confidence intervals (up to 7 would be expected by chance alone). Response rates varied between trusts from 33% to 100%, but individual hospital trust volumes (median 26, IQR 19-38) and CPES response (median 17, IQR 12-23) were low.

As a sensitivity analysis, response rates were pooled for the 2013-2015 CPES waves. The overall response rates for both of these surveys was 64%. Variation in CPES response increased with 22 hospital trusts outside the 95% confidence intervals and response rates varying from 26% to 81% (Figure 2b). The median hospital trust volume was 85 (IQR 65-118) and CPES response volume 52 (IQR 39-71).

### iii) Clinical validity and accuracy of responses

#### ***Clinical Validity***

A section of the CPES survey focussed on how many times patients went to see their General Practitioner (GP) with the symptoms that led to identification of their CRC. The response rate for this question in our eligible NBOCA cohort was 94%. Most patients saw their GP once prior to hospital referral, however, just under one fifth of patients attended 3 times or more (Figure 3).

CPES responses indicating more primary care attendances prior to referral on to secondary care correlated with more advanced tumour stage at presentation (Table 2). Patients who reported diagnosis immediately via the hospital also had more advanced tumour staging which is in keeping clinically with likely emergency presentations in this group. Similarly, patients who reported being diagnosed via screening had less advanced disease.

**Figure 2a** – Funnel plot of the proportion of patients with a completed CPES survey according to hospital trust of diagnosis for 2015 wave

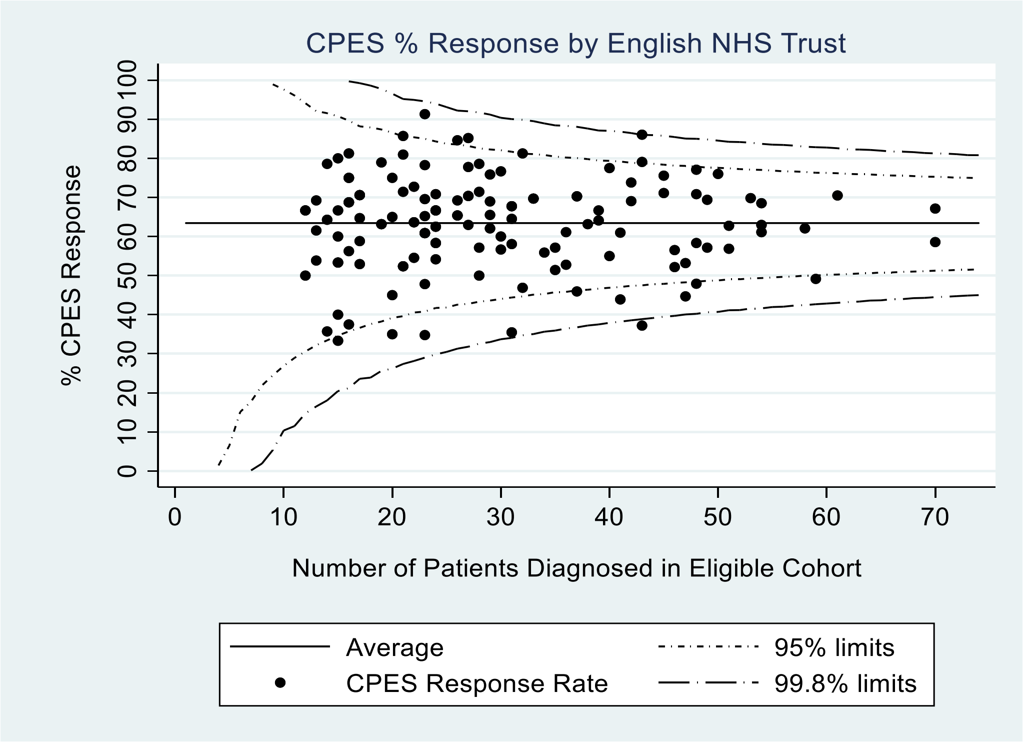


**Figure 2b** – Funnel plot of the proportion of patients with a completed CPES survey according to hospital trust of diagnosis pooled over 3 years (2013-2015)

