



Exploring the relationship between patient experience and outcomes; how well represented are the cancer population in the English Cancer Patient Experience Survey?



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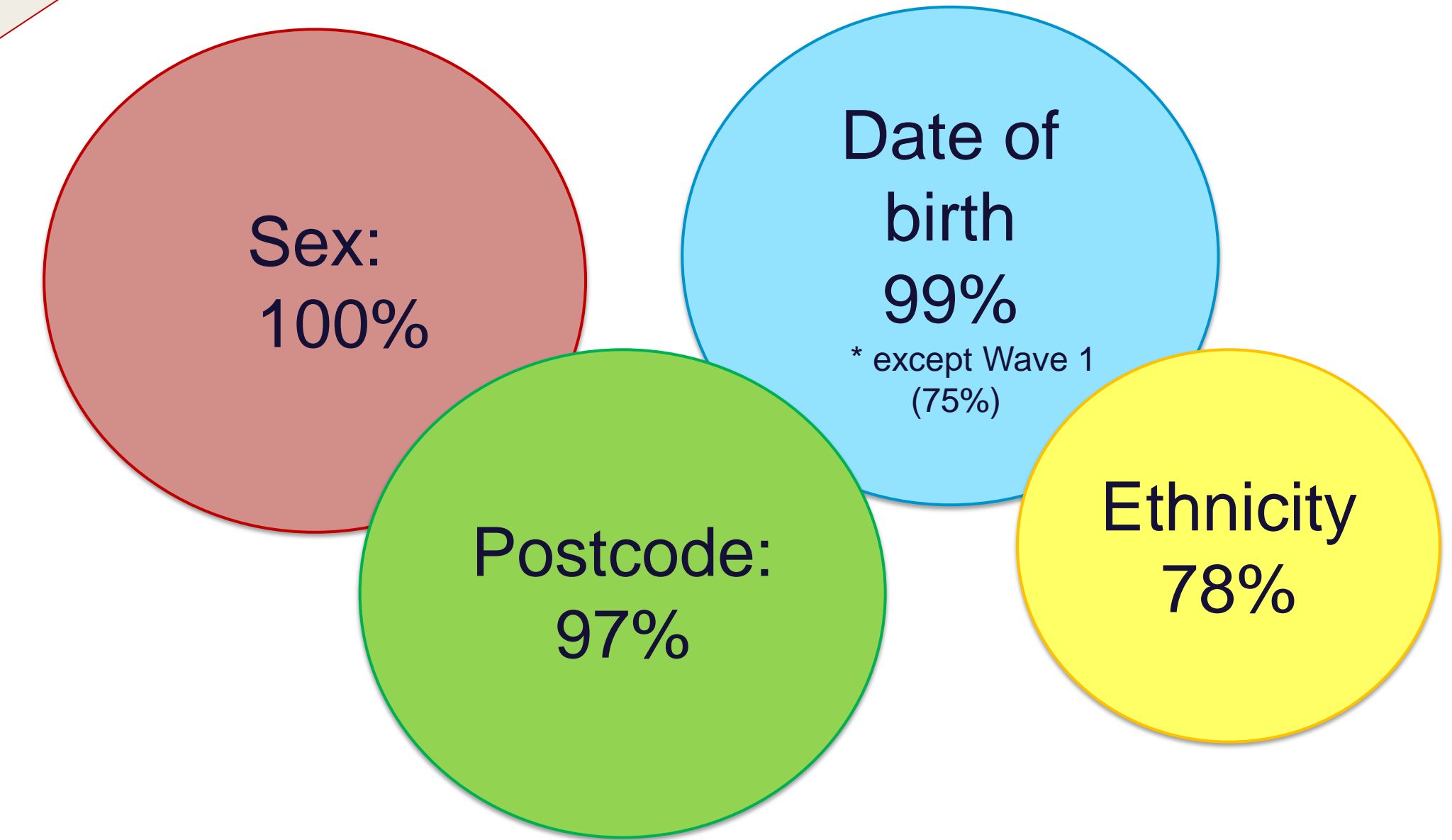
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INTRODUCTION

The National Cancer Patient Experience Survey (CPES) is a survey sent out to all adult cancer patients (aged 16 and over) with a primary diagnosis of cancer who have been admitted to an acute or specialist NHS Trust in England providing adult cancer services as inpatients or day cases, and discharged within a specified three month sampling period each year. The survey aims to collect information based on the patient's experience from their route to diagnosis (e.g. initial GP or hospital visit prior to diagnosis), through diagnosis and treatment, to life after being discharged and the ongoing management of their cancer.

