

## **Racial misclassification and disparities in mortality among American Indians/Alaska Natives and other races, Washington**

**Authors:** Jenine Dankovchik, BSc<sup>1</sup> (presenter); Megan Hoopes, MPH<sup>1</sup>; David L. Nordstrom, PhD<sup>2</sup>; Elizabeth Knaster, MPH<sup>3</sup>;

<sup>1</sup>Northwest Tribal EpiCenter, Northwest Portland Area Indian Health Board; 2121 SW Broadway Dr. Suite 300 Portland, OR 97201

<sup>2</sup>University of Wisconsin-Whitewater, Department of Occupational & Environmental Safety & Health, 800 West Main Street Whitewater, WI 53190-1790

<sup>3</sup>Urban Indian Health Institute, Seattle Indian Health Board, P.O. Box 3364 Seattle, WA 98114

**Correspondence:** Jenine Dankovchik, 503-416-3265; [jdankovchik@npaihb.org](mailto:jdankovchik@npaihb.org)

### **Background**

*(slides 3-6)* American Indians and Alaska Natives (AI/AN) are commonly reported to be at higher risk than the general population for numerous health conditions, and experience higher rates of mortality from many causes. While all-cause, age-adjusted death rates for both AI/AN and Whites declined for much of the 20<sup>th</sup> century, in the mid-1980s they began to increase for AI/ANs, and AI/ANs have a markedly lower life expectancy than the general population. Specifically deaths due to injuries, both intentional and unintentional, reveal major racial disparities which have led to a public health focus on Injury Prevention in Indian Country.

Health status assessment for racial/ethnic groups is often hindered by the lack of complete and accurate data on race/ethnicity in surveillance systems. Death certificate race data is often recorded by coroners, funeral directors or medical examiners based on the decedent's appearance or other information. There may be hesitation to ask the next-of-kin questions about the decedent's race, and if the question is asked, the proxy may not answer as the decedent would have. Errors may be compounded when systems interact; for example, cancer & other disease registries often rely on death records for demographic data. Because AI/ANs are commonly miscoded as another race, rather than other races being incorrectly coded as AI/AN, the net result of racial misclassification for AI/ANs is under-ascertainment of health events, and underestimates of population-based rates.

In response to this problem, the Northwest Tribal Epidemiology Center formed the Northwest Tribal Registry Project in 1999 to conduct record linkages with various public health datasets. This project evolved into the current iteration, IDEA-NW (Improving Data & Enhancing Access), with funding from the Agency for Healthcare Research and Quality, funded from 2010-2013. IDEA-NW's goals are to improve the validity and reliability of AI/AN race data in state data systems and increase the availability of accurate and complete health status data for Northwest tribal communities, to inform public health decision-making and efforts to eliminate health disparities.

Improving race data in state data systems is achieved through record linkages with a list of known AI/AN in the Northwest, which we call the “Northwest Tribal Registry”. Throughout the rest of the talk today I will refer to this list as “The Tribal Registry”. The Tribal Registry is generated from the registration data of all Indian Health Service and tribal clinics in the Northwest. It is a cumulative list beginning with patients registered in the mid-1980s, and it includes only demographic information (no health status or diagnostic information). Through partnerships with urban clinics such as the Seattle Indian Health Board/UIHI it has been augmented to better represent urban AI/AN.

## **Methods**

*(slides 8-9)* We conducted a linkage with Washington death certificates from 1980 to 2009, from the Center for Health Statistics, Washington State Department of Health. The death certificate file was linked with The Tribal Registry to identify individuals who appeared in both files. The linkage was conducted using LinkPlus software, which allows for probabilistic matching. Those interested in more details about the linkage process should feel free to ask me after the presentation. Since The Tribal Registry is a list of known AI/ANs, any records in the death certificate file which matched The Tribal Registry are considered to be AI/AN race, regardless of how their race was recorded on the death certificate.

For this study, analysis was restricted to deaths between 1990 and 2009. This time frame was chosen for the sake of consistent rates, as this is the period for which NCHS bridged race population estimates were available. Cause of death was defined based on the ICD-9 and ICD-10 codes found in the underlying cause of death field. AI/AN race was defined as any record which was coded as AI/AN on the death certificate and/or had a match in The Tribal Registry. White race (alone) was chosen as the comparison group, including Hispanic and non-Hispanic ethnicity. No other races were included in the analysis, as these two groups accounted for 95% of the deaths in Washington State. For the rates, NCHS bridged race estimates were used as the denominator. Rates are age-adjusted and presented per 100,000 population. Trends were analyzed using linear regression.

## **Results**

*(slides 11-12)* Between 1990 and 2009, there were 12,212 AI/AN deaths and 794,409 White deaths. These numbers reflect the correction for racial misclassification. Note that some AI/AN were coded as other races or missing race data on the death certificate which is why the two totals are not the same. During the linkage it was determined that 1,342 AI/AN deaths were misclassified as another race (usually White). The linkage with The Tribal Registry increased case ascertainment of AI/AN deaths by about 12%. Among records for which a race had been coded, 83% were classified correctly as AI/AN in the state data system.

*(slides 13-15)* Both AI/ANs and Whites shared the same top two causes of death through the two decades in this study (cardiovascular disease and cancer). However, these top two causes accounted for a larger proportion of deaths among Whites than AI/ANs. Unintentional injury was the third leading cause for AI/ANs, and accounted for a higher percentage of deaths than among Whites. Unintentional injuries stayed in the 3<sup>rd</sup> spot for AI/ANs in the latter decade, but dropped to the 5<sup>th</sup> spot for Whites.

Influenza & pneumonia and Alzheimer's were in the top five causes for Whites, but did not appear in the top five for AI/ANs, while chronic liver disease (in 1990-1999) and diabetes (in 2000-2009) were among the top five for AI/ANs but not Whites.

Throughout the twenty year period, all-cause mortality rates for AI/ANs were 1.4 times that of Whites. Unintentional injury and chronic liver disease were notable for even higher disparities (rate ratios of 2.3 and 4.3 respectively).

The disparity in life span was more marked in Washington than the US life expectancy numbers shown earlier; between 1990 and 2009, AI/ANs died on average about 16 years younger than Whites.

*(slides 17-20)* As mentioned earlier, Injury Prevention has become a main public health focus for Indian Country as a significant disparity exists and this is an area where prevention is truly possible, as opposed to other causes of mortality that are not always preventable. Thus we decided to focus our analysis on this area, and the rest of the results will be injury related.

The majority of injury deaths for both AI/ANs and Whites were unintentional, followed by suicides and homicides. Males had higher rates of unintentional mortality than females for both races, but AI/AN rates were higher (80.41 (95% CI 75.87 to 85.30)) than Whites (34.7 (95% CI 34.36 to 35.09)) for both men and women.

The majority of unintentional injury deaths among both racial groups were attributable to motor vehicle crashes (MVC) and accidental poisoning, although MVC accounted for about ten percent more deaths among AI/ANs than Whites. Whites had a much higher proportion of unintentional injury deaths due to falls than AI/ANs, possibly related to the disparity in age at death.

AI/ANs had higher rates of suicide (18.20 (95% CI, 16.31 to 20.42)) and homicide (11.09 (95% CI, 9.64 to 12.87)) than Whites (13.43 (95% CI 13.20 to 13.65)), (2.72 (95% CI 2.61 to 2.82)). AI/AN males bore the burden of intentional injury more heavily than females, most notably in suicides. It is worth noting that while other racial and ethnic minority groups experience higher rates of homicide but lower rates of suicide than Whites <http://www.doh.wa.gov/hws/IV2004.shtm>), AI/ANs in Washington had higher rates of both.

*(slides 22-26)* Linking with 20 years of death certificate data allowed us to present trends over a long period with race data corrected for misclassification. We investigated injury trends, looking specifically at the top two contributors for unintentional injury deaths: MVC and drug overdoses.

