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ORIGINAL PAPER

Comprehensive capture of cutaneous melanoma by the Ontario Cancer Registry: validation study using community pathology reports

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Abstract Melanoma is often managed outside hospital settings, creating the potential for underreporting to cancer registries. To our knowledge, completeness of melanoma capture in cancer registries has not been assessed using external data sources since the 1980s. We evaluated the melanoma capture rate from 1993 to 2009 in a provincial cancer registry. We identified all melanoma diagnoses in pathology reports from a major community laboratory in Ontario, Canada. Pathologically confirmed diagnoses were linked to Ontario Cancer Registry (OCR) records using health insurance numbers. We calculated capture rates as the proportion of patients with melanoma confirmed by a pathology report, with a corresponding melanoma diagnosis in OCR. OCR captured 3,798 of 4,275 (88.8, 95 % confidence interval: 87.9, 89.8 %) invasive melanoma diagnoses over the 17-year period. Annual capture rates of 94 % or higher were found for over half the study period. Among all 29,133 melanoma diagnoses in OCR, 27.6 % were registered based on a pathology report alone, compared with 3.4 % for non-cutaneous malignancies. This suggests that comprehensive capture of melanoma cases by a provincial cancer registry is achievable using source data from community laboratories. There is a need for ongoing validation to ensure data remain accurate and complete to reliably inform clinical care, research, and policy.

Keywords Melanoma · Validation · Cancer registries · Cancer · Cancer reporting

Abbreviations

ICD	International Classification of Diseases for Oncology
OCR	Ontario Cancer Registry

Introduction

The incidence of cutaneous melanoma continues to increase, ranking as the fifth–seventh most common malignancy in North America and Europe [1–5]. Population-based data from cancer registries are critical for surveillance of temporal trends in melanoma incidence and appropriate allocation of resources to implement and evaluate preventative and therapeutic interventions. Unlike non-cutaneous malignancies, which are mostly treated in hospital settings where registry reporting systems are well established, the diagnosis and treatment of melanoma are often performed in community clinic settings. To capture these melanoma diagnoses, cancer registries must rely primarily on pathology reports from community-based laboratories. Physician reporting of melanoma has historically accounted for less than 1 % of registered melanomas, even when required by law [6].

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These challenges in ascertainment have raised concerns about significant underregistration of melanoma diagnoses [6–12]. To our knowledge, the completeness of melanoma capture in cancer registries has not been audited directly using an external community data source since the 1980s [10, 11]. We evaluated the Ontario Cancer Registry (OCR) capture rate for invasive cutaneous melanomas diagnosed from 1993 to 2009 using pathology reports from a community laboratory in Canada.

Methods

The OCR is the primary source of population-based information on cancer diagnoses in the province of Ontario, Canada, and its 13.5 million residents. The registry, founded in 1964 and coordinated by Cancer Care Ontario, passively registers incident cases of invasive cancer (excluding cutaneous basal and squamous cell carcinomas). OCR records only the first cancer diagnosis per tissue site in a given individual. Diagnoses are classified according to the International Classification of Diseases for Oncology (ICD-9/ICD-O-1). OCR also records which of its four major data sources were the basis for registering a cancer diagnosis: (1) hospital discharge and ambulatory care records from the Canadian Institute for Health Information; (2) pathology reports from hospital and community laboratories; (3) consultations and treatment records from regional cancer centers; and (4) death certificates from the Ontario Registrar General, with a given cancer listed as the underlying cause of death [5, 13, 14].

To evaluate completeness of melanoma capture in OCR, we obtained all pathology reports for skin specimens collected from Ontario residents and submitted to LifeLabs in 1993–2009. Under the single-payer, provincial government-administered healthcare system, LifeLabs is the one of four community laboratories accredited in Ontario to process specimens collected outside of hospital settings. LifeLabs maintains electronic records of pathology reports for skin biopsy specimens. The synoptic reports contain two standard fields with menu-driven terminology (laboratory diagnostic code; diagnosis text), and two free-text fields (diagnosis; body site).