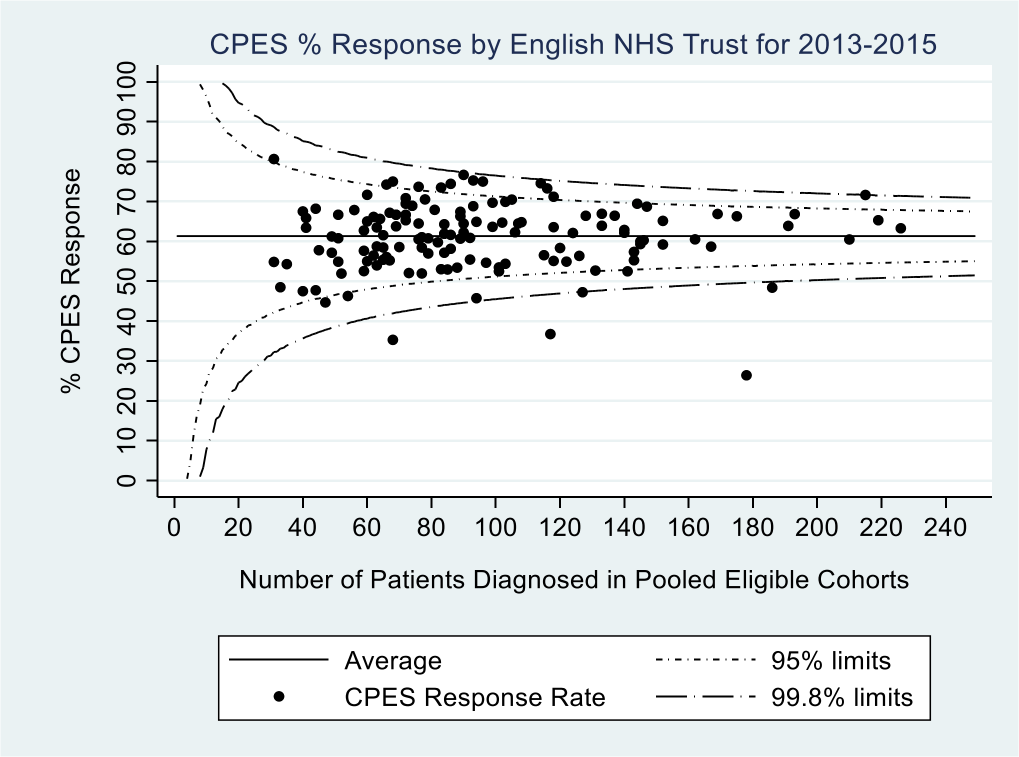


**Figure 3** – CPES results for attendances in primary care prior to referral to hospital for patients in the eligible NBOCA cohort