Unintentional injury mortality rates were consistently higher for AI/ANs than Whites during this time period, averaging over two times higher. AI/AN males and females both experienced similar trends, with male rates above females, but female AI/AN rates increased more rapidly. Overall, both AI/AN and White unintentional injury mortality rates increased significantly over the time period, with an annual percent change (APC) of 1.7% for AI/ANs and 1.4% for Whites.

Looking at the largest contributor to unintentional injury, we found that AI/AN rates of MVC deaths were, on average, about 3 times higher than Whites, and the disparity increased throughout the time

period as Whites experienced significant decreases in MVC mortality (APC=-2.66%) while AI/AN rates did not change significantly. This suggests that there may be some effective public health interventions in motor vehicle safety that have impacted the White population but have not yet made it to the AI/AN population. Suggestions we have heard from Tribal members for the difficulty in moving the needle on this measure include rural roads, distance from hospitals and time spent in the car. When these data were analyzed by age group we found the highest rates between ages 17 and 25. There were no notable differences between AI/AN and White children under 17.

The second largest contributor to unintentional injury deaths was accidental poisoning, in particular drug overdose. The trend showed that, since 1994, AI/AN rates were higher than Whites, and increasing more quickly. While both populations had a significant increase in drug overdose deaths over this time period, the APC for AI/ANs was 14.61%, compared to 10.73% for Whites.

Since 1999, prescription drugs<sup>\*</sup> have outpaced illicit drugs as the most common type of drug overdose. Whites and AI/ANs have both seen steep increases in prescription drug ODs, but AI/AN rates have increased at almost twice the pace (APC = 16.20% versus 8.69% for Whites). Most worrisome are deaths due to prescription opioid pain relievers<sup>†</sup>, from which AI/ANs have seen a 22% increase annually since 1999.

Intentional injury rates were also higher for AI/ANs when compared to Whites, with suicide rates on average 1.4 times higher and homicide rates on average 4.1 times higher. Whites experienced a small but significant decrease in suicides during the time period (APC=-0.47%) while AI/AN suicide rates did not change. Both racial groups experienced a significant decrease in homicide mortality rates, with AI/ANs dropping slightly more quickly (APC = -3.88%) than Whites (APC=-2.62%). Homicide mortality rates were higher for AI/AN men than AI/AN women, but were dropping more quickly (APC = -4.15%), so the gap between men and women was seen to be closing in recent years.

## **Discussion & Limitations**

*(slides 28-30)* Our assessment of death certificates in Washington state has highlighted several disparities between AI/ANs and the majority White population in the state: AI/ANs are dying younger, and are more likely to die from all causes, with a specific disparity seen in injury deaths. Some improvements in injury mortality that have been seen in the White population have not made it into the AI/AN population at this time (motor vehicle crashes), and other trends that are effecting both groups negatively are amplified for AI/ANs (drug overdoses).

The ability to link death certificates to The Tribal Registry allows for correction of racial misclassification, and more accurate mortality surveillance for AI/ANs in the Northwest. This work has built upon an existing partnership with the Washington State Department of Health and provided the State an accurate assessment of the level of AI/AN race misclassification on death certificates. It has also opened up the conversation about how these misclassifications impact epidemiological work in general and the information on which public health efforts in Indian Country rely in particular. It is our hope that this conversation will continue and lead to improvements in race data accuracy upstream, at the point of collection.

These data are also being provided to the Northwest Tribes in presentations and articles throughout the Northwest, and local-level reports will be generated allowing Tribes to better assess the health of their communities, plan public health programs and grant opportunities, and provide policy-makers with data on which to base their decisions.

Some of these efforts are already in place at NPAIHB, and are drawing on results from this study and others IDEA-NW has undertaken. For example, NPAIHB has an injury prevention program which has created an action plan specific to the needs identified here; Native CARS is another intervention being implemented by NPAIHB now, addressing child safety seat use in an effort to improve MVC mortality. Our THRIVE program is a suicide prevention program focusing on training community members and building protective factors among youth.

One of the main functions of IDEA-NW is to respond to requests from the Tribes, and findings from this study have already been requested for community outreach events, tribal health assessment reports and grant applications.

It should be noted that the Tribal Registry is not a complete list of all AI/AN in the Northwest. The Tribal Registry is derived from Indian Health Service and tribal health clinic registration, so it under-represents those who do not use these facilities. These are primarily patients with private insurance. While The Tribal Registry has been augmented with data from one large urban Indian health facility, it does not capture data from the other urban facilities in the area, so it also under-represents urban AI/ANs. As the IDEA-NW project moves forward, we are pursuing partnerships with the other urban facilities and with individual Tribes to increase the representativeness of The Tribal Registry. At this time we believe it captures 75-80% of the Northwest AI/AN population.

We also note that AI/AN rates presented are somewhat unstable due to the small numbers in the population.

A final but important limitation, particularly from the tribal perspective, is that death certificate data lacks context and doesn't always allow us to answer the "why" questions. For example, while we know that AI/ANs are not experiencing the same decreases in rates of death from motor vehicle crashes as Whites, we don't have an answer for tribal leaders wanting to know "why not?" or what successful interventions they should be implementing. As we move forward with the project we hope to work with other data sources such as the National Highway Traffic Safety Administration's fatality analysis reporting system to better answer these questions.

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\* Those with underlying COD X40--X44, X60--X64, X85, or Y10--Y14 and contributing COD T36--T39, T40.2--T40.4, T41--T43.5, and T43.7--T50.8 – note that this includes some OTC medications

† Those with underlying COD X40--X44, X60--X64, X85, or Y10--Y14 and contributing COD T40.2--T40.4

# Racial misclassification and disparities in mortality among American Indians/Alaska Natives and other races, Washington

Improving Data & Enhancing Access (IDEA-NW) Project

Jenine Dankovchik

[jdankovchik@npaihb.org](mailto:jdankovchik@npaihb.org)

503-416-3265

Megan Hoopes, MPH

David L. Nordstrom, PhD

Elizabeth Knaster, MPH



Northwest Portland Area  
Indian Health Board  
*Indian Leadership for Indian Health*

Presented at:  
2012 Annual CSTE conference  
Omaha, NE June 2012

# Background



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# Excess mortality among AI/ANs

- AI/AN life span 6 years below U.S. average
- After declining in 1900s, AI/AN death rates rose in mid-1980s
- Large racial disparities in injury deaths
- Injury prevention has become a public health priority area for Indian Country





# AI/AN race often misclassified on death certificates

- Race not often based on family's own report
- AI/ANs misclassified more frequently than other races/ethnicities
- Misclassification errors may follow a patient between data systems
- Net result: morbidity and mortality measures are *underestimated* for AI/AN



