

**The Reporting of Cutaneous Melanoma to Cancer Registries
in the United States**

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ABSTRACT

BACKGROUND. Central cancer registries provide data to monitor incidence rates of cutaneous melanoma, which have increased significantly during the past decades. The completeness of melanoma reporting is largely unknown, however.

METHODS. Data provided by central cancer registries to the North American Association of Central Cancer Registries were used to assess the completeness of melanoma reporting. Age-adjusted, average annual incidence rates were calculated and compared by time period (1992-1994, 1995-1997), stage, and program (National Program of Cancer Registries [NPCR] and Surveillance Epidemiology and End Results [SEER] Program; the latter is considered to have higher rates of case ascertainment). Completeness was also measured with the incidence/mortality (I/M) ratio. The analyses were restricted to whites only.

RESULTS. Melanoma incidence rates among white persons for 1995-1997 from SEER registries ranged from 11.8 to 33.9 per 100,000 population; 18 of 40 NPCR registries were within this range. For 1992-1994, eight of 30 NPCR registries were within the range of incidence rates in SEER registries. Among NPCR registries, incidence rates were generally higher for the 1995-1997 than 1992-1994, with increases in incidence rates of up to 93% versus a maximum increase of 32% among SEER registries. The percentage of localized melanoma did not increase substantially in most SEER registries over the study period, but some NPCR registries had substantial increases. Among NPCR registries that had incidence rates comparable to those of SEER in 1995-1997, the I/M ratios were generally lower among NPCR registries than SEER registries.

CONCLUSIONS. Increases in incidence rates reported by NPCR registries over the time period are

likely due to increased case ascertainment and reporting. Careful attention must be given to data quality, particularly to the completeness of reporting, when studying trends, patterns, and risk factors for melanoma.

INTRODUCTION

In the United States, incidence rates of cutaneous melanoma have increased by 6.1% between 1973 and 1981 and by 2.8% from 1981 to 1998 (Ries 2001). Estimates of melanoma incidence rates have been primarily based on data from the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program, which covers only about 14% of the U.S. population but provides high-quality data for time trend analyses (Jemal 2001; Hall 1999; Dennis 1993). To develop national incidence rates of melanoma, it would be useful to combine SEER data with information from additional state cancer registries. The completeness of melanoma reporting to state cancer registries is largely unknown, however.

Ascertainment of melanoma cases is especially likely to be incomplete for early stage cancers diagnosed and treated at physician offices which, unlike hospitals, do not routinely report cancer cases to the central cancer registries (Karagas 1991; Seiffert 1992; Melia 1995). In early stage cancer, underreporting of localized disease (an invasive cancer that has spread no farther than the organ in which it started [Young, 2001]) is of greater concern than underreporting of *in situ* cases, as generally only invasive cases are included in the calculation of incidence rates. Underreporting of 1982-1986 melanoma cases was found to be about 12% in Massachusetts (Koh 1991), and a case-finding study of all 1987 cancer diagnoses in SEER registries found that 10 melanoma cases had been missed (3 of them *in situ*) among a total of 149 missed cases (Zippin 1995). In Iowa, a survey of dermatologists showed that 10.4% to 17.1% of cases of cutaneous melanoma were underreported to the SEER state cancer registry (Merlino 1997). In western Washington, an increase was found in underreporting of this disease from 2% in 1974 to 21% in 1984 (Karagas 1991). Finally, in northern California, a study

was conducted to determine how many cutaneous melanoma cases were diagnosed solely in a private physician's office, dermatology clinics, or dermatopathology offices. This study found that the underreporting of cutaneous melanoma to the SEER registry increased from 4% in 1973 to 16% in 1985, with a larger number of *in situ* cases being missed (Seiffert 1992).

Methods to determine the extent of underreporting of cancer include audits, estimation of completeness based on the incidence/mortality ratio (Howe 2001), and other comparisons. Information on completeness of reporting is often not available from audits, however, as melanoma is generally not included, and audits are costly to conduct. In the present study, we used indirect methods to examine the completeness of melanoma case reporting in U.S. cancer registries.

