

## UNDERREPORTING OF MELANOMA IN ARIZONA AND STRATEGIES FOR INCREASING REPORTING: A PUBLIC HEALTH PARTNERSHIP APPROACH

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The incidence of melanoma has been reported as increasing in the United States.<sup>1-3</sup> The American Cancer Society reported a 2.1% to 2.4% annual increase in rates from 1999 to 2008 for men and women.<sup>3</sup> In Arizona, the age-adjusted melanoma incidence rates from 1999 to 2001 were reported as also increasing but slightly higher than for the United States as a whole.<sup>4</sup> However, in a 2005–2007 report, the incidence rates for melanoma were 30% lower for Arizona men and 21% lower for Arizona women than the U.S. rates.<sup>5</sup> Reasons for this change in trends were not known.

In Arizona, cancer data management is the responsibility of the Arizona Cancer Registry (ACR).<sup>6</sup> In 1992, reporting of all cancer cases, including melanoma, by hospitals, clinics, and physicians became mandatory by Arizona Revised Statutes §36-133.<sup>7</sup> The ACR is a passive registry, meaning that ACR personnel do not actively visit pathology laboratories or health provider offices to identify and abstract cancer cases. Instead, the registry relies solely on providers sending appropriate forms to the ACR, although the ACR does perform quality control with high-volume providers and laboratories. Although the ACR is considered a population-based registry with more than 95% coverage, it lost substantial funding in 2003, which resulted in fewer quality-control visits to assure compliance. Cancer incidence rates are calculated from data maintained by state cancer registries, and these data are highly dependent on the actual reporting of cancer cases from community sources, including physicians. The potential for underreporting can be especially high with melanoma, as it is frequently diagnosed and treated in outpatient settings.<sup>8,9</sup>

In 2012, because of concerns that the observed drop in melanoma incidence in Arizona represented underreporting rather than real change, an ad hoc statewide public health partnership was formed to assess the degree of underreporting of melanoma, identify barriers to reporting by providers, and recommend strategies for increasing reporting. We describe the partnership, the magnitude of the problem for Arizona, strategies identified to increase reporting, and results after implementing new strategies.

## METHODS

### Arizona Melanoma Task Force

The Arizona Melanoma Task Force (hereinafter, Task Force) was formed after two separate groups of Arizona stakeholders—local dermatologists and ACR staff—approached faculty at the University of Arizona Skin Cancer Institute about concerns with melanoma reporting in the state. A local dermatologist suggested that a state registry for melanoma was needed because she was not aware there was one. These conversations provided initial evidence of a lack of provider awareness of the state cancer registry and providers' responsibilities for case reporting.

Since mid-2012, the Task Force has met monthly, usually via teleconference, with a set agenda and minutes reported to interested parties. Faculty from the Skin Cancer Institute facilitate the teleconferences and one of the community dermatologists serves as chair of the Task Force. Members of the group have fluctuated, but the core members include three primary registry personnel from the ACR; dermatologists and dermatopathologists from Phoenix and Tucson, Arizona; a University of Arizona dermatologist; and an epidemiologist representing both the University of Arizona Zuckerman College of Public Health (UACOPH) and the Skin Cancer Institute. Graduate students from the UACOPH also attend the meetings and provide support in data collection and analysis.

This all-volunteer Task Force was self-appointed based on interest. The Skin Cancer Institute provided meeting space when needed and teleconferencing. The ACR identified ancillary funding from the Centers for Disease Control and Prevention for the UACOPH to conduct a survey of Arizona dermatologists, prepare a formal report on barriers for underreporting, and make recommendations to reduce underreporting. The Task Force provided oversight and reviewed and

approved the final report. The Task Force also used report findings to develop strategies to overcome barriers, outline a process to implement the strategies, and evaluate the impact of these strategies.

