Estimating cancer distant recurrence rates from administrative datasets: comparison of cancer registry and hospital records

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Study objective

To assess agreement between the NSW Central Cancer Registry (CCR) and the NSW Admitted Patient Data Collection (APDC) for identification of progression to metastatic disease in women with breast cancer.

Introduction

- Population-based estimates of rates of progression to metastatic cancer are important for doctors, patients and health service planning.
- State cancer registries receive notifications of new cancer diagnoses, but notifications of metastases are not routinely validated.
- Hospitals also record diagnoses of secondary (metastatic) cancers.
- Record linkage of cancer registry and hospital data can be used to estimate rates of progression, however the validity of this approach has not been reported.

NSW Central Cancer Registry (CCR)	NSW Admitted Patient Data Collection (APDC)
Data sources	
• Receives cancer notifications for NSW residents from hospitals, pathology laboratories, and radiotherapy units. • Records information including: diagnosis date, degree of spread (localised, regional, distant, unknown); tumour site; and morphology.	• Records ICD-10 AM diagnosis and procedure codes for every hospital episode of care in NSW.
Study definition of metastatic breast cancer (MBC)	
• Notification with degree of spread classified as distant following an initial diagnosis of non-MBC. • Coded by hospital coder or pathology laboratory, or if this classification is missing, ICD-10AM diagnosis codes for C78 and C79 are used.	• Diagnosis of secondary malignant cancer (C77-C79, excluding C77.3-secondary and unspecified malignant neoplasm of lymph nodes and C79.81-secondary cancer of breast) • CCR-verification required if known other non-breast cancer

