National Council of Urban Indian Health

EXCELLENCE, EQUITY, EFFECTIVENESS.

Racial Misclassification of American Indian and Alaska Natives on Death Certificates: The Role of Funeral Directors in Policy and Prevention

Executive Summary

Racial Misclassification of American Indian and Alaska (AI/AN) people endangers lives. It marginalizes AI/AN people and leaves the organizations that serve them without sufficient data to make decisions or fund the services they provide.

This report examines the problem of racial misclassification on death certificates, with a particular focus on the role of funeral directors in urban communities. For over a year, the National Council of Urban Indian Health (NCUIH) investigated possible factors that may create racial misclassification, and looked for solutions to prevent these factors. This document is intended as a broad and introductory guide for a variety of stakeholders that can help prevent this problem, including funeral directors, businesses and industry associations, statisticians and public health experts, and policy stakeholders.

The report consists of 5 parts:

I. A review of the vital records system, racial misclassification of deaths, and relevant literature on this topic.

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II. A description of the survey, listening sessions, and interviews conducted by NCUIH to learn about funeral director policies, practices, and experiences.
III. Results from these activities.
IV. A discussion summarizing what NCUIH has learned.
V. A list of recommendations geared at the prevention of racial misclassification on death certificates before it occurs.

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Glossary of Terms and Acronyms

- AI/AN – American Indian or Alaska Native. This is one of the six minimum categories for data on race and ethnicity for Federal statistics as specified by the Office of Budget and Management (OMB). OMB defines an AI/AN person as "a person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community Attachment", and notes that the "response option should be accompanied by a request for tribal affiliation when possible"
- CDC – Centers for Disease Control and Prevention
- CPS – Current Population Survey
- Decedent – A deceased person, used within the funeral industry to refer to the person whose
- Federal Trust Responsibility - the basis for Health Services at IHS, or the "*legal basis for the federal obligation to provide health care to American Indians and Alaska Natives… important when designing health care programs, developing federal budgets, coordinating with other agencies, and obtaining regulation waivers for selected Indian programs.*"
- IHS – Indian Health Service. The I/T/U system is comprised of IHS facilities, Tribally-operated programs, and Urban Indian Organizations, all of which receive federal funding through IHS.
- NAME - National Association of Medical Examiners
- NAPHSIS – National Association for Public Health Statistics and Information Systems
- NCHS - the National Center for Health Statistics
- NCUIH– National Council of Urban Indian Health
- NDI - National Death Index
- NFDA – National Funeral Directors Association
- NVSS - National Vital Statistics System
- UIO - Urban Indian Organization

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Part I. Introduction

What is the Vital Statistics System?

The United States' National Vital Statistics System (NVSS) is formed through various autonomous jurisdictions, each contracted with the Division of Vital Statistics (DVS) within the Center for Disease Control's National Center for Health Statistics (NCHS).[1] In general, state registrars rely on a minimum of three different entities to provide data about a deceased party when legally registering deaths:

- A medical provider inputs the time and cause of death
- Either a medical examiner's or coroner's office performs biological or legal investigations and confirms cause of death, whenever necessary
- A third party – funeral directors – coordinate the overall process and work with families, collecting demographic information and ensuring that a certified copy is given to the next of kin in a reasonable time.

The state registrar's office then performs quality control on data from all entities, provides death certificates, monitors and publishes state-level reporting, and reports death registration data to the DVS for national purposes (including public health surveillance and the National Death Index).[2]

[1] "NVSS - About the National Vital Statistics System." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, January 4, 2016. https://www.cdc.gov/nchs/nvss/about_nvss.htm.

[2] Curtin SC, Tolson G, Arias E, Anderson RN. Funeral director's handbook: Death registration and fetal death reporting. Hyattsville, MD: National Center for Health Statistics. 2019.

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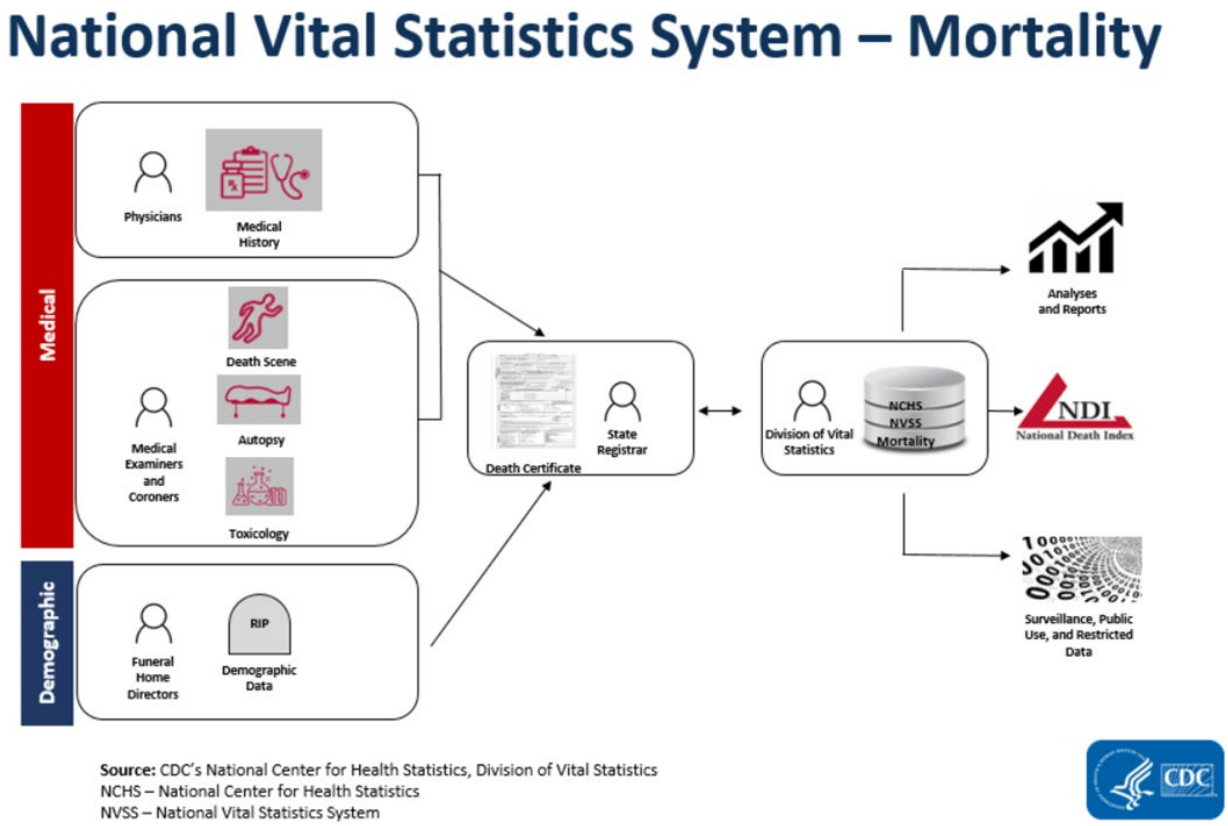
FIGURE 1.[3]



For the purposes of advancing health equity, the demographic and medical portions both need to be recorded and reported consistently for all people, in all jurisdictions. Public health professionals need to know what people are dying of, where they lived, and emerging patterns. However, data collection and reporting can vary widely across and within jurisdictions. State offices, not just vital records offices, have the autonomy to inform policies and procedures that will affect data collection and reporting (see Table 1).[4]

[3] Figure from Curtin 2019.

[4] For table citations, see: "Mortuary Science State and Federal Laws, Rules and Regulations - Minnesota Dept. of Health." Minnesota Department of Health. Accessed November 15, 2020. https://www.health.state.mn.us/facilities/providers/mortsci/regulate.html.; "Continuing Education Requirements" Oklahoma Funeral Board. https://www.ok.gov/funeral/For_the_Licensee/Continuing_Education/; "Arizona Health Status and Vital Statistics Annual Reports." Population Health and Vital Statistics. ADHS | Arizona Department of Health Services. Accessed November 2020. https://pub.azdhs.gov/health-stats/report/ahs/index.php. 'Shen, Xuejun. "Alabama Vital Statistics 2018." Division of Statistical Analysis. Center for Health Statistics, 2018. https://www.alabamapublichealth.gov/healthstats/assets/113causes_2018.pdf

TABLE 1.

EXAMPLES OF STATE ACTIONS THAT AFFECT DATA QUALITY OR REPORTING

- Many state registrar's offices have adopted a standard form and switched to an electronic certificate with built-in quality control measures.
- Some public health departments – such as the Minnesota Department of Health – set and monitor funeral directing licensure requirements.
- Some states offices – like the Oklahoma Funeral Board – require periodic Continuing Education (CE) trainings to renew business licenses, including ethics.
- Some states include AI/AN people in their periodic vital records reporting, like the Arizona Department of Vital Statistics.
- Some states collapse AI/AN people into an "other" category - like the Alabama Department of Vital Statistics.

Within each jurisdiction's unique policy environment, each data collector can also make a variety of practical choices on how they collect and report data. Funeral directors generally submit the final death registration and provide a family with the copy. Medical examiners, coroners, or both may be responsible for providing medical data depending on the jurisdiction, and in rare instances submitting demographics.[5] The Centers for Disease Control and Prevention (CDC) National Center on Health Statistics (NCHS) provides guidance to all parties on how to accurately collect data – including race, ethnicity, tribal affiliation, and other demographic data – in its series of *Handbooks for Physicians, Medical Examiners, and Funeral Directors*.[6] However it is unclear how many professionals are aware of these materials or trained in their use.

Funeral directors likely make different choices and employ different practices when collecting racial information from families, based on whatever prior training and

[5] States have different laws about whether a coroner and/or a medical examiner is required to complete records and medicolegal investigations. Either a provider, medical examiner, or coroner always certifies the medical information, depending on whether an investigation is conducted and the jurisdiction. For more information on how death investigation systems work in your state and county, see: "Coroner/ Medical Examiner Laws." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, October 26, 2016. https://www.cdc.gov/phlp/publications/topic/coroner.html.

[6] Curtin SC, Tolson G, Arias E, Anderson RN. Funeral director's handbook: Death registration and fetal death reporting. Hyattsville, MD: National Center for Health Statistics. 2019.

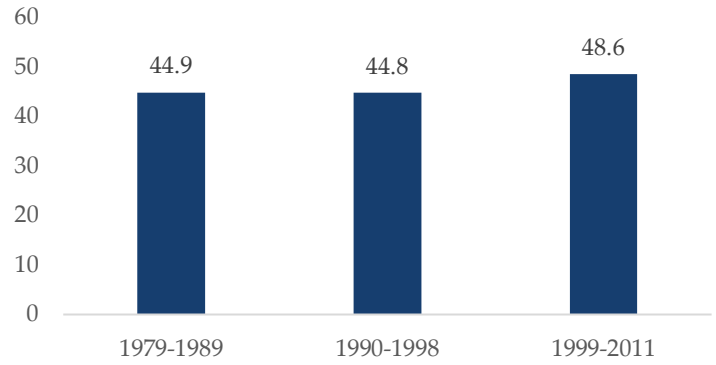
experience they have. In a survey of 5 urban funeral homes in Oklahoma, 52% of responding funeral directors reported receiving no formal training in death certification, 79% reported finding certain demographic items difficult to complete, and 26% specified race as the most problematic item to complete.[7] Different methods for determining race were used – 58% of respondents determined race through personal knowledge of the family and 43% determined race by observation.[8] The self-reported race of these funeral directors was strongly associated with whether they found it a problem to determine the race of the decedents they served.

Given the high variation between and within jurisdictions, it can be difficult to pinpoint the exact effect size that different practices have in creating systemic errors in national mortality surveillance as a whole. However, these errors are likely the result of the combination of many different practices at different levels. Each practice can contribute to an undercount of AI/AN mortality, and each is worth addressing.

What is Racial Misclassification?