Until recently it was not possible to combine analysis on outcomes with experience, mainly due to data availability. Last year a partnership team of Public Health England, Cancer Research UK and Macmillan Cancer Support started a work stream to link the survey dataset back to the cancer registration data, linking surveys from 2010 (Wave 1), 2011/12 (Wave 2), 2013 (Wave 3) and 2014 (Wave 4).

Figure 1. Concordance of attributes between CPES Waves 1, 2, 3 and 4 and cancer registration comparator population



METHODS

CPES records from the surveys were linked to PHE's cancer registration data (Cancer Analysis System – CAS) using the recorded NHS number. The cancer registration dataset used is the snapshot of all cancer registrations taken as of February 2016.

A patient with more than one tumour will have multiple tumour records in the cancer registration data. Therefore, the same CPES survey result could be mapped onto multiple tumour records in the cancer registration. Hence, it was necessary to also match by cancer site to identify the record that corresponds to the correct CPES response. This was achieved by matching the ICD-10 diagnosis codes from both datasets, and if necessary also utilising the time frames from diagnosis to discharge to best assess the correct match of records. The yield for these linkage procedures can be found in Table 1.

Details for the sampling period for each wave can be found below:

Wave 1: 2010 survey sent to patients discharged between 1st Jan 2010 and 31st March 2010

Wave 2: 2011/12 survey sent to patients discharged between 1st Sep 2011 and 30th Nov 2011

Wave 3: 2013 survey sent to patients Discharge between 1st Sep 2012 and 30th Nov 2012

Wave 4: 2014 survey sent to patients discharged between 1st Sep 2013 and 30th Nov 2013

Table 1. Ranking match of patients between CPES surveys and cancer registration

	Wave 1	Wave 2	Wave 3	Wave 4
	N=67,105	N=71,306	N=68,737	N=70,131
Matched by NHS number	66,608 (99%)	70,756 (99%)	68,076 (99%)	69,670 (99%)
Matched by NHS number and ICD10 Code	51,821 (77%)	55,786 (78%)	54,355 (79%)	56,426 (81%)

