REGISTRAR PIP

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March 2025 Registrar PIP
The Good, Bad, Consistent, and Unique

Introduction

For registries, collecting race information is important because it is used in cancer research to assess the different racial groups' experience of varying rates of cancer incidence, mortality, and survival. In order to understand the underlying biological and socio-environmental conditions contributing to these differences and to develop targeted treatments, studying these disparities is important.

Given the importance of race information to others, it's not surprising completeness goals related to this data item have been developed by the standard setters for central registries. The North American Association of Central Cancer Registries (NAACCR) goal is less than 3% for invasive (/3) malignancies. Unfortunately, the percentage of cases with race coded to unknown is growing. What happens when a problem is discovered? We gotta talk about it!

Representatives from the SEER Program central registries (four in California, Iowa, New Mexico, Utah and Seattle-Puget Sound) gave presentations addressing this topic during the January 2025 SEER Manager Meeting because there was a growing percentage of patients with race coded to unknown in their November 2023 file submission compared to their prior submissions; us included! Our registries were the "outliers" when compared to the other SEER registries.

In reviewing a summary of the meeting, we were not surprised by the good news, bad news, or a couple of the consistent findings in the updates provided by the registries. The goal of these presentations was to not only explain what was happening locally, but to provide an opportunity to share procedural ideas that might help others improve current race completeness levels. We are all in when it comes to trying anyone else's successfully implemented procedure.

Other Registries' "Whys" to Explain the Problem

Let's start with good news that might not seem "unknown race" related; but it is when you look at the big picture. There is a growing number of outpatient cases being identified, which has ***improved incidence reporting*** since 2019. The bad news? With the increase in outpatient reporting from ***laboratories*** and ***physician offices***, there has been a ***decrease in the percentage of usable race*** information. It was observed by all the presenters that many physicians diagnosing their patients in an outpatient setting, do not routinely submit race information when reporting directly to the central registry. Most of these same physicians also do not include race information when submitting their specimens to a laboratory to be both processed and subsequently reported to the central registry.

When hospitals were the primary initial reporters of nearly all the cancer patients, the number of cases with unknown race could more easily reach the SEER and NAACCR race completeness goals. For example, in California they showed that with their increasing reliance on non-hospital casefinding sources to improve incidence reporting, there was a corresponding increase in the percentage of unknown race values coded. For outpatient casefinding sources, the percentage of unknown race cases grew from 5.6% in 2000 to 40% in 2022. In contrast, the hospital percentage of unknown race grew from 0.2%

to 0.5% during that same time. A difference between outpatient and inpatient race completeness percentages was a common finding among all the outliers.

Registry representatives suspected some of the following additional reasons were responsible for the rising incompleteness of race reporting:

- In **California** following the State's mandate of electronic reporting, central registry staff no longer reviewed and reported physician office diagnosed patients. They maintain registry staff reviewing records improved the completeness of race reporting.

- **Utah** found outpatients ages 60-79 diagnosed with ***prostate*** or ***melanoma*** cases in laboratories, physician offices, and ***treatment centers*** were responsible for the majority of unknown race codes. They attribute their increase in unknown race to the fact they decreased the labor-intensive practice in 2016 of manual follow back to physicians in order to obtain missing race for pathology only and other cases.

- **Iowa** noted the increase in unknown cases was associated with e-path only reported cases. Given that e-path reporting in the State continues to expand because it is necessary to improve the completeness of incidence reporting, they anticipate the number of unknown race cases to continue to climb.

- In **New Mexico**, most sources of patient reporting (hospital inpatient, chemotherapy/radiation therapy offices, physician offices, and laboratory only) have unknown race percentages over the NAACCR 3% goal. Some patients are declining to provide race information on hospital demographic sheets; some facilities are no longer asking for race information; and many Hispanics are checking "Other" race, which is not considered meaningful race information, rather than white.

Other Registries' Improvement Strategies

Just as there are some differences to explain how others also found themselves in our situation, some registries also shared their different strategies to improve race reporting:

- **California**: The two main approaches included physician-directed follow back (faxes and phone calls) and hospital follow back (generate facility-specific lists of previously reported cases with unknown race). In addition, they developed and made available on their website a demographic data collection toolkit in which they share the importance of race collection for medical facilities and central registries.

