



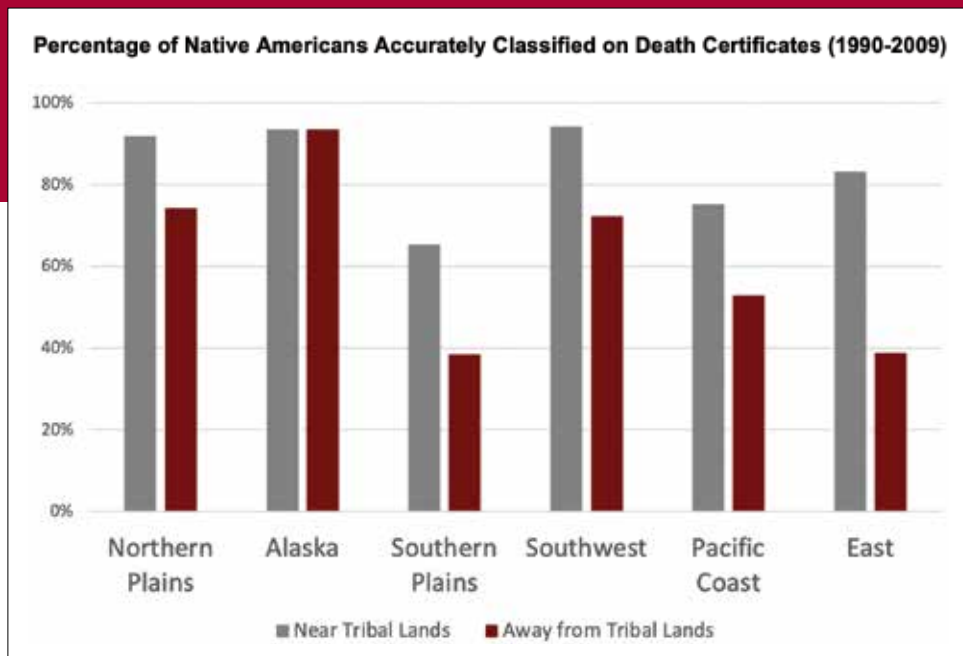
Why Death Certificate Demographics Matter

*And how inaccurate information harms
Native American communities.*

BY EMMA WAUGH, IMANI RANSBY AND JAMIE PIATT

Funeral directors have long played a vital role in this country's public health system. And although demographics from death certificate data may appear mundane at first glance, they guide the decisions of hundreds of thousands of federal, state, local and tribal public health professionals and elected leaders every day.

Our mission, as public health professionals, is to prevent unnecessary death, injury and suffering from disease. To understand where to focus our efforts, we examine data. By means of the vital statistics system, every single death is counted and compiled into the National Death Index, a comprehensive database the Centers for Disease Control and Prevention (CDC) manages. Given this information's completeness, death certificates create a powerful data source that can be used to understand living populations' health.



Source: *Percentage of Native Americans Accurately Classified on Death Certificates (1990-2009)*: Melissa A. Jim, Elizabeth Arias, Dean S. Seneca, Megan J. Hoopes, Cheyenne C. Jim, Norman J. Johnson, Charles L. Wiggins, 2014.

Age-Adjusted Influenza and Pneumonia Mortality, Oklahoma 2010-2015

Race	Number of Deaths		Death Rate (per 100,000 population)		Difference
	Before Linkage	After Linkage	Before Linkage	After Linkage	
White	3,389	3,306	18.5	18.0	2.7% Decrease
Black	207	202	9.8	9.5	3.1% Decrease
American Indian	336	425	13.2	16.8	27.3% Increase
Asian/Pacific Islander	44	43	6.8	6.6	2.9% Decrease

Source: Melissa A. Jim, et al., 2014

Although the vital statistics system ensures that we have an accurate count of deaths, additional information is needed to allow us to understand completely the burden of disease in specific populations.

If 100 people died from lung cancer across all 50 states, public health professionals would likely not be alarmed. If 100 people died from lung cancer in one rural town, small religious community or tribal nation, there would be much greater cause for alarm and public health authorities would be compelled to act. Although death counts and causes can paint a broad picture of what people are dying from and what diseases may need our attention, the detailed demographic information funeral directors collect allows us to understand the finer details. That data

steers public health recommendations, directs the flow of public health funding, guides the development of prevention programs and even shapes policy decisions.

According to the “Percentage of Native Americans Accurately Classified on Death Certificates (1990-2009)” research, nearly half of Native Americans living away from their tribal homelands are misclassified on their death certificates. The research, published in 2014, was conducted by Melissa A. Jim, Elizabeth Arias, Dean S. Seneca, Megan J. Hoopes, Cheyenne C. Jim, Norman J. Johnson and Charles L. Wiggins.