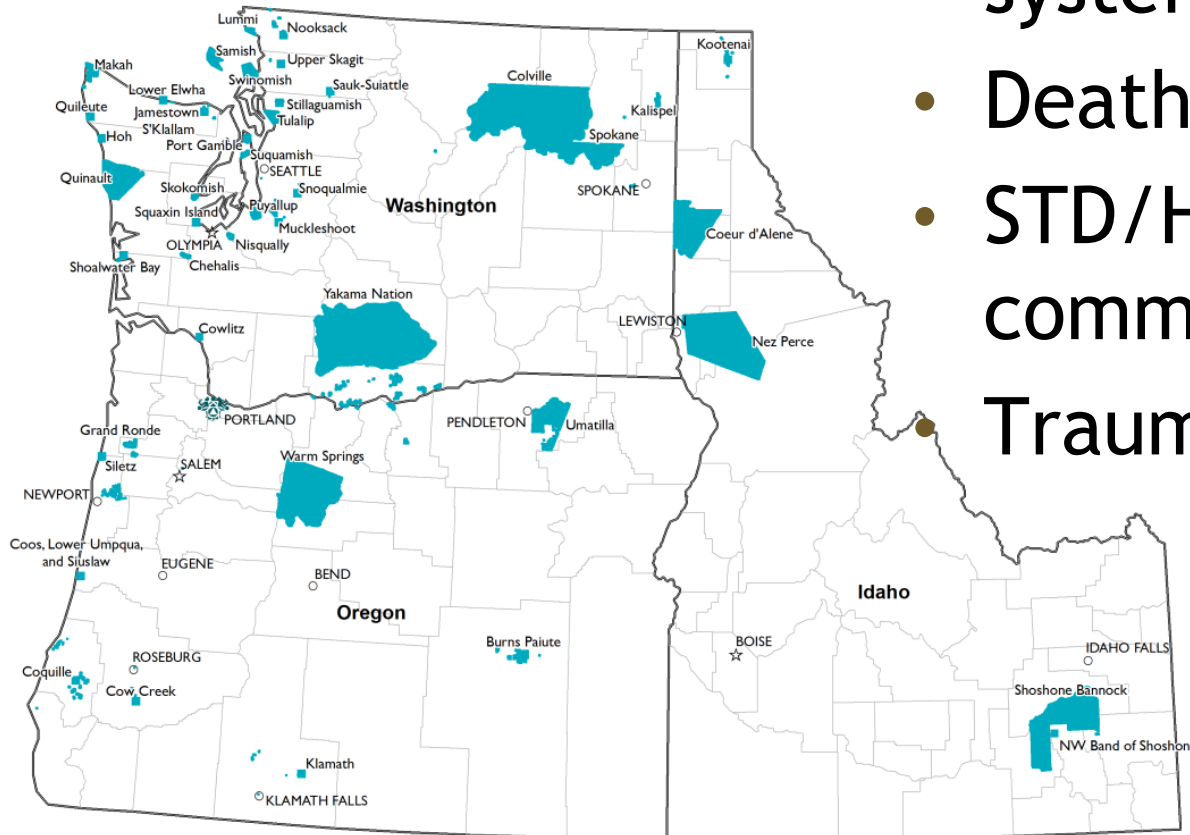
# IDEA-NW Project

- Improving Data & Enhancing Access (IDEA-NW)
  - Goal: Reduce misclassification of AI/AN race in surveillance systems; disseminate local-level health data to NW tribes.
  - Grant funded through AHRQ (2010 to 2013)
- **Northwest Tribal Registry (“The Tribal Registry”)**
  - All AI/AN registered at IHS or tribal clinic in the NW
  - Augmented with data from urban clinics
- Linkages conducted with public health datasets



# Linkages in the Northwest

- Cancer registries
- Hospital discharge systems
- Death certificates
- STD/HIV and other communicable diseases
- Trauma registries



# Methods



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# Data Sources

- Washington death certificates, 1990-2009
- Linked with The Tribal Registry (known AI/AN)
  - Using LinkPlus software, compared data sets to find individuals who appear in both
  - Names, birthdates, SSN, etc. are compared
  - Probabilistic linkage - allow for errors, misspellings, missing data, nick names, etc.
  - Each pair given a score indicating likelihood of a match
  - “Grey area” matches reviewed by hand



# Analysis

- Cause of Death defined using ICD-9/10 **only underlying COD**
- AI/AN in analysis = AI/AN on death certificate and/or matched NTR
  - White race (alone) selected for comparison
  - AI/AN & White comprised 95% of the data
- NCHS bridged-race population estimates used as population denominators
- Rates age-adjusted and presented per 100,000 population

# Results



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# Washington Deaths

- Total cases used for this analysis
  - 12,212 AI/AN deaths
  - 794,409 White deaths





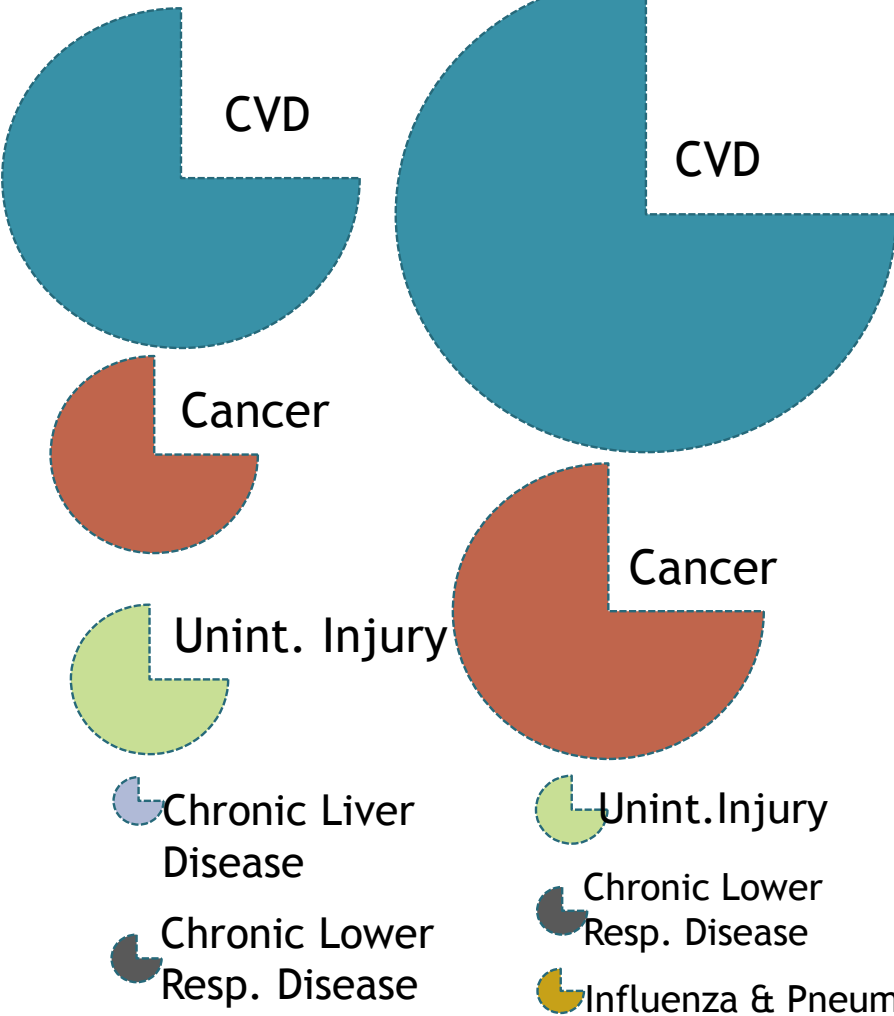
# Linkage Results: Racial Misclassification

	Before linkage	After linkage
AI/AN Deaths	10,870	12,212
White Deaths	795,675	794,409

