

Chapter 3

EVALUATION METHODOLOGY OF THE SPECIAL DIABETES PROGRAM FOR INDIANS

The Indian Health Service (IHS) National Diabetes Program conducted an evaluation of the Special Diabetes Program for Indians to determine whether the initiative met its legislative intent to provide diabetes prevention and treatment services for American Indians and Alaska Natives (AI/ANs) and to measure the outcomes of these activities. Evaluation of this initiative was challenging since the diabetes grant programs developed activities to meet local needs, and therefore a wide variety of services were implemented with the Special Diabetes Program for Indians funding. As a result, the IHS National Diabetes Program designed the evaluation using accepted public health evaluation frameworks and a variety of quantitative and qualitative measures and data sources to measure the extent of services implemented and any outcomes attributable to these efforts.

A. Conceptual Models for the Evaluation

1. Purpose of the Evaluation

The Balanced Budget Act of 1997 required an evaluation of the Special Diabetes Program for Indians and two reports to Congress: an interim report in 2000, and a final report in 2002. In FY 2000, the IHS National Diabetes Program completed the interim report to Congress, which detailed the various programs and activities implemented under the initiative. Subsequent legislation moved forward the deadline for the final report to Congress with the extension of this initiative to FY 2008. However, many stakeholders, including Congressional members, federal agency staff, and tribal leaders, have asked about the progress of the Special Diabetes Program for Indians now that it is in its sixth year. In response, the IHS National Diabetes Program conducted a formal evaluation of the initiative to date and completed this Interim Progress Report for Congress. The objectives of this evaluation were as follows:

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Evaluation of this initiative was challenging since the diabetes grant programs developed activities to meet local needs, and therefore a wide variety of services were implemented with the Special Diabetes Program for Indians funding.

The IHS National Diabetes Program used two accepted health evaluation frameworks in its evaluation of the Special Diabetes Program for Indians: 1) the CDC Framework for Program Evaluation in Public Health, and 2) the Chronic Care Model.

The task of evaluation has become more complex as the targets of public health actions have expanded beyond infectious diseases to include chronic diseases and the social contexts that influence health disparities.

- 1) To determine whether the Special Diabetes Program for Indians implemented prevention and treatment services to address the growing problem of diabetes in AI/ANs.
- 2) To measure whether the prevention and treatment services implemented through the Special Diabetes Program for Indians have resulted in short-term, intermediate, or long-term positive outcomes.

2. Conceptual Frameworks for the Evaluation

The IHS National Diabetes Program used two accepted health evaluation frameworks in its evaluation of the Special Diabetes Program for Indians: 1) the CDC Framework for Program Evaluation in Public Health, and 2) the Chronic Care Model.

- **CDC Framework for Program Evaluation in Public Health** - The Centers for Disease Control and Prevention (CDC) developed this framework for public health evaluation to ensure that the agencies that conduct evaluations remain accountable and committed to achieving measurable health outcomes.¹ The CDC framework provides an evaluation model for the various diabetes prevention and treatment methods used by AI/AN communities. It also acknowledges that the task of evaluation has become more complex as the targets of public health actions have expanded beyond infectious diseases to include chronic diseases and the social contexts that influence health disparities. The key features of this framework are that it:
 - Uses scientific findings as a basis for public health evaluation.
 - Focuses the evaluation on specific outcomes of interest.
 - Allows findings to be interpreted to determine the practical significance of what has been learned.
 - Can help future programs improve health status for future generations.
 - Identifies effective activities and strategies.
 - Demonstrates the results of resource investments.
 - Stimulates dialogue and raises awareness about diabetes and diabetes prevention.

Central to the CDC framework is the *logic model*. The logic model provides a critical framework to summarize the essential elements of program evaluation:

- Short-term (process) outcomes
- Intermediate outcomes
- Long-term outcomes

This evaluation model provides a framework to understand that the Special Diabetes Program for Indians is a complex initiative and many different outcomes can be measured along a continuum. During the first few years of the program, *short-term outcomes* included accomplishments related to the development and implementation of the initiative, including information on the specific programs and activities implemented. Since the programs were encouraged to implement activities relating to primary, secondary, and tertiary prevention (i.e., prevention, screening and treatment and prevention of complications of diabetes, respectively) and to implement best practice approaches (i.e., programs shown to be effective through research or prior experience), many programs implemented programs with a similar theme, such as foot care, physical activity, and diabetes education services. Many programs also implemented supplemental programs that addressed a certain at-risk group, including different age groups and groups with related co-morbidities.

