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Melanoma Under-reporting: why does it happen, how big is the problem, and how do we fix it?

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Introduction

Melanoma incidence trends from population-based cancer surveillance programs, such as the National Cancer Institute-funded Surveillance, Epidemiology and End Results (SEER) program, are central to evaluating primary prevention and screening programs^{1,2}, and raising awareness of increasing trends in subgroups that should be targeted for primary and secondary prevention³. However, it is widely recognized that trends in melanoma incidence are affected by reporting and surveillance issues. For example, previous reports have detailed both under-reporting⁴ and delayed (up to 7-10 years) reporting⁵ of melanomas to cancer registries. Inaccurate surveillance will mislead melanoma control efforts and impact our ability to respond in a timely fashion with public health initiatives.

Melanoma, like other cancers, appears on the Confidential Morbidity Report (CMR), and is mandated by law in all 50 states to be reported by diagnosing physicians to central registries. Poor reporting can occur for cancers of any site⁵, but the potential of reporting inconsistencies and corresponding bias in trend estimation is especially high for melanoma, and likely to worsen with the increasing decentralization of melanoma diagnosis and outpatient treatment away from hospital settings. In some hospitals, cancers are now identified automatically via electronic reporting systems. Outside of those systems, diagnosing physicians must ensure that their patients' melanomas are being reported to central cancer registries by confirming their reporting arrangements or through direct contact with the regional cancer registry.

In this review, we provide an overview of the most likely reasons for melanoma under-reporting, describe the seriousness of the problem using dermatologist survey data recently collected by two SEER cancer registries, and provide information for clinicians on how to get involved in the solution.

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Why are melanomas more likely to be under-reported than other cancers?

Melanoma diagnoses are more often occurring in an outpatient setting, which makes these cancers more likely than others to be underreported to cancer registries. With the adoption of narrower excision margins for melanoma⁶ and the potential use of Mohs micrographic surgery for superficial melanoma, greater numbers of thin cutaneous melanomas are likely to be diagnosed and treated in the outpatient setting⁷ where automated surveillance systems do not always exist. Using these records to cross-check the already-reported diagnoses is also an essential component of ensuring completeness in population-based reporting. All central cancer registries are skilled at removing duplicate records by consolidating reports of the same cancer from multiple sources. However, reports from hospitals and pathology laboratories do not represent all melanomas being diagnosed in recent years.

Figure 1 shows the typical distribution of sources of reporting for melanomas for three years in Los Angeles County. About 80% of melanoma reports come from 'routine reporting' (reports obtained from hospitals and clinics), while 20% come solely from the Registry's additional efforts to obtain information on melanoma diagnosis from a physician who should have reported the case. These occur when we receive a report implying that a melanoma was followed-up (e.g. a report of 'clear margins' from a pathology laboratory), but we cannot find the original case in our records because it was never reported in the first place. To our knowledge, these reports are not routinely collected by Registries (other than Los Angeles and the San Francisco/Greater Bay Area). The pathology resolution process provides some indication of the minimum number of melanomas being missed if we relied on 'routine' reporting only. In Los Angeles County about 10% of melanoma incident cases annually are found only from pathology laboratory sources.

These data suggest that less than one percent of all melanomas reported to the Registry come from physician reporting. Data from most population-based registries show a similar 'passive' system of reporting, with comparable proportions of melanomas being reported by physicians. These low proportions of reporting underscore the potential for an unacceptably high percentage of melanomas to be missed in population-representative data.

What is the extent of the problem?

