SIDEBAR

Impact of Racial Misclassification of Health Data on American Indians in North Carolina

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North Carolina is home to eight state-recognized tribes including the Coharie, Haliwa-Saponi, Lumbee, Meherrin, Occaneechi Band of the Saponi Nation, Sappony, Waccamaw-Siouan, and the Eastern Band of Cherokee Indians, who are also federally recognized. All eight state-recognized tribes hold a membership on the North Carolina Commission of Indian Affairs, per NCGS 143B-(404–411) [1]. According to the 2020 US Census, there are an estimated 130,032 American Indians living in North Carolina, and approximately 318,279 when considering American Indians in combination with other races [2].

Despite this large population, data on the health of North Carolina's American Indians are significantly lacking, due in part to race misclassification. We know that health status assessments for racial/ethnic groups are often hindered by the lack of complete and accurate data on race/ethnicity in state surveillance and data systems [3]. For example, the race of American Indian children is commonly incorrectly recorded on the child's birth certificate. Parents faced with this situation find themselves angry and frustrated when they learn that this has happened to their child. Correcting this issue is costly on multiple levels: financially, logistically, and mentally. An amended birth certificate raises questions later on as to why it was amended in the first place. The best practice is for American Indians and other citizens to receive an original, non-amended birth certificate at birth. This happens on death certificates as well; the race of the deceased is often recorded by coroners, funeral directors, or medical examiners based on appearance rather than confirmation by family. This practice results in the misclassification of the deceased person's race, which is ultimately reported to state vital records and is expensive to correct.

In order to fully understand the impact of racial misclassification, it is important to note current health disparities and the health services available within American Indian communities. American Indians and Alaska Natives are reported to be at higher risk for adverse health conditions and experience higher rates of mortality than the general population for most health conditions. According to the US Department of Health and Human Services (USDHHS), American Indians and Alaska Natives have long experienced lower health status when compared to other Americans, and this can be attributed to issues such as poverty and discrimination in the delivery of health services [4]. American Indians and Alaska Natives born today have a life expectancy that is 5.5 years less than that of the broader US population, according to a disparity report by the Indian Health Service [4]. Misclassification may contribute to this through underestimation of factors such as cancer rates in the American Indian population [5].

The Indian Health Service (IHS), an agency within the USDHHS, is responsible for providing health services to federally recognized American Indians and Alaska Natives. The IHS is the principal health care provider for federally recognized Indians. The IHS provides a comprehensive health service delivery system for approximately 2.6 million federally recognized American Indians and Alaska Natives, covering 573 federally recognized tribes [3]. However, the IHS does not provide health services for the millions of American Indians who are not federally recognized and who live throughout the United States in off-reservation communities, including most American Indians in North Carolina. State-recognized tribes are authorized under state statutes and federally recognized tribes are authorized through federal statutes governed by the US Department of Interior, Bureau of Indian Affairs. State-recognized tribes must rely on private, state, and local health systems for health care and treatment. There are 63 state-recognized tribes in the United States and

none are eligible to receive federal Indian Health Services [6]. Even federally recognized Indian tribes that are eligible to receive IHS services can only do so if they have access to an IHS clinic or a tribal hospital. The only IHS or tribal hospital in North Carolina is the Cherokee Indian Hospital in Cherokee, North Carolina. The next-closest IHS or tribal health facility is the Catawba Nation facility in South Carolina. State-recognized Indian tribes are not eligible to receive assistance at these federal facilities.

In North Carolina, accessing health services requires many American Indians to understand unfamiliar policies and practices. North Carolina service reviews typically do not include a review of data and reporting specifically on American Indian communities, due to population size. Thus, the North Carolina Department of Health and Human Services (NCDHHS) should develop best practice strategies that will result in effective mental, clinical, and oral health services for American Indians. The IHS facilities provide extremely good health care service and are quite adept at collecting accurate data on federally recognized American Indian patients. For example, IHS uses the Clinical Reporting System (CRS) to collect and report clinical performance results annually to USDHHS and to Congress [7]. The case is not the same for American Indians who receive health care at local, state, and regional public and private hospitals. Data on race collected at non-IHS hospitals are often inaccurate due to misclassification. American Indians are frequently coded as another race and that data is often reported to the Centers for Disease Control and Prevention and other health agencies. Therefore, the North Carolina Commission of Indian Affairs and North Carolina's state-recognized tribes have no way to determine the true number of American Indians who suffer from a variety of health issues such as diabetes, stroke, cardiovascular disease, COVID-19, and Alzheimer's disease.

In summary, there have been improvements in data collection in recent years by health care agencies, NCDHHS, and hospitals, particularly when collecting COVID-19 data. Other improvements include the incorporation of racial/ethnic identity codes for American Indians and Alaska Natives as well as proactively asking patients their race during hospital visits. However, improvements are still needed to ensure that accurate Indian health data is collected for American Indians in North Carolina.

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