The U.S. standard death registration form follows the minimum standards of the Office of Management and Budget's (OMB) Statistical Policy Directive No. 15, and asks two questions – one about race and another on Hispanic origin. It also allows for Tribal affiliation to be entered when "American Indian or Alaska Native" is selected for race.[9] However, many people who self-identified as AI/AN during their life are not recorded as such on their death certificates, with most of these misclassified AI/AN people

FIGURE 2. PERCENT WHO SELF-IDENTIFIED AS AI/AN ON THE CPS AND WERE CLASSIFIED AS AI/AN ON THEIR DEATH CERTIFICATE



[7] Hahn, Robert A, Scott F Wetterhall, George A Gay, Dorothy S Harshbarger, Carol A Burnett, Roy Gibson Parrish, and Richard J Orend. "The Recording of Demographic Information on Death Certificates: a National Survey of Funeral Directors." *Public Health Reports* 117, no. 1 (February 2002): 37–43. https://doi.org/10.1016/s0033-3549(04)50106-1.

[8] Ibid

[9] For a full description of Statistical Policy Directive No. 15 (updated in October, 1997) and how these categories are listed on the Standard Death Certificate, see Appendix A.

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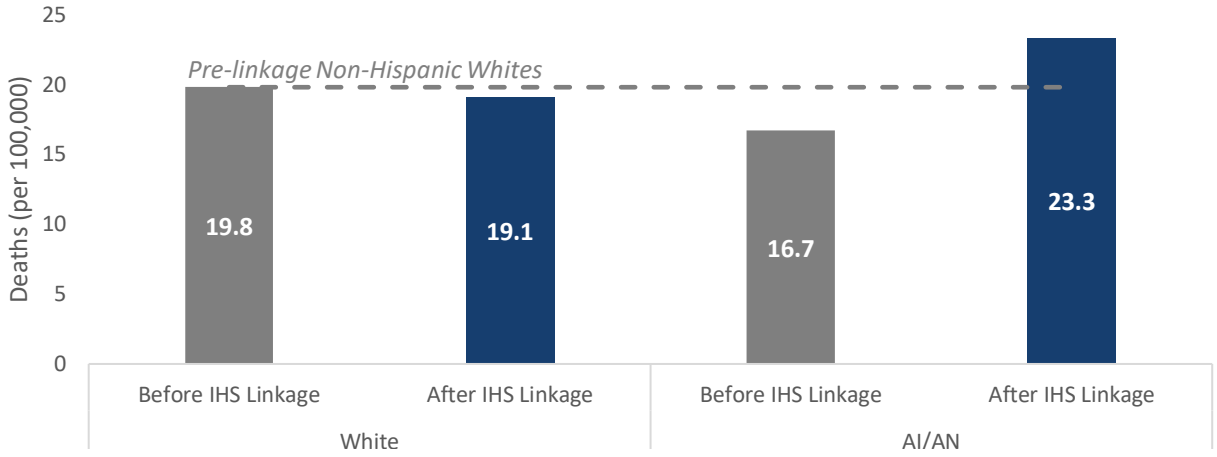
instead being categorized as White alone. The extent of this misclassification has not changed much at a national level since 1979 (see Figure 2).[10] Beyond this, tribal affiliations are underreported, even when AI/AN race has been selected. An AI/AN person is much more likely to be misclassified if they live in an urban area, in the northeast, or in an area with a low co-ethnic concentration of AI/AN people.[11]

Although death registration is generally an accurate source of mortality data for other racial groups, epidemiologists have had to develop methods to "correct" for the misclassification of AI/AN decedents in order to make these records more representative. This method of involves comparing the personal information collected on a death certificate to a "linked" data set – often an Indian Health Service (IHS) medical record, Tribal registry, public survey like the Current Population Survey (CPS), or other civic registration such as a birth certificate. By comparing matches between the two sets, a statistician can include people who likely *would* have marked AI/AN on their death certificate based on other records that were created during their lifetime. The final grouping of "who is included" can change based on whether each reference set defines "AI/AN" based on self-identified race or tribal enrollment.

FIGURE 3. AGE-ADJUSTED SUICIDE MORTALITY (PER 100,000) OKLAHOMA 2011-2015



[10] 44.6% of people who self-identified as AI/AN on the CPS and died 1999-2011 were classified as white on their death certificates, 3.6% were classified as Black, and 0.5% were classified as Asian or Pacific Islander. See: Arias E, Heron M, Hakes JK. The validity of race and Hispanic-origin reporting on death certificates in the United States: An update. National Center for Health Statistics. Vital Health Stat 2(172). 2016.

[11] Ibid.

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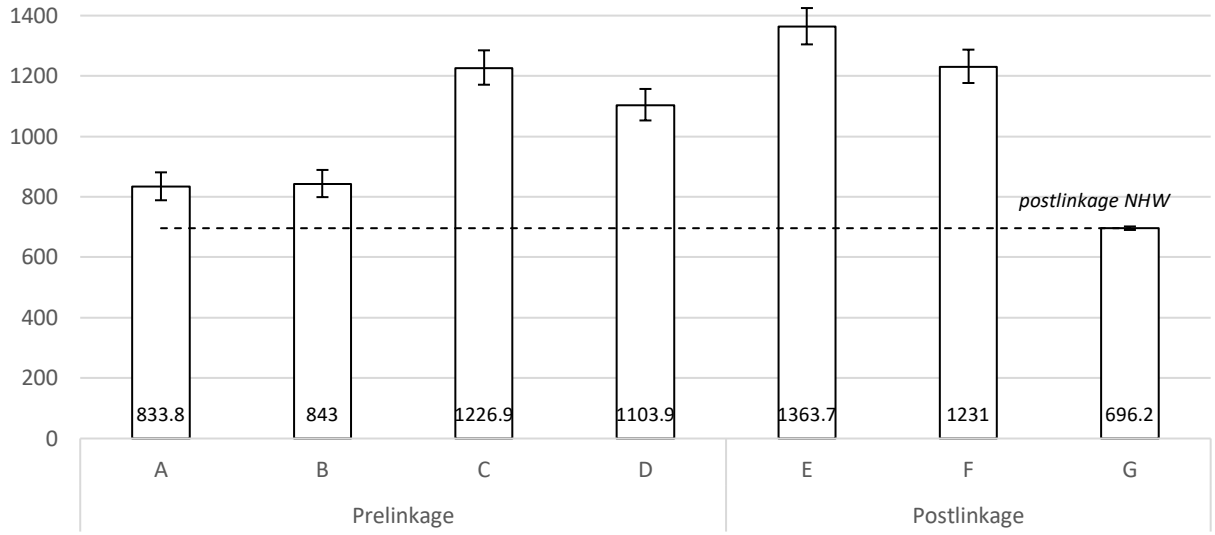
Statistical estimates show that racial misclassification can drastically underestimate the burden of disease that AI/AN communities face and mask disparities compared to the general population or other groups (see Figure 3) [12,13]. However, these studies can only account for misclassification after it has occurred. As a result, the extent to which the data represents any individual's self-identified selection in life is dependent on the choices that are available to epidemiologists during analysis. For instance, a 2019 study linking death records to IHS and Tribal registries in the northwest found large variation in mortality estimates depending on whether AI/AN data was linked, included Hispanic or non-Hispanic white (NHW) people, and allowed for single or multiple races categories. Though estimates were generally above the NHW group, all-cause mortality estimates for an "AI/AN" group ranged from 20 - 96% higher depending on how that category was defined (see Figure 4).[14]

[12] Dougherty, Tyler M., Amanda E. Janitz, Mary B. Williams, Sydney A. Martinez, Michael T. Peercy, David F. Wharton, Julie Erb-Alvarez, and Janis E. Campbell. "Racial Misclassification in Mortality Records Among American Indians/Alaska Natives in Oklahoma From 1991 to 2015." *Journal of Public Health Management and Practice* 25 (2019). https://doi.org/10.1097/phh.0000000000001019.

[13] Joshi, Sujata, Thomas Weiser, and Victoria Warren-Mears. "Drug, Opioid-Involved, and Heroin-Involved Overdose Deaths Among American Indians and Alaska Natives — Washington, 1999–2015." *MMWR. Morbidity and Mortality Weekly Report* 67, no. 50 (2018): 1384–87. https://doi.org/10.15585/mmwr.mm6750a2.

[14] Joshi, Sujata, and Victoria Warren-Mears. "Identification of American Indians and Alaska Natives in Public Health Data Sets." *Journal of Public Health Management and Practice* 25, no. 5 (2019). https://doi.org/10.1097/phh.0000000000000998.

FIGURE 4. AGE-ADJUSTED MORALTIY RATE (PER 100,000) WASHINGTON 2015-2016



A = Non-Hispanic Single-race AI/AN, **B =** Bridged Race AI/AN, **C =** Non-Hispanic multiple-race AI/AN, **D =** Multiple-race AI/AN, **E =** Non-Hispanic multiple-race AI/AN, **F =** Multiple-race AI/AN, **G =** Non-Hispanic White
Data: Death Certificates linked with the Northwest Tribal Registry

Because the extent of misclassification is based on varying local factors, the creation of local, disease-specific estimates based on these linkages are vital for public health information that includes AI/AN. However, the quality of these estimates are also tied to whatever datasets are available for linkage – which can themselves be marked by drastic undercounting. For instance, the source of the data presented in Figure 3 is the IHS record database, which has been found to undercount AI/AN people by as much as 30%, and particularly in urban areas.[15] While local, post-misclassification "corrected" estimates are often the best source of public health data, they require constant time and maintenance, creating an additional burden to analyze health effects in AI/AN populations. Furthermore, it is difficult to use local estimates to track national implementation goals, as estimates are often not available or comparable across regions.

Defining "accuracy" in the context of racial classification.

As noted, racial misclassification can only be diagnosed after it has occurred, through the statistical comparison of at least two data sources.[16] Defining its opposite –

[15] Joshi 2018.
[16] There are two opposing phenomena in many datasets that erode accuracy: (1) undercounting and (2) misclassification. A description of how this is measured is specified in Appendix B.

"accurate classification" of a population – is a thornier task. Defining "accurate race" is thornier still in the context of health research, where care attention must be paid not to conflate genetic ancestry with socially-constructed race.[17] Any discussion of "accuracy" for AI/AN classification should be centered on the reality that "federal policies continue to enact a racialized AI/AN identity through strict requirements to obtain federal recognition and services".[18]

The current minimum standards of the OMB Statistical Policy Directive No. 15 and resultant categories of "AI/AN" and "race" do not necessarily neatly fit or reflect how all Indigenous people understand their ancestry or their families, and the notion of collecting race as separate from ethnicity has been widely challenged by both anthropologists and a 2020 Census working group on the issue.[19, 20, 21] The OMB definition of AI/AN race in particular includes conceptual items such as "community attachment" that are difficult for data collectors to communicate or interpret, and should not be neatly conflated with political status.[22] A person may descend from tribal members, yet may or may not be tribally enrolled and may or may not identify as AI/AN themselves. Although biological ancestry may be a factor in some deaths and diseases, "race" is often not a meaningful way to measure or describe biological ancestry.[23] However imperfect, the current category of AI/AN race does allow for the

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[17] Paradies, Yin., M. J. Montoya, and Stephanie M. Fullerton. "Racialized Genetics and the Study of Complex Diseases: The Thrifty Genotype Revisited." *Perspectives in Biology and Medicine* 50, no. 2 (2007): 203–27. https://doi.org/10.1353/pbm.2007.0020.; Borrell, Luisa N., Jennifer R. Elhawary, Elena Fuentes-Afflick, Jonathan Witonsky, Nirav Bhakta, Alan H.B. Wu, Kirsten Bibbins-Domingo, et al. "Race and Genetic Ancestry in Medicine — A Time for Reckoning with Racism." *New England Journal of Medicine* 384, no. 5 (2021): 474–80. https://doi.org/10.1056/nejmms2029562.

[18] Hazdous, page 3.

[19] Lieber, Carolyn A. "Counting America's First Peoples." *Ann Am Acad Pol Soc Sci.* 677, no. 1 (May 2018): 180–90. https://doi.org/doi:10.1177/0002716218766276.

[20] American Anthropological Association. "American Anthropological Association Response to OMB Directive 15." Race and Ethnic Standards for Federal Statistics and Administrative Reporting, September 1997. http://s3.amazonaws.com/rdcms-aaa/files/production/public/FileDownloads/pdfs/cmtes/minority/upload/AAA_Response_OMB1997.pdf

[21] US Census Bureau. "2020 Census: Race and Hispanic Origin Research Working Group - Final Report." *Census Advisory Committees (CAC)*. The United States Census Bureau, August 4, 2016. https://www.census.gov/about/cac/nac/wg-rho.html.

