



## A REVIEW OF THE QUALITY OF HEALTH CARE FOR AMERICAN INDIANS AND ALASKA NATIVES

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**ABSTRACT:** The author documents health care disparities for American Indians and Alaska Natives (AIANs) and reports on progress made in the last five years to reduce or eliminate gaps in care. In examining the demographics of this group, she notes in particular a substantial urban AIAN population that is both understudied and which may be underserved by the traditional AIAN health care infrastructure. The author also reports on changes to this infrastructure, with management shifting from the Indian Health Service (IHS) to tribes and the use of more managed care—neither of which changes have been well studied. New initiatives for quality monitoring are described, including the IHS's initiatives under the Government Performance and Results Act. The author also reviews initiatives on the treatment and control of specific medical conditions. The author offers 10 conclusions/recommendations with respect to disparities between medical care for AIANs and the general population.

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## ABOUT THE AUTHOR

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## **EXECUTIVE SUMMARY**

American Indians and Alaska Natives (AIANs) continue to suffer significant disparities in their health status, despite the efforts of the Indian health system to improve the quality of care in AIAN communities. This system is severely underfunded, resulting in concerns over the quality of health care delivered to this population. This paper is a review of the current status of the quality of health care for AIANs.

### **REVIEW OF QUALITY CARE FOR AIANS: FRAMEWORK**

A review of the quality of health care for AIANs is challenging given the diversity of the AIAN population and its multiple sources of health care. The Indian Health Service (IHS) reports that its service population is approximately 1.6 million AIANs (IHS, 2004), a number far lower than the total number of AIANs reported by the U.S. Census. Other potential sources of health care for AIANs include private health care/managed care, Medicare, Medicaid, Veterans Administration health care, public or community health systems, and in some cases their own traditional sources of care. Also, the management of Indian health programs has recently shifted from the IHS to tribes, so that over half of the current IHS budget is managed by tribal health programs. Although the majority of AIANs actually live in urban areas, only approximately 1 percent of the IHS budget is earmarked for urban Indian programs.

This review of the quality of health care for AIANs examines a variety of sources of data and information, most of them from the past five years. The selection of data is based on a conceptual framework that includes Donabedian's original three dimensions of quality: structure, process, and outcome.

### **SUMMARY OF FINDINGS**

#### **STRUCTURE OF CARE FOR AIANS**

The IHS gathers data on the structure of care for its user population and has systems in place to measure the quality of care. However, more data are needed on the impact the changing structure of the Indian health system is having on tribal management and the services provided in urban Indian health programs. The effectiveness of the structure of care for AIANs in IHS, tribal, and urban Indian health programs needs further study.

#### **PROCESS OF CARE FOR AIANS**

##### **Access to Care**

Even though the Indian health system serves as a valuable resource for the health care needs of AIANs, disparities in access and utilization persist for this population, especially

for those that live in urban areas. Compared to other racial and ethnic groups, AIANs seem to have less insurance coverage, less access, and lower utilization of services. Studies should be undertaken to determine the causes of these disparities; greater policy efforts to improve access to care for AIANs within and outside the Indian health system are also necessary.

### **Clinical Performance**

The IHS monitors the quality of clinical care by means of measures called for in the Government Performance and Results Act (GPRRA), as well as IHS's diabetes program, and some improvements have been documented. However, much clinical care is still of poor quality, and more data on the quality of care for health conditions other than diabetes are needed. (As stated previously, the IHS data only reflect care for the 1.6 million served by the Indian health system, and more studies are needed on the quality of care for urban AIANs.) The reasons for the disparities in clinical performance and on potential interventions and strategies to continue improvements in care should be studied.

### **OUTCOMES OF CARE**

Few studies report on improvements in outcomes of care for AIANs, but indicators of more general outcomes, including health status, reveal significant and persistent health disparities for AIANs. The disparities in health status for AIANs compared to other racial/ethnic groups are well documented and have persisted. More data are needed at the Indian health system level, at the level of specific programs or interventions, and on the outcomes of culturally appropriate care.

### **CONCLUSIONS/RECOMMENDATIONS**

This review finds that, although some improvements in care have been demonstrated, significant disparities are evident in the quality of care and health outcomes for AIANs. The author drew the following conclusions and makes these recommendations:

- Significant disparities in the quality of health care for AIANs exist in all dimensions of quality.
- Measuring the quality of health care for AIANs is challenging due to the diversity of the population and its potential sources of health care.
- More data are needed on the changing structure of the Indian health care system, including measuring the impact of the shift toward tribal management of health programs.

- More data are needed on the quality of health care and services in urban Indian health programs.
- More studies are needed to determine the reasons for continued disparities in access to care for AIANs and to develop strategies to improve access to needed health services.
- More data are needed on the clinical performance of the Indian health system and more efforts are needed to develop potential interventions and strategies to improve care.
- More studies are needed to document outcomes of specific quality improvement initiatives and programs.
- In terms of the ultimate outcome of Indian health care, more efforts are needed to reduce disparities in health status for AIANs.
- Research on health care quality in AIAN communities needs to be culturally appropriate.
- More data are needed on other dimensions of quality.
- A better understanding of research considerations for measuring the quality of health care for AIANs is needed.

#### **SUMMARY**

There clearly is a need for more data on the quality of health care for AIANs, and in particular for information that goes beyond a simple description of care, for example, direct testing of improvements in care or interventions and measurement of specific outcomes of care. The health disparities in the AIAN population compared to other groups have been clearly demonstrated, and improvements in the quality of care are needed urgently.



## **A REVIEW OF THE QUALITY OF HEALTH CARE FOR AMERICAN INDIANS AND ALASKA NATIVES**

### **INTRODUCTION**

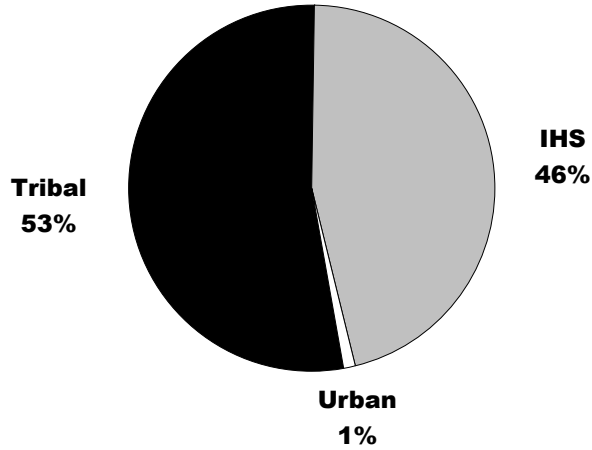
American Indians and Alaska Natives (AIANs) continue to suffer significant disparities in health status, despite the efforts of the Indian health system to improve the quality of care in AIAN communities. Currently, the federal government oversees a system of hospitals and clinics managed by the Indian Health Service (IHS), tribes, and urban Indian programs. Unfortunately, this system of health care is severely underfunded, resulting in concerns over the quality of health care delivered to this population. In addition, the facilities are mostly on or near reservations, when the majority of AIANs actually live in urban areas. Given the persistent disparities in the health status of AIANs and the diversity of, and likely varying quality of, their sources of health care, more efforts are needed to study and improve the quality of health care for AIANs. This paper is a review of the current status of the quality of health care for AIANs.