- **Iowa**: Like California, they also generated and sent facility-specific lists to their reporting facilities requesting they review the electronic medical record to determine whether updated race information was available.

- **Utah**: Continues to perform an annual linkage with the State Office of Vital Statistics checking birth certificates for updated race, ethnicity, place of birth, and other patient demographics to improve their dataset. Another procedure involves checking new and existing e-path installations to ensure race is identified as a requested and needed data item. They have had some success with the percent of electronic pathology reports with missing race dropping drastically between 2015-2024 from missing 100% in 2015 to 36% in 2024.

- **NCI-SEER**: Pursuing an Interagency Agreement with the Centers of Medicare & Medicaid Services (CMS) for a linkage that would include race. This linkage depends upon individual registries, such as ours, completing extensive security assessment documentation as part of the agreement, and it also depends upon available federal funding. At this point, we have a call scheduled for March 11th to discuss the continued interest and feasibility among the SEER registries for a FY26 linkage.

The Seattle-Puget Sound Experience

As other registries suspect, we believe patients are choosing to decline to provide race information when requested at admission. Subsequent central registry staff searches of the electronic medical record notes seldom result in updated race

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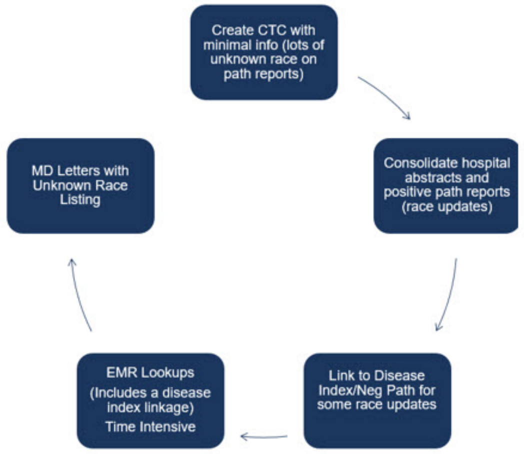
information for those who initially declined to provide this information at admission, or they selected "Other" for race. As noted above, "Other" is not considered meaningful race information.

As was observed in all the other registries, there is increasing volume of ***Lab Only/Physician Office Only*** cases with race coded as unknown. In the early 2000's, our unknown race percentage from these facilities was about 8%, but now it is 13-15% when considering all solid tumors. Taking a second look at our data, we found melanoma cases have the highest percentage of unknown race in our region.

Attempts at physician follow-back for melanoma cases at times frustrates some dermatologists who believe we should assume these patients are white. Responses to our queries have been met with comments such as "Are you stupid? They are melanoma patients. What do you expect?" or simply the word "human." However, to date, SEER has not established a melanoma-specific guideline that will allow us to assume these patients are white even if we agreed to exclude those patients with names that could indicate a potential different race from any update.

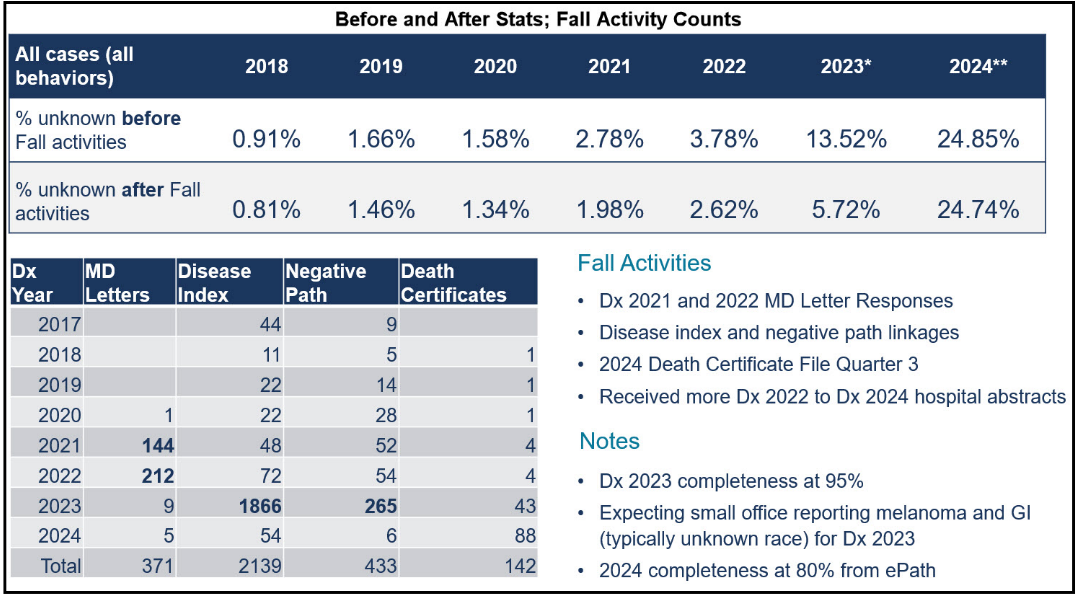
Figure 1 shows the current CSS process used to improve the completeness of race information. We start by identifying those with an unknown race, which primarily come to us through the pathology reports used to initiate case reporting close to the time of diagnosis. When abstracts are received from hospital registrars and consolidated with the pathology reports, many of the unknown races are able to be updated. However, as Figure 2 illustrates for 2023 and 2024 diagnosed cases, the unknown race percentages are far above 3% goals established by NAACCR.