[22] Lieber 2018.

[23] Racial information on death certificates is collected according to government policy, using socially-defined categories. Although it may partially overlap with ancestry, it is understood throughout this

approximation measurement of a population that shares some health determinants and resource pathways, in this case access to healthcare in recognition of the federal trust responsibility.[24, 25, 26]

For the narrow purposes of discussing the prevention of misclassification in this report, the term "misclassification" has been defined broadly to include any person whose race or ethnicity has not been recorded on their death certificate in a manner consistent with what that they would have indicated in their medical records or another survey during their lifetime. Conversely, an "accurate classification" therefore indicates a consistent match between self-reported race across different self-identified sources. In this context, the quality of a funeral director's methods would be more or less accurate depending on how neatly they reproduce an individual's self-reported choice, for instance on the Census. "Accuracy" does not necessarily mean the racial category itself is precise or sufficient when describing any given person's identity. "Accuracy" does not indicate that this racial category is an innate biological characteristic. "Accuracy" also does not indicate enrollment or eligibility for enrollment in a Tribe, as sovereign tribes determine their own membership.[27]

Prevention of Racial Misclassification

Preventing racial misclassification in mortality data ultimately prevents disease. Accurate data leads to appropriate resource allocation and disease prevention that meets the health needs of a population, and this matters even more for AI/AN people who can suffer large disparities in both burden of disease and federal healthcare spending.

As such, the long-term reduction and elimination of misclassification remains a strategic priority. This requires broader inquiry into the variety of reasons why misclassification may occur. Although misclassification is more frequently described

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report that its primary use as a measurement tool is in the investigation of social determinants of health. See: Williams, David R. "Race and Health: Basic Questions, Emerging Directions." *Annals of Epidemiology* 7, no. 5 (1997): 322–33. https://doi.org/10.1016/s1047-2797(97)00051-3.

[24] Ibid.

[25] Haozous, Emily A., Carolyn J. Strickland, Janelle F. Palacios, and Teshia G. Solomon. "Blood Politics, Ethnic Identity, and Racial Misclassification among American Indians and Alaska Natives." *Journal of Environmental and Public Health* 2014 (2014): 1–9. https://doi.org/10.1155/2014/321604.

[26] Indian Health Service. "Basis for Health Services." Newsroom: Fact Sheets, January 2015. https://www.ihs.gov/newsroom/factsheets/basisforhealthservices/.

[27] "Tribal Enrollment Process." U.S. Department of the Interior, September 5, 2019. https://www.doi.gov/tribes/enrollment.

through epidemiological estimates, fewer public health researchers engage with a consistent narrative explaining why it has occurred and the many factors at play throughout history.[28] A 2014 review explored the phenomenon in factors at system, policy, and individual levels, and forms the theoretical basis of how this report views misclassification (see Table 2).

TABLE 2. REASONS FOR RACIAL MISCLASSIFICATION IN AI/AN DATA[29]

Systems Level	Policy Level	Individual Level
No electronic medical record	Spanish surnames automatically classified as Hispanic	Refusal to answer
Unable to link registries	Physical appearance of individual	Not identifying with particular ethnic or racial identity fields
Not asked or lack of appropriate race, ethnicity, and Tribal affiliation options on forms	Age	Forced to identify single races (or perception/assumption of single-race choice)
Inadequate definitions of AI/AN identity	Decreasing blood quantum	Previous generation did not enroll

* This review acknowledges that there are additional issues regarding changing enrollment requirements for Tribal members, but that this issue is broad, complex, and beyond the scope of the paper.

While Hoazous, et. al describe misclassification in medical records and administrative data more broadly, little has been reported specifically about the role of funeral directors in mortality records at systemic, policy, and individual levels. NCUIH began systematically collecting information on the topic in 2018 to expand these existing frameworks on misclassification, with the goal of better understanding the policies and practices that create misclassification, identifying possible solutions to prevent the error, and learning more about the funeral director audience we had engaged on this topic.

To do so, NCUIH used a mixed-methods approach to learn more about the experience of funeral directors on the job, as well as their interactions with other professionals in the vital records systems. Qualitative and quantitative methods were employed to answer a series of questions:

[28] Haozous, et. al 2014
[29] Adapted from Haozous, et. al 2014

- How do funeral directors describe their role in collecting racial data?
- What practices do funeral directors use to classify race?
- What challenges do they face when classifying race?
- What policies and trainings structure this work? Are they implemented by government, businesses, or education?
- Do interactions with families, demands of the job, or reporting mechanisms change the process of classification or reporting to the state?
- Have funeral directors identified anything that impedes or facilitates accurate racial classification, or would expand their capacity to implement improvements?

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Part II. Methods

Starting in October 2018, NCUIH conducted a review of existing literature to understand the procedures involved in completing a death certificate and possible drivers of misclassification. Concurrent with this review, NCUIH staff began gathering feedback from the perspective of Urban Indian Organization (UIO) staff, Tribal leaders, and a variety of Subject Matter Experts (SMEs) such as AI/AN funeral directors and epidemiologists. Through November 2019, NCUIH participated in discussions with Tribal Leaders[30] and Tribal Epidemiology Centers[31] (TECs) in order to gain an understanding of how Tribes, Tribal organizations and members are affected by racial misclassification and their community priorities.

In addition to gathering Tribal perspectives, NCUIH engaged in several conversations with other organizations to understand their industry's role in death registration and racial misclassification. In addition to discussions with the National Funeral Directors Association (NFDA), NCUIH had information gathering conversations with the National Association for Public Health Statistics and Information Systems (NAPHSIS) and the National Association of Medical Examiners (NAME) to gain their perspective on the issue and how to address it. After conversations with NAPHSIS and NAME, NCUIH decided to expand the scope of primary data collection to include staff from state vital records departments and medical examiner offices.

Based on this literature review and input from Tribes and SMEs, NCUIH developed primary data collection instruments in the form of a survey, interviews, and focus groups.

Primary data collection

NCUIH conducted an online survey, two virtual listening sessions and four key informant interviews via telephone with funeral directors from across the country. As a result of conversations with NAPHSIS and NAME, NCUIH expanded the scope of its inquiry to include listening sessions with state vital records and public health statistics offices staff and medical examiners. Two SMEs were contracted with to assist with tool development and review listening session guides: an American Indian Funeral Director and a Medical Examiner. All survey and interview participants consented to participate with full knowledge that their de-identified responses might be used in this report.

[30] Centers for Disease Control and Prevention Tribal Advisory Committee Meeting, February 2019
[31] California Tribal Epidemiology Center, Northwest Tribal Epidemiology Center, Navajo Epidemiology Center and Oklahoma Area Tribal Epidemiology Center

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Online Survey of Funeral Directors:

Between May and September 2019, NCUIH conducted an online survey to collect information from funeral directors about their experiences and practices when completing death certificates.[32] The anonymous survey was conducted via SurveyMonkey, which prohibited multiple entries from the same IP address. Response data was downloaded and imported into IBM SPSS for final analysis.

Participants were recruited directly from industry contact databases and via snowball sampling from state licensing boards, state funeral directors associations, and national industry organizations. Recruitment partners spread interest in their networks via word of mouth, e-blasts, and newsletter articles. All states were contacted, but not all passed along recruitment materials. In the end, a total of 163 funeral directors participated in the survey – about 1% of the total funeral directors in the country in 2018.[33]

Listening Sessions:

Listening session guides were developed in partnership with the SMEs and NAPHSIS, who also assisted in recruiting participants for and facilitating the listening sessions with their colleagues. Two sessions were held with vital records professionals, and two were held with medical examiners and professionals from these offices. All listening sessions took place in June and July 2019. Recruitment took place by word of mouth, invitation, and advertisement through state and national professional networks.

Qualitative Interviews:

Lastly, NCUIH conducted key informant interviews with 4 funeral directors between October and November 2019. Key informants were recruited from a pool of survey respondents who provided an optional follow-up contact. The interview guide was developed based on what had been learned from prior listening sessions and survey results, with input from an AI/AN funeral director SME. Each worked in a separate state, representing different rural, urban, eastern, and western areas.

Key informants were asked to provide more in-depth detail on their work process and experiences with the public. Interviewees were also asked to respond to the initial aggregated survey results from the 163 of their peers to help contextualize responses about common on-the-job practices and comfortability in identifying race, Hispanic Origin, and Tribal affiliation for the purpose of death registration.

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[32] The survey queried 163 participants on their demographic information; professional history and affiliation(s); characteristics of their funeral home; practices and comfortability in identifying race, Hispanic origin, and Tribal affiliation; training needs; and practice recommendations. See Appendix C.
[33] There were 19,136 funeral homes operating in 2019. See Statistics from National Funeral Director Association (2019). https://www.nfda.org/news/statistics

To analyze results of key informant interviews, NCUIH developed an *a priori* codebook with categories and themes of interest. Themes were refined by the research team and finalized prior to analysis. Full code details with examples can be found in Appendix C. Transcribed interviews were content coded based on the codebook themes. Coding was verified by a second member of the research team before results were summarized. Sections with disputed codes were evaluated by a neutral 3rd party and the initial interviewer, before being discussed with the coder to build a consensus code and interpretation of the passage.

FIGURE 5 QUALITATIVE ANALYSIS PROCESS

Generally, there was a high level of agreement between coders – with only 16% of codes being initially disputed.[34] The majority – 72% – of disputes were resolved by including both codes; for instance a phrase like "*our companies standard procedure is to use of an electronic form*" should have been coded as both "procedures" and "forms" instead of one or the other. Disputes most commonly involved "procedures" and "forms" (involved in 47% of disputes combined) as these were often mistaken for each other, though about 20% of disputes involved "barriers". This usually occurred when one coder identified a barrier yet the other assumed a more neutral statement in the transcript.

After finalizing coded transcript content, the research team extracted major findings from the key informant interviews, which are presented in the results section below.

[34] This number ranged between 9 and 26% depending on the interview. For full inter-coder reliability data in each interview, see appendix C.

Part III. Results

Survey Results

Demographic Information

Simplified demographics of participants can be found in Table 3.[35]

TABLE 3. RESPONDENT CHARACTERISTICS

Number of Respondents	163				
Completion Rate[36]	136 (83%)				
States Represented	36 states				
Gender *(n=151)*	Female	48	32%		
	Male	102	68%		
Average Years in Profession	25.4 years (standard deviation 14.2)				
Business Type *(n=162)*	Family-Owned or Small Business			110	67.9%
	Part of a Corporation, Large Business, or Conglomerate			38	23.5%
	Other			14	8.6%
Age *(n=149)*	< 18	0	0.00%		
	18-24	1	0.67%		
	25-34	15	10.07%		
	35-44	30	20.13%		
	45-54	44	29.53%		
	55-64	35	23.49%		
	65+	24	16.11%		
Race and Ethnicity[37] *(n=151)*	White			136	90.07%
	Hispanic, Latino, or Spanish origin			11	7.28%
	American Indian or Alaskan Native			6	3.97%
	Some other Race, Ethnicity or Origin			3	1.99%
	Black or African American			5	3.31%
	Asian			1	0.66%
	Middle East or North African			1	0.66%
	Native Hawaiian or Other Pacific Islander			0	0.00%

[35] Full sample demographics are available in Appendix C.

[36] The number of respondents who completed all mandatory portions of the survey. The largest single contributor to non-completion are the 12 respondents (7.4%) who dropped out without completing the final mandatory questions (identifying their own gender and race/ethnicity).

[37] Respondents could make multiple selections, using the combined race and ethnicity question format recommended by the Census Bureau for the 2020 Census. Kelly Mathews et al., "2015 National Content Test Race and Ethnicity Analysis Report: A New Design for the 21st Century," Census.gov (United States Census Bueau, February 28, 2017), https://www2.census.gov/programs-surveys/decennial/2020/program-management/final-analysis-reports/2015nct-race-ethnicity-analysis.pdf.

Funeral directors who participated most frequently reported being over 45 (64% of the sample), and represented a wide range of experience in their position from 1 to 69 years, with an average of 25 years' experience. There were 151 participants who reported their gender; 68% of these were male. Of this same group, 92% selected a single race/ethnicity category and 8% reported two categories.