### **POPULATION AND SOURCES OF HEALTH CARE**

AIANs include approximately 2.5 million individuals who self-identify as AIAN alone, and an additional 1.6 million individuals who self-identify as AIAN in combination with one or more other races (U.S. Census 2002). Currently, there are 562 federally recognized AIAN tribes in the United States representing numerous distinct languages and cultures (Bureau of Indian Affairs 2003). Tribes are sovereign nations, so they determine their own criteria for membership, and, as a result, membership criteria vary widely, usually by differing degrees of Indian blood quantum.

The sources of health care for AIANs are also very diverse. AIANs from federally recognized tribes are eligible to receive health care in the Indian health system, which now consists of hospitals and clinics on or near Indian reservations. These hospitals and clinics are managed by either the IHS or, more recently, tribes under P.L.93-638, the Indian Self-Determination and Educational Assistance Act. The federal government has a trust responsibility to provide health care for AIANs from federally recognized tribes as a result of numerous treaties, court decisions, and legislation. Over the past two decades, the management of Indian health programs has shifted from the IHS to tribes, and over half of the current IHS budget is managed by tribal health programs (IHS 2003a; IHS 2004) (see Figure 1).

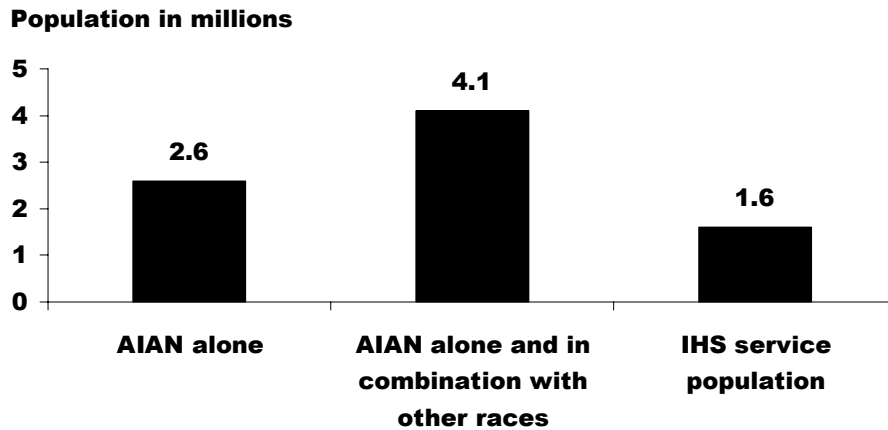
**Figure 1. Tribes manage the majority of the Indian Health Service budget.**



Source: IHS, FY2005 Budget Justification, February 2004.

The IHS reports that its service population is approximately 1.6 million AIANs (IHS 2004), which is far less than the total number of AIANs reported by the U.S. Census (see Figure 2). This difference is partly due to the location of most IHS facilities in rural areas, even though the majority of AIANs actually live in urban areas. The IHS has tried to address the needs of urban AIANs and currently funds 34 urban Indian health programs in cities with large AIAN populations. However, only approximately 1 percent of the IHS budget is earmarked for urban Indian programs (Forquera 2001).

**Figure 2. The U.S. Census estimates of the AIAN population are much greater than the population served by IHS.**



Sources: U.S. Census, 2000; IHS FY2005 Budget Justification, February 2004.

AIANs who are not from federally recognized tribes, do not have proof of descendency, do not live near Indian health facilities, or choose not to use the Indian health system must try to obtain health care from other sources. These include private health care and managed care plans, Medicare, Medicaid, Veterans Administration health care, public or community health systems, and, in some cases, their own traditional sources of care (Roubideaux 2002). However, eligibility and access are likely to be issues with some of these other providers.

## **REVIEW OF THE QUALITY OF HEALTH CARE FOR AIANs**

### **FRAMEWORK**

This review examines a variety of sources of data and information, including current IHS initiatives to measure quality, MEDLINE-indexed articles on AIAN health (found using MESH terms “Indian, North American” in combination with “Quality of Health care” and/or a variety of key issues and health conditions affecting AIANs), references in key articles, government reports and monographs, and other Indian health references. Given the author’s desire to review the current quality of health care for AIANs, mainly data and information from the past five years were studied.

Data for review were selected based on a conceptual framework that includes Donabedian’s original three dimensions of quality: structure, process, and outcome (Donabedian 1980). Measuring the quality of care by gathering data on the *structure* of the

health care system involves determining whether key characteristics or resources are in place. Gathering data on the *process* of care includes measuring the clinical performance of the system and its providers (including an assessment of the technical aspects of care, such as accuracy and timeliness of diagnosis, appropriateness of therapy, and whether there has been any overuse, underuse, or misuse of care). Measuring *outcomes* of care includes determining the effects of therapy, relief of symptoms, patient satisfaction with care, and other medical outcomes (Donaldson 1999). This paper reviews literature and existing data in all three of these dimensions of quality; however, most of the information available on AIAN health care represents process data or clinical performance in the Indian health system or in specific communities for specific conditions or health issues. Very few studies address outcomes of care as a result of specific interventions.

According to the recent Institute of Medicine publication *Crossing the Quality Chasm: A New Health System for the 21st Century*, improvements in the quality of health care are needed in six areas: safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity (Institute of Medicine 2001). The review for this paper also looked for data and information on quality in these six dimensions. However, given the relative lack of information on quality of health care for AIANs in general and specifically in most of these dimensions (particularly safety, timeliness, efficiency, and equity), this review did not focus on identifying data in each of these areas. A discussion of the need for more data is addressed later in this paper.

### **STRUCTURE OF CARE FOR AIANS**

Information on the structure of care for AIANs is available mostly through the IHS, an operating division of the Department of Health and Human Services. It provides health care services for AIANs from federally recognized tribes through a network of hospitals, clinics, and health stations located on or near Indian reservations. The IHS structure consists of an administrative headquarters in Rockville, Md., 12 area offices that serve portions of the IHS service area, and over 500 hospitals and ambulatory facilities on or near reservations. The IHS has implemented a variety of initiatives to monitor and assess the quality of health care delivered within its system: it uses quality improvement initiatives, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) process, and specific clinical initiatives. According to the IHS, in 1999, all of its IHS and tribal hospitals and eligible health centers were JCAHO accredited (IHS 1998).