We conducted an electronic text search for pathology reports containing the word "melanoma." For each identified report, we manually reviewed the diagnosis fields and classified the diagnosis as melanoma in situ, invasive melanoma, or other. Reports with inconclusive diagnoses of melanoma were not classified as melanoma cases. For individuals with multiple tissue specimen collections during the study period, we included only the first invasive melanoma diagnosis. Data extraction was completed independently by two individuals; any disagreements were resolved by discussion, and if necessary, involvement of a third individual.

LifeLabs pathology reports and OCR data were held securely in a linkable and coded form at the Institute for Clinical Evaluative Sciences, Toronto, Canada. We linked all LifeLabs pathology reports to OCR using unique encrypted identifiers, enabling us to identify patients who had an invasive cutaneous melanoma diagnosis recorded in both a LifeLabs pathology report and OCR.

Our main objective was to determine the melanoma capture rate in OCR, defined as the proportion of individuals with their first-ever invasive cutaneous melanoma confirmed by a LifeLabs pathology report who had a melanoma diagnosis recorded in OCR within 60 days of the pathological diagnosis date. We defined the pathological diagnosis date as the specimen collection date recorded on the pathology report. The OCR diagnosis date corresponds to the date of the first-ever melanoma diagnosis registered for a given individual in OCR. We excluded cases where the OCR diagnosis date preceded the pathological diagnosis date by more than 60 days because the older OCR record likely represented a separate melanoma diagnosis. For cases captured in OCR, we tabulated the time difference between the pathological and OCR diagnosis dates.

To examine whether cases were more likely to be captured if other OCR data sources (hospital records, cancer center records, death certificates) also contained melanoma diagnoses, we reviewed the non-pathological data sources for a period within 180 days of the pathological diagnosis date. To evaluate the extent to which melanoma was treated in community clinic versus hospital settings, we determined the proportion of all melanoma registrations in OCR that were based solely on pathology reports and no other information source (hospital records, cancer center records, death certificates), compared with other non-cutaneous cancers.

Results

We identified 6,044 pathology reports from LifeLabs containing the word "melanoma" in the diagnosis field from 1993 to 2009. The majority had a diagnosis of invasive melanoma ($n = 5{,}200$). The remaining reports described melanoma in situ ($n = 523$), inconclusive diagnoses of possible melanoma ($n = 32$), and diagnoses other than melanoma ($n = 289$). The 5,200 pathology reports of invasive melanoma corresponded to 4,528 unique patients. We excluded 253 of these cases because the OCR date preceded the pathological diagnosis date by more than 60 days. Our final cohort consisted of 4,275 patients with melanoma.

Overall, OCR captured 3,798 of 4,275 melanoma patients (88.8, 95 % confidence interval: 87.9, 89.8 %) over the 17-year period (Table 1). Annual rates of 94 % or higher were found for over half of the study period (9 of the 17 years). The capture rate in 1993 was 80.4 % and improved in subsequent years (88.7–98.2 %), with the exception of 2004 (66.8 %) and 2005 (51.4 %). In the anomalous period from 2004 to 2005, there was no substantial annual decrease in the overall number of melanoma cases recorded in OCR (Fig. 1).

Of the 3,798 patients with pathologically confirmed melanoma captured in OCR, the majority ($n = 3{,}514$; 92.5 %) had an OCR diagnosis date matching the pathological diagnosis date (Table 2). The OCR diagnosis date preceded the pathological diagnosis date for 3.0 % ($n = 116$) of patients; about one-fifth of these discrepant dates differed by 30–60 days. For the remaining 168 cases (4.5 %), the OCR diagnosis date trailed the pathological diagnosis date; the discrepancy was 30–60 days for about one-third of these patients.