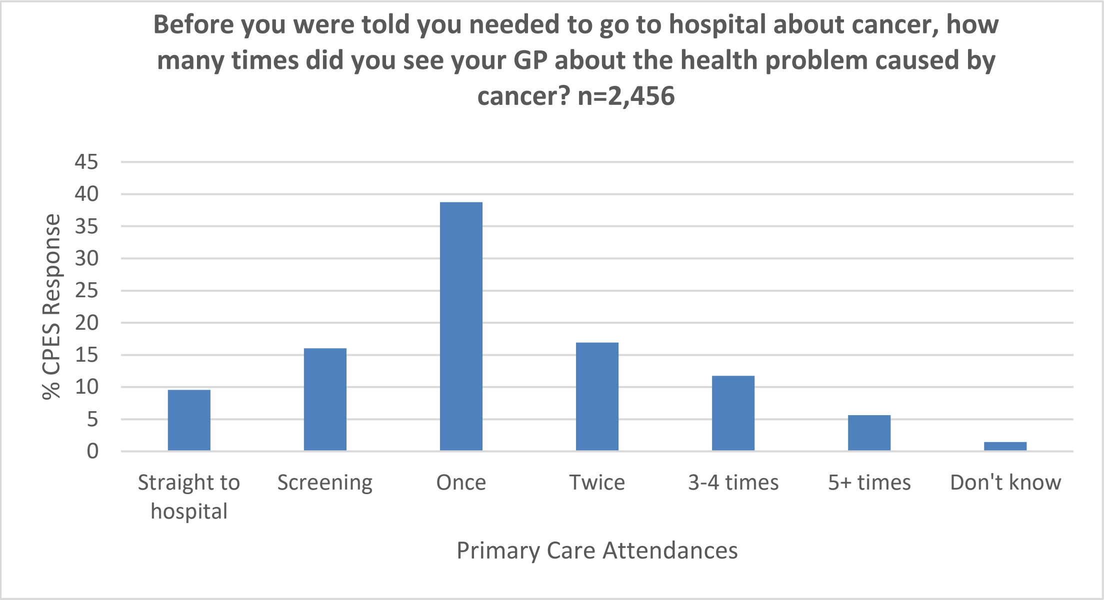


**Table 2** - Number of visits to GP (primary care) and pre-treatment TNM staging (n=2,456)

| | **Number of visits to GP according to CPES** | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **None - Straight to hospital** | | **None – Via Screening** | | **Once** | | **Twice** | | **3-4 times** | | **5 or more** | | **Don't know** | |
| | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % | No. | % |
| **Pre-treatment T-stage** | | | | | | | | | | | | | | |
| **T1** | 15 | 6.7 | 58 | 15.2 | 71 | 7.7 | 25 | 6.3 | 13 | 4.6 | 2 | 1.5 | 2 | 5.9 |
| **T2** | 52 | 23.1 | 126 | 33.0 | 224 | 24.3 | 74 | 18.5 | 55 | 19.5 | 27 | 20.5 | 8 | 23.5 |
| **T3** | 114 | 50.7 | 178 | 46.6 | 509 | 55.1 | 233 | 58.4 | 150 | 53.2 | 67 | 50.8 | 15 | 44.1 |
| **T4** | 44 | 19.6 | 20 | 5.2 | 119 | 12.9 | 67 | 16.8 | 64 | 22.7 | 36 | 27.3 | 9 | 26.5 |
| **Missing** | 10 | | 11 | | 29 | | 16 | | 6 | | 6 | | 1 | |
| | | | | | | | | | | | | | | |
| **Pre-treatment N-stage** | | | | | | | | | | | | | | |
| **N0** | 121 | 53.5 | 227 | 59.6 | 463 | 50.3 | 205 | 51.4 | 131 | 46.5 | 47 | 35.9 | 20 | 58.8 |
| **N1** | 74 | 32.7 | 132 | 34.6 | 291 | 31.6 | 129 | 32.3 | 100 | 35.5 | 46 | 35.1 | 8 | 23.5 |
| **N2** | 31 | 13.7 | 22 | 5.8 | 167 | 18.1 | 65 | 16.3 | 51 | 18.1 | 38 | 29.0 | 6 | 17.6 |
| **Missing** | 9 | | 12 | | 31 | | 16 | | 6 | | 7 | | 1 | |
| | | | | | | | | | | | | | | |
| **Pre-treatment M-stage** | | | | | | | | | | | | | | |
| **M0** | 189 | 85.5 | 332 | 93.3 | 789 | 89.4 | 330 | 86.6 | 208 | 79.1 | 92 | 75.4 | 30 | 96.8 |
| **M1** | 32 | 14.5 | 24 | 6.7 | 94 | 10.6 | 51 | 13.4 | 55 | 20.9 | 30 | 24.6 | 1 | 3.2 |
| **Missing** | 14 | | 37 | | 69 | | 34 | | 25 | | 16 | | 4 | |

*Accuracy*

Of the 2,221 patients reporting in the survey that they had undergone surgery in the preceding 12 months, 95% had a corresponding record of this within NBOCA data. Of the 2,095 patients responding to the CPES question about receipt of radiotherapy within the last 12 months, there was 94% concordance with linked Radiotherapy Dataset (RTDS) records (Table 3a). Similarly, for the 2,082 patients responding to the CPES question pertaining to receipt of chemotherapy within the last 12 months, there was 88% concordance with linked Systemic Anti-Cancer Therapy (SACT) records (Table 3b).

For each of these questions, CPES asks patients whether these treatments have been received in the last 12 months at one of the hospital trusts named in the cover letter. A limitation was that the exact date when each patient completed their survey was unknown. A timeframe was therefore used to account for 12 months prior to completion of the survey at any point within the 6-month survey fieldwork window.

It was also not known which hospitals were named on the covering letter, however, most CRC patients undergo surgery in their diagnosing trust. Radiotherapy and chemotherapy are more likely to be provided in alternative hospital trusts and this may account for the lower agreement levels.