### **Assessing the magnitude of the problem**

Two approaches were taken to address the magnitude of underreporting of skin cancer in Arizona. The first was to review ACR data in more depth to determine if the secular trends were consistent by stage of melanoma at diagnosis. The second approach sought to more directly estimate the level of underreporting. The Task Force voluntarily undertook a pilot project to determine the degree to which melanoma might be underreported to the ACR and the stage of disease that was underreported most frequently.

### **Incidence of melanoma by stage at diagnosis**

Data on national melanoma incidence were obtained from the Surveillance, Epidemiology, and End Results (SEER) website for the nine SEER registries (Atlanta, Georgia; Connecticut; Detroit, Michigan; Hawaii; Iowa; New Mexico; San Francisco, California; Seattle, Washington; and Utah).<sup>10</sup> The incidence of melanoma in Arizona was based on case counts and population estimates provided by the ACR. Stage was categorized according to SEER Derived Summary Stage 2000 classification methods (e.g., in situ, local, regional, or distant).<sup>11</sup> We calculated age-standardized melanoma incidence rates for 1995–2008 using direct adjustment with 18 age groups and the 2000 U.S. standardized population.

### **Pilot study of dermatology practices**

Dermatology practices were recruited by members of the Task Force from dermatologists who had been practicing in either the Tucson or Phoenix areas since 2009. Seven practices in Tucson agreed to participate, including six community dermatology practices and one academic practice. Eight community practices in Phoenix were also recruited. Because this project was conceived as a pilot study to examine the potential for underreporting, the Task Force recruited dermatologists who the members felt would be willing to complete the additional work on a voluntary basis and who represented a range of practice types. The Tucson and Phoenix metropolitan areas account for more than 75% of the total population in Arizona, and more than 88% of the dermatologists on the Board of Medical Examiner listings are from these two areas.

Practice staff members abstracted information from all diagnosed cutaneous melanoma (i.e., in situ and invasive) cases from 2009 by reviewing biopsy logbooks.

The dermatologist or a member of the practice staff filled out official ACR case forms and sent them directly to the ACR. The ACR then cross-referenced these cases with cases registered in the ACR database to determine how many of the physicians' cases had been previously reported to the registry. Frequency counts and percentages were calculated for cases diagnosed that were previously reported to the ACR. Cases diagnosed but not previously contained in the ACR database were grouped by melanoma stage according to SEER Derived Summary Stage 2000 classification.<sup>11</sup>

### **Identifying barriers to reporting**

A multimethod approach that included a statewide survey of Arizona dermatologists and in-depth interviews of selected Arizona practices was used to identify barriers to reporting and potential strategies to increase reporting.

**Online survey.** The online survey assessed (1) the current level of awareness of reporting requirements and (2) physicians' perceptions of the most and least acceptable approaches to inform them of the reporting requirements. The survey was designed to take less than 15 minutes to complete and to be anonymous with no follow-up. The target population included actively practicing dermatologists, dermatopathologists, and dermatologic surgeons in Arizona. A total of 313 providers were identified from publicly available lists (i.e., the Board of Medical Examiners and telephone directories). Initial recruitment occurred through faxes to offices and mass e-mails sent by dermatology societies. The Tucson and Phoenix dermatology societies had combined e-mail lists of 235 dermatologists. A cover letter described the purpose of the survey and how to access the online survey. A \$40 gift card was offered for survey completion. Letters went out on June 1, 2012, and recruitment ended in December 2012. A total of 38 surveys were completed initially, and a second e-mail yielded 40 additional responses. Four surveys were incomplete, thereby yielding a total of 74 eligible survey responses.

**Dermatology practice interviews.** Structured, in-depth interviews were conducted in June 2012 with six dermatology or dermatopathology practices to (1) identify workflow processes that achieve efficient melanoma reporting to the ACR, (2) obtain data on physician and reporting staff perceptions of factors driving the underreporting of melanoma to the state cancer registry, (3) discover barriers to effective reporting, and (4) record suggestions for increasing melanoma reporting in Arizona. Selected in consultation with the Task Force, the six practices—three dermatopathology

practices, two general dermatology practices, and one mixed practice that included physicians in general dermatology, dermatopathology, and surgery—were located in both the Tucson and Phoenix metropolitan areas. Three of the practices were already reporting cases to the ACR, while the other three practices were not reporting cases to the ACR at the time of interview.