Of the 3,798 pathologically confirmed LifeLabs cases captured in OCR, 54.7 % ($n = 2{,}079$) did not have a melanoma diagnosis recorded in any other data source (hospital records, cancer center records, or death certificates) within 180 days of the pathological diagnosis date, compared with 79.7 % (380/477) of the cases that were not captured in OCR.

Among all 29,133 patients with melanoma diagnoses in OCR from 1993 to 2009, 27.6 % were registered based on a pathology report alone, without information from hospital records, cancer centre records, or death certificates. The proportion increased from 16 % in 1993 to over 30 % after 2004. The corresponding overall figure for non-cutaneous malignancies was 3.4 %.

Table 1 Ontario Cancer Registry capture rates for pathologically confirmed invasive melanoma cases, stratified by year of pathological diagnosis at LifeLabs

Year	Capture rate[a]
1993	80.4 % (78/97)
1994	93.3 % (97/104)
1995	92.9 % (104/112)
1996	94.1 % (143/152)
1997	90.3 % (158/175)
1998	93.9 % (215/229)
1999	94.2 % (259/275)
2000	95.6 % (240/251)
2001	96.7 % (263/272)
2002	95.2 % (218/229)
2003	88.7 % (268/302)
2004	66.8 % (225/337)
2005	51.4 % (171/333)
2006	96.0 % (286/298)
2007	96.1 % (294/306)
2008	95.7 % (352/368)
2009	98.2 % (427/435)
Total	88.8 % (3,798/4,275)
Excluding 2004–2005	94.4 % (3,402/3,605)

[a] Proportion of patients with invasive melanoma diagnosed on LifeLabs pathology report whose diagnosis is recorded in Ontario Cancer Registry within 60 days of the pathological diagnosis date

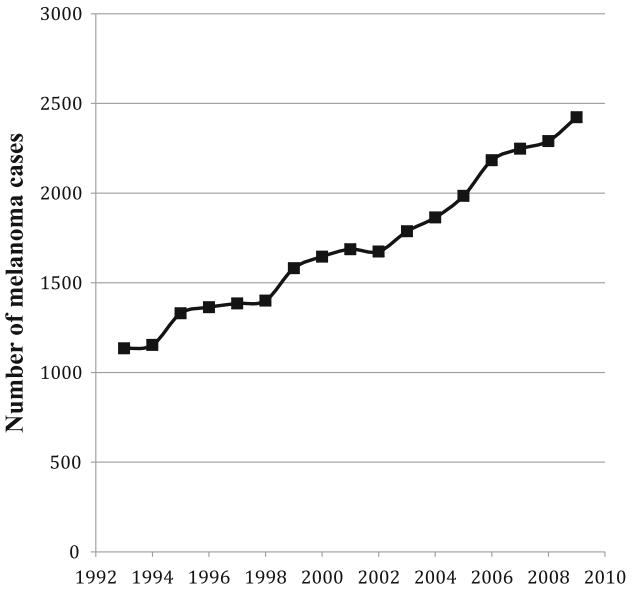

Fig. 1 Number of patients with melanoma registered annually from 1993 to 2009 in the Ontario Cancer Registry

Table 2 Time difference between OCR diagnosis date relative to LifeLabs pathological diagnosis date

	Number of patients (%) $n = 3{,}798$
31–60 days before	24 (0.6 %)
1–30 days before	92 (2.4 %)
Same date	3,514 (92.5 %)
1–30 days after	105 (2.8 %)
31–60 days after	63 (1.7 %)

Discussion

Population-based cancer registries are widely used for epidemiological research and melanoma surveillance. Rigorously evaluating the completeness of registered diagnoses enables a better understanding of the degree of underestimation of melanoma incidence, which can impact public health policy and resource allocation. Most studies

have estimated melanoma capture rates using indirect methods of assessment with inherent limitations [6, 8, 9, 12, 13, 15–19]. Two direct audits using external pathological and clinical data from the 1980s found melanoma capture rates of 74 % in England; 96 % in Scotland; and 88 % in Massachusetts, USA [10, 11]. To our knowledge, we have conducted the first direct assessment of melanoma capture rates in recent decades using case ascertainment from an external community data source. By linking OCR data to melanoma pathology reports from a major community laboratory, we found a melanoma capture rate of 91 % overall and at least 95 % annually for over half of the 17-year period.