A structure is also in place for measuring the quality of health care for AIANs who use IHS. The IHS conducts ongoing surveillance and tracks morbidity and mortality for common medical conditions. Every two to three years, the IHS publishes two data

volumes, *Trends In Indian Health* and *Regional Differences in Indian Health*, which are national and regional (respectively) collections of the most current IHS data on the health of AIANs. These publications document data on the structure of the Indian health system, including the number of facilities operated by the IHS and tribes, the accreditation status of Indian health facilities, population statistics on AIANs, and other administrative data, such as the number of ambulatory visits and hospitalizations overall and for specific diagnoses. The IHS uses a variety of data sources for these reports, including patient care statistics from the IHS Resource Patient and Management System, population data from the census, vital event statistics from the National Center for Health Statistics, and other community or federal data sources.

The process of monitoring the quality of care has become more complex due to recent changes in the Indian health system. Since the mid-1990s, more tribes have contracted or otherwise agreed to manage the health programs in their communities under P.L. 93-638, the Indian Self-Determination and Educational Assistance Act (Dixon and Roubideaux 2001). Therefore, the Indian health system is now composed of programs managed by the IHS, tribes, and urban Indian health programs. With the reorganization and a substantial reduction in the administrative infrastructure at the IHS headquarters and its area offices, there has been some concern about how the Indian health system would maintain the core function of public health surveillance as the system became more decentralized. The IHS has reaffirmed the need to continue to measure quality of care on a national level (IHS 1996; IHS 1999), but currently no studies exist comparing the quality of care in tribal vs. IHS health programs or the impact of the trend toward tribal management on the quality of care.

Although the structure of care and systems to measure quality are in place for IHS and tribal health facilities, the situation for urban Indian health programs is less clear and in need of further study. Title V of the Indian Health Care Improvement Act (P.L. 94-437) in 1976 gave IHS the authority to fund urban Indian organizations to provide outpatient health services directly or by referral in select cities with significant numbers of AIANs. In 2001, IHS funded 34 urban Indian health programs in 20 states. However, the types of services provided by these urban Indian health programs are highly variable; not all programs provide direct medical services, and some only provide referral services. Urban Indian programs also receive only a portion of their funding from the IHS and must seek other sources of funding and reimbursement. Other sources of coverage, such as Medicare, Medicaid, the State Children's Health Insurance Program, and private sources of care, play a significant role in the financial base of these programs (Forquera 2001).

However, no studies exist that evaluate the structure or services of these urban Indian health programs.

Measuring the quality of health care for urban AIANs is difficult. Urban Indian health program services are diverse; even determining the exact AIAN population of a large metropolitan area, as opposed to a reservation (AIANs tend not to live in defined areas or specific neighborhoods in cities) is difficult. Until recently no effort was made to measure routinely and systematically the quality of health care in urban Indian programs, and very little data exists on the quality of health care for urban AIANs. IHS recently funded an urban Indian epidemiology center to develop methods to measure and monitor the quality of health care in urban Indian health programs.

In summary, the IHS gathers data on the structure of care for its user population and has systems in place to measure quality. However, more data are needed on tribal management and urban Indian health programs. The effectiveness of the structure of care for AIANs in IHS, tribal, and urban Indian health programs needs further study. The next sections review available data on the quality of care for AIANs in terms of processes and outcomes of care.

## **PROCESS OF CARE FOR AIANS**

Most of the available data on the quality of health care for AIANs focuses on processes of care, in particular on access and clinical performance. The following sections review access to care and clinical performance for AIANs both within and outside the Indian health system. Sources include IHS data, national surveys, and local or regional research.

### **Access to Care**

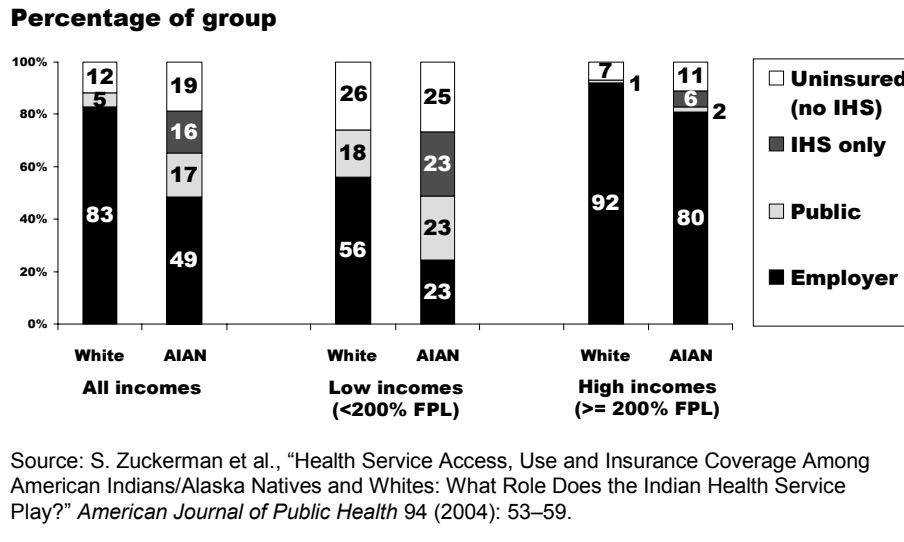
A number of studies have documented persistent disparities in access and utilization of health care by this population. The 1987 Survey of American Indians and Alaska Natives was a part of the National Medical Expenditure Survey and interviewed approximately 2,000 AIAN households where at least one person was eligible to use the IHS. The resulting sample of approximately 6,500 individuals was surveyed for sociodemographic information, use of health services, illnesses, and health expenditures. All respondents had IHS coverage by definition, but only 41 percent had some other type of public or private health insurance coverage, including 16 percent who had other public coverage (Medicare or Medicaid). Only 60 percent of adults were employed at some time during the year and over one-third were below the federal poverty level. Private insurance coverage increased with income and the majority of low-income individuals relied on IHS coverage as their only source of health care (Cunningham 1993).

