

## Linking the English Cancer Patient Experience Survey to Cancer registration: relating patient experience to outcomes, a step towards better services and outcomes

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### Objectives

To link the English Cancer Patient Experience Survey (CPES) to Public Health England's cancer registration records and allow new exploration of the association between patient experience and outcomes and eventually improve service provision and patient outcomes.

### Approach

Patients' responses from the first 4 waves (2010, 2011/12, 2013, 2014) of CPES were linked to tumour level cancer registration records. Cancer registration is available via the Cancer Analysis System (CAS).

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 necessary to match the patient records to identify the tumour records in CAS that most likely corresponded to the correct CPES response. The following criteria were used to match records at patient-tumour level: a match in the ICD-10 diagnosis codes from both datasets; and the time frames from diagnosis to discharge to best assess the correct match.

In order to increase the matching yield, the linkage also flagged related tumour types in the two datasets, following consultation with clinical and research experts in the field.

### Results

Over 75% of records in the survey cohort were successfully linked for each year of the survey waves. Analysis based on concordance

between data items in both CPES and cancer registrations were mostly the same in the two datasets.

As an example of the linkage potential, the overall experience of patient care was compared with stage at diagnosis. The results show that patients diagnosed at later stages have significantly lower scores of overall care. To our knowledge, this is the first time these two variables have been analysed together in regards to the care of cancer patients in England and emphasise the need for earlier cancer diagnosis.

### Conclusion

This is the first time the CPES has been linked to cancer registrations. The new linkage provides insight into how well represented the overall cancer patient population is within CPES and also assess concordance of data between them. This work is essential to support a programme of further analysis at NCRAS, in partnership with Macmillan Cancer Support and Cancer Research UK.

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