Most interviews were conducted with the physicians, and two interviews included other practice staff members who were or could be involved in the reporting process. The structured interview included questions about the practice, how many melanoma cases they diagnosed each year, whether or not they had reported cases to the ACR in the past, and their perceptions of current methods for reporting to the state registry. Interviews were conducted in person for two practices and by phone for four practices, and took approximately one hour to complete at each location. Interviews were audiotaped, notes were taken during the interviews, and three interviewers reviewed the notes to identify themes and common perceptions.

## RESULTS

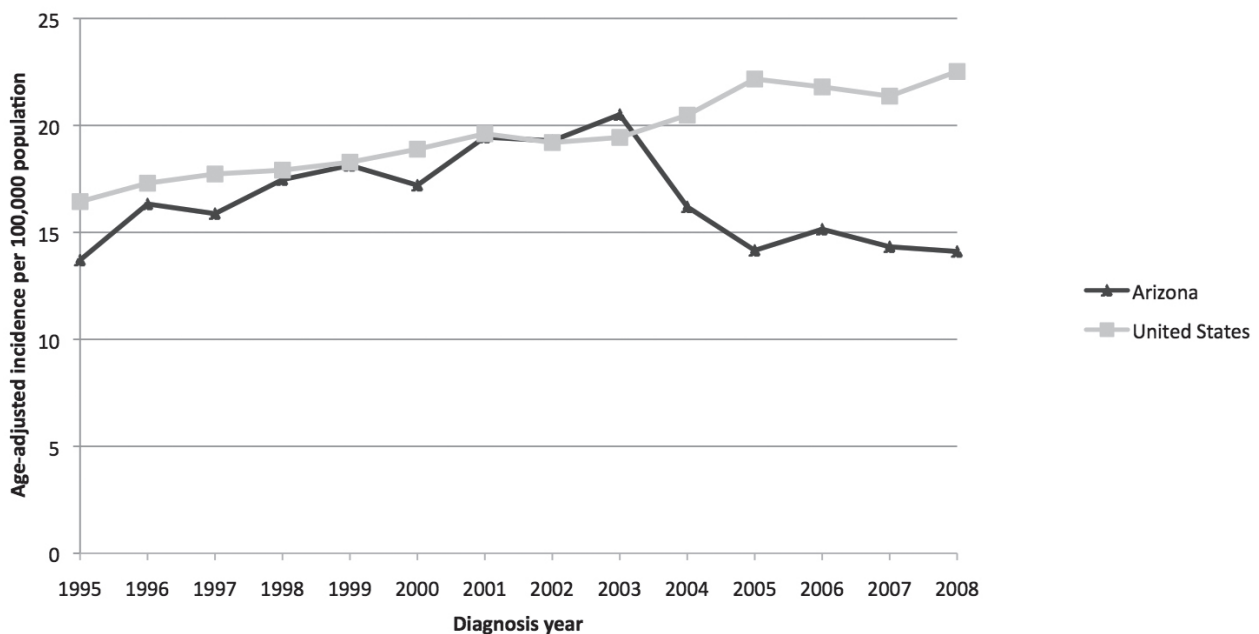
### Melanoma incidence trends in Arizona

ACR data demonstrated an increase in age-adjusted incidence rates in Arizona for invasive melanoma from 1995 to 2003 similar to what was observed for the U.S. SEER states (Figure 1). However, although the incidence rates for the United States continued to rise through 2008, there was a steep decrease for invasive melanoma incidence rates in Arizona, from 20.5 per 100,000 population in 2003 to 14.1 per 100,000 population in 2008. The total number of reported cases in Arizona from 2000 to 2008 decreased primarily for early-stage, in situ, and localized tumors. The count of more advanced-stage cases (i.e., with regional or distant spread) reported to the ACR remained relatively constant during the time period (Figure 2).