In terms of health care utilization, 82 percent of the sample used health care services in 1987, and over 80 percent used the IHS. Those that used the IHS exclusively were in general poorer, lived in rural areas, and had less private insurance. However, more used both IHS and non-IHS sources than those using only non-IHS sources. In terms of use of services, persons with both IHS and non-IHS sources of care indicated use of more services of all types. This is consistent with recent interviews of tribal employees, which have found that, in general, AIANs with access to both IHS and private insurance tend to use both in a manner that maximizes choice while minimizing costs. They tend to use IHS for simple or routine medical care and private insurance coverage for specialty care (Dixon et al. 1997). The Survey of American Indians and Alaska Natives was the first large evaluation of health care access and utilization by AIANs who had IHS coverage. It provided important information on other sources of care and illustrated the central role that IHS coverage plays for AIANs and their likely underutilization of, or poor access to, other sources.

Although AIANs are included in other national studies on an incidental basis, the total sample size for this group is often very low and results are often included in the category of “other” when racial and ethnic groups are compared on indicators of quality. If these studies do not sample in rural areas or on Indian reservations, which is often the case, then the sample usually represents a primarily urban group that has varying or unknown sources of health care. In these cases it is often impossible to determine the influence of IHS coverage, because national surveys often do not include a question asking about IHS as a source of health care and it is unclear whether respondents would then include themselves in the uninsured category or various public coverage categories.

An analysis was recently conducted combining data on approximately 2,500 AIANs from 1997 to 1999 in the National Survey of America’s Families, a nationally representative survey of individuals under age 65 that oversamples low-income households and measures aspects of insurance coverage, access to care, utilization, and some quality of care measures. This analysis revealed lower socioeconomic status, poorer perceived health status, lower rates of employer insurance coverage, higher rates of public/state coverage, more problems with access, and lower utilization of health care for AIANs compared to non-Hispanic whites (Zuckerman et al. 2004). As shown in Figure 3, the disparities in sources of health care coverage were greater in AIANs with the lowest incomes.

**Figure 3. AIANs, especially those with low incomes, have less insurance coverage and higher rates of no insurance.**



In summary, even though the Indian health system serves as a valuable resource for the health care needs of AIANs, disparities in access and utilization persist for this population, especially for those who live in urban areas. Compared to other racial and ethnic groups, AIANs seem to have less insurance coverage and poorer access and utilization of services. More studies are needed to determine the causes of these disparities and more policy efforts are needed to improve access to care for AIANs within and outside the Indian health system.

### Clinical Performance

The IHS routinely gathers data on clinical performance as a part of its quality improvement efforts. Other data on the quality of clinical care for AIANs are available from a number of non-IHS sources, including national surveys and investigator initiated research in regional or community sites. This section reviews data on the quality of care as measured by the IHS and by non-IHS sources.

#### *Indian Health Service*

The IHS has recently worked to measure the quality of health care, in response to congressional direction through the Government Performance and Results Act (GPRA). The GPRA requires that, each year, federal agencies define and report on a set of indicators to measure performance on specific targets and goals. The GPRA indicators used by IHS include information on clinical performance (prevention and treatment),

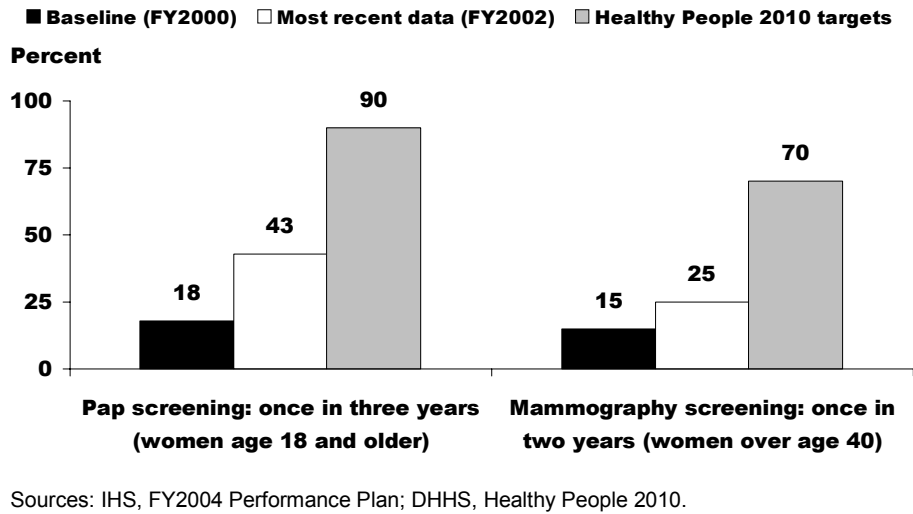
quality of care, and administrative/infrastructure functions. The IHS generates data for clinical performance indicators using the Resource and Patient Management System, its main clinical data system (IHS 2003b). After clinical information is entered into the system, local program and facility reports are generated and data is forwarded to the IHS area offices and headquarters for further analysis.

The GPRA+ Clinical Indicator Reporting System includes data on processes and outcomes of care for a variety of conditions, including diabetes, cardiovascular disease, hypertension, obesity, cancer screening, and mental health. All of the GPRA indicators relate to the four strategic goals of the IHS:

- Build healthy communities;
- Achieve parity in access by 2010;
- Provide compassionate, quality health care;
- Embrace innovation.

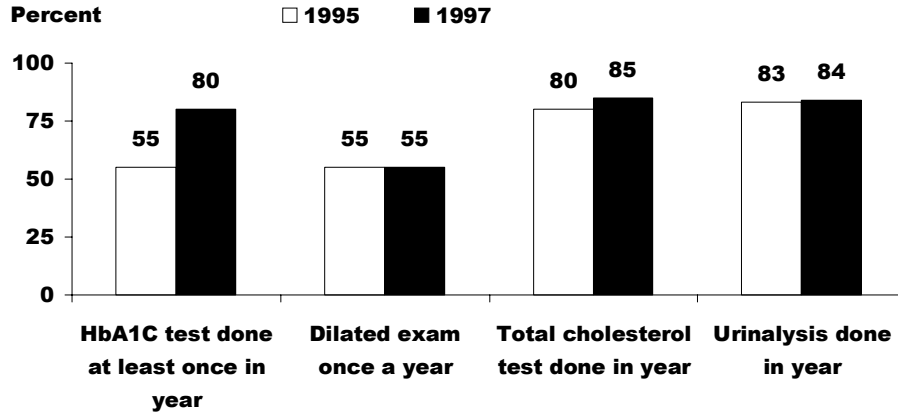
Since 1999, the IHS has reported results on up to 32 indicators and in fiscal year 2002 met targets on 25. For example, improvements have been documented each year since 1997 in diabetes care, blood pressure control, cancer screening, well-child visits, alcohol and substance abuse treatment, access to dental services, and prevention indicators such as vaccinations, injury rates, and tobacco control plans (IHS 2003c). Even though the IHS has met its own targets for most of the GPRA clinical performance indicators and has documented improvements, results for most indicators still fall below national targets. For example, IHS rates of screening for pap tests and mammography have improved but remain much lower than Healthy People 2010 target levels (Department of Health and Human Services 2000) (see Figure 4).