METHODS

We used data from U.S. population-based central cancer registries included in *Cancer in North America* (CINA); registry data are included in CINA only if they meet specific data completeness and quality indicators (Chen 2000). For 1992 to 1997, information was available for all years from 10 registries of the SEER program and 30 registries that joined the National Program of Cancer Registries (NPCR) effective with diagnosis year 1995 but had been operating for at least several years previously. Information for 1995-1996 was available for an additional 10 NPCR registries and for 1997 for 8 of these 10. Five of the SEER registries are regional population-based cancer registries located within and reporting to NPCR statewide population-based cancer registries. The analyses were restricted to whites only as the incidence rates are much higher than those in blacks (Ries 2001), and the number of cases of melanoma are low for black and other minority populations.

We used three approaches as proxy measures of the completeness of melanoma reporting. First, we compared incidence rates from NPCR registries with those from SEER registries. The SEER program generally has a high case ascertainment rate (97.7% for all cancers assessed [Zippin 1995]), although it may be lower for melanoma (Merlino 1997). Average-annual incidence rates were calculated, age adjusted to the 1970 U.S. population standard, for the combined years 1992-1994 and 1995-1997. These periods were chosen because federal funding for NPCR became available to states in 1994 and the NPCR reference year for most registries (the year in which the collection, storage, and analysis of reportable malignancies began under the NPCR program) is 1995, when improved cancer reporting is expected. Second, we compared the SEER and NPCR registries by the differences seen between the two time periods in the percentage of invasive melanomas that were in the localized stage (27 NPCR registries had stage information available). Reporting bias is most likely to be seen in localized cancers, as underreporting is most likely from nonhospital sources that diagnose and treat less advanced cases. An increasing trend toward non-hospital melanoma diagnosis and/or treatment is likely to affect reporting of early stage melanomas, making it more likely that the proportion of nonlocal invasive melanoma compared to local (and *in situ*) melanoma is biased upward. In addition, relative increases in melanoma screening could, over time, lead to higher percentages of reported early stage cancers.

We also calculated the incidence-to-mortality (I/M) ratios for the time period 1995-1997. The I/M ratios of NPCR registries with incidence rates similar to those of SEER registries were compared with the I/M ratios of the SEER registries and the other NPCR registries.

RESULTS

Average annual invasive melanoma incidence for 1995-1997 for SEER registries ranged from 11.8 to 33.9 per 100,000 white population (Figure 1). The incidence rates of 18 NPCR registries (of a total of 40 registries or 45%) were within this range, and rates for 4 other NPCR registries were within 10% of the lowest SEER rate. Among the 30 NPCR registries for which this information was available for 1992-1994, 8 were within the range of incidence rates of SEER registries (range 10.8 to 25.6 per 100,000 white population), and 7 others were within 10% of the lowest SEER rate.

Between 1992-1994 and 1995-1997, incidence rates increased a minimum of 0% to a maximum of 32% among SEER registries (Figure 2a). Among the 30 NPCR registries for which this information was available, incidence rates were generally higher for 1995-1997 than 1992-1994 (Figure 2b) with increases in incidence rates of up to 93%. Incidence rates decreased in two registries.

The percentage of invasive cases that were localized melanoma did not change substantially in most SEER registries between the two time periods (Figure 3). Among the 27 NPCR registries for which this information was available, substantial changes in the percentage of localized melanoma cases were observed for some registries.

Among the 17 NPCR registries that had incidence rates comparable to those of SEER in 1995-1997, the I/M ratio ranged from 4.20 to 7.13. In contrast, the I/M ratios for SEER registries ranged from 5.50 to 9.46.

DISCUSSION

We observed that the number of NPCR registries with incidence rates similar to those of SEER registries increased from 1992-1994 to 1995-1997. An increase in incidence rates may be related to increases in new melanoma cases, greater screening efforts, changes in diagnostic criteria, or improved case ascertainment. Although increases in incidence rates are still expected based on historic trends that continue to rise (Hall 1999), it is unlikely that the large increases observed truly reflect greater incidence rates, as they represent an increase much larger than expected in such a short period (expected average annual increase is 2.8% [Ries 2001]). Screening is also unlikely to be the answer, as screening for skin cancer during the observed period was not widespread and had a low yield (Koh 1996; Jonna 1998; Rigel 1986). For example, the large screening efforts conducted by the American Academy of Dermatology and offered to the general population at participating medical care facilities had a 0.1% melanoma detection rate among 282,555 persons screened during 1992 to 1994 (Koh 1996). In other screening initiatives, 0.4% to 0.6% of participants had melanoma (Jonna 1998; Rigel 1986).