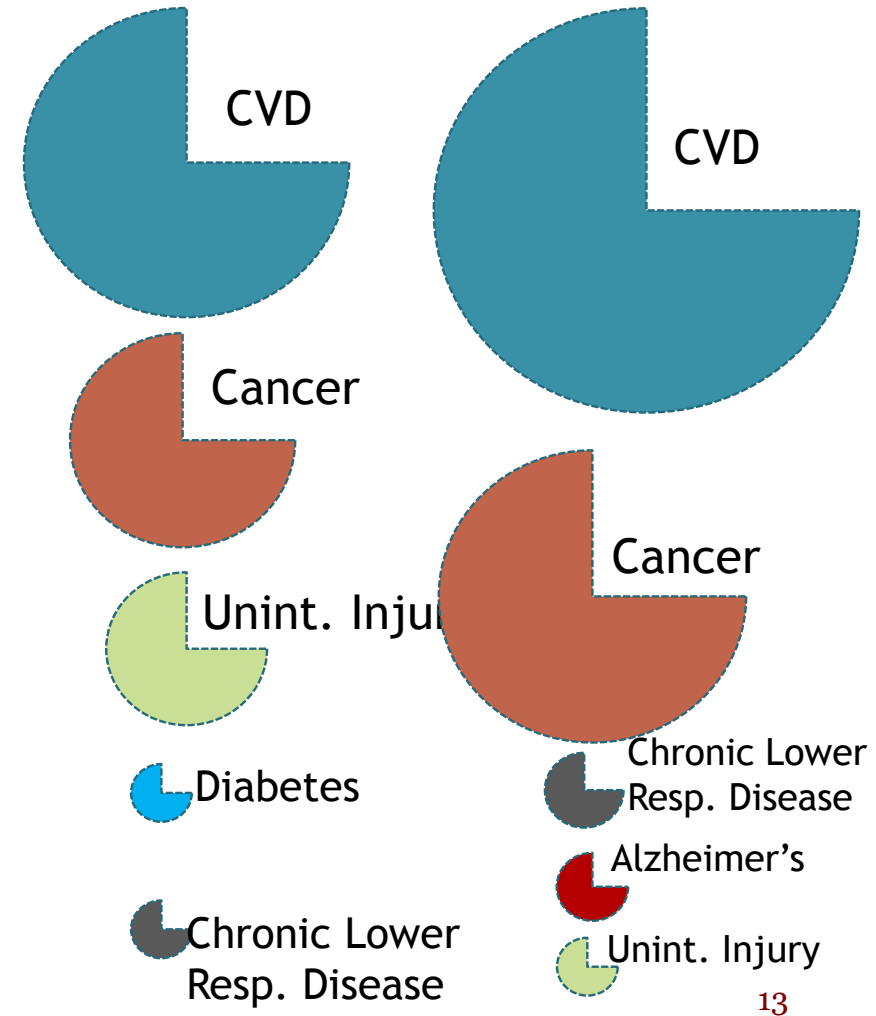


# Leading Causes of Death

AI/AN 1990-1999 White

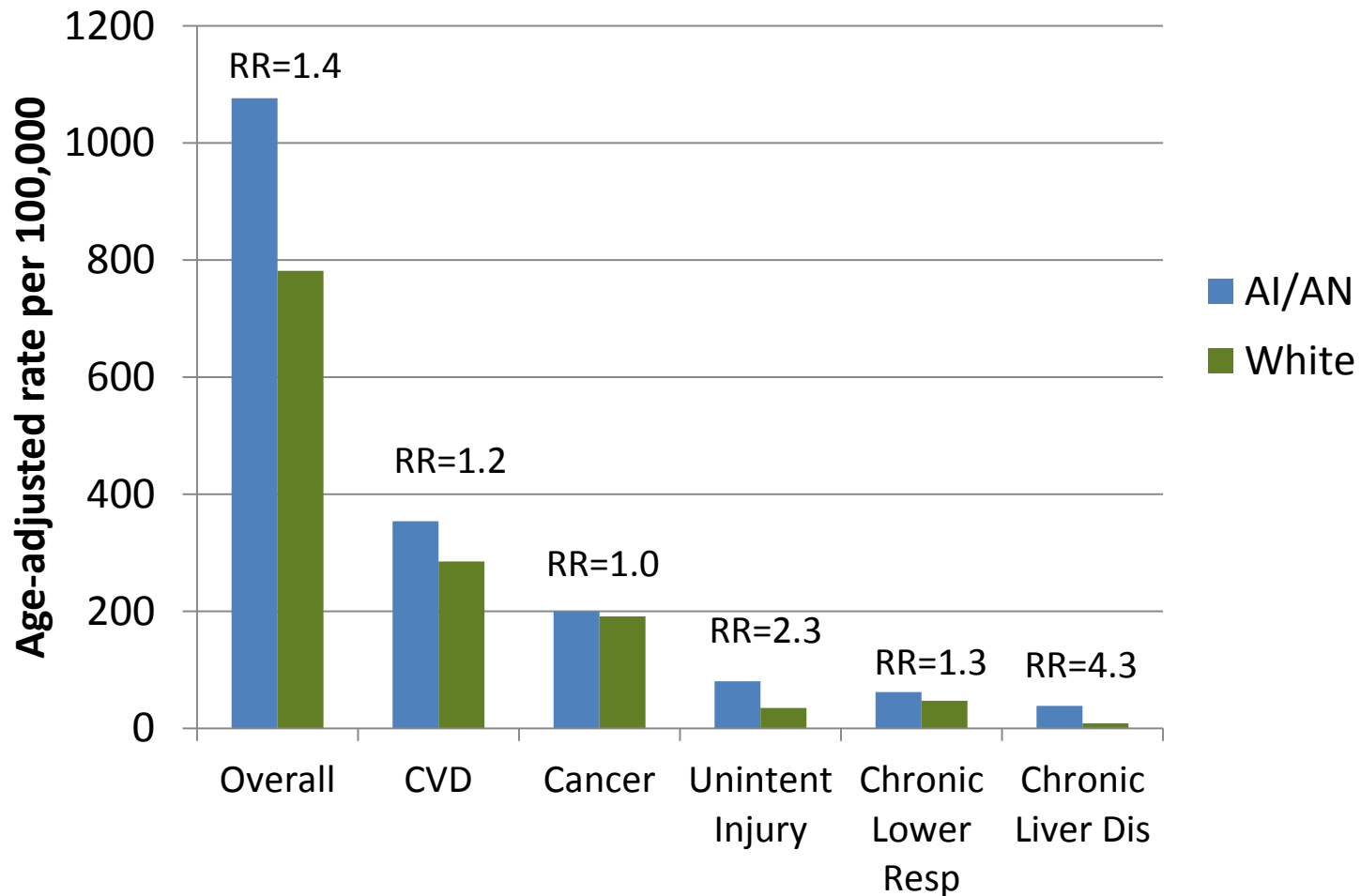


AI/AN 2000-2009 White





# Rates and rate ratios, leading causes of death, 1990-2009





# Washington AI/ANs died at younger ages

	AI/AN	White
Total Deaths	12,212	794,409
Mean Age at Death	57.7	73.6

# Injury Results



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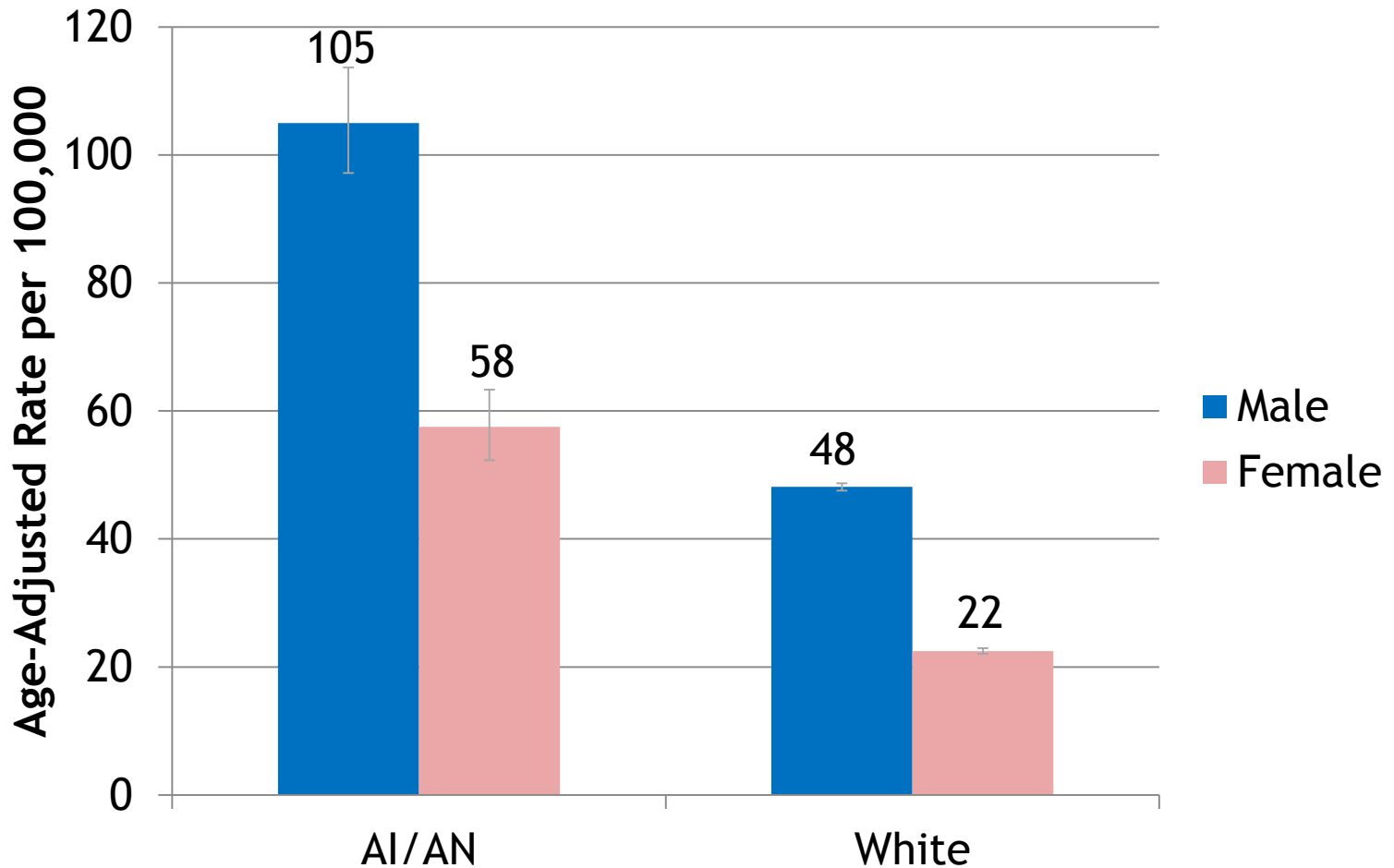


# Injury Deaths 1990-2009

- **AI/AN Injury deaths**
  - 2,163 unintentional
  - 391 suicide
  - 247 homicide
- **White injury deaths**
  - 50,804 unintentional
  - 13,930 suicide
  - 2,802 homicide

