Long-term Outcomes

What are long-term outcomes?

Long-term outcomes measure whether programs and interventions eventually reduce the morbidity and mortality from diabetes in a population. This can be measured through improvements in diabetes prevalence, mortality, earlier diagnosis, complications rates, improved health costs, and improved health behaviors of the community.

The IHS National Diabetes Program improved the accuracy of baseline long-term outcomes measures (i.e., prevalence and mortality) so that changes resulting from the Special Diabetes Program for Indians and other interventions could be assessed.

The IHS National Diabetes Program also established a Diabetes Data Warehouse, using Resource and Patient Management System (RPMS) data, with funds from the Special Diabetes Program for Indians. The purpose of the data warehouse is to enable the IHS National Diabetes Program to accurately track long-term complications of diabetes in AI/AN communities.

This section includes data on the following long-term outcomes:

- Diabetes prevalence
- Diabetes mortality

The IHS National Diabetes Program improved the accuracy of baseline long-term outcomes measures so that changes resulting from the Special Diabetes Program for Indians and other interventions could be assessed.

CHAPTER FOUR

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Long-Term Outcomes

"I don't say that I am diabetic. But I do say that I have high blood sugar, and I can combat it."

Willard D. Phillips, Sr. (Omaha)

Diabetes prevalence: Accurate baseline data for ongoing measurement of the prevalence of diabetes in AI/ANs over time was established with implementation of the Special Diabetes Program for Indians.

Why is this important?

The Special Diabetes Program for Indians allowed local programs to use grant funding to improve their screening efforts for diabetes. As a result, diabetes grant programs were able to diagnose and treat a significant number of individuals who had diabetes but did not know it. This process of finding undiagnosed cases of diabetes led to an expected increase in the prevalence of diabetes during the first few years of the Special Diabetes Program for Indians. Despite the challenges of addressing diabetes, the many prevention and treatment activities implemented with the Special Diabetes Program for Indians are expected to reduce the prevalence of diabetes over the next few decades.
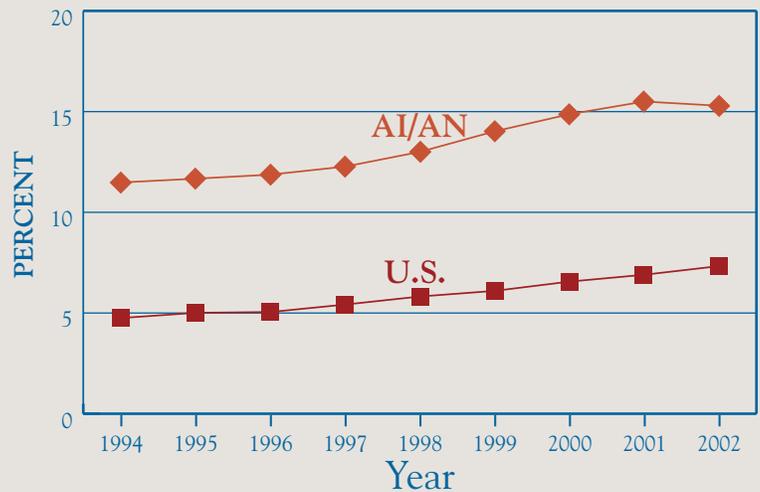
Many IHS Areas used the grant funds to improve the accuracy of diabetes prevalence data. Prior to the Special Diabetes Program for Indians, the capacity of programs to measure diabetes accurately varied widely, with most programs undercounting the number of people who have diabetes in their communities. Although these data and surveillance system improvements have resulted in an increase in diabetes prevalence estimates during the first few years of the Special Diabetes Program for Indians, they have created an accurate and reliable baseline of prevalence data. This baseline will allow the IHS to track the effects of Special Diabetes Program for Indians activities on prevalence over time.