### The magnitude of underreporting of melanoma to the ACR

A total of 498 melanoma cases were identified as diagnosed in 2009 from the 15 participating practices (307 from eight practices in Phoenix and 191 from seven practices in Tucson). Of these cases, 357 (71.7%) were

**Figure 1. Age-adjusted incidence rates<sup>a</sup> for invasive melanoma, Arizona<sup>b</sup> and the United States,<sup>c</sup> 1995–2008**

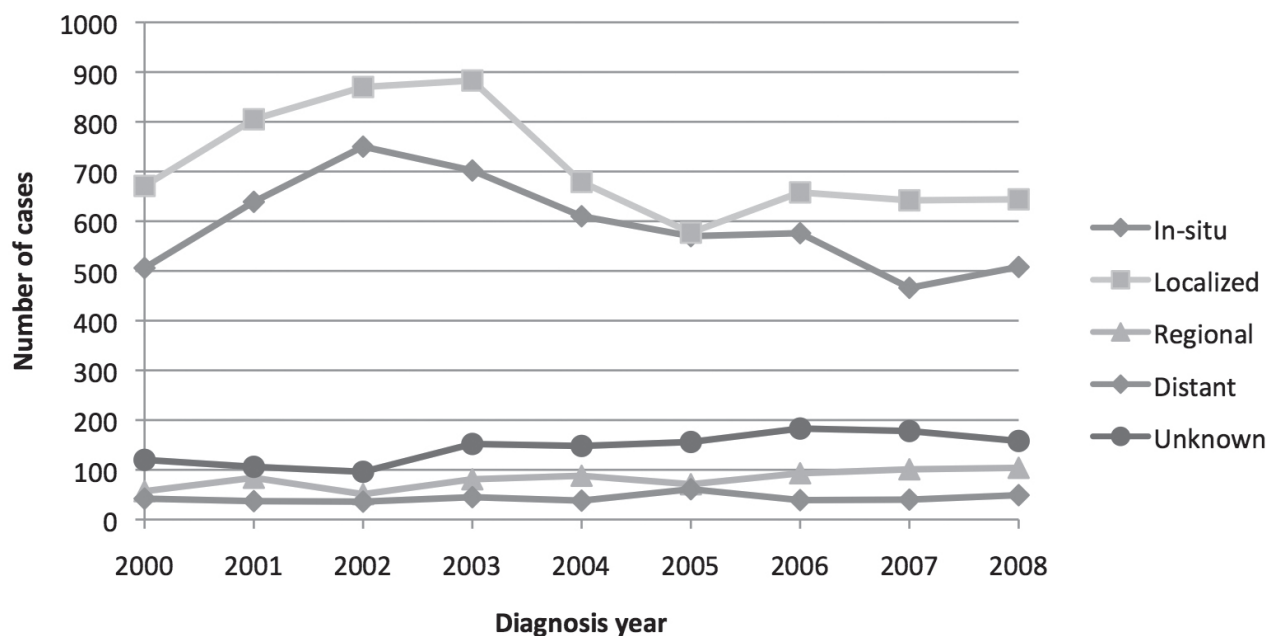


<sup>a</sup>Rates are age-adjusted to the 2000 U.S. standard population.

<sup>b</sup>Source: Arizona Department of Health Services. Arizona Cancer Registry. Data received April 14, 2011.

<sup>c</sup>Source: National Cancer Institute (US). Surveillance, Epidemiology, and End Results (SEER) Program: SEER\*Stat databases: incidence—SEER 9 regs research data, Nov 2011 sub, vintage 2009 pops (1973–2009) [cited 2013 Nov 1]. Available from: URL: <http://seer.cancer.gov/data/seerstat/nov2011>. Rates are based on nine areas (Atlanta, Georgia; Connecticut; Detroit, Michigan; Hawaii; Iowa; New Mexico; San Francisco, California; Seattle, Washington; and Utah).