SOME SELECTED MORE THAN ONE RACE/ETHNICITY:

12 respondents selected multiple choices, including:

- White and Hispanic, Latino, or Spanish.
- White and Asian
- White and American Indian or Alaska Native
- White and Middle Eastern or North African
- White and Other ("Portuguese")

Participation in the survey about completing death certificates was most common among funeral directors licensed in Arizona (22%), Texas (12%), and Utah (7%), likely due to strong recruitment networks in these states. Although the majority of funeral directors reported having licensure in one state only, nearly 20% said they were licensed in multiple states.[38] Nearly 10% of funeral directors reported neither working for a small/family business or as part of a Corporation, Large Business, or Conglomerate, but instead specified they were licensed individuals or retired funeral directors who work for a funeral-home serving business, state licensing board, state government, or family-owned corporation with several locations.

Professional Organizations

A total of 83% of funeral directors reported belonging to professional organizations, with the National Funeral Directors Association (NFDA) being the most commonly held membership. A total of 29% of funeral directors had membership in 2 associations, 10% had membership in 3 associations, and 5% had membership in 4 or more associations. Among those with 2 or more associations, the most frequent combination of organizations was NFDA and "Other organizations", such as state-specific funeral

[38] The 3 most represented state licenses were AZ (n=36), TX (n=20), and UT (n=11), with <10 respondents from 37 other states. A full breakdown of all 163 responses by state are available in Appendix C.

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service/directors associations, though dual ICCFA/NFDA memberships were nearly as common. Full organizational membership, and correlations between multiple memberships are provided in Appendix C.

Practices in Identifying Race, Hispanic Origin, and Tribal Affiliation

Funeral directors were asked if they provide worksheets to family members to fill out, ask verbal questions, use observation/working knowledge, and/or use medical history and other forms to assess race, Hispanic origin, and Tribal affiliation among the deceased. Medical history and other forms were the most frequently reported of these methods for identifying race, Hispanic origin, and Tribal affiliation, with 57% doing this at least sometimes. (see Figure 6). Sixty-nine percent of participants report never asking verbal questions about race, and 48% reported using observation or knowledge of the family to complete these items.

Some funeral directors wrote-in additional information about their process in identifying race, Hispanic origin, and Tribal affiliation.

Selected quotes include:

- *"I always have the next of kin/family member read over my work before I submit."*
- *"I ask no questions in regard to the death certificate."*
- *"[…] they only allow one principle Tribe and descendants classification. If we mark White, it changes the category."*
- *"There is no specific Tribal affiliation section on [our] state death certificate."*
- *"On occasion our decedents are unclaimed indigents, so we are unaware of demographics and have to list as 'unknown.'"*

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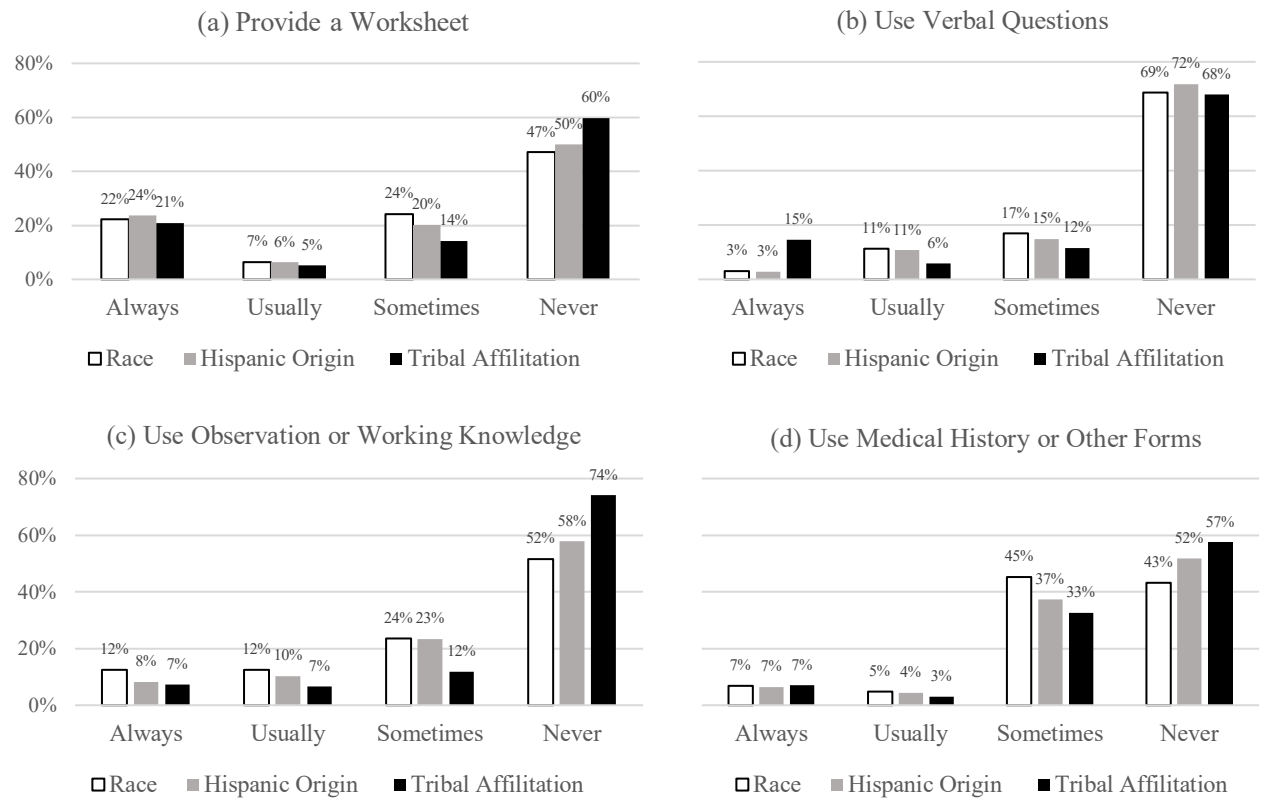
FIGURE 6: WHEN COMPLETING THE FOLLOWING DEMOGRAPHIC INFORMATION SECTIONS ON A DEATH CERTIFICATE, DO YOU EVER….



Full options are: (a) Provide a worksheet for a family member or other informant to fill out (b) Ask questions verbally to a family member or other informant, (c) Fill this section out based on observation or working knowledge of the family, and (d) Use information from the medical history or other forms provided by the hospital, medical examiner, and/or coroner. Respondents could use multiple methods in combination, so percentages across methods may add up to more than 100%.

Correlations between Identification Methods.

Bivariate (Pearson) correlation analyses assessed whether these four methods of identifying race, Hispanic origin, and Tribal affiliation were statistically associated. Results revealed that some survey respondents used methods in concert, or used some methods to the exception of others. Specifically:

- Using any particular method to determine race was strongly and positively associated with using the same method to identify Hispanic origin and tribal affiliation ($p<.001$).
- Using "verbal questions" was negatively associated with using "observation or working knowledge of the family" ($p<.001$).

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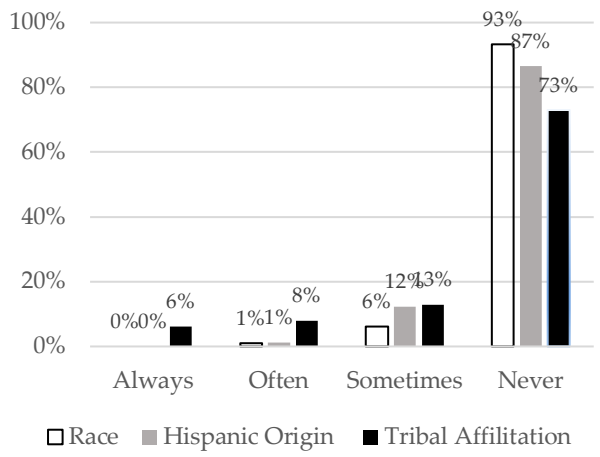
- Using a decedent's "medical history" was positively associated with "providing worksheets for the family" (p<.01).
- Using a decedent's "medical history" was also positively associated with "observation or working knowledge of the family" when recording race, Hispanic origin, and tribal affiliation (p<.01).

Full correlation tables demonstrating the relationship of the use of these methods for collecting race, ethnicity, or tribal affiliation in our sample are available in Appendix C.

Leaving Race, Hispanic Origin, and Tribal Affiliation Blank

When asked how often race, Hispanic origin, or Tribal affiliation is left blank on a death certificate, most reported that these fields are never left blank. However, over one-fourth of funeral directors (27%) reported that Tribal affiliation is always, often, or sometimes left blank (see Figure 7). Tribal affiliation is left blank on death certificates often or always by 15% of survey respondents, yet race only left blank 1% of the time. This was the only question where responses were statistically different between race and tribal affiliation.

FIGURE 7. CATEGORY LEFT BLANK ON DEATH CERTIFICATE



Reasons for leaving categories blank on the death certificate are presented in Table 4. Write-in responses highlight hesitancies in reporting being of Hispanic origin, and a perceived lack of requirement to report Tribal affiliation in many states or for specific deaths.

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TABLE 4. REASONS PROVIDED FOR LEAVING CATEGORY BLANK ON DEATH CERTIFICATE

Shared across Race, Hispanic Origin, and Tribal Affiliation

- Information is not available/unknown by the funeral director.
- The person is unidentified or abandoned.
- The family or next of kin refuses to answer or does not know.

Specific to Hispanic Origin

- In some states, if the person is not of Hispanic origin, you do not need to fill in.
- Families are embarrassed.
- Funeral director does not "get into race debates with families."
- It is seen as unimportant or none of the state/government's business.
- Family has multiple origins and does not know what to put.
- Status of citizenship.

Specific to Tribal Affiliation

- Families are unsure and do not want to make an incorrect statement.
- Failure to ask families because [funeral directors] are uncomfortable or do not know how.
- Family wants another race listed.
- Facility does not serve Tribal families.
- Families do not understand the importance.
- Not required to report.
- People are not actually enrolled in a Tribe.
- Family does not affiliate with the Tribe.
- Native American is [already] selected.

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THE TYPES OF QUESTIONS FUNERAL DIRECTORS RECEIVE INCLUDE…

- Why do you need that?
- Is it required?
- Why is this information important to the state/government?
- Why is Hispanic not a race option?
- How do [you] spell the tribe's name?
- Who is going to see or use the information and for what purpose?
- Why is White marked?
- Why are [they] Mexican when they were not born in Mexico?
- How much Tribal is recognized? (i.e., "Grandma always claimed to have a little Cherokee").
- Are there benefits for affiliations?
- Can I just say human?
- What percent [counts]- do I count my DNA results?
- Why are Hispanics listed as Caucasian?
- Why is my [German/Other] heritage not important (or asked about)?
- What if he/she is mixed race?

Questions About Race, Hispanic Origin, and Tribal Affiliation.

A total of 26% of funeral directors said they are never asked about race, Hispanic origin, and Tribal affiliation by family members or parties of deceased individuals, but 59% said they are sometimes asked, 12% said they are usually asked, and 3% said they are always asked.

Family Member Concerns.