As the Special Diabetes Program for Indians interventions mature, *intermediate outcomes* can be measured to determine if the programs efforts and activities have resulted in measurable changes in outcomes including improvements in risk factors for the onset of diabetes and diabetes complications.

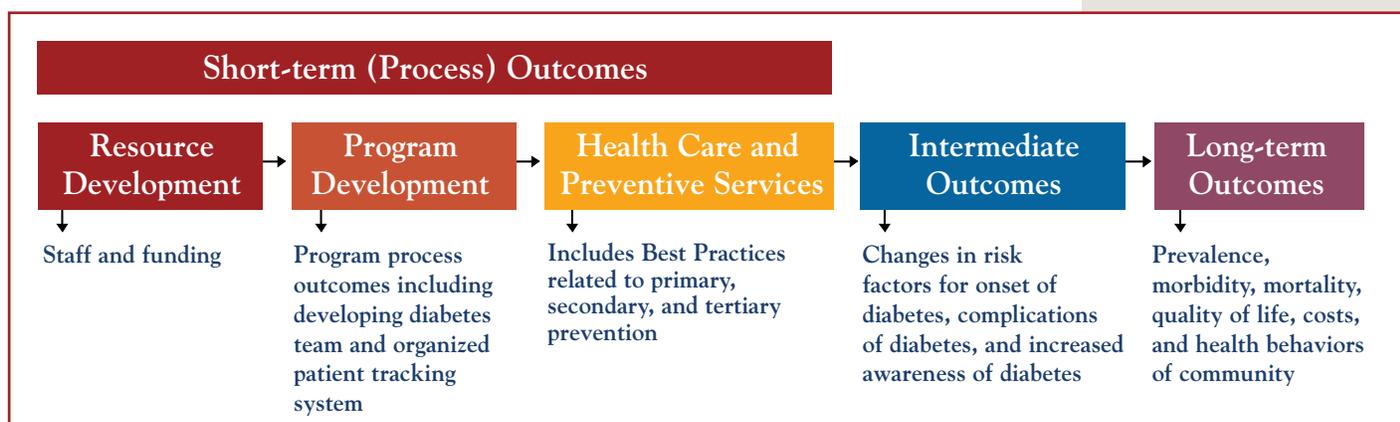
Long-term outcomes, including reduced morbidity and mortality from diabetes, will be measured as data systems have been put in place to measure these important long-term outcomes.

The CDC Public Health Evaluation Framework logic model was applied to the Special Diabetes Program for Indians as follows:

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Since its introduction over a decade ago, managed care organizations, public health agencies, and the World Health Organization have used the Chronic Care Model to evaluate their effectiveness in managing diabetes and other conditions.

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- **The Chronic Care Model** – The IHS National Diabetes Program used the Chronic Care Model to evaluate the effectiveness of its *systems of care* in dealing with diabetes as a chronic disease.

The MacColl Institute of the Group Health Cooperative of Puget Sound developed the model to help health systems develop the basic elements necessary to improve care at the community, health system, provider, and patient levels. The model addresses the need to focus on the health care system as a whole to improve care of chronic diseases.² Since its introduction over a decade ago, managed care organizations, public health agencies, and the World Health Organization have used the Chronic Care Model to evaluate their effectiveness in managing diabetes and other conditions.

The Chronic Care Model recommends that health systems implement the following components to effectively address chronic diseases:

- Community resources and policies
- Health system organization
- Self-management support
- Delivery system design
- Decision support
- Clinical information systems

Since the 1980s, the IHS National Diabetes Program has successfully implemented many of the elements that are now part of the Chronic Care Model to improve diabetes care and management. The Special Diabetes Program for Indians, however, allowed more Indian health programs, particularly tribal programs, to build the infrastructure needed to implement these elements. Also, the Special Diabetes Program for Indians enabled the Indian health system, for the first time, to comprehensively measure its effectiveness in implementing these system changes.

A recent independent review using the Chronic Care Model's Assessment of Chronic Illness Care (Version 3.5) revealed that the IHS National Diabetes Program and the Special Diabetes Program for Indians *scored in the highest level* for most of the model's components. (See Appendix II for more information.) With this success, the Special Diabetes Program for Indians made it possible for the Indian health system to serve as an example of a large health system effectively putting the Chronic Care Model into practice.