**Figure 2. Arizona melanoma cases reported to the Arizona Cancer Registry,<sup>a</sup> by SEER summary stage,<sup>b</sup> 1995–2008**



<sup>a</sup>Source: Arizona Department of Health Services. Arizona Cancer Registry. Data received April 15, 2011.

<sup>b</sup>Young JL Jr, Roffers SD, Ries LAG, Fritz AG, Hurlbut AA, editors. SEER summary staging manual—2000: codes and coding instructions. Bethesda (MD): National Cancer Institute (US); 2001. NIH Pub. No. 01-4969.

SEER = Surveillance, Epidemiology, and End Results Program

not matched to records in the ACR. A difference in reporting between the community practices and the academic practice was noted. Specifically, 19.7% of the academic practice cases and 78.6% of the community practice cases had not been reported to the ACR. In both regions, the nonreported cases were almost exclusively in situ or local-stage melanomas; only two cases in regional or distant stages had not been reported.

#### Assessment of barriers to reporting

Most respondents were in solo or small practices, and 51.4% perceived that melanoma diagnoses increased during the past five years (Table 1). Almost 31% of the dermatologists reported that either they read all (8.1%) or some (10.8%) of the histological specimens or that a staff pathologist read some or all of their practice's biopsy specimens (12.2%). Also, 79.7% of respondents reported that they or someone on their staff had reported melanoma in the past to a registry. The dermatologists were then asked about barriers to cancer reporting and some potential strategies to overcome the barriers (Table 2). Fifty-one percent of respondents reported lack of awareness as a barrier to cancer reporting. About two-thirds of respondents (63.5%) felt that their own specialty should be respon-

sible for the reporting. Other perceived barriers to reporting included a lack of time/staff (64.9%) and difficulty with forms or the reporting system (48.7%). Nearly three-quarters (70.3%) of respondents said that a simplified reporting form would increase reporting, 54.1% thought that attaching a reporting form to pathology reports would increase reporting, and others noted an electronic reporting system and reminders from the ACR as potentially effective strategies for boosting reporting.

In-depth structured interviews with the six practices identified similar barriers and strategies. Of the three practices that did report melanoma, two practices thought it was important to report melanoma and indicated seeking out information about how to report it; one practice started reporting melanoma to the ACR only after its involvement with the earlier reporting pilot study. Of note, none of the interviewees remembered ever receiving a reminder from the ACR to report cases of melanoma.

When asked who was responsible for reporting melanoma cases to the ACR, the respondents had a wide array of beliefs. One dermatologist, who was from a reporting practice, stated that the clinician who receives the pathology report is the responsible party.

**Table 1. Characteristics of Arizona dermatologists participating in a survey about reporting melanoma to the Arizona Cancer Registry, 2012**

Characteristics	Number (percent) <sup>a</sup>
Total	74 (100.0)
Sex	
Male	37 (50.0)
Female	36 (48.7)
Unknown	1 (1.4)
Type of primary practice	
General dermatology	57 (77.0)
General dermatology and cosmetic/other	4 (5.4)
Dermato-oncology	7 (9.5)
Dermatopathology	6 (8.1)
Size of practice	
Solo, shared, or small practice (1–5 clinicians)	47 (63.5)
Larger group practice (>5 clinicians)	25 (33.8)
Other	2 (2.7)
Practice setting	
Private practice	60 (81.1)
Hospital/academic	5 (6.8)
Multispecialty	8 (10.8)
Other	1 (1.4)
Average number of annual melanoma diagnoses	
≤20	43 (58.1)
21–50	21 (28.4)
≥50	9 (12.2)
Unknown	1 (1.4)
Who reads majority of skin biopsy specimens <sup>b</sup>	
General community pathologist	1 (1.4)
Community dermatopathologist	52 (70.3)
Laboratory outside community	9 (12.2)
Pathologist on staff	9 (12.2)
Physician completes own histology readings	6 (8.1)
Physician completes non-pigmented specimens and sends out melanocytic lesions	8 (10.8)
Perceived that melanoma diagnosis has increased in last 5 years	
Yes	38 (51.4)
No	18 (24.3)
Uncertain/unknown	18 (24.3)
Reported (or had staff report) melanoma cases in past	
Yes	59 (79.7)
No	5 (6.8)
Uncertain	10 (13.5)

<sup>a</sup>Percentages may not total to 100 because of rounding (except for histology readings, where multiple responses were possible).