**Table 3a** – Proportion of patients receiving radiotherapy within the previous 12 months according to CPES response versus linked NBOCA-RTDS data

| | **NBOCA-RTDS – Yes** | **NBOCA-RTDS - No** | **Total** |
|---|---|---|---|
| **CPES – Yes** | 268 | 49 | 317 |
| **CPES – No** | 68 | 1,710 | 1,778 |
| **Total** | 1,759 | 336 | 2,095 |

**Table 3b** – Proportion of patients receiving chemotherapy within the previous 12 months according to CPES response versus linked NBOCA-SACT data

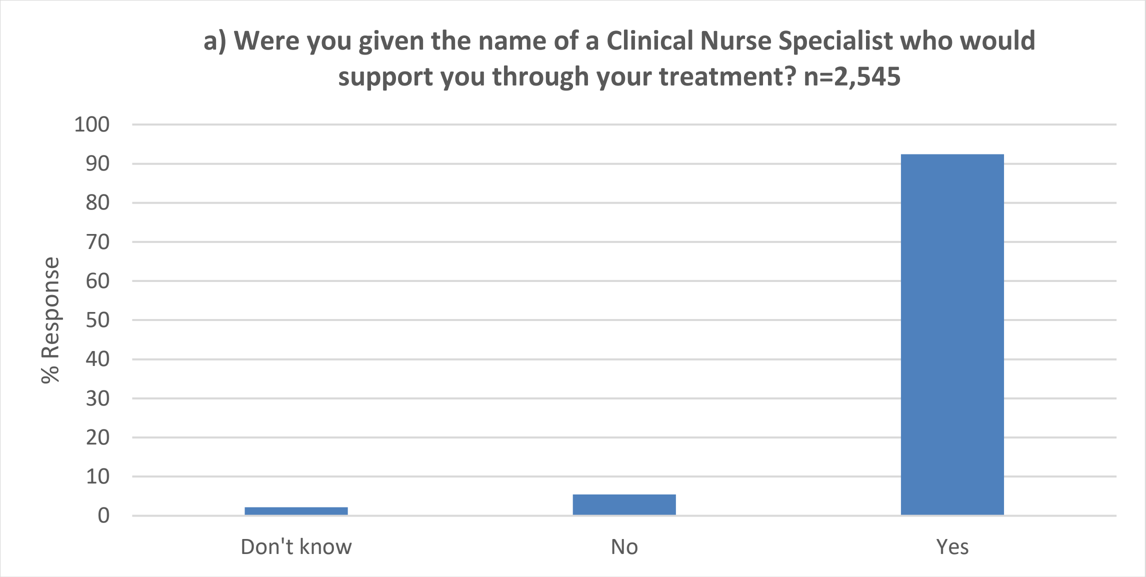
| | **NBOCA-SACT – Yes** | **NBOCA-SACT - No** | **Total** |
|---|---|---|---|
| **CPES – Yes** | 912 | 188 | 1,100 |
| **CPES – No** | 63 | 919 | 982 |
| **Total** | 1,107 | 975 | 2,082 |