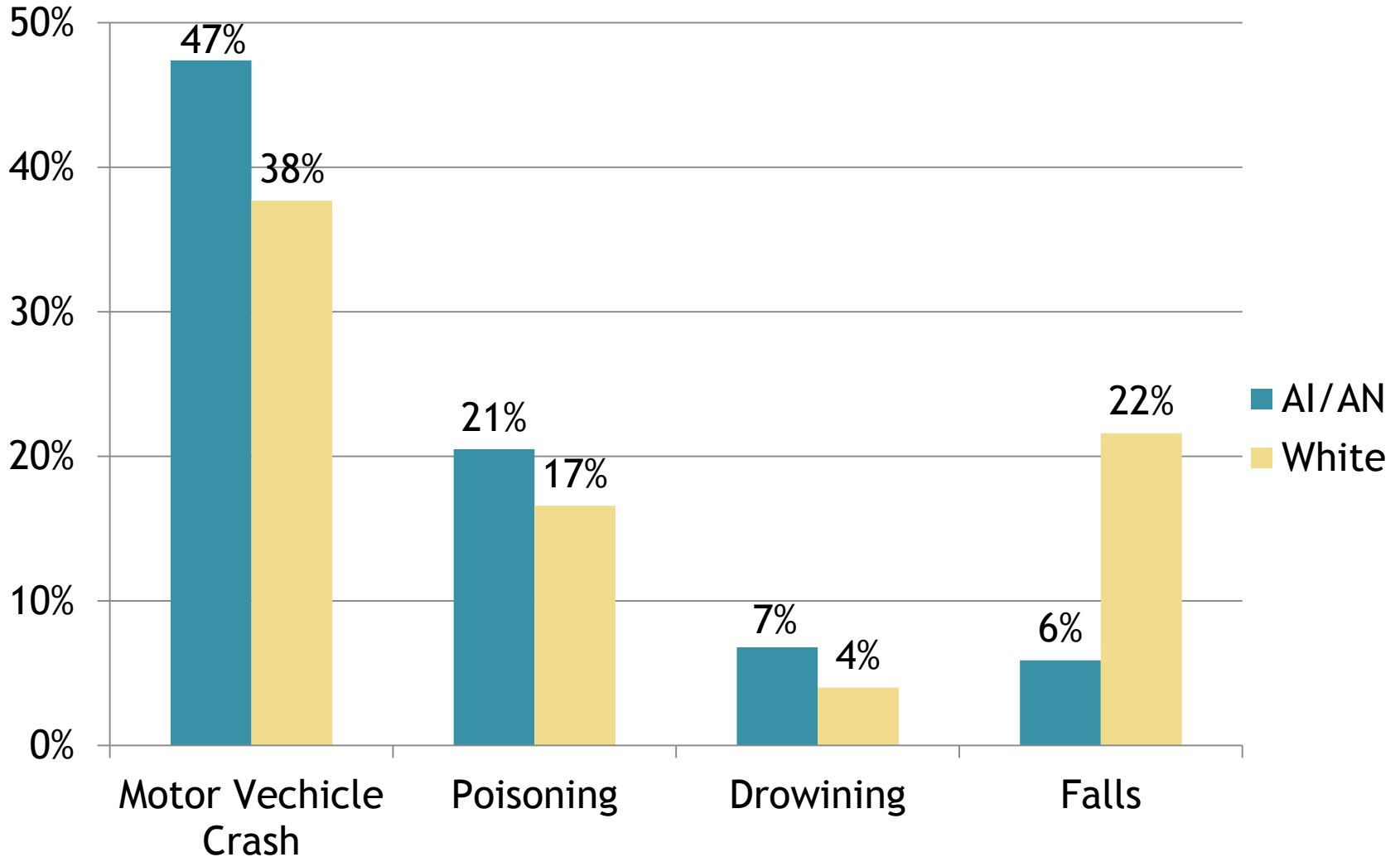


# Unintentional Injury Mortality by Sex, 1990-2009





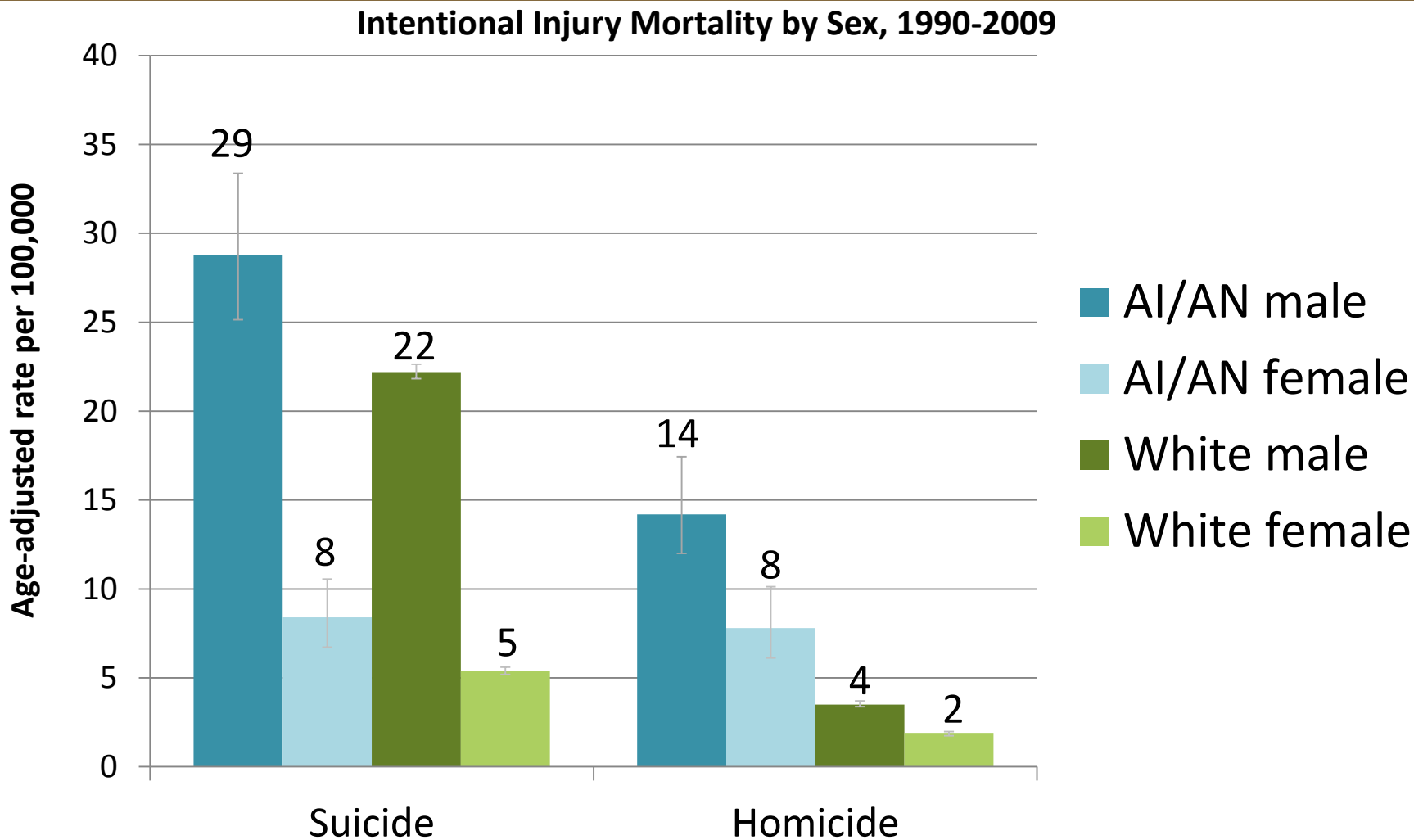
# Most unintentional injury deaths are by MVC and poisoning







# AI/AN intentional injury rates were higher than whites, with males bearing the burden more than females in both homicide and suicide