B. Measures and Data Sources for the Evaluation

1. Measures

The IHS National Diabetes Program identified and analyzed the following categories of measures for this evaluation:

- **Short-term outcomes** – Describe programs and activities implemented to prevent and treat diabetes:
 - Systems and diabetes program development
 - Basic clinical care for people with diabetes
 - Diabetes education, activities, and programs
 - Community diabetes awareness and activities
 - Focus on children and youth for diabetes prevention
- **Intermediate outcomes** – Measure whether the programs and activities resulted in the prevention of long-term diabetes complications through improving the following intermediate outcome measures:
 - Blood sugar (glycemic) control
 - Blood pressure control
 - Protein in the urine (proteinuria)
 - Cardiovascular disease risk factors
 - Body Mass Index (a measure of overweight or obesity)
- **Long-term outcomes** – Measure whether activities of the Special Diabetes Program for Indians intervention reduce the morbidity and mortality from diabetes through improvements in:
 - Diabetes prevalence
 - Diabetes mortality
 - Prevalence of complications (e.g., eye disease, amputations, heart disease, stroke, and kidney disease)

2. Data Sources

The IHS National Diabetes Program used a variety of qualitative and quantitative data sources to measure the above outcomes as follows:

Short-term outcomes:

- **Progress Report Questionnaires** – The Special Diabetes Program for Indians Request for Grant Application (RFA) outlined specific annual

The assessment tool focused on key best practice approaches, which the IHS National Diabetes Program and a consensus panel determined were a basic part of a successful diabetes program according to scientific evidence and data from the IHS Model Diabetes Programs and other diabetes grants programs.

reporting requirements for each diabetes grant program. All diabetes grant programs submitted an annual progress report. The report was composed of a narrative that described program goals and objectives, accomplishments, challenges, and problems in achieving program goals and objectives. Beginning in August 1999, the IHS National Diabetes Program required that diabetes grant programs complete an annual progress questionnaire, in addition to the program narrative. The questionnaires were designed to obtain more detailed quantitative program information in selected areas, such as diabetes program development, settings in which screenings occur, and methods to increase physical activity.

- **Community Assessments** – To help the diabetes grant programs design their new or expanded diabetes programs, the IHS National Diabetes Program designed a community assessment tool for the FY 2001 and 2002 RFAs. The diabetes grant programs used the assessment tool to decide if they wanted to use the additional diabetes funds (from the Consolidated Appropriations Act of 2001) to enhance current diabetes activities or develop one or more new diabetes activities. The questions in the assessment tool focused on key best practice approaches, which the IHS National Diabetes Program and a consensus panel determined were a basic part of a successful diabetes program according to scientific evidence and data from the IHS Model Diabetes Programs and other diabetes grants programs.
- **Regional meeting reports** – To collect qualitative data on the diabetes grant programs, the IHS National Diabetes Program held eight regional meetings that covered all 12 IHS Areas in late 1999 and early 2000. Following the regional meetings, the IHS National Diabetes Program analyzed and compiled the qualitative data into a regional meeting report.
- **Special Diabetes Program for Indians Compendium Report** – In August 2002, the IHS National Diabetes Program completed a compendium report on the activities of 66% of the diabetes grant programs. The report documented the activities and accomplishments of each diabetes grant program.
- **Key informant interviews** – To support the data compiled from the progress report questionnaires, compendium, and community assessment tools, an independent resource conducted targeted key informant interviews at sentinel diabetes grant programs.
- **Annual grant application reviews** – Each year, when the diabetes grant programs applied for Special Diabetes Program for Indians funding, the

Area Diabetes Consultants and Chief Medical Officers reviewed each application for program and fiscal compliance. In addition, the Area Diabetes Consultants and Chief Medical Officers evaluated the diabetes grant programs on their use of the best practice approaches with a simple review tool.

Intermediate Outcomes:

- **Annual IHS Diabetes Care and Outcomes Audit** – Since 1986, the IHS National Diabetes Program has coordinated the annual IHS Diabetes Care and Outcomes Audit. Each year, more than 90% of IHS and tribal facilities, which collectively provide care to over 100,000 AI/ANs with diabetes, review their medical records for compliance with the IHS Diabetes Standards of Care. The audit uses a strict protocol to ensure statistical integrity and comparability of measures over time.

Using data collected from the audit, the IHS National Diabetes Program examined intermediate outcomes from before the Special Diabetes Program for Indians (prior to 1998) and again for 2001 data.

- **Progress Report Questionnaires** – As described above, the Special Diabetes Program for Indians RFA required that diabetes grant programs complete an annual program narrative and progress questionnaire. The questionnaires were designed to obtain more detailed quantitative program information in selected areas. The progress questionnaire responses from the diabetes grant programs were linked to data from the IHS Diabetes Care and Outcomes Audit to obtain information on intermediate outcomes. The IHS National Diabetes Program corroborated the questionnaire responses with key informant interviews, personal interviews, and expert observations by the Area Diabetes Consultants.