<sup>b</sup>Respondents were allowed to provide more than one response; however, no respondents selected more than one of the options for in-practice readings (pathologist on staff, physician completes all or some of own histology readings/specimens).

**Table 2. Arizona dermatologists' perceptions of barriers to reporting melanoma and strategies to increase reporting in a survey of melanoma reporting to the Arizona Cancer Registry, 2012**

Variable	Number (percent) <sup>a</sup>
Total	74 (100.0)
Perceived barriers to cancer reporting <sup>a</sup>	
Lack of staff/time	48 (64.9)
Lack of awareness	38 (51.4)
Difficulty with forms or reporting system	36 (48.7)
Not currently available electronically	17 (23.0)
Concerns about HIPAA	13 (17.6)
Cost concerns	11 (14.9)
Concerns regarding benefits of reporting	8 (10.8)
Belief that reporting being mandatory is a reason to report	
Among physicians who have reported cases to the registry	28 (47.5)
Among physicians who have not reported cases to the registry or were uncertain about reporting	3 (6.7)
Belief that their own specialty is responsible for reporting	
Yes	47 (63.5)
No	25 (33.8)
Unknown	2 (2.7)
Suggested methods to increase reporting <sup>a</sup>	
Reminders to report	33 (44.6)
Receive annual Registry reports	34 (46.0)
Receive feedback from Registry after case is reported	23 (31.1)
Simplified reporting form	52 (70.3)
Education on reporting, how to	23 (31.1)
Communication about benefits of reporting	9 (12.2)
Establish electronic reporting	39 (52.7)
Attach reporting form to pathology reports	40 (54.1)
Someone comes to office to abstract information	10 (13.5)

<sup>a</sup>Respondents were able to provide more than one response so that the estimate is the percentage of respondents selecting that option. HIPAA = Health Insurance Portability and Accountability Act

However, another dermatologist believed that although clinicians could report melanoma cases to the ACR, it would be much easier for pathologists to do so because they had all the reports and records. Conversely, one dermatopathology practice's laboratory manager and pathologist felt that the clinicians (i.e., dermatologists) should be responsible for reporting cases to the state registry. Unlike the prior dermatologist's belief that pathologists have all the needed information, staff members at the dermatopathology practice felt they did not have enough information to submit a report, stating they lacked information on patient demographics and treatment. They believed that because

they already submit pathology and quarterly reports of melanoma cases to clinicians, clinicians had all the patient information needed to report and, thus, should be the responsible party.

The clinical practice with a consistently high level of melanoma reporting to the ACR described the most effective steps to report a case:

Have at least one staff member who is responsible for reporting melanoma cases to the ACR. In this specific case, it is a medical assistant. When that staff member sends feedback to the primary care physician after a case of melanoma has been diagnosed, that staff member immediately also sends the case to the ACR. It is a standardized procedure that is routine practice when a melanoma case is diagnosed. (Taken from interview notes from a dermatologist in a medium-large practice in the Phoenix area, June 2012.)

### Strategies to increase reporting

Starting in September 2012, the Task Force began implementing four strategies to increase reporting of melanoma cases to the ACR:

1. Presentations about the Task Force's findings were made to local dermatology societies.
2. The melanoma reporting form for the ACR was redesigned and made available on the ACR website.<sup>12</sup>
3. Negotiations were made with state dermatopathologists to include a specific statement on pathology reports going back to providers for melanoma diagnoses to notify them that melanoma is a reportable disease.
4. The Task Force and the ACR mailed a newsletter report to all dermatologists about the need for accurate reporting, their role in reporting, and the number of cases each provider had previously sent to the ACR. The ACR updated its physician lists with help from the Task Force and dermatological societies. A copy of the newsletter without specific provider information was made available on the ACR website. Additionally, the Task Force continued biannual publication of the newsletter to the physician lists and posted it on the ACR website.<sup>13</sup>

