

SHORT REPORT

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

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J Epidemiol Community Health 2004;58:1052–1053. doi: 10.1136/jech.2004.020008

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.¹ 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 certification 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”.² Although there is some evidence that DCO registrations are more common in deprived populations,³ 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*.⁴

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 of cancer at diagnosis—both of which are required data in all cancer registrations and are derived from

both clinical and pathological data.¹ Socioeconomic position was quantified using Townsend deprivation scores (TDS)⁵ 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 25 224 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

Abbreviations: DCO, death certification only; NYCRIS, Northern and Yorkshire Cancer Registration and Information Service; TDS, Townsend deprivation score

Table 1 Odds ratios and tests for trend of odds of registration by death certification only and missing data on stage and grade at diagnosis by quintiles of Townsend deprivation score (adjusted for age and sex)

Quintiles of TDS	TDS range	Total number of registrations	Registration by DCO		Data on stage at diagnosis missing		Data on grade at diagnosis missing	
			Number (%)	Odds ratio (95% CI)	Number (%)	Odds ratio (95% CI)	Number (%)	Odds ratio (95% CI)
1 (most affluent)	–8.89 to –3.24	5040	54 (1.07)	1.00 reference	662 (13.13)	1.00 reference	860 (17.06)	1.00 reference
2	–3.24 to –1.64	5052	60 (1.19)	1.02 (0.70 to 1.47)	656 (12.98)	0.93 (0.82 to 1.05)	893 (17.68)	1.00 (0.89 to 1.11)
3	–1.64 to 0.31	5037	55 (1.09)	0.86 (0.59 to 1.26)	750 (14.89)	1.05 (0.93 to 1.18)	971 (19.28)	1.07 (0.96 to 1.19)
4	0.31 to 2.84	5056	60 (1.19)	0.89 (0.61 to 1.29)	928 (18.35)	1.31 (1.17 to 1.47)	1111 (21.97)	1.22 (1.10 to 1.36)
5 (most deprived)	2.84 to 8.45	5039	54 (1.07)	0.87 (0.59 to 1.28)	910 (18.06)	1.34 (1.19 to 1.50)	1083 (21.49)	1.25 (1.12 to 1.38)
Test for trend of odds			$\chi^2 = 0.78$, $p = 0.378$		$\chi^2 = 50.85$, $p < 0.0001^*$		$\chi^2 = 28.36$, $p < 0.0001^*$	

*Significant at the 0.1% level. TDS, Townsend deprivation score; DCO, death certification only.

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.

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

Thanks to Caroline Brook and Cheryl Craigs at NYCRIS for help in abstracting the data used in this analysis.

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 on line (<http://www.jech.com/supplemental>).

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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Funding: this analysis was funded by the Faculty of Public Health/BUPA joint research fellowship (2001–4) awarded to JA. All of the authors are independent from this funding source.

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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Accepted for publication 31 March 2004

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