Figure 2. Cancer site distribution in CPES Wave 4

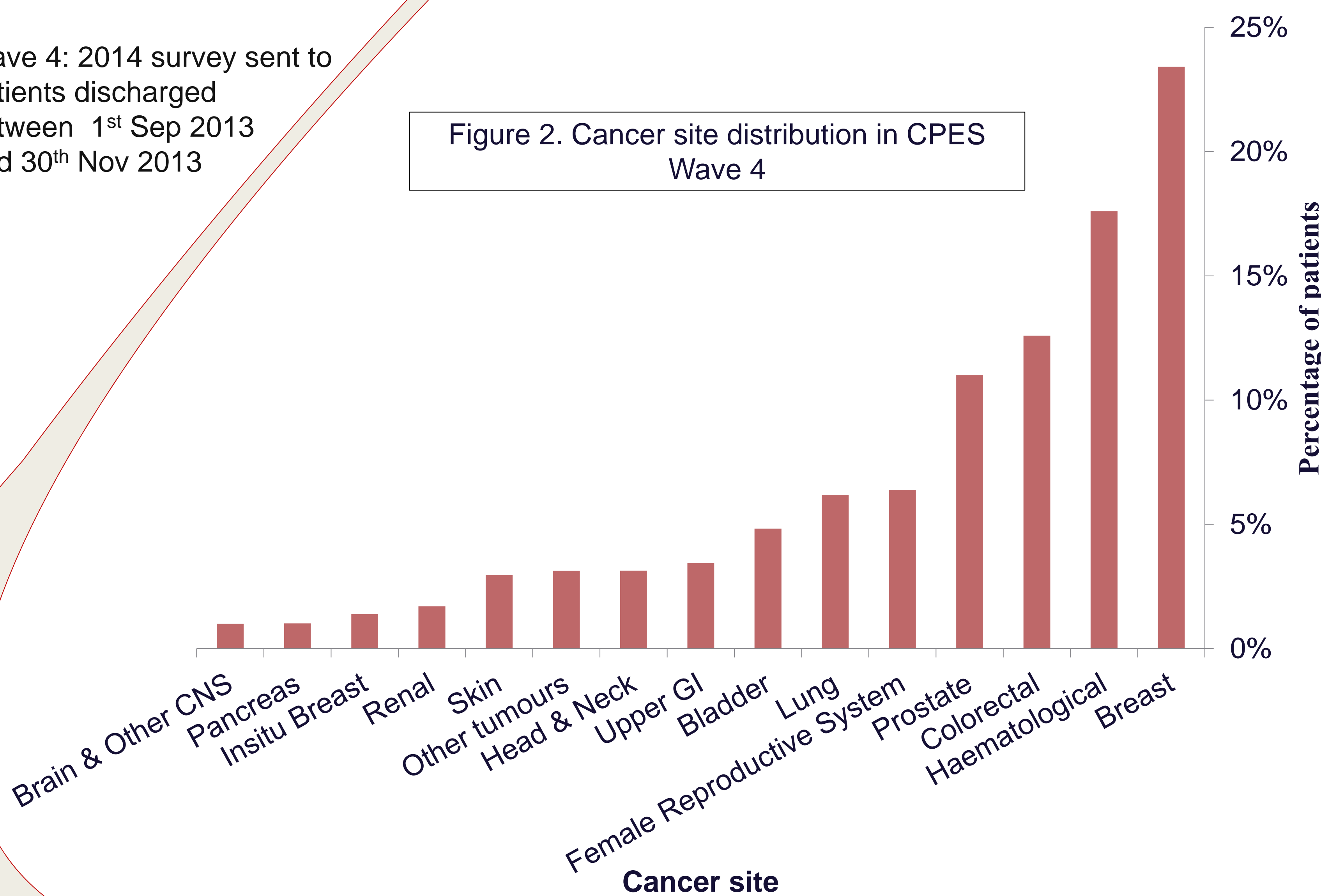
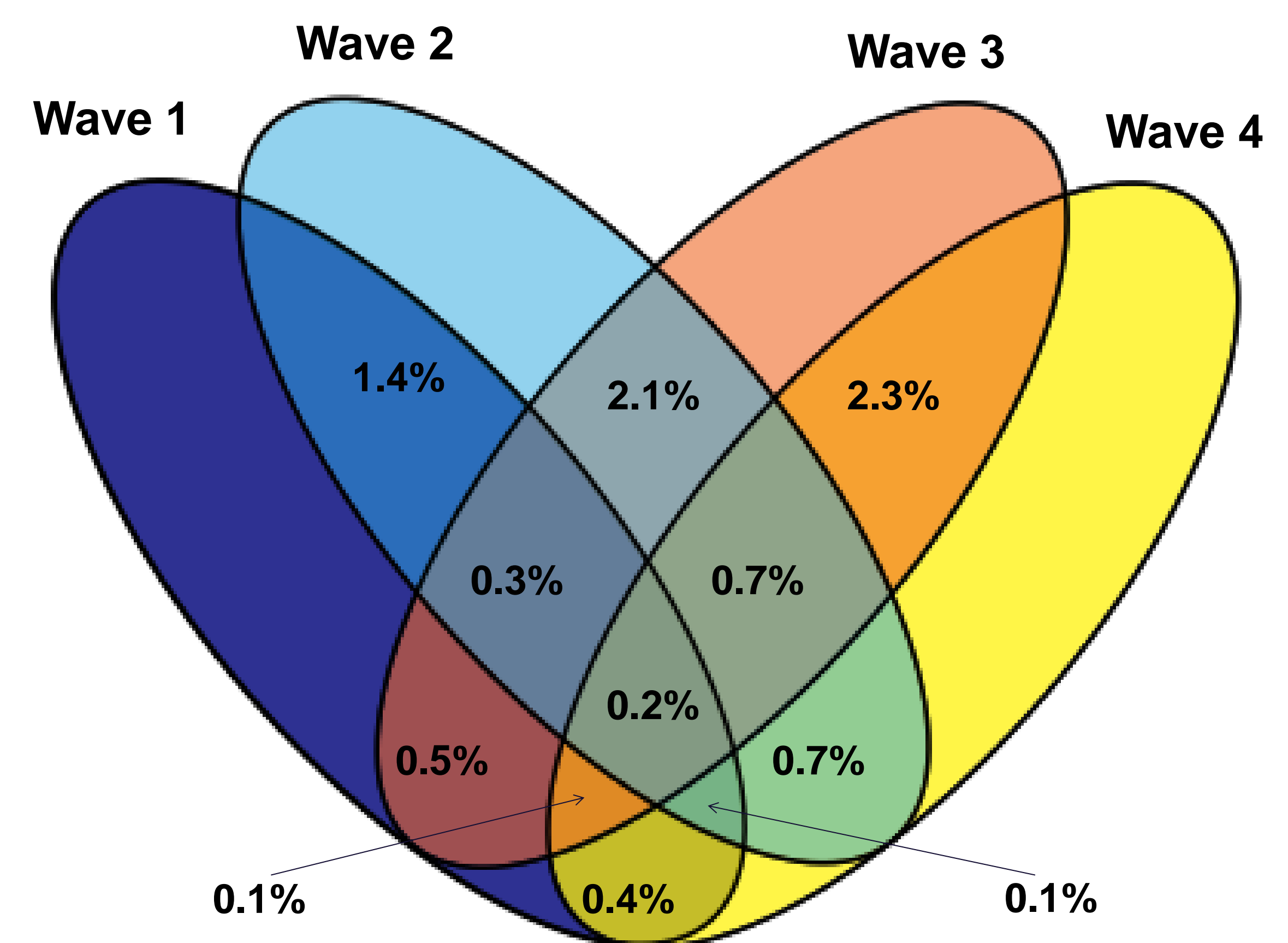