Long-term outcomes:

- **RPMS** – The Resource Patient Management System, or RPMS, is the IHS patient computerized database containing clinical and demographic information on both inpatient and outpatient encounters—including laboratory and pharmacy data—for 550 IHS and tribal health facilities. Since the early 1980's, data retrieval has been possible via several search methodologies.
- **Data Warehouse** – Since 2002, the Data Warehouse has incorporated the information stored in the current Indian Health Performance Evaluation System database into a new data warehouse, which is an enhanced national repository of administrative and clinical data. The Data Warehouse provides information to more focused data marts for specific

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The IHS National Diabetes Program generates annual diabetes prevalence reports by age, gender, region of the country, prevalence over time, magnitude of change in prevalence over time, and prevalence of diabetes among AI/ANs compared to other racial and ethnic groups.

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reporting purposes, such as the Government Performance and Results Act (GPRA) objectives and diabetes surveillance.

- **Specific information on data sources for each long-term outcome measure:**
 - **Diabetes prevalence** – The IHS National Diabetes Program tracks diabetes prevalence data collected from RPMS based on the user population. (The user population reflects the number of people who: 1) are classified as AI/AN; 2) are considered eligible to receive services at IHS, tribal, or urban Indian health facilities; and 3) received services at IHS, tribal, or urban Indian health facilities at least once during the last three fiscal years.) The IHS National Diabetes Program generates annual diabetes prevalence reports by age, gender, region of the country, prevalence over time, magnitude of change in prevalence over time, and prevalence of diabetes among AI/ANs compared to other racial and ethnic groups.
 - **Mortality** – The IHS National Diabetes Program uses data from death certificates to calculate diabetes death rates. Because of underreporting of diabetes on death certificates and racial misclassification, most experts agree that the true diabetes mortality rates are underestimated for AI/ANs in national statistics.
 - **Complications surveillance** – The IHS National Diabetes Program monitors diabetes complications and risk factors at IHS and tribal facilities, thereby providing these facilities with the ability to track their progress in reducing complications and treating the complications at earlier stages. Using Special Diabetes Program for Indians funds, the IHS National Diabetes Program and Indian Health Performance Evaluation System is developing a national clinical data mart that contains aggregate, patient-level information on people with diabetes. This information includes outpatient, hospitalization, and contract care data, allowing the IHS National Diabetes Program to monitor and track the following complications in a more comprehensive manner than has been previously possible:

Eye disease

People with diabetes need annual eye exams to detect and prevent diabetic eye disease, or retinopathy. The IHS National Diabetes Program tracks individuals who receive eye exams for:

- Extended ophthalmologic work-up (ICD-9 procedure code 95.03)
- Other eye conditions (ICD-9 V80.2)
- Diabetes with ophthalmic manifestations (ICD-9 250.5)
- Other retinal disorders (ICD-9 362)
- Acute and sub-acute iridocyclitis (ICD-9 364)
- Unspecified cataract (ICD-9 366.9)

Lower extremity amputation

The IHS National Diabetes Program monitors and tracks people with diabetes who have undergone lower extremity amputations (ICD-9 procedure codes 84.10–84.19).

Cardiovascular disease (heart disease)

The IHS National Diabetes Program monitors and tracks people with diabetes who have cardiovascular disease complications (ICD-9 codes 390–429).

Cerebrovascular disease (stroke)

The IHS National Diabetes Program monitors and tracks people with diabetes who have cerebrovascular disease complications (ICD-9 codes 430–438).

Kidney disease

The IHS National Diabetes Program uses data from the U.S. Renal Data System (USRDS) to identify the number of people with diabetes who initiated treatment for end-stage kidney disease (with diabetes as the primary cause of kidney failure). The USRDS is a surveillance system for end-stage kidney disease supported by the Centers for Medicare and Medicaid Services (formerly the Health Care Financing Administration [HCFA]). USRDS collects, analyzes, and distributes information about the incidence, prevalence, treatment, and costs of end-stage kidney disease in the U.S.

C. *Data Considerations*

The distribution of the Special Diabetes Program for Indians funding was based, in part, on the reported prevalence and mortality estimates of diabetes in each IHS Area. Given the need for accurate and complete data to ensure equitable distribution of the funds, the following limitations in diabetes data quickly became apparent:

- A central location for data on diabetes among AI/ANs was not available.
- The majority of primary care data on diabetes were scattered among the individual IHS, tribal, and urban Indian health programs.
- The accuracy of data from most IHS, tribal, and urban Indian health programs had not been evaluated.
- A systematic approach to ensure quality health data for diabetes was not available.
- Racial identifiers were frequently missing or inaccurate in external diabetes data sets.