Melanoma is unique among registered cancers because it is amenable to diagnosis and treatment in an outpatient community setting, meaning that pathology reports from community laboratories are often the sole data source for ascertaining diagnoses. Overall, a quarter of all melanoma cases captured in OCR were diagnosed and managed entirely outside of hospital settings, compared with only 3.4 % for non-cutaneous malignancies. This presents challenges to cancer registries that rely on hospital records and death certificates as major sources of information.

Our study showed that the proportion of melanoma cases registered based on a pathology report alone (i.e., cases that were diagnosed and managed outside of hospital settings) increased from 16 % in 1993 to over 30 % after 2004. This trend may be due to improved detection of early-stage melanomas, which are more amenable to treatment in the community. Also, a new electronic reporting system for pathology laboratories was introduced by OCR in 2003, which may have led to increased reporting thereafter from community laboratories.

Despite the greater reliance on a single community-based data source, we found that high capture rates (up to 98 % annually) are achievable for melanoma. This contrasts with previous studies where melanoma was historically estimated to have one of the lowest capture rates among any major cancer type [16, 17]. There is no legal requirement in Ontario to report cancer diagnoses directly to OCR, and reporting by the four accredited community pathology laboratories is voluntary [20]. Since reporting of pathology data is negotiated independently with each laboratory, the relatively small number of community laboratories likely helped to achieve high capture rates for melanoma in OCR.

Potential explanations for the missing melanoma diagnoses in OCR include lack of voluntary data transfer from pathology laboratories to OCR, or miscoding of melanoma diagnoses received by the OCR registration system. Missed cases were more likely than captured cases to have the LifeLabs pathology report as the only data source reporting a melanoma diagnosis (80 vs. 55 %), confirming the challenges with capturing melanoma cases treated outside of hospital settings. The other 20 % of missed cases had melanoma diagnoses coded in multiple data sources routinely available to OCR, including hospital records and death certificates. These cases may have been missed due to coding errors or failure to transmit data to the registry. Studies based on other cancer registries have suggested that missed cases of melanoma tend to be less advanced, with diagnosis and treatment performed in an outpatient setting [9, 10].

We identified two anomalous years (2004 and 2005) during which capture rates were significantly lower (66.8 and 51.4 %, respectively). The transition to the new OCR electronic pathology data submission system in 2003 may explain the lower capture rates in the subsequent 2 years. Low capture rates of LifeLabs cases in 2004–2005 did not, however, produce a substantial decrease in the overall number of melanoma cases recorded in OCR during these 2 years. Epidemiological analyses based on OCR melanoma data should, nevertheless, consider the potential impact of decreased capture rates from LifeLabs in 2004–2005.

Our study was also the first to compare the diagnosis date recorded in OCR relative to the diagnostic pathology report. The majority (92.5 %) of melanomas had matching OCR and pathological diagnosis dates. For the 3 % of cases where the OCR date preceded the pathological diagnosis date, it is likely that the OCR melanoma registration reflected either the same or a separate tumor diagnosed from another data source, such as a tissue specimen submitted to a different pathology laboratory. In 1.7 % of cases, the OCR diagnosis date was more than 30 days after the date of the LifeLabs pathology report, suggesting that the particular report was missed or incorrectly recorded by OCR.