Figure 1 only estimates the potential problem of melanoma under-reporting. While many studies have outlined the potential for under-reporting^{4,8}, we are aware of no data enumerating the extent of the problem. Of course, it is not possible to accurately measure the number of missing cases, but we do have some insight from case audits recently conducted in Los Angeles County (2005-06) and the Greater San Francisco Bay (2006) areas of California. In these separate but coordinated surveys, we interviewed dermatologists and dermatopathologists regarding their melanoma caseloads and reporting practices. Our methods differed somewhat, limiting our ability to pool our results, but generally involved obtaining comprehensive member listings from the American Academy of Dermatology, regional dermatologic societies in Los Angeles County and the Greater Bay Area, and Internet searches (using the search words "dermatologist" and "dermatopathologist"), and removing duplicate listings to create a master roster. In Los Angeles, we also included in our study sample all physicians listed in the Registry as the diagnosing physician for any melanoma reported in the previous 5 years. Physicians were asked to complete a questionnaire regarding their melanoma diagnostic caseloads, most importantly estimated counts of melanoma diagnosed in the past one- and five-year periods. In Los Angeles, physicians were first telephoned and interviewed personally. If physicians could not respond personally, office managers were recruited to provide needed information. In the Greater Bay Area, electronic and paper surveys were provided for self-administration as a first option; physicians who did not respond to emailed or mailed communications were then telephoned directly and asked to participate in a telephone

version of the survey. Surveys in both centers were reviewed and approved by the appropriate local Institutional Review Board.

In Los Angeles, we identified 701 dermatologists and dermatopathologists. Among these, 145 were determined to be ineligible because they reported not diagnosing melanoma (n=96) or were retired or deceased (n=49); 235 could not be reached or did not respond. Responses were obtained from 321 physicians (overall response rate of 57.7%). In the Greater Bay Area region, we identified 495 dermatologists and dermatopathologists. Of these, we could not identify a working address or telephone number for 26 and thus could not determine their eligibility for the study. Of those we could contact, a total of 85 were deemed ineligible because they reported being retired in the prior year (n=40), relocated out of the catchment area in the prior year (n=19), were no longer practicing dermatology (n=23), or were deceased (n=3). Forty-five of the 410 eligible physicians (11%) declined to participate in the survey, yielding a final sample size of 339 physicians and an overall response rate of 83%. Although they agreed to participate in the survey, some 85 physicians employed by several large healthcare systems with known melanoma reporting systems could not or did not want to estimate their number of yearly diagnoses and as such were not included in the relevant calculations.

We compared physicians' self-reported numbers of cases with those appearing in the cancer registry. In Los Angeles County, we discovered:

- Out of 321 dermatologists and dermatopathologists in the Los Angeles County area, only 4 physicians reported that they had used CMR to report melanoma cases to the Registry. Their responses to this study accounted for a total of 26 cases in the previous year and 221 in the previous 5 years (there are approximately 1,100 melanoma cases diagnosed annually, and over 6,000 in the last 5 years, in Los Angeles County)
- Of 403 clinics in which the 321 physicians practiced, 124 (30.8%) responded that their melanoma cases were routinely reported to Registry. Four sites did so by using CMR cards, 63 "waited for a follow-up from the Registry", and 57 responded that they reported by some other (unspecified) method. The comments from this last group of 57 sites usually indicated that they were not sure how their melanoma cases were being reported.
- The comments from those physicians who did not report melanomas generally indicated confusion about the reporting requirements and avenues available, noting that they were unsure whose responsibility it was to report diagnosed melanomas.
- We also received information from pathology labs that commonly provided additional information on the diagnosis of melanoma. A total of 57 such pathology labs within Los Angeles County were identified (used by one or more of the 321 above physicians). We had no previous knowledge of 21 of these, which accounted for 3.0% of self-reported 'missing' melanoma cases. Three labs were known to us but were never visited (because of resource constraints), accounting for 11.6% of self-reported 'missing' cases. Twenty nine other laboratories were visited accounting for 85.3% of 'missing' cases.
- The majority of clinicians who said they had not reported melanomas, also asked "why, am I supposed to?"