Figure 1
CSS Unknown Race Process



Because the majority of hospital abstracts associated with the 2023 cases were already submitted by the Fall of 2024, these cases, along with all other cases missing race data, became part of our annual Fall linkage, look-up, and mailout activities. As you can see in Figure 2, these annual clean-up activities when done in the past used to be enough to help us achieve the NAACCR race goal.

Figure 2



Before and After Stats; Fall Activity Counts

All cases (all behaviors)	2018	2019	2020	2021	2022	2023*	2024**
% unknown **before** Fall activities	0.91%	1.66%	1.58%	2.78%	3.78%	13.52%	24.85%
% unknown **after** Fall activities	0.81%	1.46%	1.34%	1.98%	2.62%	5.72%	24.74%

Dx Year	MD Letters	Disease Index	Negative Path	Death Certificates
2017		44	9	
2018		11	5	1
2019		22	14	1
2020	1	22	28	1
2021	**144**	48	52	4
2022	**212**	72	54	4
2023	9	**1866**	**265**	43
2024	5	54	6	88
Total	371	2139	433	142

Fall Activities

- Dx 2021 and 2022 MD Letter Responses
- Disease index and negative path linkages
- 2024 Death Certificate File Quarter 3
- Received more Dx 2022 to Dx 2024 hospital abstracts

Notes

- Dx 2023 completeness at 95%
- Expecting small office reporting melanoma and GI (typically unknown race) for Dx 2023
- 2024 completeness at 80% from ePath

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Although the Fall of 2023 procedures were somewhat effective in reducing the percentage of 2023 diagnosed cases with unknown race cases from that eye-popping 13.52%, the post processing percentage of 5.72% is far from the standard setters' expectations. Like the other outlier registries, we found the topic of the January SEER Managers Meeting both timely and necessary. Some of the suggestions offered by others (perhaps with some local tweaking) may be considered by CSS staff. Bottomline, in a changing world, being open to new ideas can potentially enhance performance, keeping us relevant and funded.

Conclusion

The collection of race and ethnicity information helps central registry scientists and epidemiologists identify existing health disparities. Ultimately, complete and accurate race and ethnicity data collection by registries provides the basis for assessing disparities in care, creates opportunities to address the issues discovered, and provides a means for monitoring progress. We are going to have to continue to think creatively about how we can more efficiently collect this information.

Keep in mind, improved completeness of race and ethnicity coding not only benefits central registries, but local health care organizations too. As noted by the Greater Bay Area Cancer Registry during their presentation, the improved data collection of birthplace and language in addition to race and ethnicity provides an opportunity for local facilities to "identify and address unique patient needs. This information can be used to help identify and reduce unfair and illegal disparities and improve health care for all patients. It can be used to assist facilities in providing culturally competent care, all while fulfilling legal and regulatory mandates."

If you have any ideas about how we can improve race and ethnicity data collection, please email us. We'd love to hear your thoughts and suggestions!

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