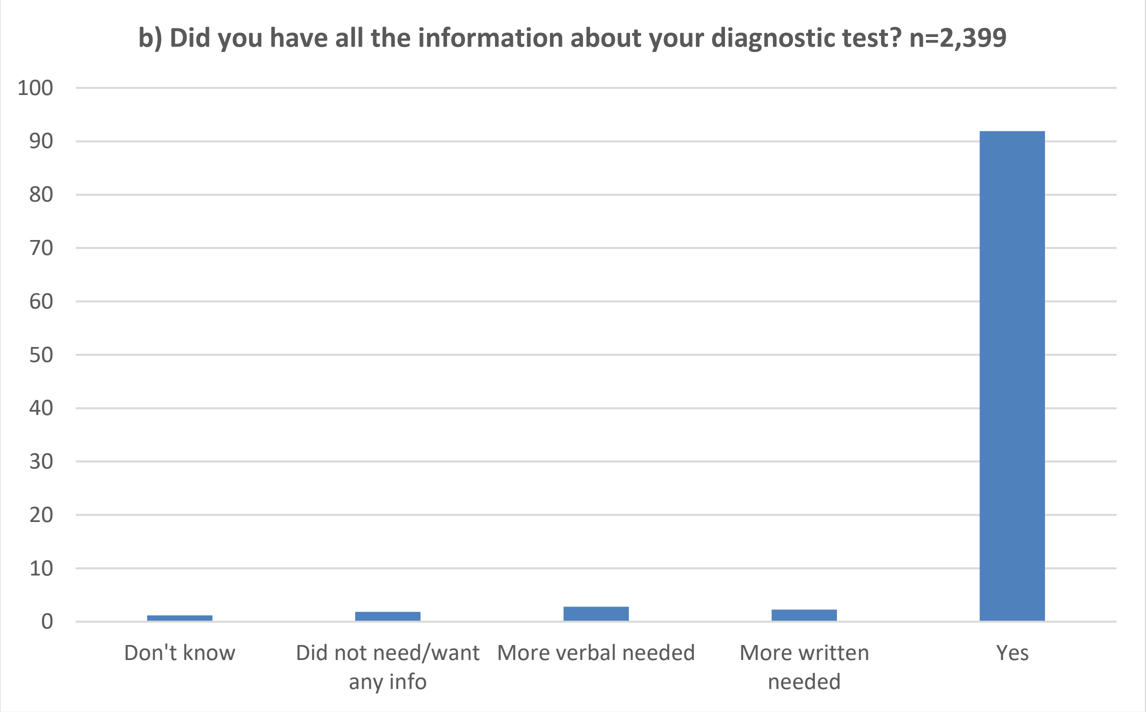
92% of patients with a CPES survey response reported having been given the name of a Clinical Nurse Specialist (CNS). This matched in 92% of cases with NBOCA data on whether the patients saw a CNS. The CPES survey also contains a question which asks ‘Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?’ which was compared to NBOCA pre-treatment M-staging. 2,110 patients had a valid CPES response with accompanying pre-treatment M-stage data. There was 90% concordance between results.

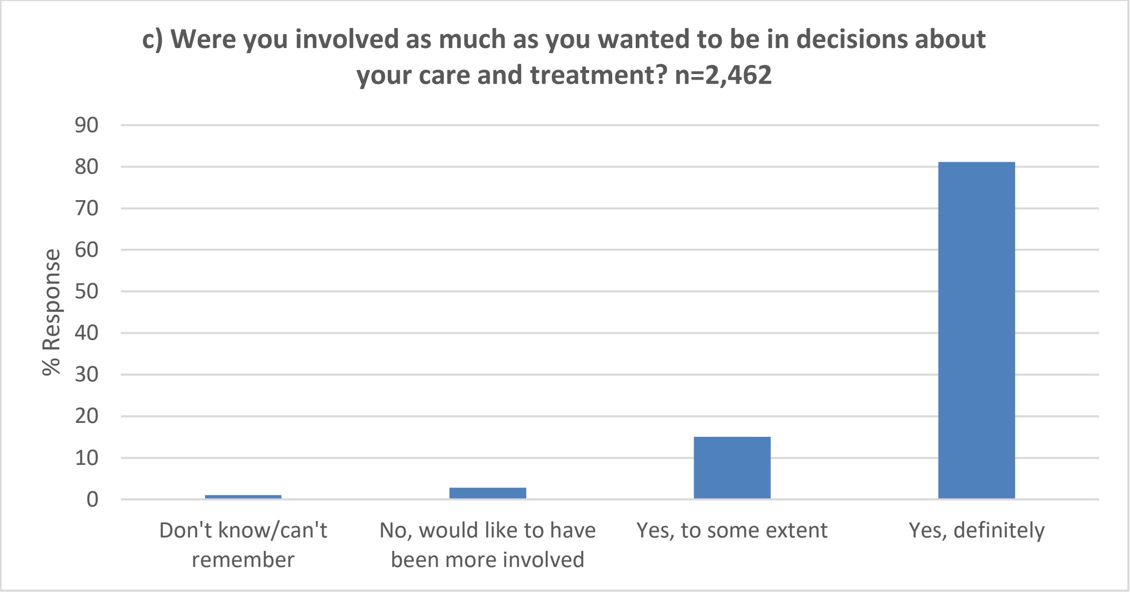
### i) Use of CPES measures as performance indicators