Our study has some limitations. First, we only used pathology data from one major community laboratory in Ontario. However, our results should be generalizable to melanomas diagnosed at other laboratories in the province, as there are unlikely to be systematic differences between laboratories that would affect the completeness of OCR registration. Second, OCR registers only the first incident melanoma diagnosis for a given patient. This method of dealing with multiple primary tumors is particularly problematic for melanoma, given that 3–9 % of patients develop a second primary melanoma [21–24], and that previous melanoma is an independent risk factor for a subsequent primary melanoma [25–27]. For patients with multiple primary melanomas whose first melanoma diagnosis preceded the LifeLabs pathology report, the LifeLabs report would not have been registered as a distinct melanoma diagnosis in OCR. To avoid misclassifying these cases as missed melanoma registrations, we excluded from

our cohort any patients who had a prior melanoma diagnosis recorded in OCR more than 60 days before the pathological diagnosis date. Third, because we only had pathology reports from one major laboratory, we were unable to calculate the accuracy of OCR melanoma diagnoses. For example, if the LifeLabs pathology report stated a diagnosis other than melanoma, yet there was an OCR diagnosis of invasive melanoma registered for the same patient at a similar time, we could not be sure whether this represented a false positive record in OCR or whether the patient also had a separate melanoma diagnosed based on hospital records or a biopsy submitted to a different laboratory. Fourth, we focused on melanoma diagnoses made in the community setting. The OCR capture rate would be higher if we included cases diagnosed at hospitals and cancer centers, where additional source records would be available to help identify melanoma diagnoses for registration. However, the overall effect would be relatively minor, as the majority of melanoma diagnoses are made in the community.

We have shown that comprehensive capture of melanoma cases by a provincial cancer registry is achievable using source data from community pathology laboratories. There is a need for ongoing validation of cancer registries to ensure that registered melanoma data remain accurate and complete in order to reliably inform clinical care, research, policy, and public health interventions.

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Compliance with ethical standard

Conflicts of interest None.