To address these concerns, the IHS Director set aside funding from the Special Diabetes Program for Indians for the purpose of improving data collection within each IHS Area. Complete and accurate data on diabetes would permit the diabetes grant programs to: 1) estimate the true impact of diabetes; 2) plan appropriate programs to address the impact of diabetes; and 3) evaluate the success of local diabetes prevention and treatment endeavors.

Each IHS Area was provided the opportunity to use the data improvement funds to verify, validate, and refine data on diabetes prevalence, complications, surveillance, and mortality. The data improvement funds also were used to enhance tribal participation in the IHS Diabetes Care and Outcomes Audit, which allows diabetes grant programs to obtain data on their level of diabetes care and compare it to other programs in the region and throughout the Indian health system. In addition, the data improvement funds helped diabetes grant programs identify tribal resources, hire personnel skilled at data systems and analysis, and expand opportunities to provide training and technical assistance to other tribes.

The following four examples demonstrate how the **data improvement funds** were used in the Special Diabetes Program for Indians:

Each IHS Area was provided the opportunity to use the data improvement funds to verify, validate, and refine data on diabetes prevalence, complications, surveillance, and mortality.

1. IHS Area Data Improvement Projects

Diabetes grant programs in many IHS Areas have accomplished one or more of the following data improvements with the Special Diabetes Program for Indians funds:

- Improved and updated patient registries and patient care record systems
- Developed new systems to extract data for reporting requirements
- Examined the accuracy of diabetes data
- Provided training in patient care registry systems, data use, IHS Diabetes Care and Outcomes Audit, and other epidemiology-related activities

For example, the Albuquerque Area provided hands-on training on RPMS with a focus on using the diabetes management component of RPMS to retrieve data for the IHS Diabetes Care and Outcomes Audit. In addition, the Albuquerque Area hired a registered nurse who conducted regular site visits to IHS Service Units and tribal sites to provide technical assistance on diabetes data management.

The California Area utilized their data funding to form a partnership with a data improvement project located at the Northwest Area Indian Health Board in Portland, Oregon (see description below). Like the Albuquerque Area, they have also provided local training on RPMS data entry and retrieval.

2. Western Tribal Diabetes Project, Northwest Portland Area Indian Health Board

The Northwest Portland Area Indian Health Board, located in Portland, Oregon, developed the Western Tribal Diabetes Project in 1998 with data improvement funds from the Special Diabetes Program for Indians. The goal of the project was to develop a sustainable and systematic approach to capture diabetes data among AI/AN communities located in the Northwest and California by providing technical assistance on several data improvement activities. First, the project developed tools, conducted site visits, and provided ongoing technical assistance to help the diabetes grant programs develop electronic diabetes registries to track data on people with diabetes and use the data for program planning, evaluation, quality improvement, and case management. Second, the project helped the diabetes grant programs develop plans to build an infrastructure for ongoing data surveillance. Third, the project developed a database to help the diabetes grant programs track data on the prevalence of diabetes and related complications over time. The database

automatically performs statistical calculations on the data and is designed to help individuals, with various levels of skill, read and apply the statistical information. Tribal epidemiology centers in the Nashville and Bemidji Areas are using Special Diabetes Program for Indians funds to replicate this successful model.

3. Seattle Indian Health Board

In 2002, using Special Diabetes Program for Indians funding, the Seattle Indian Health Board, located in Seattle, Washington, developed and produced a web-based diabetes survey and audit tool for the diabetes grant programs that delivered non-clinical services. The tool was designed to collect descriptive program data, such as program services, data collection capabilities and methods, client demographics, and service volume.

4. National Indian Council on Aging (NICOA)

The IHS National Diabetes Program, in partnership with the National Indian Council on Aging, initiated a project to utilize Geographic Information Systems (GIS) technology to map the problem of diabetes in AI/AN communities. In addition, NICOA and tribally-operated regional epidemiology centers worked in partnership to refine the capabilities of RPMS in capturing diabetes data. NICOA also worked with IHS, tribal, and urban health clinics to develop an automated diabetes outcome and audit measures report using RPMS.

D. Summary

The IHS National Diabetes Program evaluated the Special Diabetes Program for Indians using accepted frameworks for public health evaluation and incorporated quantitative and qualitative methodologies to provide information on short-term, intermediate, and long-term outcomes. 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 reviewed the implementation of programs and activities for diabetes prevention and treatment under the Special Diabetes Program for Indians, determined the clinical outcomes that resulted from these activities, and established baseline parameters for measurement of long-term outcomes. The findings of the IHS National Diabetes Program evaluation of the Special Diabetes Program for Indians are highlighted in the following chapters.