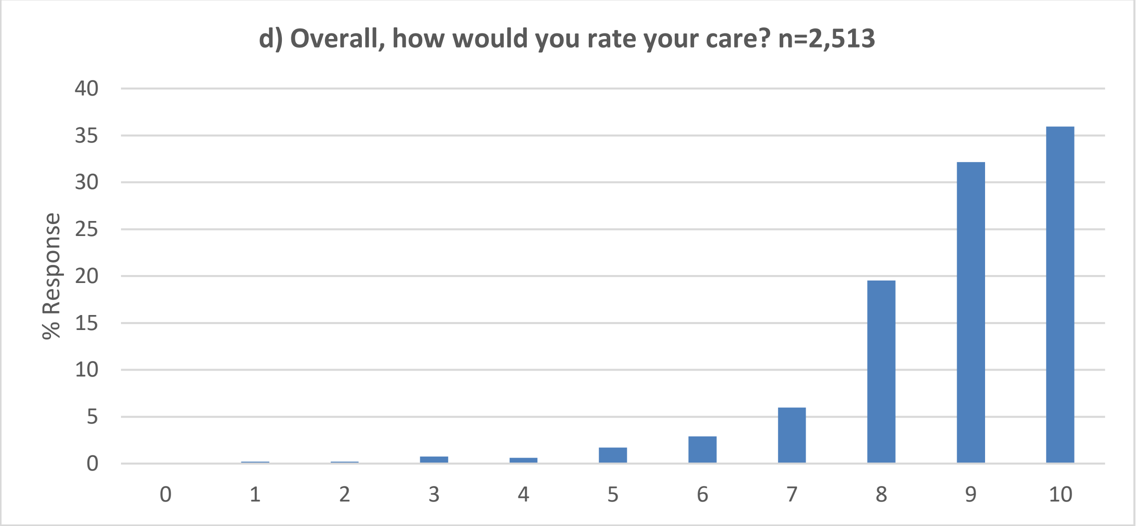
The questions selected as potential performance indicators related to CNS allocation, having all the information required before undergoing diagnostic tests, involvement in decision-making and overall cancer care rating. The distribution of responses for the four selected questions are shown (Figure 4a-d).

**Figure 4** – Distribution of responses for CPES questions relating to CNS allocation, information provided before diagnostic testing, involvement in decision-making processes and overall cancer care scores









The distribution of responses within these questions are negatively skewed. Funnel plots for CNS name, information provided and involvement in decision making were performed at hospital trust level but had low volumes and showed minimal variation, making them unlikely to facilitate useful comparisons at this level.

Within the eligible cohort, 90% of patients regarded their overall care as scoring 7 or higher. The most frequent rating of their overall care was 10 (36%). The clinical validity of this measure was assessed by evaluating the differences in ratings of care between patients according to different patient and tumour characteristics and outcomes at different score thresholds (Table 4). Patients reporting better overall care scores were less likely to have long length of stay, returns to theatre and emergency readmissions as might be expected. There was generally an increased difference in scores between patients with and without these factors as the score thresholds increased from 7 to 10.

Different thresholds for the scoring cut-off were also evaluated using funnel plot methodology and calculation of ICCs. These showed that between-hospital variation increased with an increasing score threshold (Figure 5 and Table 5). Power calculations were carried out for a hospital trust volume of 52 CPES responses which represents the median value for 3 years.

Our findings suggested that a reasonable choice of cut-off for this performance indicator would be 9, providing a balance between statistical power, between-hospital variation, and clinical validity. Results, however, are based on low volumes. Unfortunately, it was not possible to pool results for this question because in the 2013 and 2014 iterations of the survey the responses are graded on a different 5-point scale.

**Figure 5** – funnel plot of the proportion of patients scoring their overall care as 9 or above according to hospital trust of diagnosis