Early detection of cancer resulting from screening, heightened medical awareness, or early response to symptoms may result in the increasing diagnosis of small tumors before they become life-threatening. The effect may be to raise incidence (and survival rates), although the effect on incidence rates of heightened medical awareness about melanoma was found to be small in one study (Gong 1992). Little or no change from early detection is expected in mortality rates; rates of thicker, more invasive melanomas have been found to be similar between communities with and without heightened awareness among the population about early detection (Gong 1992). Changes in diagnostic criteria are an unlikely explanation, especially considering the short time period studied (Phillipp 1987; Van Der

Esch 1991).

Improved case ascertainment, however, may explain the higher incidence rates found among NPCR registries for the second study period. Federal funds for NPCR authorized under the Cancer Registries Amendment Act (Public Law no. 515 of the 102nd Congress) were made available to states in the fall of 1994 for data collection of cases diagnosed from 1995 onward. The additional funds allowed existing registries to enhance case-finding efforts. In addition, cases diagnosed in 1995-1997 could have been found in later years, adding to the incidence for that period.

We also assessed the percentage of cases classified as localized stage, because any screening effects or better case ascertainment from nonhospital reporting sources would be expected to yield higher rates of localized cases. On the other hand, the increase over time in the proportion of cases treated in nonhospital settings and low reporting rates from these sources would lower rates of localized disease. We observed that the increase over the two time periods in the proportion of cases reported as localized was larger among NPCR registries than SEER registries, which is consistent with improved case ascertainment and reporting and unlikely due to the effects of screening. Abstracting and coding errors may be more frequent for cutaneous melanoma than for other cancers, as they are frequently diagnosed and treated in facilities that do not have cancer registries (Roffers 1990). Additional training on abstracting and coding of early stage cutaneous melanoma among NPCR registries may have also increased reporting.

Even among NPCR registries that had incidence rates comparable to those of SEER in 1995-1997, the I/M ratio was generally lower among NPCR registries (range 4.20 to 7.13) than for SEER registries (range 5.50 to 9.46). The range in I/M ratios observed for the SEER registries is considered

a real difference between locales because SEER registries are assumed to achieve high case completeness (Fulton 1995). Underreporting of melanoma will lead to low numbers for the numerator (I) and a low ratio (assuming melanoma mortality reporting to be stable). Underreporting is related to the difficulty in melanoma registration because treatment is generally administered in outpatient, nonhospital settings. Very low I/M ratios thus may indicate substantial melanoma underreporting.

Our assessment of the completeness of melanoma case reporting is subject to several limitations. First, we used indirect methods of assessing completeness that did not allow for counting the actual number of cases missed; future case-finding audits may provide this information. We also did not have information on other variables. For example, completeness of case reporting was found by Zippin and colleagues to vary by hospital cancer caseload and case-finding source (Zippin 1995). Some registries receive reports from pathology laboratories (6 of 21 states) and/or survey their dermatologists to report cases (4 of 21 states) (personal communication with states, Gayle Clutter, CDC). These states may attain better completeness than others; but this issue will need to be formally investigated in future studies. Active case finding with visits by medical record abstractors may also improve completeness. For example, Arizona used data on melanoma from the Southeastern Arizona Skin Cancer Center, which primarily collects information on basal cell and squamous cell carcinomas in the four counties of Southeastern Arizona (including Tucson) to add 40-50 cases of 741 total in 1996 (personal communication, Chris Newton, Arizona Department of Health Services). Another potential limitation of our assessment may be that different staging systems are used by different registries, making comparisons of incidence rate by stage potentially problematic. Finally, we compared NPCR registries to SEER registries, but underreporting of melanoma cases may also occur in SEER registries

(Merlino 1997).