**Figure 4. IHS GPRA indicators have improved over time, but remain below target levels.**



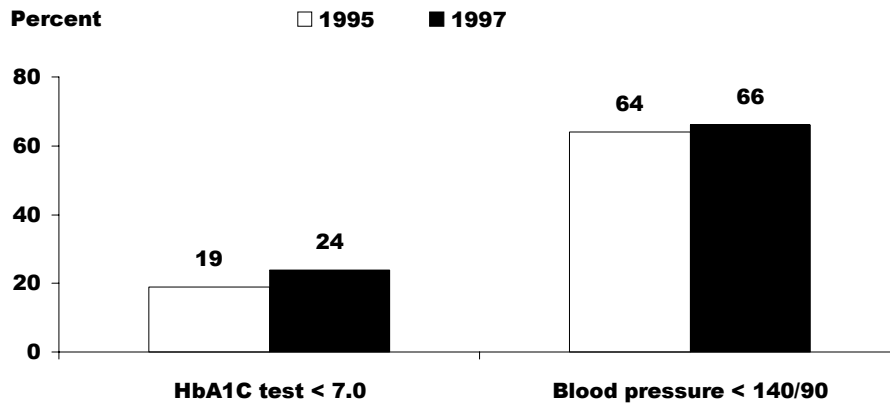
The IHS, recognizing the need to address the growing problem of diabetes in the American Indian population, established its National Diabetes Program in 1979 (Mayfield et al. 1994). It now serves as an example of a program for measuring the quality of care in the Indian health system: the program model has been recognized as one of the best in the nation and as even more comprehensive than some mainstream managed care diabetes data efforts. The program’s activities include setting standards of care for patients with diabetes, providing resources and education, developing patient education materials, implementing staged diabetes management to encourage community involvement in diabetes care, and evaluating the quality of diabetes care through the annual IHS Diabetes Care and Outcomes Audit. This annual medical record review helps monitor adherence rates to standards of diabetes care. Several studies have shown improvements in the quality of diabetes care in the IHS in general and as a result of specific interventions, such as implementation of specific program elements (Gohdes et al. 1996; Acton et al. 1993), and by using national measures (Acton et al. 2001) (see Figure 5). Figure 6 illustrates that, even though results are often better than some non-Indian health diabetes programs, improvements in processes of care and outcome measures are still needed.

**Figure 5. Adherence to diabetes care guidelines has improved over time for most indicators.**



Source: K. J. Acton et al., "Applying the Diabetes Quality Improvement Project Indicators in the Indian Health Service Primary Care Setting," *Diabetes Care* 24 (2001): 22–26.

**Figure 6. While outcomes of diabetes care have improved over time, further improvements are needed.**



Source: K. J. Acton et al., "Applying the Diabetes Quality Improvement Project Indicators in the Indian Health Service Primary Care Setting," *Diabetes Care* 24 (2001): 22–26.

The IHS monitors the quality of clinical care (by using the GPRA and its diabetes program); however, more data on the quality of care for health conditions other than diabetes are needed. In addition, the IHS data only reflect care for the 1.6 million served by the Indian health system. Even though improvements have been documented for some

GPRA indicators and the diabetes audit, many of the results are still far below recommended levels. More studies are needed on the reasons for the disparities in clinical performance and on potential interventions and strategies to continue improvements in care. The next section reviews other sources of data on the quality of clinical performance for AIANs.

#### *Other Sources of Data on Clinical Performance*

In addition to the data gathered by the IHS, a number of other studies have reported on the quality of clinical care for AIANs in a variety of settings. Efforts to measure the quality of health care for AIANs nationally outside of the IHS are limited by the difficulty in gathering representative data and the problem of varying sources and types of care.

Some national studies that focus on racial and ethnic disparities in the quality of care incidentally find AIANs in their sample and report on this group if a sufficient sample size exists or if they are able to accurately combine several years of data. Even though these studies are not designed to be nationally representative of AIANs, their results help inform future studies. In a study of the quality of care among Medicare+ Choice enrollees using enrollment data from the Centers for Medicare and Medicaid and individual level Health Plan Employer Data and Information Set (HEDIS) measures of quality and access to care, results were compared among whites, blacks, Asian Americans, Hispanics, and Native Americans. Native Americans were less likely to receive a mammogram and those with diabetes were less likely to have their LDL cholesterol checked and to have HbA1C testing. Native Americans were more likely to have an eye exam if they had diabetes and control of high blood pressure, but less likely to have access to ambulatory/preventive care (Virnig et al. 2002). However, the numbers of Native Americans in the sample were small for most measures, and the only significant results ( $p < 0.01$ ) were for receipt of mammograms and access to ambulatory and preventive care. Yet the trends are consistent with other studies showing disparities in the quality of care for AIANs.

Another national source of data on the quality of health care for AIANs is the Behavioral Risk Factor Surveillance System (BRFSS), an ongoing annual random telephone survey conducted by the Centers for Disease Control. This survey measures adult health behaviors, includes a few measures of quality of care, and includes a small number of AIANs in its sample each year. In one published study combining AIAN results from 1992 to 1995, AIANs were more likely to report perceived health status as fair or poor and that cost had stopped them from visiting a doctor in the past year (Denny and Taylor 1999). In a study of the years 1997 to 2000, AIAN women were more likely to

report never having a pap test compared to other racial/ethnic groups (Denny et al. 2003). A study of preventive health care among 1,273 rural American Indian adults using an adapted BRFSS survey was conducted in New Mexico and found high rates of receipt of preventive services such as routine health checks (72.8 percent), blood pressure checks (85 percent), pap smears (88.3 percent), clinical breast exams (79.5 percent), and mammograms (75.6 percent) (Gilliland et al. 1999). However, less than half had ever had a cholesterol check, and among those age 50 or older, only 60 percent had an influenza immunization and only 30 percent ever had a pneumococcal vaccination. The BRFSS is a telephone survey and therefore misses the significant proportion of the AIAN population that does not have telephones, especially in rural areas, and does not provide information on the source of health care (i.e., IHS vs. other).

Some studies have reviewed general preventive care for AIANs, such as screening for certain health conditions. In a study of the frequency of preventive care services for 550 older urban AIANs in a primary care urban Indian clinic, low rates of adherence to screening guidelines “ever” were found for most measures, including mammograms (56 percent), fecal occult blood testing (37 percent), audiometry (33 percent), visual acuity testing (50 percent), smoking cessation counseling (50 percent), and immunizations [pneumococcal (22 percent) and influenza (49 percent) vaccinations]. Those who adhered to recommendations were more likely to be female, have insurance, and to have more health problems and medications (Buchwald et al. 2001).