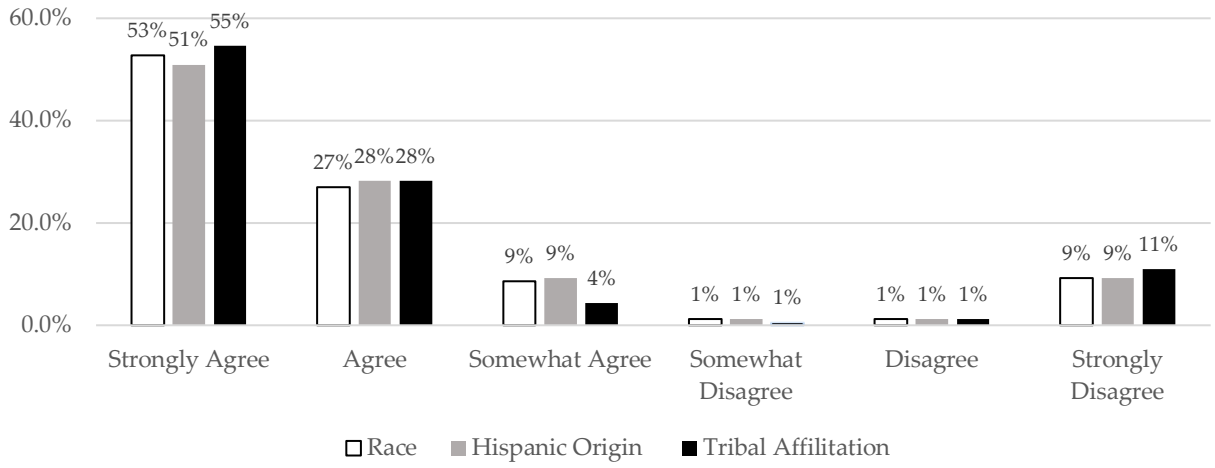
A total of 32% of funeral directors said that family members have expressed concerns, discomfort, or confusion about providing the deceased party's race. Approximately one-third reported family member concerns about reporting Hispanic origin, and 16% reported family member concerns about reporting Tribal affiliation. The types of concerns that family members and other individuals had included not wanting to provide the information to the government, being ashamed about being Indian or

Hispanic, not knowing how to report multiple races, thinking the information is not useful, disliking the terminology [on the form] because it does not describe them or their family, cultural differences in labeling race (i.e., some cultures do not identify races), and lack of awareness about being Hispanic and other races (quote: "Most Hispanic people do not want to be listed as White.").

Comfort Talking About Race, Hispanic Origin, and Tribal Affiliation.

When queried about their comfortability in asking a family member or deceased party's race, Hispanic origin, or Tribal affiliation, nearly 90% of funeral directors agreed they would be comfortable requesting this information. However, approximately 10% of funeral directors disagreed that they would feel comfortable asking a family member or informant about race, Hispanic origin, or Tribal affiliation.

FIGURE 8. I AM COMFORTABLE ASKING ABOUT THE DECEASED PARTY'S…



Correlation between Comfort and Other Variables.

Preliminary analyses revealed that some variables were fairly evenly distributed making them well-suited for additional analyses. Based on information from Literature and SME discussions, Bivariate (Pearson) correlations were run between comfortability in asking about race, Hispanic origin, and Tribal affiliation and the variables in Table 5.

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Of these, the race of the funeral director was not significantly correlated with their comfort asking about race, Hispanic origin, or Tribal affiliation, likely due to small numbers of non-white respondents. However despite larger cell sizes, Pearson correlations showed no significant association between comfort asking these questions and funeral director gender, the methods used to collect demographic information, ever having left Tribal affiliation blank, awareness of the CDC handbook, frequency of trainings, or having received questions from the family.

TABLE 5

CHECKED FOR CORRELATION WITH COMFORT

- Age* (-)
- Years in the profession* (-)
- Gender
- Race of the funeral director
- The methods used to collect this information
- Ever leaving Tribal Affiliation blank
- Awareness of the CDC training handbook
- Frequency of trainings
- Having received questions from the family or informants about why race, Hispanic origin, or Tribal affiliation is being collected.

*SIGNIFICANT NEGATIVE (-) CORRELATION FOUND

Analyses revealed that comfortability in asking about race, Hispanic origin, and Tribal affiliation was negatively associated with number of years in the profession; junior-level funeral directors more frequently reported being comfortable asking questions (r=-.17, p<.05; r=-.18, p<.05; r=-18, p<.05). Apart from years in the business, comfort asking about Hispanic origin only negatively correlated with increased age (r= -.17, p<.05) – in that older participants were less comfortable - but this relationship between comfort and age was not observed to be significant for race or Tribal affiliation.

Trainings and Resources

Funeral directors reported attending trainings either multiple times per year (56%), once per year (23%), once every 2-5 years (17%) or never (4%). Most funeral directors indicated that the last time their staff were trained on collecting demographic data, the training was offered by a state agency, their own business, or a local agency.

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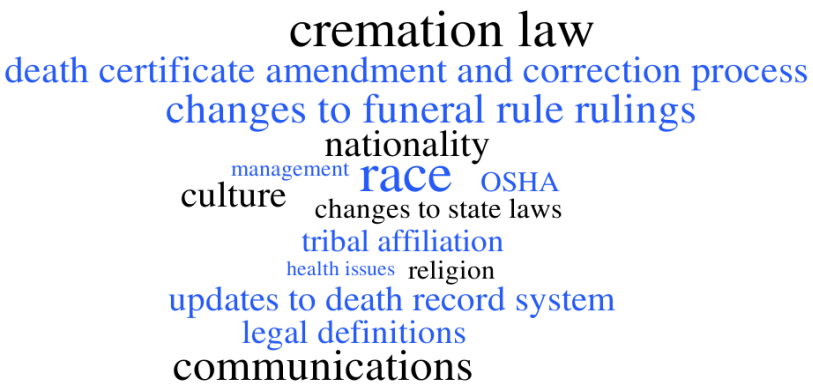
FIGURE 9. SUGGESTED TRAINING TOPICS



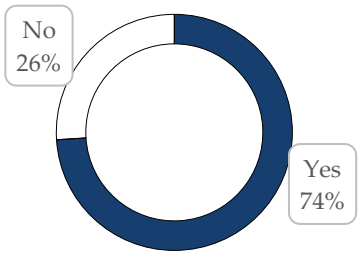
Approximately one-fourth of funeral directors said no trainings had ever covered demographic information. Funeral directors were divided on whether they would like more trainings; 55% said yes but 45% said no. Funeral directors would like to attend both online and in-person trainings, preferably ones that offer Continuing Education Credits. Training topics suggested by participants are presented visually in Figure 9.[39]

Awareness for Families.

When asked whether they believe the families they serve would benefit from more awareness about the importance of providing accurate death certificate information, most funeral directors said "yes."

Selected write-in reasons are provided in Table 6.

FIGURE 10. WOULD FAMILIES BENEFIT FROM AWARENESS?



[39] Participant training suggestions were entered into a web-based website called Word It Out to generate a cloud that includes words and phrases suggested for training. Size and color of words were generated at random by the site for visual interest/variety and do not denote emphasis on a particular training.

TABLE 6. FUNERAL DIRECTOR OPINION

Families Would Benefit from more Awareness...

- "Awareness equals accuracy."
- "Each birth certificate is as unique as the person whose life it reflects."
- "The correct information keeps the funeral home from amending a death record, which takes forever […]."
- "Explaining the reasons data are collected helps the family's understanding."
- "The information is used for genealogy."
- Demographics […] relate to tracking disease process as well as cause of death problem "clusters" […] to help with public health and safety."
- "Some families are in a group that are never classified correctly. This would give them personal satisfaction knowing their loved one was classified correctly."
- "To be more prepared for the process."
- "The funeral industry need to be more transparent […]."

Families Would Not Benefit from more Awareness...

- "All of my families have no problems answering the questions."
- "At the time of death, families could not care less about giving statistical information."
- "[I] don't feel like there's errors in our data input."
- "Families already have a good awareness of importance regarding the death certificate."
- "Most families are not concerned about the state's needs might be."
- "They do not hesitate to provide information when they know the reason."
- "Most families feel the question of race is either irrelevant, offensive or unnecessary. I tend to agree. I must often excuse the race question."

Funeral Directors' Handbook.

Less than half (43%) of funeral directors reported knowing about the CDC National Center for Health Statistics Funeral Directors' Handbook on Death Registration and Fetal Death Reporting. Less than half of those who are aware report reading at least part of the handbook (20% of the entire sample). Among those who read it, write-in comments indicate that some found it informative and use it as a resource when certificates are incorrectly signed. Others believe the book does not provide more information

Aware of NCHS Handbook?	Yes	70	43.21%
	No	92	56.79%
… of those 70 Funeral Directors aware:	Mentioned they have read at least part of it:	32	(45.7%)
	Mentioned it was…		
	helpful	18	32.1%
	not helpful	5	7.1%

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than they are already required to know as a licensed funeral director. One person pointed out that the handbook provides information that "*most families are not wanting to digest after a loved one has passed away*."

Write-in Recommendations from Participants

Survey participants provided additional recommendations for assessing race, Hispanic Origin, and Tribal affiliation (see Table 7). Some recommendations were for other funeral directors, while others were for state and national agencies that develop policies and requirements. Suggestions show that not all funeral directors agree on how death registration should occur – some think registration should be completed via worksheets, some prefer face-to-face conversations, and others think the demographic portion should not be their responsibility at all.

TABLE 7. WRITE IN SUGGESTIONS MADE BY FUNERAL DIRECTORS

Write-In Suggestions for other funeral directors:
• Use worksheets to collect race, Hispanic origin, and Tribal affiliation.
• Ask families first if they are comfortable discussing this matter then provide a place on the death certificate that states, "not willing to disclose" if they wish not to do so.
• Ask for a Tribal card and take a copy [to verify correct information].
• Have face-to-face conversations with families.
• State to the family that it is a requirement of the Department of Vital Records to collect information on race, Hispanic origin, and Tribal affiliation.
• Never assume how someone identifies.
• Add Tribal fields to death certificates if a family member mentions to do so and the state certificate does not ask about Tribal affiliation.
Write-In Suggestions for state and national agencies:
• Provide education to families on race versus origin.
• Provide explanations from your agency about why the question is being asked so we can tell families.
• Make sure guidelines are clear; give us a list of acceptable answers.
• Offer more education on how to collect information on race, Hispanic origin, Tribal affiliation, and educational attainment.
• Add more options for ethnicity to promote cultural diversity.
• Do not have funeral homes be primary/sole collector of information. Have a trained person verify or collect information from family members or other informants.
• Require licensed funeral directors and not funeral arrangers or salespeople to collect identification information: Most information collected by these individuals is automatically transferred to a death certificate and not verified for accuracy.
• Consider having a box on the death certificate for "nation" not "Tribal."
• Put in 2 text boxes

Interview Results

Common themes from interviews are summarized in this section, and the full codebook used for analysis is in Table 12 in Appendix C. Key themes raised by the funeral directors included Family (14% of final codes), Barriers (11%), Procedures (11%), Facilitators (10%), Procedures (10%) and Forms (10%). However Cultural competency of

funeral directors (8%) and community awareness (6%) were often discussed together, indicating these were amongst the most salient topics throughout (14% combined).

Key informant were a small subsection of funeral directors, and do not neatly represent the industry as a whole nor the survey sample. Instead, they likely self-selected for interviews based on their pre-existing comfort discussing race or their own AI/AN identification. As a group, interview participants shared similar opinions on practices and their industry, though have different experiences.

Procedures and Disconnect.

Key informants agreed on a core set of practices during interviews, which included always verbally asking about race directly, never copying racial classifications between forms, and never making assumptions about racial identity based on appearance. They noted the potential for disconnect when multiple procedures were used to collect race – particularly when race is collected by any person who is not the funeral director responsible for submitting the death registration.

Key informants stated that they rarely use hospital records or other information accompanying the decedent to identify race unless the individual is unclaimed, unrecognizable with no next of kin, and/or a fetal death. They indicated that there can be errors in hospital records, which is why race information is always verified by funeral directors using information from family members, next of kin, and/or other informants. As one interviewee put it: *"Usually doctors fill out as much information as they have, and it's really not a lot."* This extended beyond race, as in one recent case:

> *"We just did a burial for a gentleman, a person by the name of Jamie[40]. It turns out this person is female, but all of her identification is male. So I notified the hospital and said, "You may want to look at your hospital records. This person is definitely genetically female, and I just talked to the daughter, and she said, "No, it's my mother. Her name is Jamie"…. So no, I don't think it's a good idea to go off those records, too. I think your best and most accurate source will be family."*

They also noted that funeral directors shouldn't rely on other forms of ID that travel with the body, such as human remains transport documents or "face sheets" from nursing homes, which can contain racial information that was collected by another professional based on sight and are prone to bias based on assumptions of what different races look like. One informant said that face sheets were common in his area and said it affected "*not only Native people, but some people who were black but they were*

[40] All names and locations changed for anonymity.

very fair-skinned. It would be noted on [the face sheet] that their race was Caucasian. Or a lot of times, if they were Native American, it would be Caucasian or Black. That could be part of the problem, too."

All funeral directors reported having family members proofread death certificates prior to submission to avoid a disconnect determining what is recorded against the families wishes.