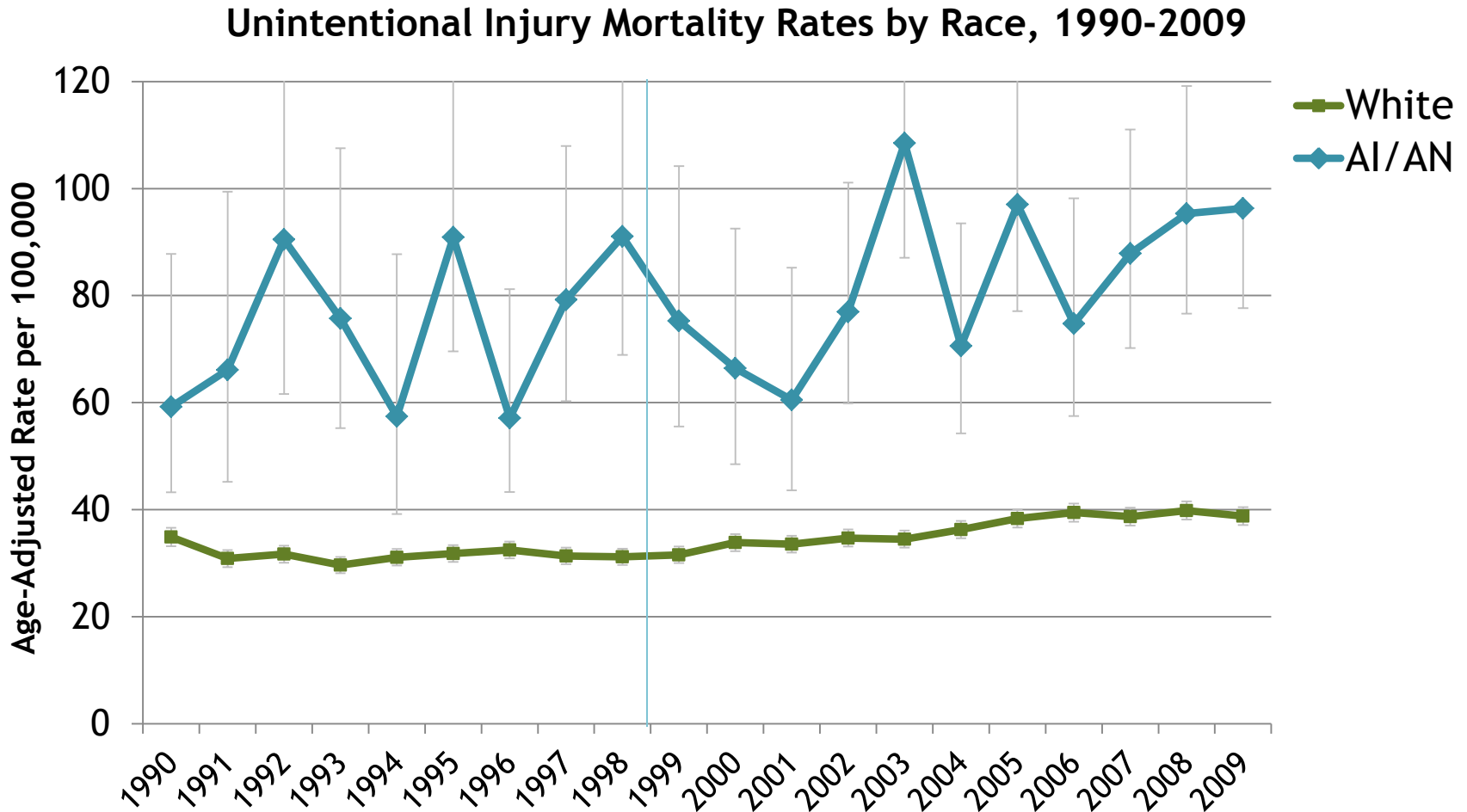
# Injury Trends



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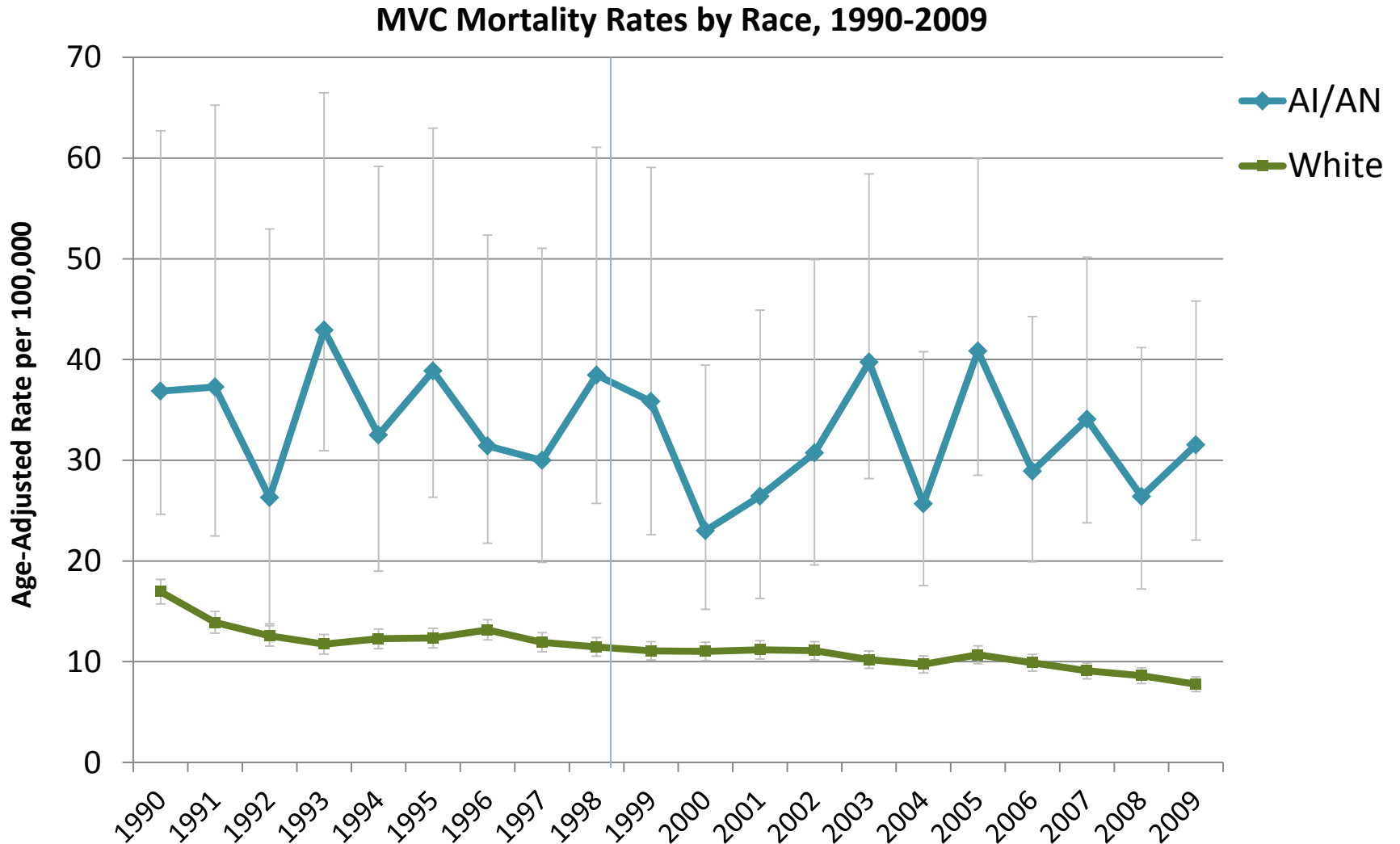