Most of the research data on quality of health care for AIANs examine care for specific health conditions that disproportionately affect this population. For example, cardiovascular disease (CVD) is the number one cause of death for AIANs (IHS 1998; Lee et al. 1998) and the incidence of CVD is now at least two times greater than rates in the U.S. population (Howard et al. 1999). The Strong Heart Study is a longitudinal study of the risk factors of CVD in three distinct American Indian populations and has provided important information on the morbidity and mortality from CVD in American Indians. Much of the literature from the Strong Heart Study focuses on risk and contributing factors to CVD, but some studies have documented improvements in care of CVD risk factors and clinical performance comparable to the general U.S. population (Hayslett et al. 2001; Welty et al. 2002). However, other studies document disparities in care for CVD and its risk factors. A study using IHS diabetes program data demonstrated regional variation in the level of control of CVD risk factors in people with diabetes (Rith-Najarian et al. 2002). Another study, of the prevalence and control of hypertension among participants in the Inter-Tribal Heart Project in Minnesota and Wisconsin, found that only 28 percent of those with hypertension had blood pressures below 140/90 (Lamar Welch et al. 2002).

A few national studies on the quality of CVD care compare results among ethnic groups and incidentally include AIANs in their samples. In a study of clinical outcomes in a national registry of myocardial infarction, AIANs, compared to whites, presented later after the onset of symptoms of an acute myocardial infarction, tended to use ambulance services less often, and were less likely to undergo primary angioplasty or bypass surgery. AIANs were more likely to receive thrombolytic therapy, but the time from arrival at hospital until initiation of thrombolytic therapy was greater. The time from hospital arrival to balloon inflation in those having angioplasty was prolonged as well (Canto et al. 1998). In another study of administrative data from over 160 nongovernmental, not-for-profit health care facilities in the U.S., clinical outcomes associated with coronary artery bypass grafting were reviewed for 155 Native Americans and compared with other ethnic groups. The adjusted risk for in-hospital death was higher for Native Americans compared to all other ethnic groups, and Native Americans tended to be younger, male gender, and to have their surgery at low-volume, rural hospitals. There were no differences in length of stay after surgery (Nallamotheu et al. 2001). Although the Strong Heart Study and other Indian health data suggest some improvements in care for CVD and its risk factors, these other non-IHS studies suggest significant disparities in the care of AIANs with CVD, and more studies are needed.

Cancer is the second leading cause of death for AIANs, and for some types of cancer, AIANs have higher incidence rates than the general population and/or have poorer survival rates due to later presentation at diagnosis (Burhansstipanov 2001). A number of studies document low rates of pap and mammography screening rates in AIANs compared to other racial and ethnic groups (Agency for Health Care Policy and Research 1991; Gilliland et al. 2000; Coughlin et al. 1999; Giroux et al. 2000; Risendal et al. 1999a; Risendal et al. 1999b; Benard et al. 2001). These data confirm the need for improvements in screening for breast and cervical cancer in AIAN women.

Few studies exist on the quality of care for AIANs with other less common medical conditions and most studies in the literature only document the prevalence and risk factors for specific diseases. Rarely, data on quality of care or clinical performance are reported. For example, rheumatoid arthritis has been reported to occur at a higher rate in the Pima Indians than the general U.S. population (Hirsch et al. 1998). Self-reported arthritis has been found to occur at a high rate in a Chippewa community, with more than half of these patients having no mention of a diagnosis of arthritis or diagnostic laboratory results upon subsequent chart review (Elliott et al. 2000). In a study of urban American Indians with arthritis, despite reports of chronic pain, those with inflammatory arthritis appeared to be undertreated (Kramer et al. 2002). In a study of infant health using the

National Center for Health Statistics data from 1989 to 1991 for urban areas, 14 percent of all AIAN births were to women who received inadequate care during pregnancy, and rates of inadequate prenatal care varied by region and were higher than for whites (Grossman et al. 2002). In a related study, inadequate prenatal care was higher for rural than for urban mothers of AIAN infants, and both were higher than for whites (Baldwin et al. 2002). Other than these few examples, studies that measure clinical performance for AIANs with other illnesses and conditions are lacking.

Overall, in terms of process of care, both IHS and non-IHS sources of data document that although some improvements have occurred, significant disparities in access and clinical performance of care exist for AIANs for a variety of health conditions and for care in a variety of settings. Even though most of the data on quality of care for AIANs focus on processes of care, documentation of disparities in clinical performance for many more health conditions, and reasons for these disparities, is needed.

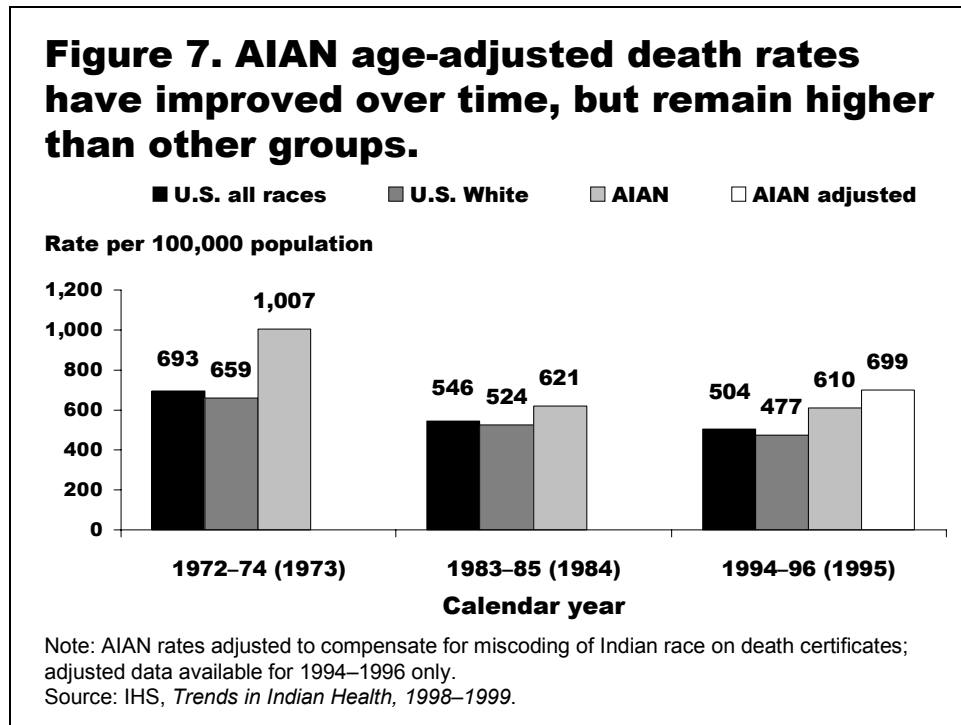
### **OUTCOMES OF CARE**

Many of the studies on the quality of care for AIANs report on process data, but few report outcomes of care as a result of specific interventions for specific conditions. The IHS conducts ongoing surveillance of the health status of its user population and tracks morbidity and mortality for common medical conditions. The IHS data on health status could be considered as data on outcomes of care for the Indian health system in general; the IHS uses it to make programmatic changes. This section first reviews data on the general health status of AIANs as the ultimate outcome of health care in the Indian health system, and then summarizes the few studies available on specific interventions that have resulted in better outcomes of care for AIANs.