Procedures described in the CDC's Funeral Director's Handbook on Death Registration and Fetal Death Reporting – for example the usage of a card with selections for different racial categories – were brought up occasionally. There were mixed opinions on the utility of this procedure – some thought it can help if a family or inexperienced funeral director is uncomfortable or uncertain, but others thought that the formality of the procedure was a barrier to engaging with the family.

Two interviewees mentioned procedures that are listed in Funeral Director's Handbook on Death Registration – the use of physical Race and Hispanic Origin selection cards. There were mixed opinions on the utility of this procedure – one thought it can help if a family or inexperienced funeral director is uncomfortable or uncertain, saying that, apart from providing a worksheet, "t*hat's probably the easiest way that I can think if that's uncomfortable… we call it a "Race Card," and it has all the choices on there. If you're sitting with the family, you'd be able to slide it out and say, "What would you choose?".* This avoids discomfort by minimizing interaction. The other thought that the formality of the procedure was a barrier to engaging with the family. One interviewee mentioned:

> *"I don't think they are ever used. I've only ever looked at that in a book. I just want to hear what people say first and then work backwards, so it's a little easier that way: How do people identify themselves and really figure out how we're going to put that on the death certificate?…. I get why they make the little cards so that we know… but it doesn't really jive with what we need to put on the certificates."*

This sentiment – that certain procedures can act interfere with their engagement with families – was a recurring theme, and emphasizes the premium that funeral directors put on building a positive relationship with the families they serve during an extremely difficult time. Those who were interviewed mentioned that for some funeral directors – particularly early-career professionals – the procedure of going through race, Hispanic origin, and Tribal affiliation with families can be awkward or bring up tensions, particularly if the family finds that these categories do not adequately represent the decedent's identity in life.

Some reported choosing methods and procedures that emphasize individualized personal support and connection with their clients. One funeral director emphasized that conversations about culture, ethnicity, and tribal affiliation can be a productive way to learn about the decedent's life and plan personalized funeral arrangements, creating a comfortable conversation that can segue into questions about defining race and ethnicity later in the process during registration. The same funeral director noted that body language during registration is important, so as to not come off too clinical, and said:

> *"if you're writing information and you're holding a pen or a pencil and you ask a question and they ask you a question back, I think one of the most effective things anyone could ever do is just put the pen down, put your hands flat on the table and not make a lot of sudden movements, and then just having a dialogue with them. Now they understand that they've got your total attention, so they're not "as soon as I get the answer I need I'm going to go right back to writing." Nope, I've stopped writing now. "I'm going to talk to you for a moment and tell you exactly why I'm asking for this information. If you don't want to give it to me, that's okay. There's no pressure here, but it is something that I think that you would—or that I think your family would benefit from knowing."*

Although interview respondents were in agreement that verbal questions or confirmation should always be part of the procedure, they had varying opinions on the use of forms (and even which forms are used in their practice or area).

Forms.

All key informants reported using either electronic death certificate forms or worksheets to collect information about the decedent's race, Hispanic origin, and Tribal affiliation for registration. Some use worksheets that they send to family or next of kin prior to in-person or telephone interviews during which the information is verified by the funeral director verbally. There were mixed opinions about whether worksheets facilitated the collection of accurate demographic information; some key informants believed that worksheets caused decedents to be less truthful about race than answering questions asked by the funeral director. Others thought worksheets were a tool that helped families familiarize themselves with the questions prior to an in-person interview with the funeral director.

When asked why other funeral directors might choose to use a worksheet, some said convenience, others said that it helps some funeral directors avoid an uncomfortable conversation.

> *"I think that that is one of the things with using the form. It's a little non-confrontational, if you will, so then the choices are there and they know it, and they know everything on there has to be filled out and filled in correctly, and everything has to be filled out and you'll have to go over it with them when you receive it. That's probably the easiest way that I can think if that's uncomfortable"*

No one thought there was much difference whether a form was provided in person, via mail, email, or fax. However, no one believed that forms or worksheets should be used as the only source of demographic information. There was broad agreement that forms should be verified in person before the registration is submitted, and some suggested providing forms in advance so that the review was more efficient. As one funeral director said, "*There is never a time I don't verify. It's amazing, actually, how often, even if there are mistakes..."* although they noted that "i*t's not usually something that's big like race or ethnicity."*

Interestingly, there seemed to be some variation in the types of forms funeral directors provide. Some key informants send a blank "write in" standard death certificate to the family to prepare for an in-person meeting, but it seems that some funeral directors will provide a separate "intake" form that is specific to their business. One funeral director on the survey attached their "death registration form" that they use to copy items into the electronic system when submitting registration. This intake form did not include box prompts for race and had no space for tribal affiliation, although the state form did and followed the standard death certificate.

Family.

Key informants reported having warm relationships with family members and next of kin. Many talked about the importance of establishing rapport with families and holding discussions to accurately complete death certificates. This individualized approach to each unique family seems like an asset, as some informants said that some families do not know what race to put on a death certificate when the decedent identified as multiple races. They said it is the role of the funeral director to ask verbal questions and help the family fill out the information. Funeral directors stated that families might still want to be identified a specific way and that they can only record as much information as the family provides:

Family dynamics can also play a role in some cases, as one native funeral director mentioned in the case of a woman in her 20's who had died in another state. She had a friend who had included her tribal enrollment on the death certificate, and was being returned to her parents for final arrangements across state lines. Because the information was collected by another funeral home, he needed to review it with the family prior to registering the death once her body was transported.

> *"She considered herself to be Native American. Her mother knew that she was Native American. Her father… Her father says, 'Native American?!' …*
> *The wife says, 'Yes, she was Native American. We're Native American.'…*
> *The husband says, 'I don't consider myself to be a Native American.'"*

Though the woman's race was recorded as AI/AN, her mother's was not.

> *"Fast forward. The grandma dies. I bury her. We put "Native American." Two weeks ago, I buried the mother… and the husband says, "I don't want 'Native American' on the death certificate. I want 'multi-racial'."*

This case underscores the complexity of asking a family unit – which is rich with multiple viewpoints, identities, and relationships – to determine race and tribal affiliation for one of its absent members in a time of extreme grief and stress. When navigating these conversations, key informants drew on the tools of their profession and emphasize comfort to families. One funeral director spoke about how to both get comfortable and ease into discussing a deceased person's self-identity.

> *"You know what makes me feel comfortable is just sitting before anything is done, and I think a rapport has to be made. So before anything is done, I ask specifics: "Give me five highlights of your father," and I just let them talk. I sit and laugh with them. I'll sit and watch them. I listen to what they're saying. You see the rapport is being built, and I notice it with some of my own employees.*
>
> *I can just watch them walk in with a family and just immediately getting specifics, and I don't like that… "That's easy. I just came in and gave them some information and I was out of there." If that's the case, do we really do our jobs? I think to build a rapport*
>
> *…, I think that's the best and the only way if you're going to feel comfortable enough to get that information from them."*

During the interview we asked why some funeral directors do not ask family members about race, Hispanic origin, or Tribal affiliation, and some responded that it was

because the individual may be inexperienced, be scared to have the conversation, or does not want to upset family members.

Cultural Competency.

During the interviews, cultural competency emerged as a key skill that helps funeral directors successfully navigate discussions with families and collect accurate information.

All key informants encouraged families to list as many races on death certificates as needed. This is crucial, given that some families assumed they were only allowed to select one, and some survey respondents also inaccurately believed that multiple selections were not allowed.

Funeral directors who personally identified as being Native or who frequently worked with tribes knew to ask for Tribal Identification or enrollment cards to verify Tribal affiliation. One funeral director mentioned that asking about culture, tribal affiliation, and veteran status was primarily useful to identify financial benefits and provide more personalized services, and data elements were a follow-up concern. For instance, interviewees mentioned that when a funeral director knows about tribal affiliation or military service, they can help the family to secure burial assistance or final disposition options that the family was not previously aware of. This can ease burdens regarding logistics and costs, and is one of the main services a funeral director provides. Other funeral directors agreed that if more funeral directors knew about how to access benefits through the military and specific Tribes, then they may ask data questions on these topics more often.

Key informants were also uniformly opposed to identifying individuals by looks or name only, despite how often this was used by survey respondents. As one funeral director put it:

> *"I don't think observation is accurate. I think you're going to create more problems and make small mistakes like that. Some people could take it really personally. That's something you don't want to mess up. Even if nothing else […], death certificates are expensive, and people often need them for things right away, so we don't want to do anything that's going to delay the amount of time it takes to get them."*

Community Awareness.

Apart from the role of the cultural competency of a funeral director, key informants also mentioned that the community was often not aware what race and ethnicity mean or why they are collected. A more culturally competent funeral director would likely be able to handle these situations better, but this also emphasizes the role that community awareness of racial data plays in this process. As one funeral director put it, "*maybe part of the problem lies in the death certificate, but I think a lot of the problems just lie in social issues beyond that.*"

Each key informant confirmed that family members can dislike being asked about race, Hispanic origin, and Tribal affiliation. They suggested that for some families, this is a sensitive subject because families are concerned about where the information will go or why it is being asked. Interviewees mentioned that family members were particularly worried about why they were being classified as Hispanic and/or confused about why they would be classified as both Hispanic and White. In other cases, changing identity over time or differences of opinion on family identity for the decedent's race may color this selection of OMB/Census category depending on the case, even when the funeral director is broadly aware of the family's ancestry. One funeral director mentioned that *"sometimes it might even be the situation of the death that might make families a little bit more on the defensive side […] and not willing to give out this information."*

Key informants typically addressed family member concerns by explaining the required elements of the state death certificate and why the information is being collected, including that it helps identify disease burden and causes of death among specific groups of people. They may give standard OMB/Census definitions of each category, sometimes using a version of the visual-aide card provided by the NCHS. Even so, families might still want to be identified a specific way and funeral directors can only record whatever information the family provides. Each funeral director who was interviewed questioned whether other professionals know how to educate their clients on these issues.

Industry Trends.

Occasionally, key informants noted both current and long-standing trends in the funeral industry. Current trends included the funeral industry being "digitized" which means funeral directors do not have as much interaction with families as they did before, and some use pre-developed electronic worksheets from vendors to fill out arrangement information. The funeral industry is also being staffed by a younger workforce than in previous generations. Funeral directors mentioned the possible influence these factors have over daily practices.

Many stated that a long-time key to their work was maintaining a good rapport – that this helps maintain their business in addition to serving the family. Key informants said that religion and race "*still play a large part*" in how families conceptualize the role of the funeral director, and which home they choose. One respondent noted that "*white funeral homes*" (i.e., funeral homes that primarily bury Caucasian individuals) may skip over any questions about race or Tribal affiliation all together, with the assumption that their business was separate. Multiple respondents noted that the opposite – competency in serving culturally diverse clientele – is good for business. They mentioned that familiarity with their clients' cultures may help with both planning a quality funeral, paying for services (such as through burial assistance provided by tribes) and possibly even accurately completing demographic information. Interviewees indicated that some senior-career funeral directors do not ask about race information because they do not want to offend family members and next of kin. This may have to do with protecting relations in an industry that is highly dependent on relationships.

Hispanic.

Throughout the interviews, references to the term "Hispanic" often related to family member confusion about why they would be classified as both Hispanic and White or why they were being asked about being Hispanic in the first place. Funeral directors said that this was difficult to explain to families and that they did not have consistent information from state agencies and/or training on how to best talk to families about race versus origin. The OMB/Census standard of separating Hispanic ethnicity from race can be confusing for both funeral directors and families, as in one recent case that resulted in a call to the health department.

> *I had to make a phone call because this family specifically said that they were Hispanic, and I left the ethnic side of the ethnic parts blank because—I mean, if you're Hispanic—is a Black person White? No. Is an Hispanic person White? Probably not… I don't know. I always cringe when I place "White," when I know they're giving me specifics…. I didn't mark anything until the system kicks back, so then you have to mark something on the race.*
> *So I didn't know what to do because the family didn't want the specific individual identified as White, so I called the Health Department themselves and they said, "Maybe you have to identify them as White. That's your fall back is White. You have to at least give them the White race."*
> *Well, not everybody's white.*
> *She said, "Yeah, I understand that."*
> *I said, "The person we're talking about isn't white."*

And she said, "What would you put it under?"
I said, "I don't know. They said not specifically White."
So that was the problem that I had, so I ended up having to put down or generate a box that said "Refused." And the system finally took it, but just the fact that I had to—I don't know. It kind of bugs me a little bit because everything seems to be so black and white, and on electronic forms that you have no mobility as far as putting down. I'd rather put down "Family has requested not to," which is essentially what I guess happened by allowing us to say they refused them."