Figure 3. Percentage of patients who were surveyed multiple times across different waves N=250,167 (all 4 Waves)



RESULTS

CPES datasets provide vast potential as resources on cancer patients' evaluation of their experience and self-reported characteristics. Linking this to registration data further increases that potential by enabling comparison with clinical information and outcomes.

The main conclusions for CPES records that were matched to cancer registrations were as follows:

- Figure 1 shows the quality of the CPES datasets compared to registration is good, with high concurrence for age, date of birth, sex, ethnicity and postcode
- Figure 2 depicts the large variations seen across reported cancers types with breast and haematological tumours showing the highest numbers of respondents.
- Figure 3 describes the small proportion (8%) of the respondents have responded to more than one of the four surveys
- CPES distributions of patients by sex, region of residence and deprivation were similar to cancer registration data, however, there were larger differences with regards to age distribution and ethnicity; this reflects a known bias among the survey responders

DISCUSSION & CONCLUSIONS

In general, there is high concordance of basic patient characteristics in the two datasets. Large variations in cancer sites is possibly due to known biases against cancer of higher mortality or patterns of treatment of each site. This also possibly affects the proportion of CPES respondents that have been surveyed multiple times.

These observed patterns of variation should be interpreted in conjunction with evidence about differential early mortality and non-response patterns. Variations in distribution of cancer sites could be related to differing CPES response rates. The distribution of cancer sites in the CPES versus the comparator population may also be partly explained by the differences in the survey sample frames, the prognosis and different use of services for different cancers.

The linkage now enables us to look into the relationship between patient experience and cancer outcomes, such as routes to diagnosis and survival.

ACKNOWLEDGEMENTS

Special thanks to the CPES Consortium who provided support, guidance and resources for this project. We would like to acknowledge the essential work of the National Cancer Registration and Analysis Service and Quality Health, without whom we would not have any cancer registration or CPES data.