#### **Outcomes of Care: Health Status indicators**

The IHS publishes *Trends in Indian Health* to provide information on general outcomes of care, including natality and infant/maternal mortality statistics, and general mortality statistics, including leading causes of death and mortality from a variety of common conditions. The IHS compares mortality rates for specific conditions over time and with the U.S. All Races population (IHS 1998). In general, mortality rates for AIANs have improved, but, as shown in Figure 7, significant health disparities still exist. Age-adjusted death rates for AIANs of all age groups decreased by 31 percent between the periods 1972–1974 and 1994–1996, but are still 39 percent higher than the All Races rate for 1995. Infant mortality decreased by 58 percent for the same comparative periods, but is still 22 percent higher than the U.S. All Races rate. Life expectancy at birth increased from 63.5 years (1972–1974) to 71.1 years (1994–1996), but it is still 4.7 years less than

the U.S. All Races life expectancy. In terms of specific conditions, age-adjusted death rates have improved but are still greater than the U.S. All Races rates for pneumonia and influenza, chronic liver disease and cirrhosis, gastrointestinal disease, alcoholism, injuries, suicides, accidents, and tuberculosis. However, age-adjusted death rates are increasing for malignant neoplasms, diabetes, cardiovascular disease, and HIV. A recent review of IHS data highlighted higher mortality rates in AIAN men compared to women, despite lower utilization of health services (Rhoades 2003).



The only population-based study of the health status of urban AIANs was conducted in Washington state using state vital event statistics and U.S. Census estimates. It revealed that significant health disparities existed between urban AIANs and urban whites. Urban AIANs experienced higher rates of low birth weight and infant mortality, higher risk factors for poor birth outcomes, and higher mortality rates for every age group except the elderly (Grossman et al. 1994).

Other national sources of data on the health status of AIANs include the health status indicators of the Healthy People 2000 initiative. In a report reviewing 17 indicators from 1990 to 1998, six indicators did not improve for AIANs, including the percent of low-birth-weight infants, total age-adjusted death rates, and age-adjusted death rates for stroke, lung cancer, female breast cancer, and suicide (Keppel et al. 2002).

One significant problem with data on mortality rates is the problem of misclassification of AIAN race on death certificates, which results in underestimates of mortality rates. The IHS recently documented these misclassifications to range from 1.2 percent to 30.4 percent of all deaths reported among IHS area offices, and has found higher mortality rates for AIANs after adjustment for this misclassification (IHS 1998). The IHS now routinely adjusts its mortality rates, and in many cases, previously reported improvements in mortality-rate disparities (between AIANs and the U.S. All Races population) have been reduced—or the disparities have been shown to be worse than first thought.

Some studies have measured hospitalizations for certain conditions as an indicator of health status or outcomes of care. For example, while annual hospitalizations for AIANs with infectious diseases decreased by 31 percent from 1980 to 1994, the proportion of all hospitalizations that were due to infectious diseases increased by 30.1 percent, and age-adjusted hospitalization rates for AIANs were higher than the U.S. general population for tuberculosis, cellulitis, oral infections, and upper and lower respiratory infections (Holman et al. 2001). AIAN hospitalization rates varied regionally, and more studies are needed to explain these differences. Infectious disease hospitalizations for AIAN infants have decreased, but still account for approximately half of all hospitalizations in this age group, with lower-respiratory infections accounting for most of these hospitalizations (Holman et al. 2003). These studies highlight that although the burden of infectious diseases has decreased in AIAN communities, disparities still exist in hospitalization rates, and further studies are needed to determine the reasons. Another study using California hospital discharge data linked to IHS user data reported higher rates of hospitalization and avoidable hospitalization for AIANs compared to the general population (Korenbrodt et al. 2003).

The disparities in health status for AIANs compared to other racial/ethnic groups are well documented and have persisted. With health status as the ultimate outcome of care, more studies are needed to understand the causes of disparities in the quality of care and to determine the best interventions and strategies to reduce health disparities for AIANs.

### **Other Outcomes of Care**

As stated above, outcomes of care include effects of therapy, relief of symptoms, patient satisfaction, and other medical outcomes (Donaldson 1999). Outcomes of care are often evaluated as short-term or intermediate outcomes (e.g., improvements in risk factors and their control for health conditions), because long-term outcomes (e.g., reduction in disease or death) may not be measured for months, years, or decades. This section reviews a few studies that have attempted to measure improvements resulting from specific interventions.

Few studies have focused on measuring specific outcomes as a result of interventions or treatments for AIANs with chronic disease. The Diabetes Prevention Program, which included a subsample of AIANs, showed a significant reduction in the risk of diabetes as a result of lifestyle changes, and to a lesser extent, medication (Knowler et al. 2002). This study points to the need to incorporate more diabetes prevention activities in Indian health programs. A staged diabetes management intervention in one IHS area resulted in a reduction in the incidence of lower-extremity amputations (Rith-Najarian et al. 1998). The IHS National Diabetes Program is currently developing mechanisms to measure the incidence of the long-term complications of diabetes using IHS patient data.

The medical literature only includes a few studies of the effectiveness of diabetes education programs or services. The Strong in Body and Spirit Program of the Native American Diabetes Project provides diabetes education related to lifestyle issues, and has culturally appropriate components. It has been shown to produce improvements in glycemic control and weight after one year (Gilliland SS et al. 2002). For the Native American Diabetes Project, results for its diabetes education program were measured; satisfaction and retention were high for the various sites and participants favored culturally appropriate elements (Griffin et al. 1999). In a formal approach to nutrition counseling on two midwestern Indian reservations, improvements in weight and fasting glucose were documented after an average of one year (Stegmayer et al. 1988). A midpoint review of outcomes of the Zuni Diabetes Prevention Program revealed trends in improvements in body-mass index, dietary intake, lower pulse rates, and glucose/insulin ratios (Teufel and Ritenbaugh 1998). Because these data represent small studies in small communities, more data are needed on the effectiveness of specific interventions. One challenge with AIAN care is that among the 562 tribes there are over 300 distinct languages and cultures and this diversity requires that diabetes education materials be adapted to the local tribe or culture (Burke 2001; Roubideaux et al. 2000; Bochenski and Longstaff 2002).