### Impact of changes and the Task Force

The ACR observed a substantial increase in the number of reported cases for 2009 from the conduct of the 2012 pilot study. These additional cases reflected 33% of the 1,044 cases reported by physicians to the ACR for 2009 diagnosed cases. Additionally, the ACR observed an increase in newly reported cases by physicians for

the 2011 and 2012 diagnosis years compared with the years prior to the pilot study implementation. Furthermore, prior to implementation of the Task Force strategies, most melanoma case reports to the ACR were received from reporting sources other than physicians. For example, in 2008, physicians reported 595 cases compared with 1,099 cases reported to the ACR from other sources (Figure 3). In the 2011 and 2012 diagnosis years, more melanoma cases were reported by physicians than by any other source.

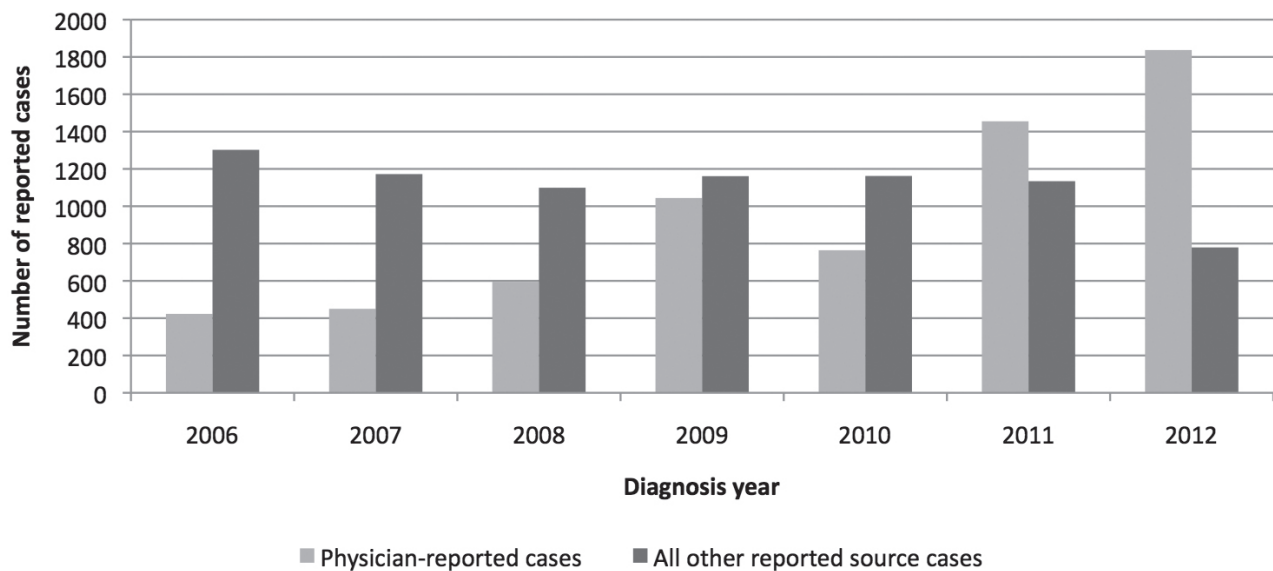
### DISCUSSION

The work of the Arizona Melanoma Task Force demonstrated high levels of underreporting of melanoma to the ACR, particularly for in situ and locally staged tumors. In a sample of dermatology practices, at least 71% of all melanomas diagnosed in 2009 were not reported to the ACR, with underreporting almost exclusively for in situ and local tumors. Although our sample did not include dermatology practices from more rural areas of Arizona, the practices did include major referral centers and larger and smaller practices from urban areas of the state. A review of addresses from our survey mail-out database indicated that 88% of physicians with a dermatology practice were from the Phoenix and Tucson metropolitan areas. The study also exclusively surveyed dermatology practices and excluded general surgeons, plastic surgeons, and primary care physicians. However, in a recent internal review by ACR personnel of physician-reported melanoma cases reported from 2009 to 2012, dermatologists provided more than 80% of these reports.