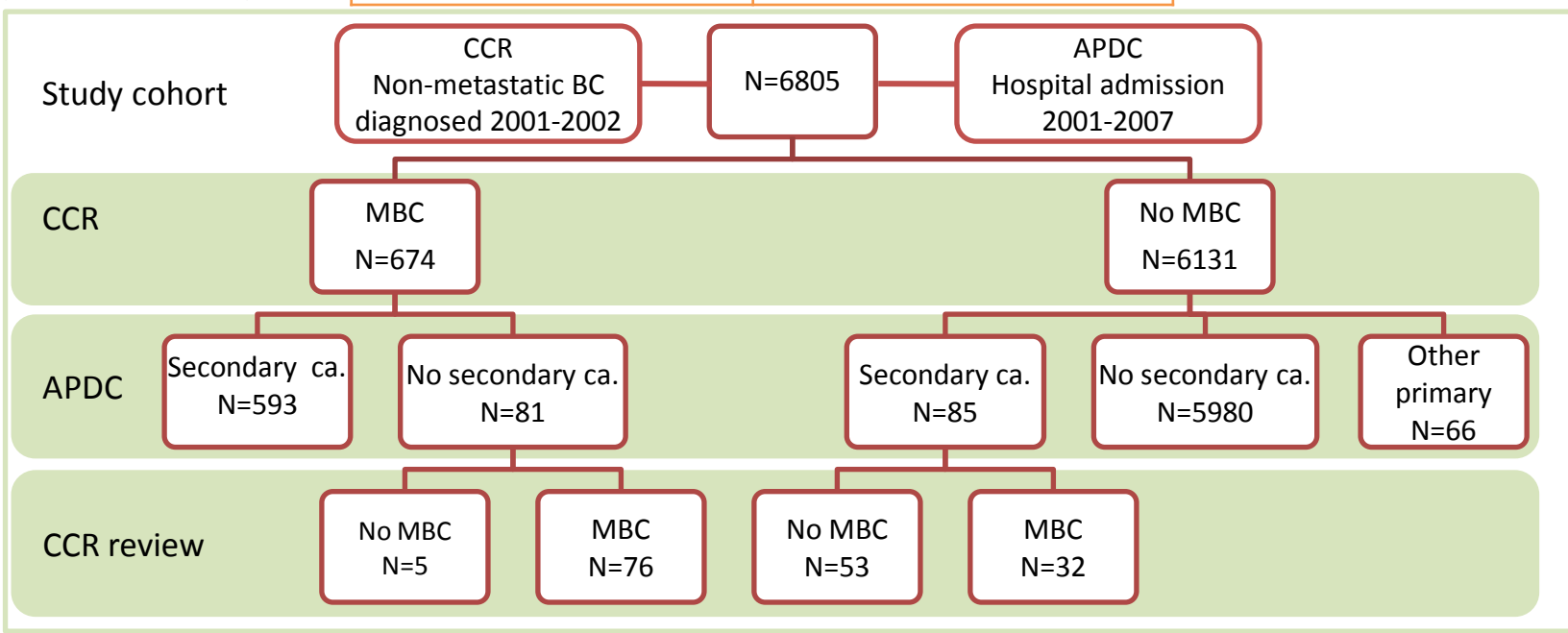
Results

Agreement CCR versus APDC

- Overall agreement between CCR and APDC for identification of MBC was 98%, agreement beyond chance was 87%.
- After CCR review, 701 subjects were classified as having MBC, giving a cumulative incidence proportion of 10.3% (95%CI 9.6-11.0%), compared with 9.9% (95%CI 9.2-10.6%), prior to review.
- The CCR yielded an additional 44 MBC than the APDC, identifying 669 verified MBC including 76 cases not detected from APDC, whereas APDC identified 625 MBC including 32 cases not detected from CCR (p<0.0001).

Time to first MBC

- 82% of CCR notifications occurred at or within 3 months of the first APDC record, 11% occurred >3 months before the APDC record, and 7% >3 months after APDC record (p=0.04).



Methods

Study population

- We used the CCR to identify all cases of non-metastatic breast cancer diagnosed in NSW in 2001-2002.
- We used health record linkage (HRL) to identify APDC records for this study cohort up to 31 December 2007.

Outcome

New metastatic breast cancer (MBC) identified by CCR or APDC within 5-years of primary breast cancer diagnosis (see table for definitions).

Analysis

- We calculated agreement between CCR and APDC for defining MBC status at 5 yrs.
- A clerical review of cases recorded as MBC on one but not both databases ('discordant' records) was performed at the CCR.
- We compared the yield of CCR-verified MBC cases and timing of first notification between each data source (McNemars test).

CCR review of MBC recorded on one database only	
CCR only N=81	APDC only N=85
Verified as MBC, n=76	Verified as MBC, n=32
• Notification included from NSW hospitals, n=48 • Notification only from non-NSW hospitals, n=28, including: interstate notification (10); pathology (15), XRT (2), death (1)	• CCR coding of loco-regional spread revised to MBC, n=14 • CCR notification received after 5 years, n= 6 • MBC only recorded on death certificate, n=12
Revised to non-MBC, n=5	Revised to non-MBC, n=53
• Secondary cancer to breast, n= 3 • CCR original misclassification, n=2	• Corresponding notification of loco-regional spread sent to CCR, n=36 • Corresponding notification of distant spread sent to CCR, but attributed to non-breast primary, n=17

Interpretation

- This study provides the first information on the validity of using CCR and APDC records to estimate breast cancer progression to metastatic disease at the population level.
- The high agreement between the CCR and APDC for MBC detection and timing illustrate hospital notifications are the major source of CCR notifications.
- The CCR holds more complete data, which is a particular advantage for determining MBC status in subjects with multiple primaries. For verified MBC, it identified a further 6.3% of cases than the APDC, with an associated small increase (0.65%) in 5-year MBC risk.

Conclusions

The overall accuracy of the CCR and APDC for detecting the first clinical diagnosis of MBC is unknown, however our findings suggest both are feasible sources for estimating risk of MBC requiring hospital care.

Abbreviations APDC= Admitted patient data collection, Ca. = cancer, CCR=central cancer registry, MBC=metastatic breast cancer, XRT=radiotherapy

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