In summary, increases in the incidence rates of cutaneous melanoma reported by NPCR registries over the time periods studied are most likely due to increased case ascertainment and reporting. Data from state cancer registries with incidence rates below the SEER range should probably not be included in studies of incidence rates that combine data from different states. Time trends in rates cannot be assessed when completeness of reporting varies over time (Zippin 1995), and regional differences cannot be assessed when completeness varies by region (Maudsley 1997). In the future, researchers may also consider using information on the completeness and accuracy of the data to adjust incidence rates (Astrom 2001). Duplication of effort should be avoided in setting up a separate melanoma registry within a state, such as the New Mexico Melanoma Registry established in 1980 (Black 1987); however, cancer registries could enhance the benefits to and support from the dermatologic community in participating in cutaneous melanoma registration. Pathologists and dermatologists may be particularly interested in receiving specific information on cutaneous melanoma and in exchanging diagnostic information. Outreach to members of the dermatology community and engaging them in active participation may then lead to better case ascertainment and data accuracy in the central cancer registry. More important, the data can then be used to describe accurately the occurrence of disease and can be used in special studies of risk factors and prevention.

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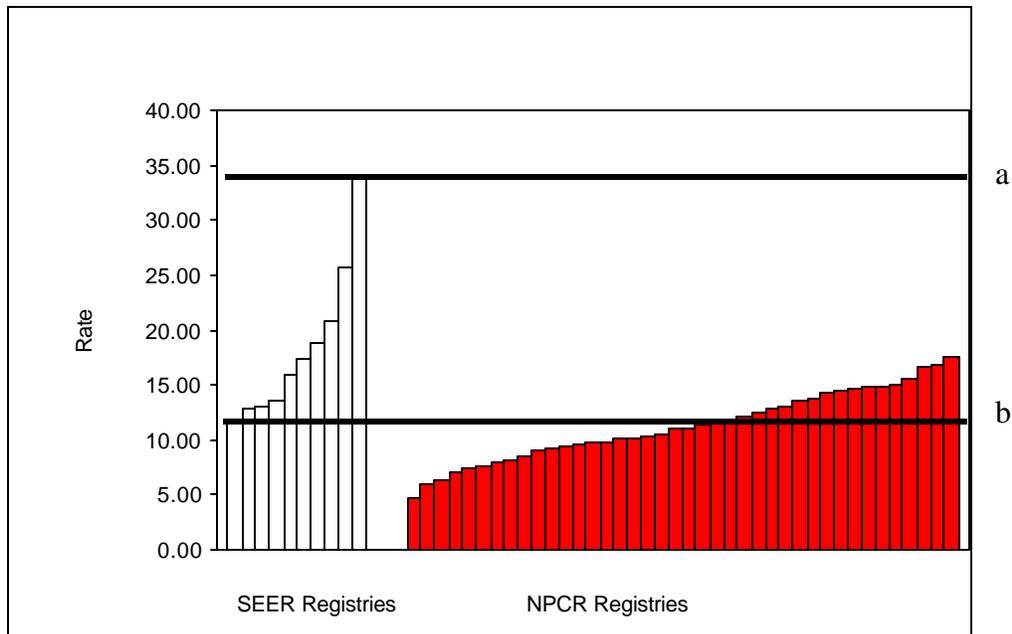
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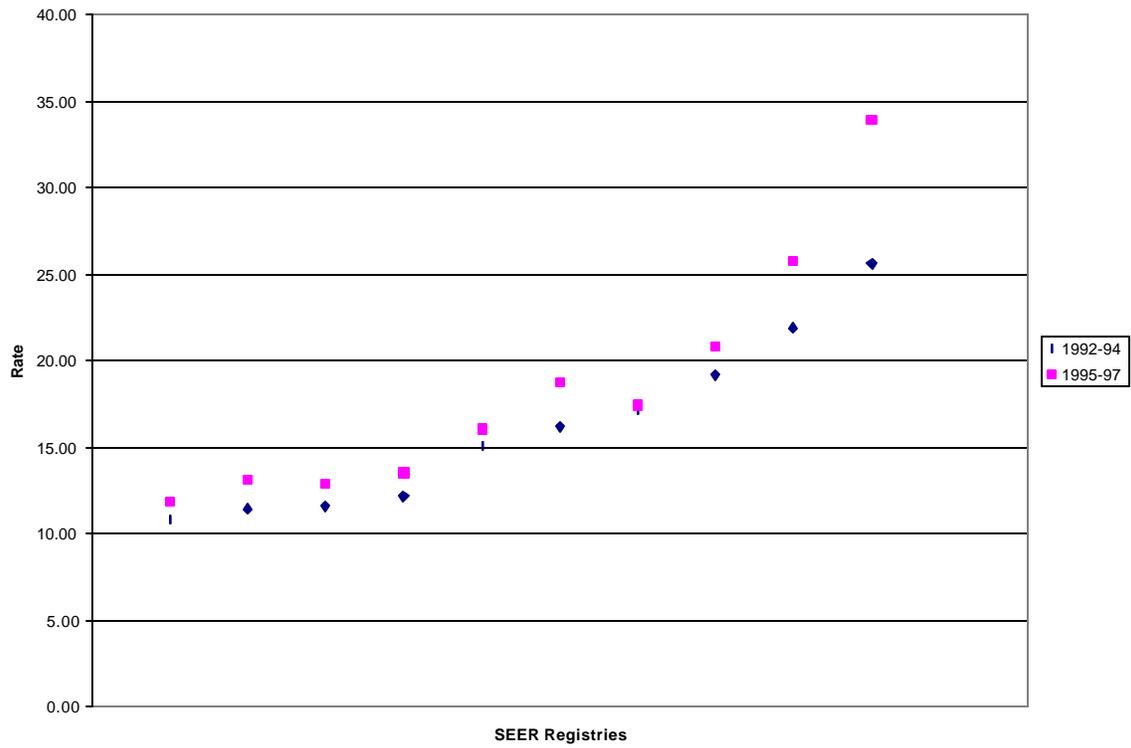
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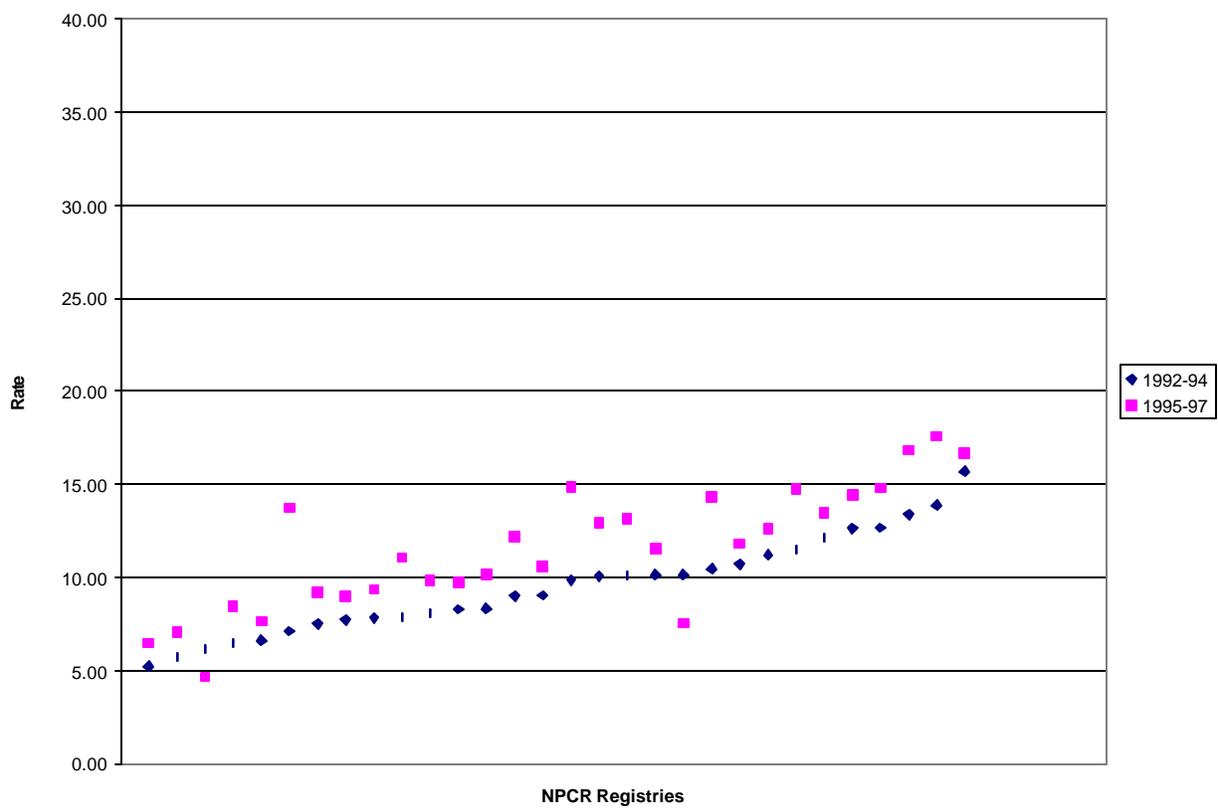
*Rates are per 100,000 and are age-adjusted to the 1970 US standard population.