In the Greater Bay Area, we discovered similar reporting issues :

- The annual estimated total number of invasive melanomas diagnosed by 254 physicians (n=8,945) was 70% higher than the numbers documented in the registry for those physicians (n=5,025). Excluding several impossibly high estimates (exceeding 1000 cases over five years), these counts were about 38% higher than the

numbers reported by the eligible physicians. Patterns were generally similar for *in situ* melanomas. Thus, a preliminary estimate of the numbers of melanomas that could be under-reported to the Greater Bay Area Cancer Registry (GBACR) was in the 30-40% range, similar to that reported in the Los Angeles region.

- Dermatologists overwhelmingly (86.5%) reported sending melanoma biopsy specimens to an outside pathologist or pathology lab for histologic diagnosis.
- Community physicians who referred skin biopsy specimens for dermatopathology diagnosis at the university hospitals generally relied on the hospital pathology service for melanoma reporting. Likewise, dermatologists within health maintenance organizations and large multi-specialty group practices in the Bay Area generally assumed all melanoma reporting was the responsibility of the affiliated pathology service.
- 47 non-hospital based pathology laboratories were reported as being used by local dermatologists. Of these, 6 out-of-state labs were not previously known to the GBACR.
- Only 27 of 410 (6.6%) physicians reported that they performed Moh's surgery for cutaneous melanoma, so changing diagnostic/outpatient surgery practices apparently did not account for the majority of potentially missing cases.

While these results from urban areas of California, covering about two thirds of the State's population, provide useful information on the specific shortcomings in melanoma reporting, to some degree, the details are moot. Successful efforts to improve melanoma surveillance clearly depend on improving awareness of the problem among physicians and seeking a new level of commitment and partnership to ensure that all cases are reported in a timely fashion. The stakes are high: when poor reporting leads to underrepresentation of melanomas by an estimated 30-40%, there will be underrepresentation in the distribution of financial and other resources directed toward melanoma primary and secondary prevention. Notably, the results from our surveys probably underestimate the true proportion of unreported melanomas because, while our response rates were excellent, survey non-responders are probably also less likely to report melanomas.

How do we fix the problem?

One partial solution to the problem of missing melanomas is to conduct regular audits of all the pathology laboratories identified, and where possible, we have started to do this. However, cancer registries have insufficient resources to carry out such an effort. Furthermore, the increasingly common practice of dermatologists using out-of-state pathology laboratories presents another hurdle to melanoma reporting, since these pathology labs do not necessarily have the means to contact the in-state cancer registry to ensure proper melanoma reporting in the state that the melanoma was diagnosed. Therefore, the most efficient solution to this problem remains the appropriate reporting of incident melanomas by the diagnosing physician.

What can dermatologists and dermatopathologists do to make a difference?

Dermatologists and dermatopathologists could immediately improve melanoma reporting by routinely reporting new diagnoses to their local cancer registry. We suggest utilization of a melanoma reporting check list as follows:

The Melanoma Reporting Check List

- Don't assume that somebody else has reported the case. All diagnoses of melanoma, based on original or secondary reviews, are reportable.

- If you're not sure how melanomas diagnosed in your practice are being reported to a central cancer registry, ask around. Double check with staff that they are doing this regularly or confirm that state cancer registry personnel are regularly reviewing your records.
- Do the same for patients who are not seen in your practice but whose slides you have reviewed.
- If you remain unsure, contact your local cancer registry for help (contact information for regional registries is available at <http://www.naaccr.org/>).
- If you learn that your patients were not reported, implement procedures available from your local cancer registry. While procedures vary among states, this may include submission of a simple mail-in form, a secure web-based system or possibly a visit by a certified cancer registrar.
- Any diagnosis (initial or verification) of melanoma should trigger reporting. Obviously, this results in multiple reports of the same cancer, but as above, all cancer registries have the resources required to remove duplicate reports.
- If confirming diagnoses in a pathology laboratory setting, you should still follow the steps above to be sure that these melanomas are being reported.
- If you determine that cases diagnosed in past years were not reported, and you have the resources, please do report these historical cases. Cancer registries are experienced in removing duplicate reports of current and historical cases.