When it is not a source of confusion, collecting "Hispanic origin" can be a cause for concern. Funeral directors noted that they record what families want listed on death certificates, but expressed concern that death certificates might not have accurate race and origin data because people do not want to answer that question because of social context that targets immigrants.

"[I ask] "are you Hispanic or of any Hispanic background?" and they laugh and they say, "Well, even if we did we wouldn't tell you," you know, because of everything going on. Then they stop and say, "Well, why do you need that anyway?" And, you know, I don't know how to answer it.
I just say, "Look, it's a question that they ask for demographic reasons for the death certificate, so I don't know how to answer you other than that so if you don't feel comfortable telling me, I'm not going to ask it again."

Tribes.

Interviewees were fairly knowledgeable about Tribes, Tribal affiliations, and/or Native American peoples. However, interviewees who agreed to participate were generally native themselves, lived in an area with a high concentration of AI/AN people, or were generally aware and supportive of the goals of project. One urban funeral director noted that even though "w*e don't have a lot of tribes where I live right now. In the past I have asked [families] to bring in their Tribal I.D. card because I know sometimes that will have the percentage or information on that card"* This does not seem common practice however, as key informants reported not being trained about Tribal affiliation terminology, and reported that their professional peers were often not as well versed in this information. This funeral director noted that she was aware because "*… my mother has a Tribal I.D. card, my uncle does, my grandpa does. I'm a little bit more aware and familiar with that because my family also is, but I don't know necessarily if other people are."*

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One funeral director said it was important to gather information on Tribal affiliation to link the decedent's family to resources from specific tribes. As he put it, "*if somebody would say "Native American", that's one of the first questions I'm going to ask them, even in {my state} where [the death certificate] doesn't specifically ask for that. I'd want to know."* This individual, who was of Native American ancestry, reported contacting specific tribes to identify resources but admitted not knowing information about every tribe which limits their ability to make these contacts. Other funeral directors agreed that having more information about how to contact tribes to ask about burial assistance or other issues would be helpful.

Rural/Urban.

One interviewee believed that funeral directors in urban areas do not often work with Native people because there are no Tribes nearby. They also said it was difficult to classify race, Hispanic origin, and Tribal affiliation because of the diversity in urban areas. Another pointed out that some states do not ask about Tribal affiliation on the death certificate regardless of whether there is an American Indian and Alaska Native population in the state.

Training.

Although each key informant received on-the-job training and formal education about filling out death certificates, every interviewee reported that formal training has never specifically covered how to discuss or collect race, Hispanic origin, and tribal affiliation information. Instead, funeral directors have learned about completing demographic information for death certificates through on-the-job learning and mentorship. Interviewees generally noted that their own understanding on the purpose of collecting these items has changed over time, whether due to personal interests in ancestry or due to changes in their own social awareness of race and culture. Some wished that they had better education on culture or anthropology. Though each informant understood the need for state statistics, none had been formally educated on the purpose or use of this data. Instead, interviewees generally relied on on-the-job experience to learn about the use of death certificates for data (and how to communicate this purpose to family members).

Some noted that trainees or they themselves became more comfortable with asking these questions further into their career, although some also noted that some colleagues remain uninterested in changing their procedures. During the interviews, participants stated that there are no resources (e.g., definitions of "Tribal" affiliation, state agency points of contact, websites) that provide consistent information on how to fill out this

information, or knowing who they can reach out to when they have questions while serving families.

Policy.

Across key informant interviews, participants said that they often highlight the state-required elements of the death certificate to explain to families why they should provide information about a decedent's race, Hispanic origin, or Tribal affiliation. Key informants recommended that state agencies requiring these fields provide more training and consistent information about what each field means and how to explain the field to families of decedents. Some interviewees indicated that Tribal affiliation is not a specific element on their state's death certificate, which means they do not always ask about it unless the family references something about Tribal affiliation or being Native American.

Barriers and Facilitators.

Barriers and facilitators to identifying race, Hispanic origin, and Tribal affiliation of a decedent include those presented in the text above and summarized in Table 8.

TABLE 8. BARRIERS AND FACILITATORS TO AI/AN CLASSIFICATION SUGGESTED BY FUNERAL DIRECTORS IN INTERVIEWS

Facilitators

- Having death certificates that allow for multiple race classifications.
- Establishing rapport with families to facilitate discussion about race and other required fields on death certificates.
- Being transparent with families about why demographic information is being collected.
- Not using medical history or other forms as only method of race identification.
- Using worksheets to familiarize family members with race questions that will be asked by the funeral director when they meet with him/her.
- Asking verbal questions to identify and/or verify race, Hispanic origin, and Tribal affiliation.
- Asking for Tribal identification cards to help link family members and next of kin to appropriate resources.
- Having family members proofread death certificates prior to submission.

Barriers

- A body being unrecognizable/unclaimed so race cannot be determined.
- No formal, separate training for funeral directors about collecting demographic information on for the death certificate.
- Using a worksheet or observation and no verbal questions to fill out information about a decedent's race, Hispanic origin, or Tribal affiliation on a death certificate.
- Diversity in urban areas making it difficult to accurately classify race, Hispanic origin, and Tribal affiliation.
- Lack of community awareness about why race information is on death certificate.
- Family member hesitancy to report race, Hispanic origin, or Tribal affiliation due to concerns about how the information will be used.
- Identifying a decedent how the family wants them to be identified despite information suggesting the person is of a different race, Hispanic origin, or Tribal affiliation (e.g., families not wanting to be listed as both Hispanic and White).
- Not asking about race at funeral homes that are primarily for "White people."
- Funeral directors and family member unfamiliarity with all federally recognized tribes or the definition of Tribal affiliation.
- Having no field for Tribal affiliation on the state death certificate.
- Not knowing about urban American Indian and Alaska Native populations.

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Part IV. Discussion

Strengths and Limitations of NCUIH's Approach

On the whole, the results of this project present novel insights, yet with certain limitations. These limitations – primarily due to the survey sample and limited perspectives that were collected – will be included wherever relevant throughout this discussion.

Although the online survey was not conducted as a representative sample of the industry and includes some states more than others, in some respects the demographics of this sample mirror the national profile of Morticians, undertakers, and funeral directors as captured by the 2018 American Community Survey. The percent makeup of gender and average age are similar to ACS estimates for the industry as a whole.[41] American Indian and Alaska Natives represent a higher proportion of NCUIH's sample than the overall professional population, and other races were generally undercounted. Likely, this can be accounted for by response bias due to the nature of the survey and sampling outreach methods through large professional organizations. Lastly, the business types are substantially different between the sample and the industry at large, with over twice the representation of funeral homes that are "part of a corporation, large business, or conglomerate" in NCUIH's sample than the proportion of publicly-traded funeral homes in the US.[42] However, some of this variation may be accounted for by differences in wording of demographic items between the online survey and the ACS.

Instead of interpreting this information as generalizable to all US funeral directors, this sample can instead comment on the relation between common experiences and practices that likely occur throughout the country. While only a segment of professionals were sampled – this segment is likely more aware of racial misclassification than the industry as a whole, due to recruitment methods through social networks and self-selection based on interest. As such, participants may be particularly culturally aware, technologically-adept, trained enough to understand and comment on these professional responsibilities, and open to industry change.

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[41] Funeral directors nationally are 73% male compared to 68% of NCUIH's sample, 81.1% White compared to 90.1% of NCUIH's sample, and of an average age between 45-54 (which is the most common response range NCUIH's sample). See "Morticians, Undertakers, & Funeral Directors." Data USA. Accessed February 18, 2021. https://datausa.io/profile/soc/morticians-undertakers-funeral-directors.

[42] "News." National Funeral Directors Association (NFDA). Accessed February 18, 2021. https://nfda.org/news/statistics.

Similarly, while key informant interviews were not exhaustive, those that participated were able to comment on policies and practices, providing some interpretation and context for the survey results. Each interview was conducted with a funeral director from a different state, and included urban, rural, eastern, and western settings.

Tellingly, few interviewees or survey respondents expressed strong discomfort or resistance to discussing race, Hispanic origin, and tribal affiliation. However, many commented that this may be factor in the profession at large.

Combined, the survey results, interviews, listening sessions, and informal conversations coalesce into a few main points that can be used to inform future work on this topic. These discussion points are listed below, followed by a final list of recommendations based on this work.

Varying Practices in the Field

A few basic points emerge from these survey and interview results. First, there is clearly no standard method that all funeral directors use when collecting race, Hispanic origin, and tribal affiliation for the purposes of death registration. Second, there is also not a uniform level of training or continuing education available on this topic. These realities have clearly created some level of confusion at times, as demonstrated by results that could occasionally seem contradictory. For instance, different survey respondents within the same state disagreed as to whether Tribal affiliation was available to report on the state form. Some survey respondents said that they leave tribal affiliation blank because is not an option or it is not required, although NCUIH later verified that these perceptions were not true. Some respondents forwarded company intake forms that did not have a clear space for "tribal affiliation" despite it being available on the state certificate. Other company forms do not easily allow for multiple races to be added, even when the electronic state system allows this. It is possible that practice of "copying" from one form to the electronic submission limits accuracy to the least culturally-competent set of options – for both AIAN and multiple race decedents.

Third, it is worth noting that some methods for collecting race are used in combination, while some methods are used to the exclusion of others. In this sample at least, there seemed to be different groups of funeral directors with different preferences. In particular, those who ask about race verbally do not use observation or working knowledge of the family. Those who observe families do not ask them questions. Those who use forms or medical history may use them to a variety of purposes in combination with other approaches.

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Fourth, the choice of method may have some relation to comfort and ease of completion, whether on the part of the funeral director or the family. Many survey respondents and interviewees reported fielding questions, concerns, discomfort, or confusion from families, and some interviewees questioned whether their colleagues remain avoidant or uncomfortable. On the survey, older and more experienced professionals were less likely to be comfortable asking these questions. Lastly, interviewees were able to emphasize that asking the family about race directly is often helpful, though complex. This is rooted in a complicated history.

Funeral Directors as Untrained Census Collectors

Changes in how indigenous people are defined and counted by public health statistics have always been tied to the Census, as well as the underlying politics that require the US government to count people.[43] Recent census practices are marked by two historical trends 1) racial categories that were once assigned and imposed by federal agents without choice and 2) a post-1960 shift towards freer choice and self-identification across modified versions of these categories.[44] During death registration, funeral directors are asked to act as proxy data collecting agent for the state, yet often without a full awareness of how their clients understand these categories within this context.

Many stories that NCUIH collected show how classification occurs messily within this system. One AI/AN funeral director described of how things have changed – and not changed – since one of the earliest cases he observed while training in the early 1980s. The funeral director was interviewing a man about his wife's race. Both man and wife were eligible for tribal membership, but had chosen not to enroll. The funeral director said:

> *"'Mr. Woods, your wife was black?"*
> *And the husband says, 'No. We never went for that.'*
> *The director says, 'Well, what nationality is your wife?'*
> *The husband says, 'Well, what are my choices?' … At the time, we have white.*
> *He said, 'No, we never could pass for white. You said black. We're not black.'*
> *And the funeral director says, 'Well, we could check 'other.''*
> *The husband says, 'Well, check 'other' and put 'colored.''"*

[43] Krieger, Nancy. "The US Census and the People's Health: Public Health Engagement From Enslavement and 'Indians Not Taxed' to Census Tracts and Health Equity." *American Journal of Public Health* 109, no. 8 (August 2AD): 1092–1100. https://doi.org/10.2105/AJPH.2019.305017.

[44] Ibid.

Although now processing these forms himself, the funeral director noted that "*That's the situation you have in this area, and I still see it a lot*". In his own practice, he tries to ground his approach in self-identification – he always verifies racial information he didn't personally collect and talks to the family directly about the decedent. However, the family always stands in as a proxy for the decedent, which can add the complexity of family dynamics.

