SHORT REPORT

Are there socioeconomic gradients in the quality of data held by UK cancer registries?

Jean Adams, Martin White, David Forman

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Twelve contiguous regional cancer registries are responsible for collecting and collating data on all incident cancers in the UK using data supplied by hospitals, including pathology departments. All death certificates mentioning cancer are returned to the appropriate registry to enable date of death to be recorded. In the event that this procedure identifies a cancer that has not been previously entered on the register, a death certificate initiated registration occurs and attempts are made to collect clinical data retrospectively. If no such data can be found (for example, if medical records have been lost or destroyed), a death registration only (DCO) registration occurs.

A recent review of UK cancer registry data concluded that “there are clear grounds for supposing that cancer registry records are largely complete, accurate and reliable”. Although there is some evidence that DCO registrations are more common in deprived populations, little previous research has investigated whether there are socioeconomic variations in the quality of other aspects of cancer registration data. Such variations may reflect socioeconomic variations in cancer care—one area of concern highlighted by the white paper, Our Healthier Nation.

METHODS AND RESULTS

We investigated the socioeconomic distribution of the quality of colorectal (ICD-10 C18-20) and breast (ICD-10 C50) cancer registration data collected by one of the UK regional cancer registries—the Northern and Yorkshire Cancer Registration and Information Service (NYCRIS)—between 1998 and 2000 inclusive. NYCRIS collects information on all cancers in the Northern and Yorkshire region of the UK and currently covers a resident population of about 6.5 million (further details on NYCRIS can be found at http://nycris.org.uk). Three measures of data quality were used: ascertainment (that is, DCO registrations) and completeness of data on stage and grade at diagnosis—both of which are required data in all cancer registrations and are derived from both clinical and pathological data. Socioeconomic position was quantified using Townsend deprivation scores (TDS) of the enumeration district of residence at the time of registration calculated from 1991 census data standardised to the Northern and Yorkshire region as a whole—giving a mean TDS of zero within the whole region (appropriate data from the more contemporaneous 2001 census had not been published at the time of analysis).

Table 1 shows the odds ratios of registrations being DCO or having missing stage or grade data by quintiles of TDS, after controlling for age and sex. Of the 23 224 registrations for colorectal or breast cancer in 1998–2000, 283 (1.1%) were registered by DCO, 3906 (15.5%) had missing data on stage of cancer, and 4918 (19.5%) had missing data on grade of cancer at diagnosis. There was a highly significant trend in the odds of data being missing on stage or grade by quintiles TDS ($\chi^2=50.58$, p<0.0001; $\chi^2=28.36$, p<0.0001 respectively). No such trend was seen in the odds of registration by DCO ($\chi^2=0.78$, p=0.378). Similar results were seen when the data were analysed separately according to cancer site (see appendix available on line http://www.jech.com/supplemental).

COMMENT

This is the first study to investigate socioeconomic variations in a number of markers of quality of recent UK cancer registration data. We found evidence of socioeconomic gradients in the completeness of detail, but not the ascertainment, of cancer registry data.

Obtaining information on the stage and grade of a colorectal or breast cancer entails more intensive investigation than that required to diagnose the cancer. One explanation of our results is that there are socioeconomic...

### Table 1

<table>
<thead>
<tr>
<th>Quintiles of TDS</th>
<th>TDS range</th>
<th>Total number of registrations</th>
<th>Registration by DCO</th>
<th>Data on stage at diagnosis missing</th>
<th>Data on grade at diagnosis missing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Number (%), Odds ratio (95% CI)</td>
<td>Number (%), Odds ratio (95% CI)</td>
<td>Number (%), Odds ratio (95% CI)</td>
</tr>
<tr>
<td>1 (most affluent)</td>
<td>–8.89 to –3.24</td>
<td>5040</td>
<td>54 (1.07), 1.00 reference</td>
<td>662 (13.13), 1.00 reference</td>
<td>860 (17.06), 1.00 reference</td>
</tr>
<tr>
<td>2</td>
<td>–3.24 to –1.64</td>
<td>5052</td>
<td>60 (1.09), 1.02 (0.70 to 1.47)</td>
<td>656 (12.98), 0.93 (0.82 to 1.03)</td>
<td>893 (17.68), 1.00 (0.89 to 1.11)</td>
</tr>
<tr>
<td>3</td>
<td>–1.64 to 0.31</td>
<td>5037</td>
<td>55 (0.98), 0.86 (0.59 to 1.26)</td>
<td>750 (14.89), 1.05 (0.93 to 1.18)</td>
<td>971 (19.28), 1.07 (0.96 to 1.19)</td>
</tr>
<tr>
<td>4</td>
<td>0.31 to 2.84</td>
<td>5056</td>
<td>60 (1.19), 0.89 (0.61 to 1.29)</td>
<td>928 (18.35), 1.31 (1.17 to 1.47)</td>
<td>1111 (21.97), 1.22 (1.10 to 1.36)</td>
</tr>
<tr>
<td>5 (most deprived)</td>
<td>2.84 to 8.45</td>
<td>5039</td>
<td>54 (1.07), 0.87 (0.59 to 1.28)</td>
<td>910 (18.06), 1.34 (1.19 to 1.50)</td>
<td>1083 (21.49), 1.25 (1.12 to 1.38)</td>
</tr>
</tbody>
</table>

*Significant at the 0.1% level. TDS, Townsend deprivation score; DCO, death certification only.
gradients in the intensiveness of diagnostic investigations performed such that people living in more materially deprived areas tend to receive less intensive investigation than those living in more affluent areas. The source of these variations may lie at one or more of a number of points along the pathway of care. Alternatively, as cancer registries currently rely on capturing results of investigations as recorded in clinical records, our results may reflect socioeconomic variations in some aspect of this process.

Further work is needed to confirm the presence and sources of socioeconomic variations in the completeness of detail of cancer registration data and to determine appropriate strategies to reduce them. Investigators using cancer registry data should be aware of socioeconomic variations in the completeness of the data available.

ACKNOWLEDGEMENTS
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CONTRIBUTORS
JA conceived the study, performed the analysis, and drafted the paper. MW supervised analysis and critically appraised an earlier draft of the manuscript. DF facilitated data extraction and critically appraised an earlier draft of the manuscript.

The appendix is available online (http://www.jech.com/supplemental).

Policy implications
- If socioeconomic variations in the completeness of detail of cancer registration data are confirmed, their source should be identified and methods of decreasing them developed.
- Investigators using cancer registry data should be aware of socioeconomic variations in the completeness of detail of the data available.

Key point
There is evidence of socioeconomic gradients in the completeness of detail, but not the ascertainment, of cancer registration data in the UK.

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Conflicts of interest: David Forman is director of information and research at NYCRIS. None of the authors are aware of any other conflicts of interest.

Formal ethical permission was not required for this study.

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