Figure 1. Average annual invasive melanoma incidence rates* among whites in SEER and NPCR registries, 1995-1997; (a) upper limit of range of SEER incidence rates, (b) lower limit of range of SEER incidence rates.



*Rates are per 100,000 and are age-adjusted to the 1970 US standard population.

Figure 2a. Melanoma incidence rates* among whites in SEER registries, 1992-1994 and 1995-1997



*Rates are per 100,000 and are age-adjusted to the 1970 US standard population.

Figure 2b. Melanoma incidence rates* among whites in NPCR registries, 1992-1994 and 1995-1997

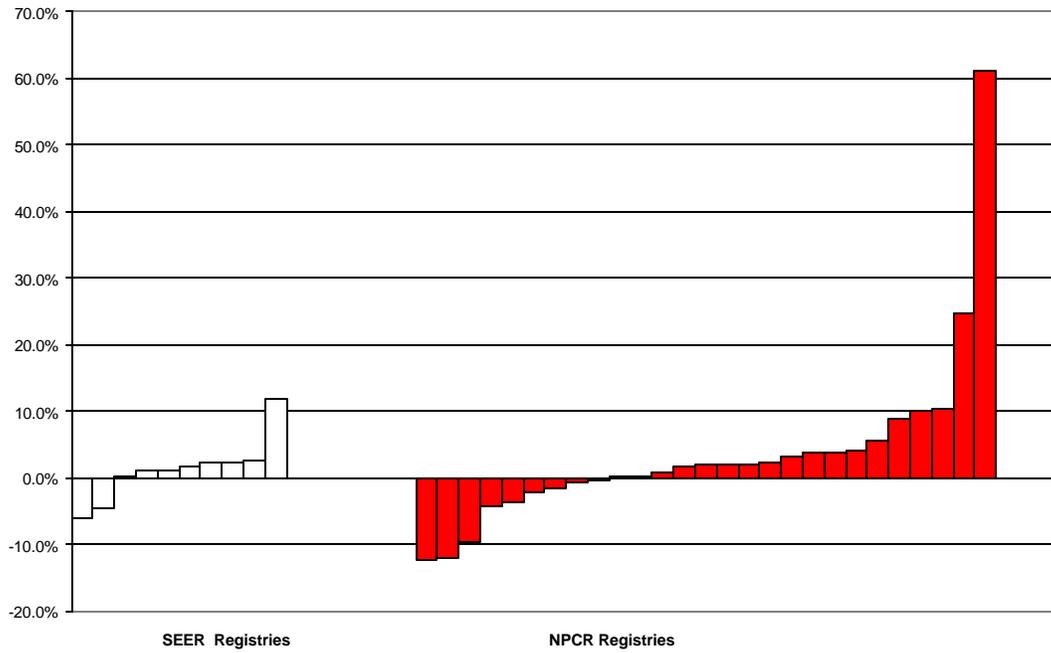


Figure 3. Percent difference between time periods, 1992-1994 and 1995-1997, in percent of localized melanoma among whites, in SEER and NPCR registries