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# Linkage of the English Cancer Patient Experience Survey to cancer registration data

## National Cancer Intelligence Network Data Briefing

### Key messages

- CPES data is now linked to cancer registration data and is available through PHE for further analysis
- surveys covered include 2010, 2011/2012 and 2013

### Introduction

The National Cancer Patient Experience Survey (CPES), commissioned by NHS England through Quality Health is a survey sent to cancer patients who have been discharged from one of the acute and specialist NHS trusts that provide adult acute cancer services in England. The survey aims to collect information from patients about their cancer journey from their initial GP visit prior to diagnosis, through diagnosis and treatment to the ongoing management of their cancer. The aim of this work was to link the CPES datasets to the core cancer registration data to extend the possibilities for analysis and our understanding of cancer patient experience.

### Data linkage method

CPES records from the 2010, 2011/12 and 2013 surveys have been linked to cancer registration data in the Cancer Analysis System (CAS) as at February 2015. The datasets were linked using the recorded NHS number. All records were subsequently included in the new dataset including those which could not be matched, either due to there being no NHS number recorded or an inability to trace the NHS number provided in the CPES dataset to the national cancer registration data. The yield for this linkage procedure can be found in table 1.

**Table 1. Records linked and not linked via NHS number**

| | 2010 | 2011/12 | 2013 |
|---|---:|---:|---:|
| CPES records (N) | 67,713 | 71,793 | 68,737 |
| CPES records linked (n,%) | 66,179 (98%) | 70,756 (99%) | 68,076 (99%) |
| CPES records not linked (n,%) | 1,142 (2%) | 551 (1%) | 661 (1%) |

Each patient should only have one CPES record for each tumour – except in the 2010 and 2011/12 surveys where a small number of patients were surveyed by two separate trusts. A patient may have multiple tumour records in CAS. Therefore, the same CPES survey result could be mapped onto multiple tumour records in the cancer registration data.

It was therefore necessary to match the patient records to identify the tumour records in CAS that corresponded to the correct CPES response. This was achieved by matching the ICD-10 diagnosis codes from both datasets and utilising the time frames from diagnosis to discharge to best assess the correct match. The results of this matching step are shown in table 2.

**Table 2. Patients linked via NHS number and subsequently ICD-10 codes**

| | 2010 | 2011/12 | 2013 |
|---|---:|---:|---:|
| **(a) CPES patients – N** | **67,321** | **71,306** | **68,737** |
| **(b) CPES records – N** | **67,713** | **71,793** | **68,737** |
| (c) CAS records linked via NHS number – n | 89,586 | 94,148 | 88,828 |
| Records matching on ICD-10 4 digits – n (% of c) | 19,044 (21%) | 31,672 (34%) | 30,369 (34%) |
| Records matching on ICD-10 3 digits – n (% of c) | 35,663 (40%) | 26,434 (28%) | 25,745 (29%) |
| Records matching on ICD-10 4 and 3 digits including duplicates – n (% of c) | 54,707 (61%) | 58,106 (62%) | 56,114 (63%) |
| **Patients matching on ICD-10 4 and 3 digits excluding duplicates – n (% of a)** | **51,792 (77%)** | **55,686 (78%)** | **54,355 (79%)** |

The analytical potential of this dataset is now available to both internal and external stakeholders. Please contact NCINenquiries@phe.gov.uk for all enquiries.

**FIND OUT MORE:**

For a detailed description of the linkage procedure and cleaning method a technical briefing can be found on the NCIN website at www.ncin.org.uk/cancer_information_tools/cancer_patient_experience

**Other useful resources within the NCIN partnership:**

What cancer statistics are available and where can I find them? www.ncin.org.uk/publications/reports

Public Health England's National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in cancer awareness, prevention, diagnosis and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

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