Accurate and complete demographic data are vital to understand populations’ health and imperative to protect vulnerable and underserved groups, particularly Native Americans. Epidemiologists and statisti-

cians regularly conduct research to understand how many people have had their race incorrectly classified on their death certificate (i.e., racial misclassification). We use a technique called data matching to search multiple data sets for the same person – using attributes such as first and last name, race/ethnicity, Social Security number and date of death – to confirm or refute that the individual was classified in death the same way they identified in life.

Native American death records have historically contained significant inaccuracies. According to Jim, of Native Americans living on or near their tribal homelands, an estimated 17% are misclassified. Of those living away from their tribal homelands, 46% are misclassified.

These statistics are particularly alarming because the overwhelming majority of Native Americans do not live on or near their tribal homelands. Despite variations by region, data for Native Americans living in the Southern Plains and Eastern regions are most often misclassified. Misclassification results in an artificially reduced burden of disease for the Native American population, making it challenging for public health professionals and tribal leaders to make informed decisions for their communities' health.

“...People may think, ‘Well, I don’t have that many Native Americans in my area, so that’s not something I need to think about.’ But the reality of it is we may not know exactly who identifies in what way.”

– Ebonē Dukes, program director,
Funeral Service Technology,
Northwest Mississippi Community College

HOW RACIAL MISCLASSIFICATION IMPACTS DATA: A REAL-WORLD EXAMPLE

Currently, Oklahoma is the only state with publicly available mortality data that have been enhanced by linking with Indian Health Service's patient enrollment records. As the table on the preceding page shows, racial misclassification affects all races, but it disproportionately affects Native Americans. Depending on the region in Oklahoma, racial misclassification of Native Americans occurs 20%-40% of the time in mortality data. As the table illustrates, after data matching, the true mortality rate for influenza and pneumonia was nearly 30% higher than originally thought.

Authors' note: The term “American Indian/Alaska Native” is a political designation the federal government uses. It is one of five standardized options on all

government documents required to record race. We use “American Indian/Alaska Native” when referring to these forms. However, Native American is our preferred term, and we use it in all other instances.

What can funeral directors do to prevent racial misclassification?

Native Americans are likely misclassified so frequently for a range of reasons. Like public health professionals, funeral directors care deeply for their communities and dedicate their professional lives to serving them. In our work with funeral service professionals, we have been moved by how willing they are to address this issue once they realize its effects on Native American communities. Moving forward, funeral directors can take many actions to prevent this issue.

Remember that any family you serve could have members who identify as Native American.

Many people assume that Native Americans exist only in the Southwest, Oklahoma or Alaska and therefore do not consider that they might encounter Native American families in their practice. Contrary to stereotypes often portrayed in the media, Native Americans live in thriving, vibrant communities in every state, city and town. Nearly 80% of Native Americans do not live on their tribal homelands but rather live in urban, rural and suburban parts of the country, according to the Office of Minority Health. Native Americans might very possibly grow up, live and work in parts of the country distant from their tribal nation's homelands. Pew Research (2015) found that there are significant urban Native American populations in New York City; Washington, D.C.; Chicago; Dallas; and many other cities.

Do not assume a decedent's race based on appearance.

Abstaining from filling out information based on a subjective observation is imperative. Native American populations are incredibly diverse. The “American Indian/Alaska Native” box represents hundreds of distinct tribal nations and indigenous groups. Each has a unique culture, traditions, history and presence in modern life. Many Native Americans identify with two or more racial or ethnic identities, which could never be accurately determined without talking to a family member.

Always ask the informant directly how the decedent would have described their race, ethnicity and tribal affiliation, if applicable.

Information collected from hospital/medical records, face sheets, etc., is also subject to racial mis-

classification. Questions about race and ethnicity can bring up discomfort for Native American families; identifying oneself as American Indian/Alaska Native has often had very real and negative consequences, which continue to this day. Asking in a caring, compassionate way and taking time to get to know the family and explaining this information's importance can help alleviate that discomfort and increase the likelihood of an honest answer.

Fill out all racial and ethnic identities whenever reported. Fill in specific tribal affiliation whenever possible.

As described in the Office of Management and Budget's revisions in 2000, all states should allow multiple racial and ethnic identities to be reported. Recording all identities honors the deceased's memory and provides public health professionals the information they need. Epidemiologists can determine how to count multiracial individuals appropriately in mortality data. Many states provide an option to type in a person's tribal affiliation. Taking time for this extra step provides the data necessary for tribal nations to ascertain tribal nation-specific information. However, you should not require families to "prove" their race, ethnicity or tribal nation affiliation.