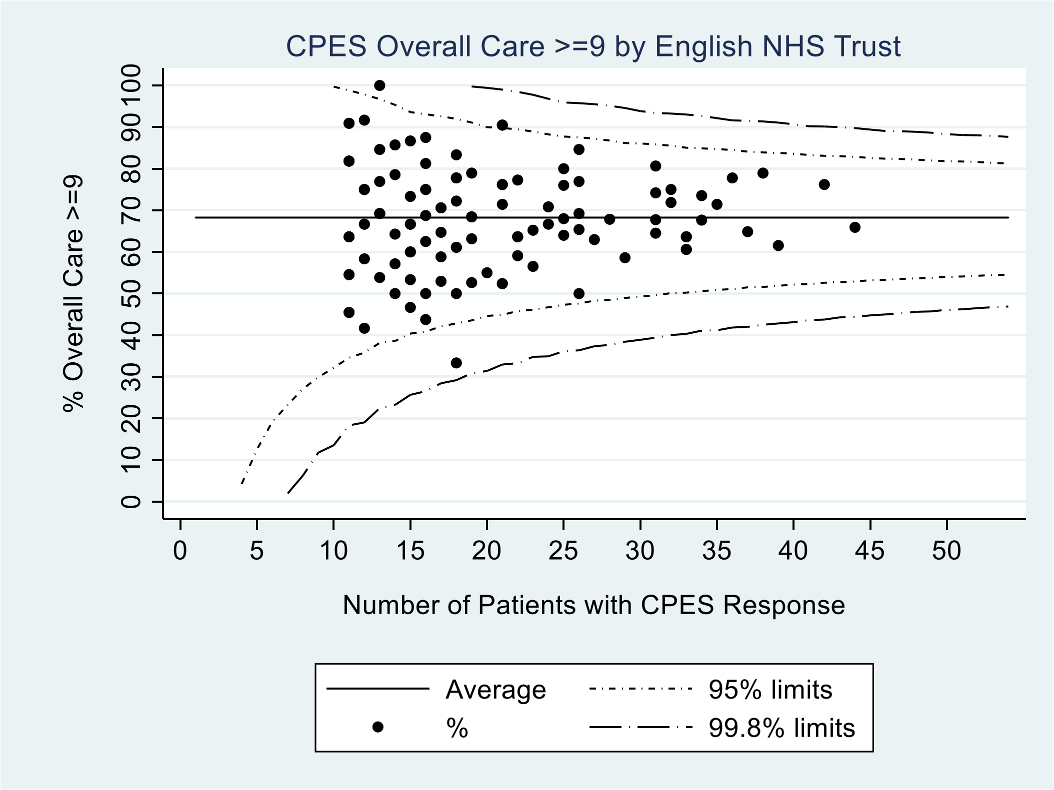


**Table 4** – Differences in ratings of overall care between patients according to patient and tumour characteristics and outcomes.

| | Overall score (n=2,513) | | | |
|---|---|---|---|---|
| | **% ≥7** | **% ≥8** | **% ≥9** | **% =10** |
| **Sex** | | | | |
| Male | 94.0 | 88.8 | 70.0 | 38.0 |
| Female | 93.0 | 86.1 | 65.7 | 33.3 |
| **Age** | | | | |
| <70 | 93.1 | 86.6 | 67.2 | 33.9 |
| ≥70 | 94.1 | 88.6 | 68.9 | 37.8 |
| **Presentation** | | | | |
| Elective | 93.7 | 87.7 | 68.4 | 36.0 |
| Emergency | 92.2 | 86.9 | 66.5 | 36.9 |
| **Length of Stay** | | | | |
| <5 days | 95.9 | 91.6 | 74.1 | 39.3 |
| 6-7 days | 95.0 | 87.3 | 68.3 | 35.1 |
| 8-10 days | 92.5 | 86.6 | 68.4 | 37.3 |
| 11-14 | 90.6 | 85.2 | 65.6 | 31.6 |
| >14 days | 93.7 | 86.8 | 64.2 | 32.1 |
| **Return to Theatre** | | | | |
| No | 94.5 | 88.8 | 70.0 | 36.7 |
| Yes | 90.7 | 82.7 | 63.0 | 28.4 |
| **Emergency Readmission** | | | | |
| No | 93.8 | 88.2 | 68.8 | 36.7 |
| Yes | 91.3 | 82.6 | 61.4 | 29.0 |

**Table 5** - Intra-class correlation co-efficients and power calculations for each threshold for overall care score

| Threshold | ICC | 95% CI | Overall rate | Power to detect a 10% absolute reduction |
|---|---|---|---|---|
| 7+ | 1.84e-06 | n/a | 0.94 | 0.76 |
| 8+ | 1.41e-06 | n/a | 0.88 | 0.58 |
| 9+ | 0.003 | 9.33e-06 - 0.551 | 0.68 | 0.35 |
| 10 | 0.013 | 0.002 - 0.085 | 0.36 | 0.31 |

# 5. Summary

This report details the results of a study examining the feasibility of reporting PREMs as part of a national clinical audit of newly diagnosed CRC patients.

