A 2017 report funded by the National Cancer Institute (NCI) painted a grim picture of early deaths among American Indians. The analysis, published in *The Lancet*, found that while premature mortality rates decreased in blacks, Hispanics, and Asians and Pacific Islanders between 1999 and 2014, the rates increased among American Indians and Alaska Natives (AI/ANs) and whites during the same time period. Between 2011 and 2014, AI/ANs had the highest premature mortality rates in the United States, driven mainly by accidental deaths—primarily drug overdoses—chronic liver disease and cirrhosis, and suicide.

The largest reported mortality increases were in young people. Among 25-year-old AI/ANs, mortality increased 2.7% annually for men and 5% annually for women between 1999 and 2014.

"Increases in premature mortality of this magnitude have rarely been observed in the US," NCI investigator Meredith S. Shiels, PhD, told *JAMA*.

But experts say the real picture could be even worse for the 5.2 million people in the United States who identify as AI/AN. Their deaths are notoriously underreported due to racial misclassification on death certificates. An astounding 40% of AI/ANs who die are listed as a different race—usually white—on their death certificates by funeral home directors, according to a 2016 report from the Centers for Disease Control and Prevention (CDC).

Shiels and her coauthors estimated AI/AN mortality based on death certificates from Indian Health Service (IHS) regions known as Contract Health Services Delivery Areas (CHSDAs), where racial misclassification tends to be lower. But even here, around 20% of AI/ANs are still misclassified as other races on their death certificates. By comparison, only 3% of Hispanics and Asians and Pacific Islanders and almost no whites or blacks are racially misclassified on death certificates, according to the CDC.

"What this basically translates to is an underestimation of mortality for the American Indian population," said Elizabeth Arias, PhD, director of the US Life Table Program at the CDC's National Center for Health Statistics (NCHS).

Public health experts say a more accurate reckoning of AI/AN deaths and their causes could help policy makers, health care practitioners, and native communities target drivers of excess mortality.

"[If we] have reliable data, we really can begin to attack these problems from a prevention perspective," said Allison Barlow, PhD, director of the Johns Hopkins Center for American Indian Health.

### Trouble With the Data

There is a way to get a more complete picture of AI/AN deaths. Linking death certificate data to IHS registration records reduces racial misclassification, especially when analyses are also limited to CHSDA counties.

In 2014, in a landmark supplemental issue of the *American Journal of Public Health* (*AJPH*) devoted to AI/AN mortality, researchers at the CDC, the IHS, and the New Mexico Department of Health demonstrated that linking these 2 data sources increased the reported all-cause death rate of American Indians in CHSDA counties by 17.3%. The linked data were used to create an AI/AN mortality database (AMD), which...
Currently spans 1990 through 2009 and is maintained by the CDC Division of Cancer Prevention and Control. The method, though an improvement, has its limitations. American Indians who weren’t registered with IHS and were racially misclassified on their death certificates aren’t included in the database. And restricting to CHSDA counties limits the data pool, excluding about 35% of the American Indian population. Urban American Indians are likely underrepresented in the AMD.

“It’s the price that we pay for trying to get more accurate information,” said David Espey, MD, a coauthor of the 2014 report and medical officer for tribal affairs at the CDC’s National Center for Chronic Disease Prevention and Health Promotion. “At least up to this point, it’s the most efficient and workable solution to addressing the problem of misclassification.”

Espey is working to update the AMD annually starting with 2010 records. Bringing the database into the present day and keeping it current will take money. The Division of Cancer Prevention and Control and the IHS Division of Epidemiology and Disease Prevention must pay the NCHS to link the National Death Index data to the IHS registration records, which cost almost $800,000 last time around.

Espey believes it’s well worth the expense. Tribes and tribal organizations frequently cite findings based on AMD data in grant applications, while funders like the CDC have developed grants addressing disparities described using the database. Shortly after the release of the AJPH supplement, for example, the CDC announced Good Health and Wellness in Indian Country, a chronic disease prevention program. The 5-year, $16 million-per-year program is the CDC’s largest ever single investment in Indian Country.

“Mortality data are a key tool for us to address health disparities,” Espey said. “[T]he longer [the data] recede into the past, the less useful they are for decision making and resource allocation.”

A Potent Stew

While the AI/AN data included in The Lancet report may be incomplete, experts say the health and mortality disparities these groups face are unmistakable.

Using the AMD, Arias reported that between 2007-2009, AI/ANs in CHSDA counties had a life expectancy at birth that was almost 10 years lower than Hispanics and about 7 years lower than non-Hispanic whites.

“Based on what we’ve seen using the best quality data that we’ve been able to produce, the mortality and health profile for that population is very poor in comparison to other groups in the US,” Arias said.