Data improvements implemented under the Special Diabetes Program for Indians now allow accurate measurement of the following types of prevalence data:

- Prevalence of diabetes in AI/AN, over time
- Increases in prevalence by age group, and compared to the general population
- Prevalence compared to other racial and ethnic groups
- Prevalence among IHS Areas
- Increases in prevalence among IHS Areas during specific time periods
- Changes in prevalence among AI/AN youth

> **Although these data and surveillance system improvements have resulted in an increase in diabetes prevalence estimates during the first few years of the Special Diabetes Program for Indians, they have created an accurate and reliable baseline of prevalence data.**

Increase in Diabetes Prevalence Among Persons Aged 20-59 Years, by Age – U.S. General Population and American Indians/Alaska Natives, 1990 and 1998

Legend:
- General Population
- American Indians/ Alaskan Natives

PERCENT (y-axis: 0, 20, 40, 60, 80)

Age (x-axis): 20-29*, 30-39, 40-49, 50-59
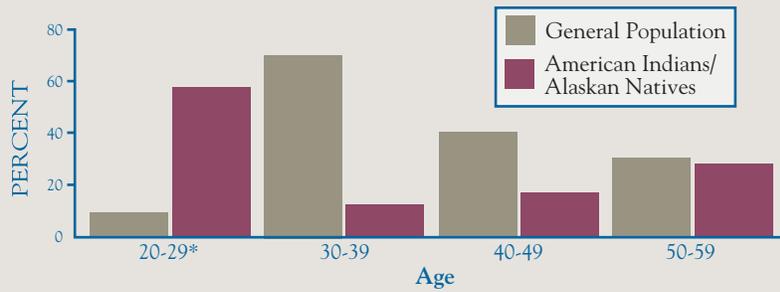
Source Mokdad et al. Diabetes Care 2000; 23: 1278-83, and Indian Health Service outpatient data.
*18-29 years in U.S. general population

The IHS can now more accurately measure the increase in prevalence of diabetes among AI/ANs by age group, and compared to the general population.

Prevalence of Diagnosed Diabetes Among Adults, by Age, Race and Sex — United States, 2002

Legend:
- White Men
- White Women
- Black Men
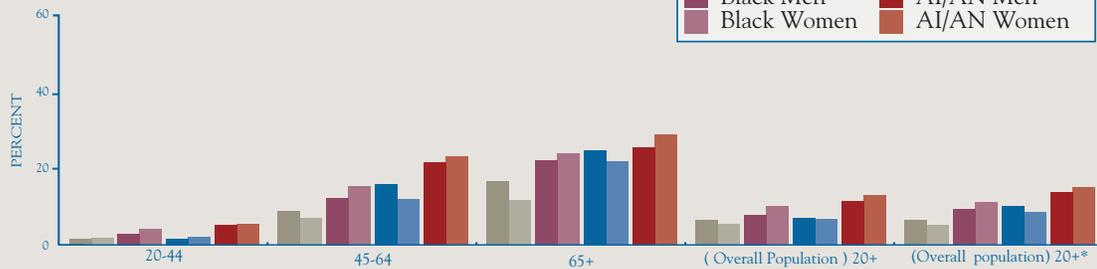- Black Women
- Hispanic Men
- Hispanic Women
- AI/AN Men
- AI/AN Women

PERCENT (y-axis: 0, 20, 40, 60)

x-axis: 20-44, 45-64, 65+, (Overall Population) 20+, (Overall population) 20+*

Source 1997-1999 National Health Interview Survey (NHIS) and 2001 Indian Health Service outpatient database
*Age-adjusted based on the 2000 U.S. population

The IHS can now more accurately compare the prevalence of diabetes among AI/ANs to other racial and ethnic groups.

Age-Adjusted* Prevalence of Diagnosed Diabetes Among American Indians/ Alaska Natives Aged 20 Years or Older, by IHS Area, 2002

PERCENT (y-axis: 0, 10, 20, 30, 40)

x-axis: Aberdeen, Alaska, Albuquerque, Bemidji, Billings, California, Nashville, Navajo, Oklahoma, Phoenix, Portland, Tucson

Source FY01 IHS APC file. Excludes data from 39 service units (7% of the IHS user population) • Age-adjusted based on the 2000 U.S. population.

The IHS can now more accurately compare the prevalence of diabetes among AI/ANs by IHS Area.

Increase in Age-Adjusted* Prevalence of Diagnosed Diabetes Among American Indians/Alaska Natives Aged 20 Years or Older, by IHS Area, 2002

Source FY98-01 IHS APC file. Excludes data from 39 service units (7% of the IHS user population) • Age-adjusted based on the 2000 U.S. population.