The patient, tumour and treatment characteristics of CPES responders differed to those of non-responders. Under-represented groups included males, those at the extremes of age, the more deprived and those with more advanced disease. Previous work supports these findings for age and deprivation in all cancer patients.[10] Another study showed that CPES responders were more likely to be male, deprived and with more advanced disease, however, the study included all cancers and not just CRC.[11] Our study is the first to directly compare responders and non-responders specifically in CRC patients. Linkage to NBOCA data also enabled us to expand upon this and demonstrate that patients with lower levels of fitness, rectal tumours and emergency presentations were also less likely to have CPES responses.

The lack of representativeness within these groups may be partially explained by the fact that these groups of patients, excluding those with rectal tumours, are more likely to be too unwell to complete the survey. In comparison to colon cancer patients, those with rectal cancers will often undergo radiotherapy prior to surgery and, sometimes, may not require surgery at all. These patients are therefore less likely to be captured within daycase or inpatient admissions, particularly as radiotherapy is often administered in the outpatient setting.

In addition to discrepancies in CPES response rate, there is a suggestion that under-represented groups, such as more deprived patients, also show systematic differences in the rating of their care. The implications of this are that methods to deal with the bias imparted by these under-represented patients are required when reporting PREMs.

There was considerable variation in CPES response rate according to diagnosing hospital trust. This may represent differences in case-mix and linkage rates between hospital trusts, but requires further investigation prior to commencement of any comparative provider monitoring. Previous work has suggested that differential response rate may in fact reflect underlying true variation in hospital administration and associated higher quality of care that should not be adjusted away.[12] Variation in response rate persisted despite pooling of data over 3 years.

This study demonstrated good clinical validity and accuracy of CPES responses compared to NBOCA data. For example, it showed that patients who present to their GP more frequently before diagnosis are more likely to have advanced disease at presentation. There was also good agreement between CPES responses and NBOCA data regarding care received, such as whether patients had undergone surgery, radiotherapy or chemotherapy.

CPES responses in newly diagnosed CRC patients at a national level appeared largely very positive. Consequently, when considering the use of PREMs as performance indicators at hospital trust level, there was a lack of between-hospital variation suggesting that they are unlikely to be helpful for quality improvement.

One outcome which was identified as being potentially useful as a provider-level performance indicator was the overall care score which demonstrated good clinical validity. For example, better overall care scores tended to be found in patients who did not have long length of stay, returns to theatre or emergency readmissions.

The CPES survey is only distributed during a 3-month window, making volumes generally small. As described previously, the survey can be distributed to any patient with CRC anywhere in their care trajectory. Having established a cohort to fit with the audit's remit this reduces volumes at hospital trust level. Due to this, it is recommended that results are pooled  over a 3-year period for this performance indicator, in order to achieve reasonable patient volumes and ensure sufficient statistical power. It was not possible to do this with the current data available but this would be something to explore in the future. In order to deliver a reasonable balance between statistical power and between-hospital variation, a threshold of 9 or above is recommended for the overall care score.

Overall, successful linkage of CPES to a national CRC audit has been demonstrated. Using NBOCA data it has been shown that the information collected within CPES for newly diagnosed CRC patients is accurate and clinically valid. Despite choosing a more homogeneous cohort, there remain inherent issues with non-representativeness of responders and the associated biases which need to be addressed prior to the use of PREMs within a national clinical audit setting. Further understanding of between-hospital variation in response rate and the role of adjustment for this would also be required prior to implementation of any provider-level outputs.

Newly diagnosed CRC patients are reporting positive experiences of their cancer care. CPES can be linked to the relevant NBOCA cohort to provide national-level results for these patients in an annual report setting and monitor overall trends in responses. However, the use of performance indicators for our chosen CPES questions, excluding the overall care score, are unlikely to be helpful for quality improvement. Expansion of CPES to a wider timeframe or, ideally, all newly diagnosed cancer patients may help.

## 6. Conclusions

1. The CPES overall care score shows potential as a performance indicator with good clinical validity and between-hospital variation demonstrated with a score threshold of 9. It is recommended that results are pooled over 3-years to give adequate statistical power.
2. If comparative performance monitoring is going to be undertaken, further methodological work is required to attempt to account for bias from non-representativeness of responders and differential non-response rates between hospital trusts.
3. The CPES questions on being given a named CNS, information on diagnostic tests, and involvement in decisions about care can be used to provide an overview of national performance within the NBOCA annual report.

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