Use the death certificate's demographic portion as an opportunity to connect with family members, build rapport and increase customer satisfaction.

Funeral directors offer compassion and healing for families going through a difficult time. Allowing families the time and space to discuss their loved one can help create connections and build a sense of trust with

clients. In addition, understanding and exemplifying cultural sensitivity while working with families can help address potential concerns about judgment or unfair treatment.

Learn about tribal nations and Native American populations where you live and work.

There are 574 federally recognized sovereign tribal nations that maintain a government-to-government relationship with the United States. These relationships are based on trust and treaty responsibilities, as well as obligations between tribal nations and other governments. They have been repeatedly affirmed by the U.S. Supreme Court, the president and Congress and exist in perpetuity. Like any other sover-


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eign country, tribal nations have the right to govern themselves, and they do so within the United States' borders. Tribal nations operate their own schools, healthcare systems, law enforcement and other services that government entities provide. It is critical to learn about this history, which is often not taught in schools; these complex relationships; and current dynamics to ensure that you are prepared to work with Native American families. (Additional resources for this education: Tribal Epidemiology Centers' Preventing Racial Misclassification and Improving Data Quality for Tribal Nations).

Tribal Epidemiology Centers (TEC) operate in similar fashion to a state or city department of health; they provide public health and epidemiological support for tribal communities and Native Americans in urban areas. They play a large role in identifying and addressing racial misclassification, as they can facilitate public health research and explore data quality issues that directly affect Native Americans.

The United South and Eastern Tribes Tribal Epidemiology Center (USET TEC) was established in 2000 and focuses its disease surveillance and prevention activities on 33 federally recognized tribal nations from the Northeastern Woodlands to the Everglades and across the Gulf of Mexico (across 13 states).

At USET TEC, we continuously work to provide tribal nations with accurate and complete mortality data. Despite challenges due to a lack of acknowledgment and awareness of TECs as a whole, the USET TEC has managed to foster relationships with states and health organizations to improve the data provided to member tribal nations. We are also working to elevate the issue of racial misclassification of Native Americans in the funeral services profession.

We have provided training on this topic to over 200 mortuary science students, offered continuing education credits for current funeral directors in four states and are working with state funeral director associations to raise awareness of the issue.

Serving the 43 federally recognized tribal nations in Kansas, Oklahoma and Texas is the Oklahoma Tribal Epidemiology Center (OKTEC). Our role is to improve public health outcomes for Native Americans through partnerships, advocacy, education and training. The OKTEC works closely with state, tribal and other health organizations to help improve public health outcomes for the tribal nations we serve.

The OKTEC is currently developing a website to serve as a resource for general information on racial misclassification, as well as specific information for the community and funeral service industry. Once completed, a tab for racial misclassification will be available on spthb.org under "Our Grants."

The OKTEC has developed the "Oklahoma Tribal Burial Resource Guide" for the funeral sciences industry. The guide will be disseminated to more than 400 funeral homes in the state of Oklahoma. It lists the tribal nations in Oklahoma that receive assistance for funeral costs and other related expenses. Additionally, the guide serves as a tool to help funeral homes ascertain the deceased's race to reduce racial misclassification on death certificates.

The OKTEC was recently awarded two additional grants to address racial misclassification. These projects are investigations of additional databases for racial misclassification. They will allow for a community of practice, as well as an advisory council, to help further develop and disseminate best practices.

For more information, email usetepi@usetinc.org or visit spthb.org/resources. ☰

Imani Ransby, MPH, is a staff epidemiologist and interim program manager with the United South and Eastern Tribes Tribal Epidemiology Center. She has experience conducting chronic and infectious disease surveillance, analyzing public health data and developing tribal nation-specific morbidity and mortality reports. She has previous experience conducting infectious disease research, particularly around HIV and antiretroviral therapy uptake. She received her Master of Public Health from Tulane University, focusing on epidemiology.

Emma Waugh, MPH, is a public health program coordinator with the United South and Eastern Tribes Tribal Epidemiology Center. She has experience working with tribal nations to identify health priorities and design, implement and evaluate health programs. She has worked on programs focused on suicide prevention, COVID-19 vaccine uptake and nutrition education. She has previous experience conducting behavioral health research with Native American communities and identifying strengths-based prevention strategies. She received her Master of Public Health from Emory University, focusing on global health.

Jamie Piatt, MPH, is a program coordinator/epidemiologist at the Southern Plains Tribal Health Board Tribal Epidemiology Center. She has experience conducting surveillance and evaluation of health indicators for tribal nations. Her experience also includes substance abuse and prevention, mental health, child and adolescent health, infant health, infectious diseases and chronic diseases. She received her Master of Public Health from the University of Oklahoma Health Sciences Center, focusing on epidemiology.