The IHS can now more accurately compare the *increase* in the prevalence of diabetes among AI/ANs by IHS Area during specific time periods.

Prevalence of Diagnosed Diabetes among Children & Young People by Age Group, 1990-2002

132% increase
69% increase
106% increase
50% increase

25-34
20-24
15-19
<15
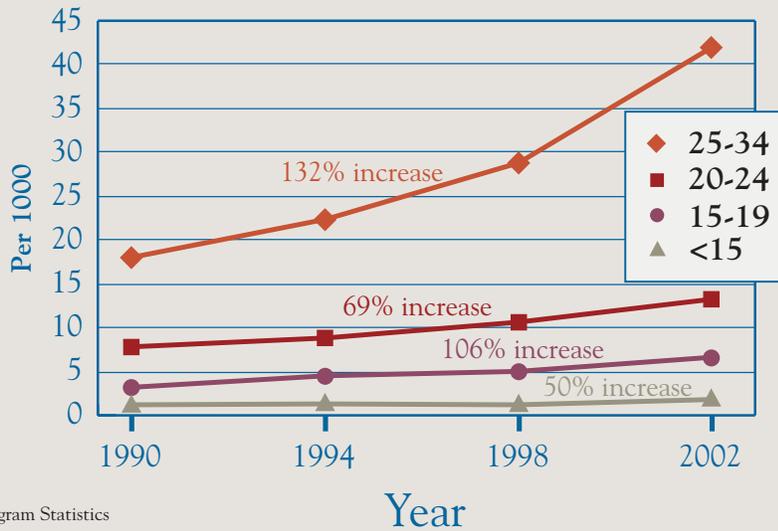
Source IHS National Diabetes Program Statistics

The IHS can now more accurately measure changes in the prevalence of diabetes among AI/AN youth.

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Diabetes mortality: Accurate baseline data for ongoing measurement of diabetes mortality was established with implementation of the Special Diabetes Program for Indians.
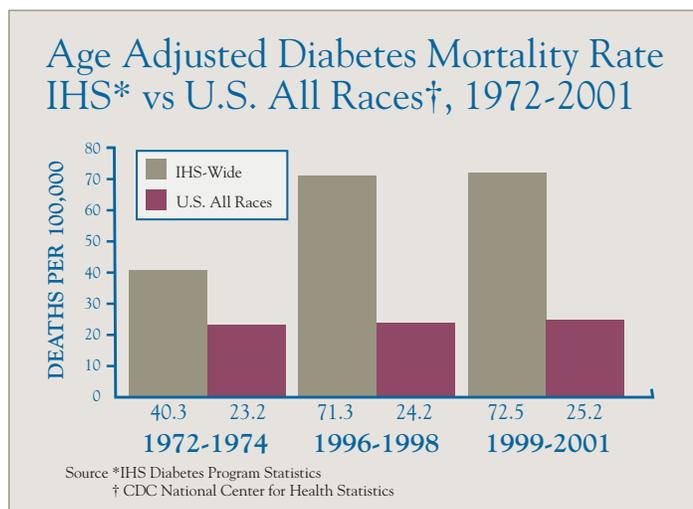
Why is this important?

Diabetes-specific mortality approximates the risk of death from diabetes and is an important indicator of health status. However, racial misidentification on death certificates has led to inaccurate AI/AN mortality data. This usually results in undercounting of AI/AN deaths which, in turn, results in lower than expected mortality rates.