Some of the most startling disparities that emerged from analyses of the AMD data were for alcohol- and diabetes-related deaths, chronic liver disease deaths, infant and pediatric mortality, suicide, and unintentional injuries including drug overdoses.

Suicide strikes particularly early on reservations. “The demographics for suicide are extremely different in American Indian communities compared to other ethnic groups,” Barlow said. “The deaths really concentrate in [the] 15- to 25-year-old range and even up to 35-years-old, whereas in the general US population suicide is more often a significant issue in middle age and later age.” Between 1999 and 2014 suicides among AI/ANs increased 89% in women and 38% in men, according to the CDC.

Although alarming, these patterns aren’t surprising, Barlow said, considering the grinding poverty, poor schools, high rates of teen pregnancy, and almost nonexistent job opportunities that many young people on tribal lands face.

A study published in 2016 by researchers in the Maternal and Child Health Bureau of the US Department of Health and Human Services (IHS) found that AI/AN children up to 17 years old have significantly more adverse childhood experiences than their white counterparts, leading to more school problems, grade failures, and greater need for medication and counseling. Another study found that in 2009 to 2012, annual heroin and OxyContin use among American Indian adolescents living on or near reservations was 25% to 229% higher than the national averages.

Social determinants are a key driver of excess mortality in AI/ANs, often leading to behavioral health issues such as depression and substance use disorder, which frequently result in suicides and unintentional drug overdoses. Alcohol use disorder and intravenous drug use–associated hepatitis B and C are the leading causes of cirrhosis and liver cancer in the AI/AN community, contributing to many cases of chronic liver disease.

“When you add on to the traumas that have come to Native people individually and collectively and cumulatively over the years—trauma has its own sequelae for behavioral health, including depression, anxiety, posttraumatic stress disorder, and other kinds of issues—it’s a potent stew,” said Ann Bullock, MD, chief clinical consultant for family medicine and director of the division of diabetes treatment and prevention at the IHS.

Yet despite these challenges—and despite treaties between the US government and American Indian tribes that included the provision of health care in exchange for land—the IHS receives substantially fewer funds per capita compared with other federal health care programs, like the Centers for Medicare & Medicaid Services and the Veterans Health Administration. Per capita expenditure for IHS users is $3688 compared with $9523 for the total US population, according to a 2016 report.

Lack of access to care is one reason AI/ANs tend to die at younger ages from chronic diseases like diabetes, cancer, and heart disease than do members of other races, according to Donald Warne, MD,
chair of the Department of Public Health at North Dakota State University.

Mental health is particularly strained under the IHS system. "We don't have the numbers of providers that we need to address mental health conditions," Warne said, adding that the closest community mental health centers may be located hours away from reservations. The same is true for inpatient behavioral and mental health facilities, such as drug rehab centers, that are contracted by the IHS.

Community Outreach

Late in 2016, the HHS announced the first National Tribal Behavioral Health Agenda, a tribal-federal blueprint of strategies and priorities for improving the behavioral health of AI/ANs that will in part focus on healing from historical and intergenerational trauma.

Yet last summer, the HHS informed grantees of the national Teen Pregnancy Prevention Program that it would end funding after 3 years instead of 5 years. More than 80 grantees around the country—some of them serving AI/AN communities—learned of the cuts last July. Barlow is studying a teen pregnancy prevention intervention in the White Mountain Apache Tribe in Arizona. Calling the funding withdrawal a "gut punch," she said the decision "annihilates our ability to prove outcomes" of a promising program that could help break the cycle of poverty on reservations.

There are bright spots, though. Barlow is also working to help reduce suicides in the White Mountain Apache Tribe. She led a team that trained community members to follow up on every suicide attempt reported to a tribal surveillance system. "They go out and work with the families, provide education in the homes about mental health, and help connect those families to the care that they want to receive," she said. The intervention led to a 38% reduction in suicides in the tribe during a period when national rates were unchanged. Based on the success of the tribal-academic partnership, the National Institutes of Health has funded 3 research hubs in tribal or urban American Indian communities to reduce suicides in AI/AN youth.

Bullock said the IHS is implementing programs to support young parents, so they don't inadvertently transfer the traumas they've experienced to their children. She also pointed out that diabetes-related end-stage renal disease fell 54% among AI/ANs, from 57% in 1996 to 27% in 2013—a much larger decline than in any other racial group—thanks in part to a decades-long IHS effort to prevent and control diabetes and diagnose and closely monitor kidney disease.

"When we look at... the poverty, the despair, the unemployment, the trauma, the food insecurity, which creates not only health problems but mental health problems, ... you see a much different picture of people who are actually being resilient in the face of incredible struggle," she said.

Note: Source references are available through embedded hyperlinks in the article text online.