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Accuracy of hospital discharge data for cancer registration and epidemiological research in Northern Ireland

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Abstract

Background: Cancer registries provide a basis for many epidemiological studies in cancer. Electronic data provide for prompt, economical data capture for disease registries; doubts, however, exist about their data quality. *Materials and methods*: We examined the accuracy for cancer registration of a subset of 7043 electronically captured hospital discharge data.

Results: Note availability was 82%. Of the notes available for examination demographic data accuracy was high; however, 7.4% of cases coded on discharge as cancer had no malignancy recorded in case notes while 4.1% had *insitu* or benign tumors. Almost a third had some inaccuracy in coding tumor site. Prevalent cases accounted for 17.2% of cases examined reflecting a new registry. Electronic data capture reduces time spent examining notes; only 40% of cases notified from PAS required a quick validation check. It enhances data completeness; without electronic discharge data 11.5% of the final database would have been missed. The validation check prevented over-inflation of the cancer registration database by 7.5%. Measures of accuracy in the final database were high. *Conclusion*: This study shows that discharge data are a valuable data source for cancer registries but require a targeted note review aimed at cases without corroborating data.

Introduction

The accuracy and timeliness of cancer registration data are important factors in determining data suitability for epidemiological studies of cancer. Advances in information technology have impacted on all aspects of health care, providing new opportunities for speedy assimilation of data for disease-specific registries. Electronic data transfer improves timeliness, reduces transcription errors and lessens the need for manual data extraction. It is also generally more cost-effective than traditional methods. Since the 1980s there has been substantial progress in electronic data capture for cancer registration. The European Network of Cancer Registries recommends that cancer registries improve the quality of information by using automated cancer registration. Ideally, registrations would only be made where verification from at least three independent electronic sources exists. However, registrations from only one source may be accepted "when augmented with active manual validation" [1]. The source of registration influences its credibility [2]. One received from a pathology report, confirmed by a cancer center record, should be more accurate than that from a single hospital administration record.

Histopathology is regarded as a reliable information source for cancer registration [2–4]. This, however, depends on accurate data transfer, and difficulties can occur in identification of recurrences and staging involving metastasis. The accuracy of electronic hospital discharge data is dependent on coder accuracy, the absence of transcriptional errors and the quality of information available to the coder. Several studies have looked at the quality of this information and have cautioned on its use in cancer registration [5–7].

The establishment of a new cancer registry for Northern Ireland (NICR) in 1994, replacing a 35-year-