References

1. Canadian Cancer Society's Advisory Committee on Cancer Statistics (2014) Canadian cancer statistics 2014. Canadian Cancer Society, Toronto
2. American Cancer Society (2014) Cancer facts and figures 2014. American Cancer Society, Atlanta
3. Cancer Research UK (2013) Cancer statistics report—skin cancer. Cancer Research UK, London
4. Ferlay J, Steliarova-Foucher E, Lortet-Tieulent J, Rosso S, Coebergh JW, Comber H, Forman D, Bray F (2013) Cancer incidence and mortality patterns in Europe: estimates for 40 countries in 2012. Eur J Cancer 49(6):1374–1403. doi:10.1016/j.ejca.2012.12.027
5. Cancer Care Ontario. The Ontario Cancer Registry. https://www.cancercare.on.ca/ocs/csurv/stats/ocr/. Updated 11 Jan 2012. Accessed 20 March 2014
6. Cockburn M, Swetter SM, Peng D, Keegan TH, Deapen D, Clarke CA (2008) Melanoma underreporting: Why does it happen, how big is the problem, and how do we fix it? J Am Acad Dermatol 59:1081–1085. doi:10.1016/j.jaad.2008.08.007
7. Cartee TV, Kini SP, Chen SC (2011) Melanoma reporting to central cancer registries by US dermatologists: an analysis of the persistent knowledge and practice gap. J Am Acad Dermatol 65(5 Suppl 1):S124–S132. doi:10.1016/j.jaad.2011.05.032
8. Hall HI, Jamison P, Fulton JP, Clutter G, Roffers S, Parrish P (2002) Reporting cutaneous melanoma to cancer registries in the United States. J Am Acad Dermatol 49(4):624–630
9. Paterson IC, Beer H, Jones DA (2001) Under-registration of melanoma in Wales in 1998: use of the capture–recapture method to estimate the 'true' incidence. Melanoma Res 11:141–145
10. Melia J, Frost T, Graham-Brown R et al (1995) Problems with registration of cutaneous malignant melanoma in England. Br J Cancer 72:224–228
11. Koh HK, Clapp RW, Barnett JM et al (1991) Systemic underreporting of cutaneous malignant melanoma in Massachusetts. Possible implications for national incidence figures. J Am Acad Dermatol 24(4):545–550
12. Karagas MR, Thomas DB, Roth GJ, Johnson LK, Weiss NS (1991) The effects of changes in health care delivery on the reported incidence of cutaneous melanoma in western Washington state. Am J Epidemiol 133(1):58–62
13. Reynolds DL, Nguyen VC, Clarke EA (1991) Reliability of cancer mortality statistics in Ontario: a comparison of incident and death diagnoses, 1979–1983. Can J Public Health 82(2):120–126
14. McLaughlin JR, Kreiger N, Marrett LD, Holowaty EJ (1991) Cancer incidence registration and trends in Ontario. Eur J Cancer 27(111):1520–1524
15. Merlino LA, Sullivan KJ, Whitaker DC, Lynch CF (1997) The independent pathology laboratory as a reporting source for cutaneous melanoma incidence in Iowa, 1977–1994. J Am Acad Dermatol 3(4):578–585
16. Robles SC, Marrett LD, Clarke EA, Risch HA (1988) An application of capture–recapture methods to the estimation of completeness of cancer registration. J Clin Epidemiol 41(5):495–501
17. Walter SD, Bimie SE, Marrett LD, Taylor SM, Reynolds D, Davies J, Drake JJ, Hayes M (1994) The geographic variation of cancer incidence in Ontario. Am J Public Health 84(3):367–376
18. Tilling K (2001) Capture–recapture methods—useful or misleading? Int J Epidemiol 30(1):12–14
19. Wang M, Hatcher J, Cancer Projection Analytical Network Working Team (2010) Data quality assessment report for canadian cancer surveillance. Cancer projections network (C-Projections), Alberta Health Services. http://www.cancerview.ca/idc/groups/public/documents/webcontent/csen_cproj_data_q_as_report_q4.pdf
20. Clarke EA, Marrett LD, Kreiger N (1991) Cancer registration in Ontario: a computer approach. IARC, Lyon **(IARC Scientific Publications, no. 95)**
21. Youlden DR, Youl PH, Soyer H, Aitken JF, Baade PD (2014) Distribution of subsequent primary invasive melanomas following a first primary invasive or in situ melanoma in Queensland, Australia, 1982–2010. JAMA Dermatol 150(5):526–534
22. van der Leest RJ, Liu L, Coebergh JW, Neumann HA, Mooi WJ, Nijsten T, de Vries E (2012) Risk of second primary in situ and invasive melanoma in a Dutch population-based cohort: 1989–2008. Br J Dermatol 167:1321–1330. doi:10.1111/j.1365-2133.2012.11123.x
23. Balamurugan A, Rees JR, Kosary C, Rim SH, Li J, Stewart SL (2011) Subsequent primary cancers among men and women with in situ and invasive melanoma of the skin. J Am Acad Dermatol 65(5 Suppl 1):S69–S77. doi:10.1016/j.jaad.2011.04.033
24. Spanogle JP, Clarke CA, Aroner S, Swetter SM (2010) Risk of second primary malignancies following cutaneous melanoma diagnosis: a population-based study. J Am Acad Dermatol 62(5):757–767. doi:10.1016/j.jaad.2009.07.039

25. Haenssle HA, Korpas B, Hansen-Hagge C, Buhl T, Kaune KM, Johnsen S, Rosenberger A, Schon MP, Emmert S (2010) Selection of patients for long-term surveillance with digital dermoscopy by assessment of melanoma risk factors. Arch Dermatol 146(3):257–264. doi:10.1001/archdermatol.2009.370
26. Rhodes AR, Weinstock MA, Fitzpatrick TB, Mihm MC Jr, Sober AJ (1987) Risk factors for cutaneous melanoma: a practical method of recognizing predisposed individuals. JAMA 258(21): 3146–3154
27. van der Leest RJ, Flohil SC, Arends LR, de Vries E, Nijsten T (2014) Risk of subsequent cutaneous malignancy in patients with prior melanoma: a systemic review and meta-analysis. J Eur Acad Dermatol Venereol. doi:10.1111/jdv.12887