Conclusion

Melanoma presents a substantial and growing threat to morbidity and mortality in the US. Although it is a potentially preventable cancer that clearly benefits from early detection, efforts to monitor melanoma and the groups affected by melanoma have been stymied by incomplete reporting to cancer registries. Our data confirm that cancer registries are missing a substantial number of incident cases in the US. This problem is likely to worsen with improvements in outpatient surgery for melanoma including an increase in the number of Moh's surgeons nationally⁹, and it is particularly relevant for melanomas *in situ* and thin invasive tumors which are more amenable to outpatient diagnosis and treatment solely within the dermatologist's office.

The melanoma reporting problem is easily solved: while cancer registries are working to improve electronic surveillance methods, the easiest solution lies in a ground swell of diligent reporting by physicians, which is required by law in all states in the US. It is notable that in our *ad hoc* studies in California, the majority of physicians diagnosed less than 5 melanomas a year, but over 500 physicians reported diagnosing melanomas. This means both that the resources required for the Registry to contact all diagnosing physicians would be enormous, but that the burden on individual physicians (most reporting less than 5 melanomas a year) is minimal. For physicians in facilities which diagnose many melanomas that go unreported, most registries have resources to implement reporting, either through establishing electronic mechanisms, or by sending in certified Cancer Tumor Registrars to enumerate cases. The key, however, is that physicians are aware of the reporting activities (or lack thereof) for their diagnosed melanomas.

Ironically, in an age of improving electronic communication and centralization of data resources, the best solution to improving melanoma reporting probably lies in the hands of individual physicians seeking responsibility to report individual diagnoses of melanoma to their regional cancer registry.

Increasing physician awareness of mandatory melanoma reporting and expanding the relationship between community practitioners and their regional cancer registries are key components to improving melanoma reporting nationwide.

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Abbreviations and Acronyms

GBACR	Greater Bay Area Cancer Registry
SEER	Surveillance, Epidemiology and End Results
US	United States

References

1. Marrett LD, Nguyen HL, Armstrong BK. Trends in the incidence of cutaneous malignant melanoma in New South Wales, 1983-1996. *International Journal of Cancer* 2001;92:457-62.
2. Chen YT, Zheng T, Holford TR, Berwick M, Dubrow R. Malignant melanoma incidence in Connecticut (United States): time trends and age-period-cohort modeling by anatomic site. *Cancer Causes & Control* 1994;5:341-50. [PubMed: 8080946]
3. Cockburn MG, Zadnick J, Deapen D. Developing epidemic of melanoma in the Hispanic population of California. *Cancer* 2006;106:1162-8. [PubMed: 16429450]
4. Hall HI, Jamison P, Fulton JP, Clutter G, Roffers S, Parrish P. Reporting cutaneous melanoma to cancer registries in the United States. *Journal of the American Academy of Dermatology* 2003;49:624-30. [PubMed: 14512907]
5. Clegg LX, Feuer EJ, Midthune DN, Fay MP, Hankey BF. Impact of reporting delay and reporting error on cancer incidence rates and trends. *Journal of the National Cancer Institute* 2002;94:1537-45. [PubMed: 12381706]
6. National Comprehensive Cancer Network. Melanoma. National Comprehensive Cancer Network, Inc; 2008. Clinical Practice Guidelines in Oncology. 2008
7. Centers for Medicare and Medicaid Services. Part B Extract Summary System (BESS) Carrier Data File.10/24/20072007.
8. Thoburn KK, German RR, Lewis M, Nichols PJ, Ahmed F, Jackson-Thompson J. Case completeness and data accuracy in the Centers for Disease Control and Prevention's National Program of Cancer Registries. *Cancer* 2007;109:1607-16. [PubMed: 17343277]
9. American Academy of Dermatology Association. Practice Profile Survey. 2005 2007.

Figure 1.
Sources of melanoma case reports received by the Los Angeles Cancer Surveillance Program, 2004-2006