The Special Diabetes Program for Indians allowed the IHS to improve mortality data by making more accurate adjustments for the undercounting of AI/AN racial identity and by better understanding the limitations of mortality data. As a result of this work, mortality estimates for AI/ANs are now considered more accurate.
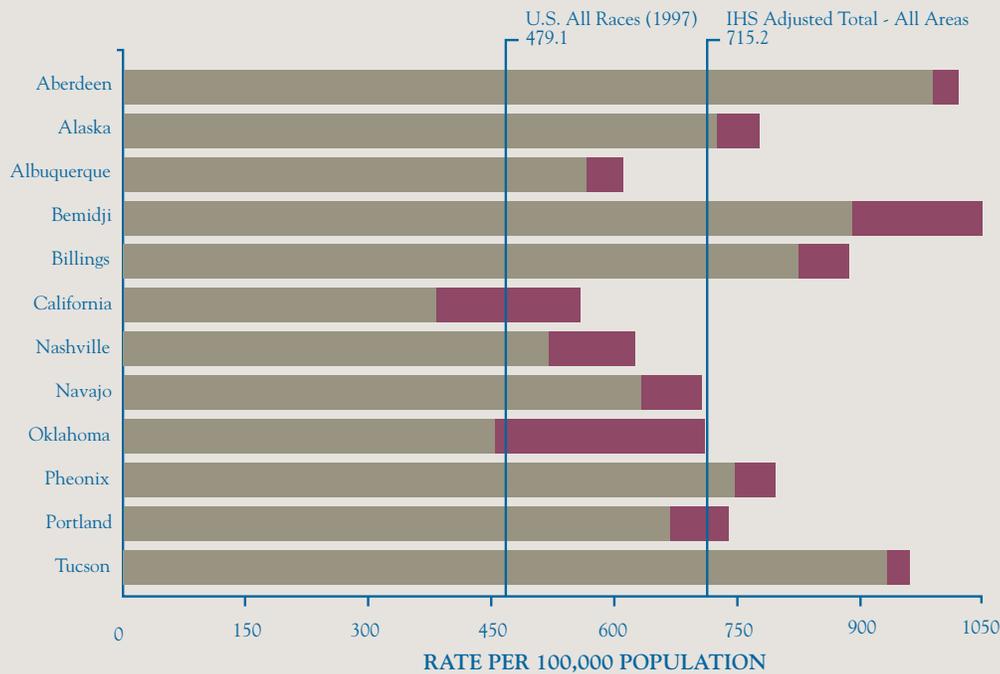
An accurate baseline for diabetes mortality has been established with implementation of the Special Diabetes Program for Indians. The IHS National Diabetes Program is now able to measure diabetes mortality in the following ways:

- Over time
- Compared with other races
- By IHS Area
- Adjusted for undercounting

The IHS can now more accurately measure diabetes mortality in AI/ANs over time and compared to other races.

Age Adjusted Diabetes Mortality Rate IHS* vs U.S. All Races†, 1972-2001

Bar chart — DEATHS PER 100,000. Legend: IHS-Wide, U.S. All Races.
1972-1974: 40.3 / 23.2
1996-1998: 71.3 / 24.2
1999-2001: 72.5 / 25.2

Source *IHS Diabetes Program Statistics
† CDC National Center for Health Statistics

Age-Adjusted Death Rates by IHS Area — CY 1996-1998

U.S. All Races (1997)
479.1

IHS Adjusted Total - All Areas
715.2

Aberdeen	
Alaska	
Albuquerque	
Bemidji	
Billings	
California	
Nashville	
Navajo	
Oklahoma	
Pheonix	
Portland	
Tucson	

0   150   300   450   600   750   900   1050

RATE PER 100,000 POPULATION

* Gray bars represent unadjusted totals. Colored bars represent totals adjusted for race misreporting

The IHS can now more accurately measure mortality by IHS Area and can accurately adjust rates for undercounting on death certificates due to racial misidentification.

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The IHS can now more accurately measure diabetes mortality in AI/ANs over time and compared to other races.

Long-Term Outcomes

> The IHS National Diabetes Program has demonstrated that many processes and outcomes have improved through implementation of the Special Diabetes Program for Indians for diabetes prevention and treatment in AI/AN communities.

Summary

The IHS National Diabetes Program used accepted frameworks for public health evaluation and incorporated quantitative and qualitative methodologies to evaluate the short-term, intermediate, and long-term outcomes of the Special Diabetes Program for Indians. Through improvements made to diabetes data in each IHS Area and using the models and data sources described in this chapter, the IHS National Diabetes Program has demonstrated that many processes and outcomes have improved through implementation of the Special Diabetes Program for Indians for diabetes prevention and treatment in AI/AN communities.

The findings of the IHS National Diabetes Program evaluation for use of a best practices approach in the Special Diabetes Program for Indians are highlighted in the following chapter.

"I hope that our focus on diabetes prevention is permanent. Look around and see all the Indian children. We surely must be ready for them!"

Alvin Windy Boy (Chippewa Cree)