Although this study is not the first to suggest high levels of underreporting in melanoma, it is the first study to document such high levels of underreporting. In both the practice interviews and the dermatologist surveys, one of the main perceived barriers to physician reporting to the ACR was lack of awareness about the need to report. This finding was in agreement with some recent national surveys. One survey of California dermatologists suggested that the percentage of underreporting of melanoma cases could be as high as 30%–40%.<sup>9</sup> Cartee et al. noted that 54% of dermatologists attending a national meeting did not believe they were required to report melanoma cases.<sup>14</sup> Also, in 1991, investigators found that cutaneous malignant melanomas were underreported in Massachusetts by 12%–19%.<sup>15</sup>

An important reporting barrier expressed by providers was the lack of understanding about the process of reporting a case. There seemed to be general confusion about who was responsible for reporting, what specific

**Figure 3. Comparison of case reporting by reporting source<sup>a</sup> for invasive and in situ melanoma among Arizona residents diagnosed from 2006 to 2012<sup>b</sup>**



<sup>a</sup>Case reports submitted by physicians and all other sources (e.g., hospitals, pathology laboratories, and other state registries) to the Arizona Cancer Registry. More than one case report may be received for each new melanoma case. Source: Arizona Department of Health Services, Arizona Cancer Registry. Arizona melanoma cases: 2006–2012 [cited 2014 Jan 8]. Available from: URL: <http://www.azdhs.gov/phs/phstats/cancer-registry>

<sup>b</sup>Physician-reported cases from 2011 and 2012 are considered preliminary. Other sources of case reports for 2012 are incomplete as of January 2014.

items needed to be reported, and how reporting is or is not affected by Health Insurance Portability and Accountability Act regulations. Other strategies suggested by physicians included registry reminders to physicians to report their cases and descriptive reports sent out by the ACR on a routine basis back to physicians. A suggestion that offered the potential to significantly impact the rate of melanoma reporting was to include a routine attachment to all pathology reports with the registry reporting form.

The underreporting of local tumors to the ACR partially reflected the finding that a relatively high percentage of dermatologists read their own pathology and treat local-stage melanomas within the practice. The relatively stable reporting of more advanced tumors likely reflected the higher probability for these tumors to be seen by hospitals or other facilities that already report cancer cases.

Using these results, the Task Force implemented strategies to improve case reporting. First, the Task Force revised the cancer reporting form to be more melanoma-specific.<sup>12</sup> Second, a statement was developed for inclusion on all melanoma pathology reports that melanoma was a reportable disease, along with information on how to report cases to the ACR. This

statement was adopted by dermatopathologists for immediate use. (A copy of this statement is available upon request.) Third, new communication channels with dermatologists were developed with presentations made to county and state dermatology societies, creation of more up-to-date mail and e-mail lists, and creation and distribution of biannual reports to state dermatologists about the need for melanoma reporting and a review of their current cases as reported to the ACR. These reports can be found at the ACR website.<sup>13</sup>

The Task Force continues to meet regularly to assure that reports to the practices continue and to evaluate new reporting methods. Physicians and practice staff members appear to have a strong desire to increase the technology related to reporting. As new technologies become available, the Task Force members will review their impact.

## CONCLUSION

This public health partnership, which was developed in response to broad concerns about melanoma incidence in Arizona, included a range of community and state partners. As a result of this public health partnership, the important role physicians play in

reporting melanoma cases to the state registry has been highlighted, and case reporting has increased. This study represents an example of a coordinated and effective multi-organizational partnership to identify and address public health needs at the state level.

Partnerships to address barriers to melanoma reporting nationwide might require a different approach depending on state-specific needs and challenges. However, concerted and sustainable efforts across multiple state partners are crucial for accurate reporting of cancer rates across regions.

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