# AI/AN Unintentional Injury Mortality Rates Were Consistently Higher Than Whites



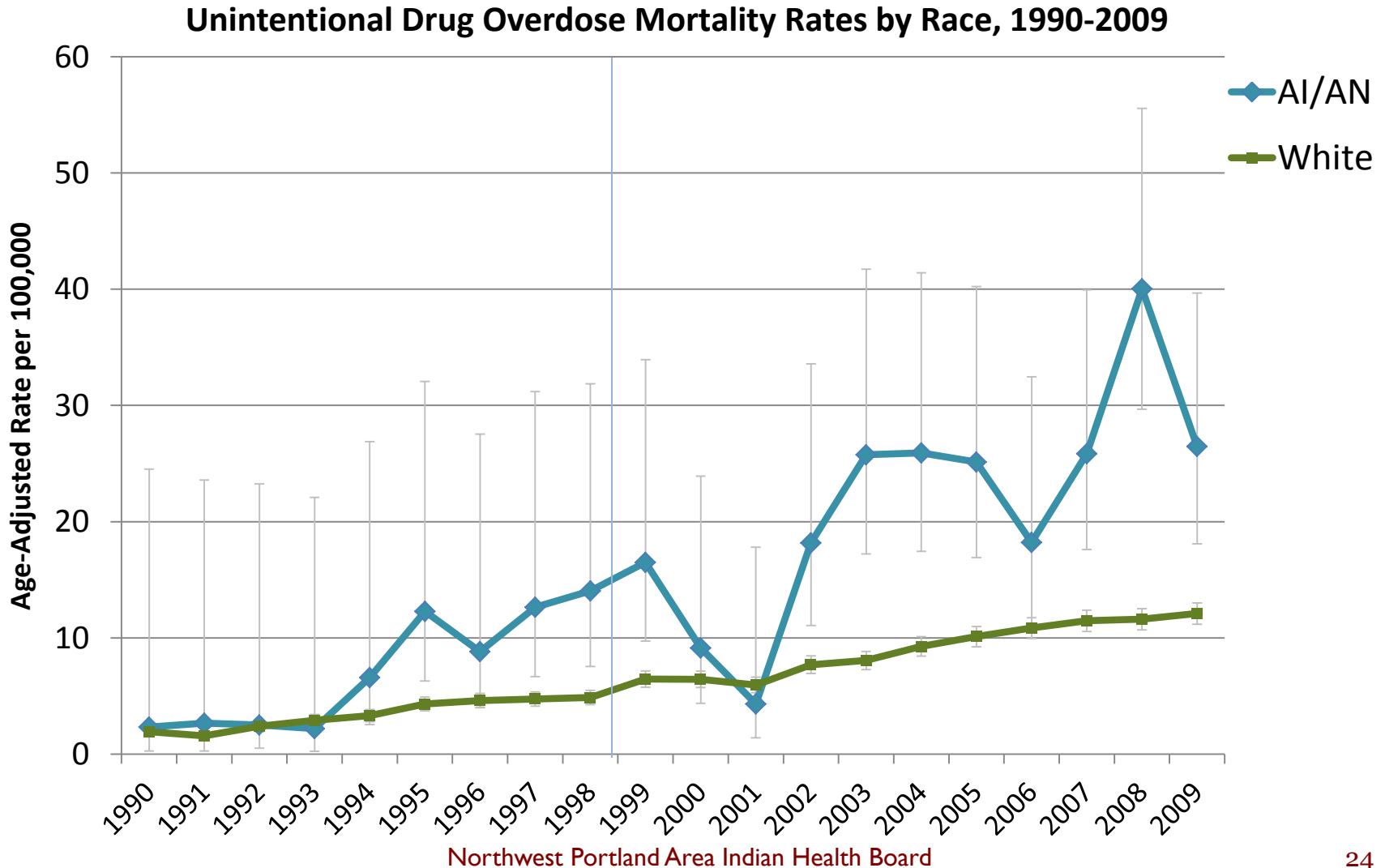


# AI/AN MVC Mortality Rates Were Consistently Higher than Whites, Gap Growing



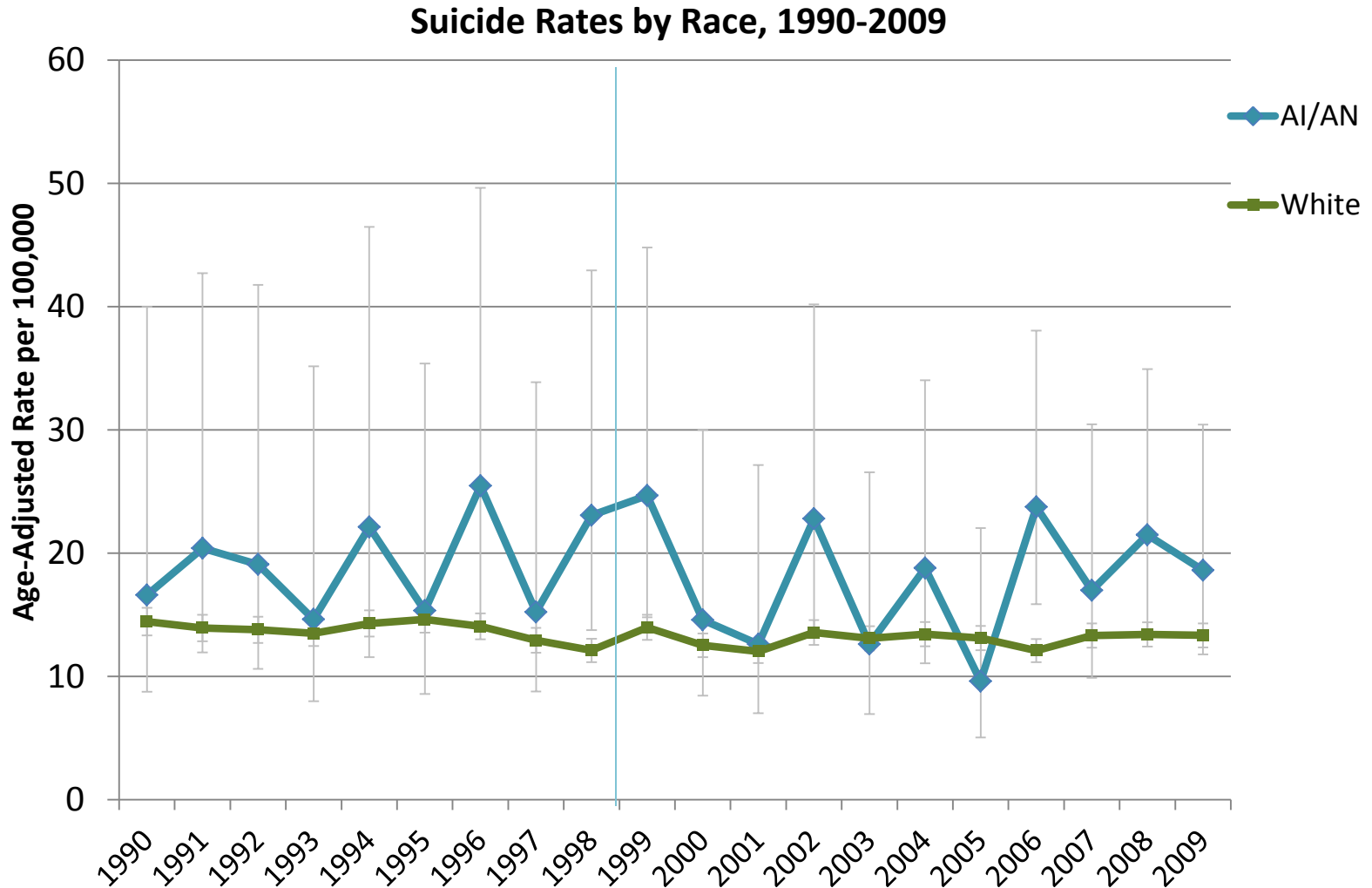


# From 1994 onward, AI/AN rates of Unintentional Drug Overdose were higher than Whites and increasing at a faster pace



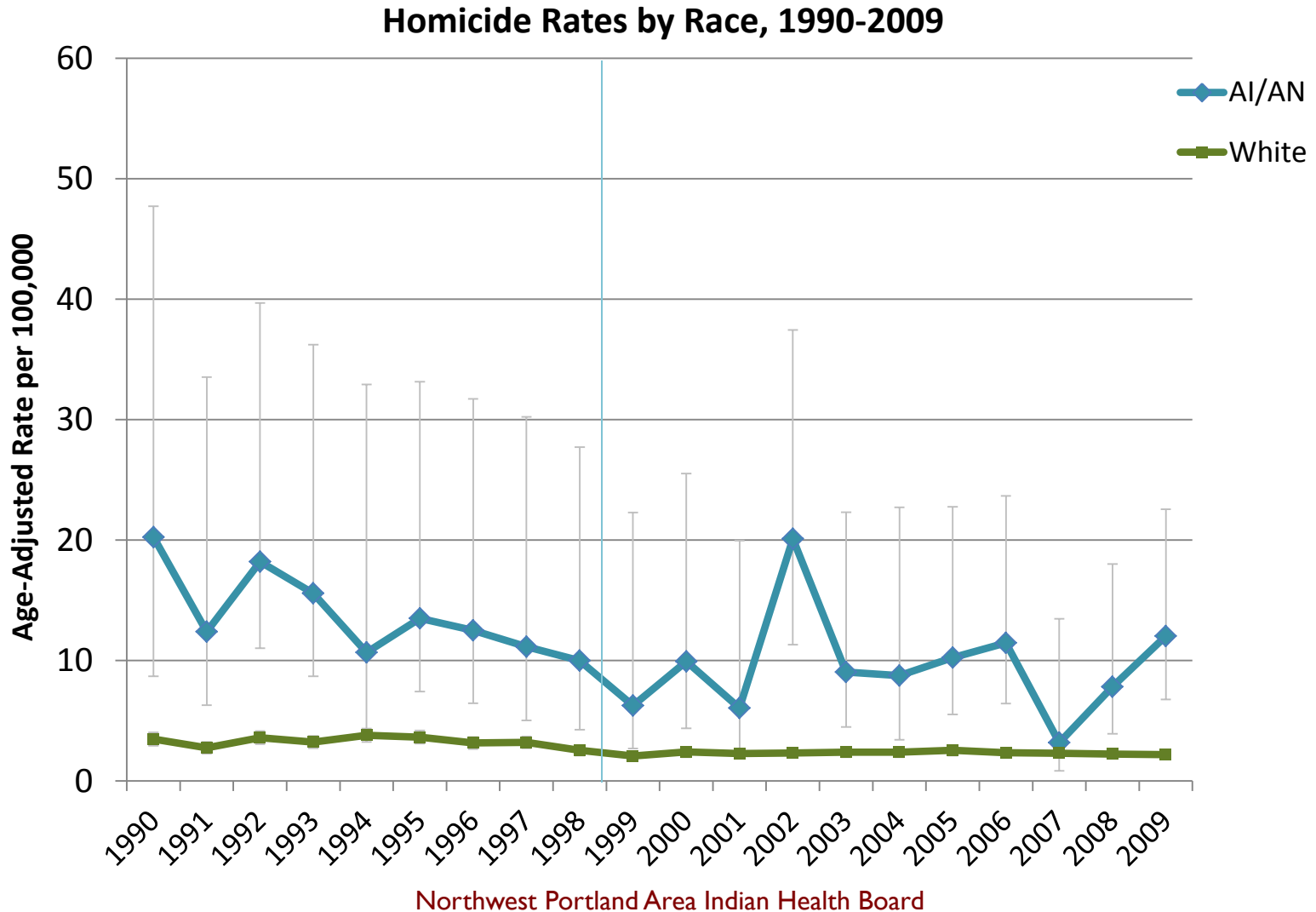


# AI/AN suicide rates were slightly higher than White rates





# AI/AN homicide rates were ~4 times higher than Whites, but dropped at a slightly quicker pace



# Discussion



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# Many disparities exist in mortality for Washington AI/ANs

- AI/ANs in Washington are dying younger than Whites
- Higher rates of mortality due to MVC, drug overdose, suicide, homicide
- Improvements in injury mortality experienced by Whites have not always occurred for AI/ANs
  - Large increases in accidental drug overdose death rates since 1999
  - No decrease in MVC rates



- Correct racial classification is a critical factor in achieving accurate surveillance of mortality
  - Linkage can help address misclassification
- Linkage-corrected mortality data used by Northwest Tribes
  - Health assessment
  - Grant writing and reporting
  - Program planning and evaluation
    - Injury Prevention Program
    - Native CARS
  - Policy and advocacy



# Limitations & challenges

- Tribal Registry under-represents urban AI/AN and those with private insurance
  - Captures 75-80% of AI/AN population
- Even with combined data years, small numbers make AI/AN rates unstable
- Death certificate data does not answer the “why” questions

# Thank You

## Acknowledgements

The Tribes of Washington – patients and their families

Victoria Warren-Mears, PhD (P.I.)

Bridget Canniff, Injury Prevention Program director

Washington DOH Center for Health Statistics

Urban Indian Health Institute, Seattle Indian Health Board

AHRQ Grant #R01HS19972



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