Another native funeral director brought up the dual nature of the death certificate as a legal document, and a desire to ensure that the document is accurate to respect the family. When asked what they would do if tribal affiliation were left blank, the director noted a situation where the family would say:

> *"our dad is Native American, we don't know what tribe", I would say, "Okay, well, to your knowledge, in this situation we might have to make our best guess, but then again I do want to record it accurately." So, I'm not sure. I could ask the family is there proof or anything out there that you have? If there's not, I would say maybe we just might have to check another box because we don't actually have proof that this person is, or a CIB, a Certificate of Indian Blood or a tribal card or anything like that, so I'm not sure."*

In this quote, the idea of "proof" of race – a construct that is intended to be self-identified – is floated, a scenario unique to AI/AN race in comparison to any other categorization. In these situations, the search for "accuracy" itself can be become a floating target through conversation between data source and data collector. Prior research on the Census has shown that when recording AI/AN race and tribal affiliation, the alignment of definitions between the data collector and citizen are particularly important in deciding who ends up "counted" as part of the

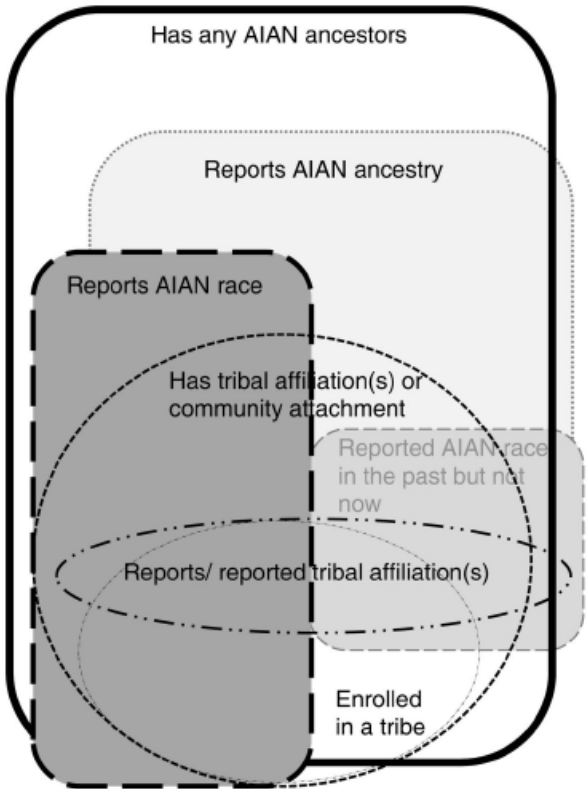

FIGURE 11. FROM LIEBER 2018

group.[45] Due to the definition of AI/AN race and the option to add tribal affiliation, these choices create partially overlapping groups with distinct characteristics and population sizes (see Figure 12). [46]

And while the population is the same between the Census and death registration, these methods of these systems differ. Census protocols are designed with rigid protocols to ask questions of specific family members within a household, and its focused in-person components are conducted by professionals trained in data collection and cultural awareness. Death registration, however, is necessarily conducted with whichever informant is best suited to provide this information during a time of extreme grief and stress. As one survey respondent wrote in a suggestion box "*Our experience has been that the families can not define where they fit, so how are we to get it correct? I mostly feel like I am making a good guess. I do not think it should be the responsibility of the funeral home to collect this information. If it is important to be correct then contact information could be collected by the funeral home and then contact should be made by a trained person*."

Deathcare professionals *are* highly trained, but generally not in the social sciences or data collection. Three out of four (75%) of survey respondents reported fielding questions when they ask about race, ethnicity, and tribal affiliation, and 13% reported their own discomfort. When navigating these conversations, they instead draw on the tools of their profession to empathize with their clients. One funeral director noted that when he asks these questions *"…a lot can be read into nonverbal communication in the way they adjust themselves in their seats, if they no longer look at you, if they look down…"* Some reported worksheets and forms were seen as less personal, for better or worse. One funeral director said that this allows people to complete this "*a little time to do it at their own pace"*, because *"when they're sitting in an arrangement face-to-face with you, they feel a little pressured to answer everything right away and not necessarily correctly".* Others point out that it can be used as a tool to avoid uncomfortable discussions of identity, however, and emphasized the importance of in-person, item-by-item verification:

> *"I always, always ask. Someone could be Caucasian. I know they're Caucasian. I'm sitting here with them. I'll say your loved one's race is white. Their race is white. I go over the nationality. … I don't know if everybody does that or not. I couldn't tell you."*

[45] Lieber 2018.
[46] Ibid.

In all likelihood, there are simply a large number of funeral directors who never have these conversations at all. When asked why tribal affiliation is left blank, some survey respondents noted that it goes unasked or that "sometimes I don't want to ask that". Funeral directors from 4 states – states that contain both Tribes and large urban populations of AI/AN people – mentioned that the state form didn't have a space for Tribal affiliation. However, responses within a state varied on whether this was the case, and NCUIH verified that at least 2 of these states have adopted the standard form and do provide a space to enter this information. Rather, some funeral directors remain unaware that this information can be captured, or possibly use intake worksheets without this option before copying to the official form. This lack of cultural competency makes the conversations that are required to record data around race less likely to occur in the first place.

Some interview participants noted that asking about race is not just beneficial for public health data, but can be helpful for the funeral home and individual clients as well. Some key informants thought it was part of their job to learn as much about the decedent as possible to assist with funeral arrangements, comforting the family, and helping them find ways to finance the services. They noted that race, Hispanic origin, and Tribal affiliation may come up naturally while discussing culturally-appropriate arrangements, which improves customer service and makes the "choosing" of racial categories seem like a less jarring transition once it comes to completing the death certificate. They noted that culturally-competent practices such as knowing about tribal affiliations can be good for business. If an informant discloses tribal affiliation, sometimes a funeral director can assist the family to make use of burial assistance funds that they were not aware existed - sentiments echoed by tribal leaders and state vital records officials. This ensures that appropriate arrangements can be paid for, while lowering the financial burden on the family. Lastly, a rural interviewee mentioned that while the industry that can be segregated by religion and race, funeral homes in his region have a competitive advantage in the market when they serve multiple racial minority groups. She said they also provide better training on working with families.

Opportunities for Culturally Competent Training Materials

In summary, NCUIH's analysis shows that policies and practices are inconsistent, likely linked to misclassification, and yet funeral directors remain largely untrained on demographic data collection. However, this indicates a set of clear opportunities.

NCUIH spoke to many positive, engaged, and deeply experienced funeral directors during this project, each committed to protecting public health and serving families in a

time of grief. A number are already working to ensure they collect accurate AI/AN racial data that respects a decedents wishes, and funeral director associations and boards are committed to a high standard of quality improvement in field. All the pieces are in place to highlight quality practices, create and disseminate trainings centered on the realities of field practice, and then require that these trainings are part of standard education or licensing. It is important that trainings cover how to handle discomfort asking about race, ethnicity, and tribal affiliation, and promote an ability to productively respond to family member questions and concerns.

Additional tools or resources to complement these trainings may be beneficial. Some funeral directors mentioned that they would benefit from more information about tribes, both general information about tribes in their region (which could be incorporated into trainings) but also how to contact tribes should they have questions about burial assistance. Such items could be covered in a brief resource guide, fact sheet, or contact list – and may serve as a reminder that AI/AN people live in their city.

Apart from funeral director factors, it seems that community members themselves might benefit from more awareness of funeral planning, data collection, and death registration. One funeral director mentioned that mistakes can be expensive to fix, but it's unclear if a family would ever notice misclassification has occurred given that the certified copy that the family receives may not report race in all states. Families may also be more prepared for the process if they receive culturally competent guidance on planning funeral services in advance of a death. Planning for funerals prior to death is an increasingly popular approach – guides on this topic can give people the comfort of knowing that their family will not be over-burdened with unexpected logistics and costs after their passing. Although not expressly about data or death registration, funeral planning guides may help a person identify tribal or veteran's services when they exist, plan culturally competent services, and may have a tangential benefit of discussing identity and culture early and directly during the planning process.

Lastly, AI/AN funeral directors exist, AI/AN statisticians exist, and AI/AN medical professionals exist. Many are aware of best practices that should be followed, policies that need to be revised or implemented, and can effectively communicate with their colleagues in a shared professional language. Centering these professionals and their experiences in trainings and resource development will pay dividends.

Part V. Summary of Recommendations

Below is a list of NCUIH's recommendations for different audiences, based on the findings in this report.

Recommendations for Funeral Directors

- **Remember that any family you serve could have members who identify as AI/AN**, regardless of their appearance, other things you already know about them, and whether you are in an urban area or near a reservation.
- **Always verbally ask about race, Hispanic origin, and tribal affiliation.** When you ask:
    - Have definitions of race and ethnicity categories handy.
    - Prepare satisfying answers to common questions such as "why do you need to know this?" ahead of time.
    - Prepare for occasional discomfort by family members. This question might reignite old tensions for some families at first, bring up distrust of government (or you for asking), or simply be confusing. But that doesn't mean this discussion will necessarily interrupt your rapport, won't be productive, or can be avoided.
    - Learn how to manage your own discomfort. Remember, learning more about the family can be an opportunity to ultimately build rapport.
    - Pay attention to non-verbal communication like body language. It might feel like paperwork, but some people feel "investigated" in an interview. Funeral directors often are a source of compassion to guide people through a difficult time, and can apply these skills when asking about race too.
- **Collect racial information yourself,** and do not copy from other professionals whenever possible.
- **Avoid copying identification from Hospital or medical records, face sheets, transport documents** as much as possible. They can be less accurate.
- If you do use worksheets to collect race, Hispanic origin, and Tribal affiliation:
    - **Use standard forms from your state**, when possible.
    - If you cannot use a state template, **make sure demographics section matches the choices on the standard death certificate, and match the wording of these categories.**
    - **Ensure your worksheets and forms allow for multiple races, ethnicities, and tribal affiliations to be entered.**

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    - **Verify the worksheet item-by-item with the family after you collect it**, preferably as you enter the electronic death registration.
- If you do work with members of a specific tribe repeatedly, **proactively familiarize yourself with customs or benefits they may offer after death**.
- **Learn how to contact tribes or Bureau of Indian Affairs for burial assistance.**
- **Do not require families to "prove" race or ethnicity**. Tribal IDs are useful legal identification, and documentation of ancestry may help you get the details right about what a family wants to put on a death certificate. They may indicate that someone is likely to self-identify as AI/AN, but they are not "proof of AI/AN race".
- **Complete continuing education trainings that include death certification procedures and cultural competency.** This will increase your comfort asking about race, communication about the process, and familiarity with different cultural norms and resources available to tribal members.

Recommendations for Business Associations

- **Provide and promote trainings that** cover how to effectively collect race, Hispanic origin, and tribal affiliation data during death registration.
- **Provide continuing education credit for** trainings on demographic data collection. Whenever possible, trainings should:
    - **Include cultural competency**
    - **Center the experiences of AI/AN funeral directors and community members**
    - **Incorporate the experiences of older, more experienced funeral directors** who have learned to manage discomfort on this topic
    - **Follow peer-to-peer and mentorship models,** whenever possible
- **Ensure that any forms or worksheets you provide for funeral directors to use match the Standard Death Certificate and are culturally competent**, as described in the section on "recommendations for funeral directors" above.

Recommendations for Government, State Boards, Health Departments, and other Policy Stakeholders

- **Fund trainings and the creation of materials such as those described in the previous two recommendations sections.** Continually promote and disseminate trainings and materials.
- **Require Continuing Education Credit (CEC) for licensing renewal**, at all levels of experience.

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- **Require that CECs cover demographic data collection and cultural competency.**
- **Train Funeral Directors on how to use Funeral Directors' Handbook on Death Registration and Fetal Death Reporting**, and provide accompanying materials.
- Center AI/AN funeral directors, statisticians, and other professionals whenever implementing trainings or strategies to improve racial misclassification.
- **Print race on the family copy of death certificates, and allow free corrections to death registration when the family identifies an error** on race, ethnicity, or tribal affiliation.
- **Invest in raising community awareness** of funeral planning, preplanning, and the purpose and effects of vital records data.

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924 PENNSYLVANIA AVENUE SE
WASHINGTON, DC 20003