Several studies report on culturally appropriate interventions to increase screening rates for breast and cervical cancer. Education—by lay health advisors (Burhansstipanov et al. 2000); nurses and other health care providers (Sellers et al. 2002; Brant et al. 1999); other interventions and incentives (Dignan et al. 1998; Stillwater 1999); and a Talking Circle format for cancer education (Hodge et al. 1996)—has been shown to improve knowledge and screening rates. These interventions are evidence of the types of education and activities that might help other programs improve their rates of pap and mammogram screenings. The IHS has worked to improve results for a few GPRA indicators with poor baselines; its Colorectal Cancer Screening Initiative includes provider and patient

education materials (IHS 2003d, IHS 2003e), for example, but it will take years to assess improvements in care and whether these improvements are associated with lower rates of death from colorectal cancer.

Finally, several reviews in the medical literature discuss the importance of performing medical care and conducting health research in a culturally appropriate manner. Sensitivity to the patient's cultural beliefs, values, and practices is felt to help facilitate the provision of quality health care, and cultural misunderstanding or insensitivity is likely to result in noncompliance or failure of treatment (Sanchez et al. 1996). However, few studies formally measure the effectiveness of culturally appropriate interventions. Culturally appropriate aspects of a program are often described, and results of program activities reported, but usually without comparison to other types of programs or usual care. Many of the interventions for the health conditions described previously have addressed the issue of cultural appropriateness in some manner, but more research is needed to determine if culturally appropriate care is associated with better outcomes.

In summary, indicators of general outcomes of care, including health status, reveal significant and persistent health disparities for AIANs. More studies are needed to test specific health care interventions and their outcomes, in order to determine the best quality of care for this population. More data are needed at the Indian health system level, at the level of specific programs or interventions, and on the outcomes of culturally appropriate care.

## **CONCLUSIONS/RECOMMENDATIONS**

Although some improvements in care have been demonstrated, significant disparities are evident in the quality of care and health outcomes for AIANs. This review generated the following conclusions and recommendations:

- **Significant disparities in the quality of health care for AIANs exist in all dimensions of quality.**

This review found disparities in all three of Donabedian's dimensions of quality (structure, process, outcomes). Even though most data were focused on processes of care in the Indian health system and some improvements were documented, many other studies revealed evidence of disparities compared to other racial/ethnic groups and compared to national benchmarks.

- **Measuring the quality of health care for AIANs is challenging due to the diversity of the population and its potential sources of health care.**

Most data focus on the Indian health system, but many AIANs access other sources of health care. Because services vary greatly throughout the IHS and among urban Indian health programs, data from small program-specific studies may not be generalizable or even comparable to other programs. Even the data from the IHS only applies to its user population. Regional or tribal differences in care also need further examination.

- **More data are needed on the changing structure of the Indian health care system, including measuring the impact of the shift toward tribal management of health programs.**

Now that tribes manage over half of the IHS budget and the Indian health system is becoming more decentralized, more efforts are needed to monitor and assess the quality of health care as the system changes, and among differing types of programs. Although many assume that the transition toward tribal management will result in better health care, whether outcomes and quality of care do indeed improve under tribal management should be studied.

- **More data are needed on the quality of health care and services in urban Indian health programs.**

Even though the majority of AIANs live in urban areas, the IHS funds only 34 urban Indian programs across the country. Funding levels and services vary, and there is no organized system for measuring the quality of care nationally. More studies of process and outcomes measures of care are needed to compare urban Indian health programs with each other and with other Indian and non-Indian health programs.

- **More studies are needed to determine the reasons for continued disparities in access to care for AIANs and to develop strategies to improve access to needed health services.**

AIANs report lower rates of insurance and rely more on public/state sources of care. For many AIANs, the IHS is their only source of health care. More information is needed on how AIANs access both IHS and non-IHS sources, and whether the quality of care differs. Further efforts are needed to develop strategies to improve access to care.

- **More data on the clinical performance of the Indian health system and more development of potential interventions and strategies to improve care are needed.**

The IHS should continue to improve its measurement of process of care indicators and assessment of clinical performance on a number of indicators against its own targets. The IHS National Diabetes Program's approach to reviewing care on an annual basis can be used as a model for measuring the quality of care for other chronic diseases.

- **More studies are needed to document outcomes of specific quality improvement initiatives and programs.**

More information on best practices and more data on the outcomes of specific quality improvement initiatives are needed for a variety of health conditions.

- **In terms of the ultimate outcome of Indian health care, more efforts are needed to reduce disparities in health status for AIANs.**

Despite improvements, the IHS continues to document disparities in health status indicators for AIANs compared to the U.S. All Races population. More work is needed to understand the reasons for these disparities and to implement strategies to reduce them. Rather than continuing to describe these disparities, more interventions are needed to reduce and ultimately eliminate them.

- **Research on health care quality in AIAN communities needs to be culturally appropriate.**

The medical literature does contain several articles about the importance of conducting culturally appropriate research in Indian communities. Researchers must understand the importance of collaboration and participation of tribes and community members throughout the research process, tribal approvals of research, confidentiality of participants especially in a small community, and defining the potential benefits of the research in a manner that is clear to the tribe and community members (Norton and Manson, 1996; Sharp and Foster 2002). Culturally sensitive, participatory research is felt to contribute to more accurate, valid findings that are more culturally relevant and beneficial (Davis and Reid 1999).

- **More data are needed on other dimensions of quality.**

Future studies should also focus on measuring quality in the six Institute of Medicine dimensions (safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity).

Measuring these more specific dimensions of quality will help provide more information on disparities in quality of care and inform future interventions to improve quality.

- **A better understanding of research considerations for measuring the quality of health care for AIANs is needed.**

Researchers need to understand the special methodological issues and challenges in conducting research on health care for AIANs. Given the diversity of the population and the sources of their health care, researchers need to be careful to not mistakenly generalize their findings to other communities or health programs. One strategy is to oversample multiple tribes or health programs in national surveys or data efforts. National studies can choose to oversample in specific Indian communities or reservations, but the cost of this type of sampling strategy is potentially high and choices regarding which communities or tribes to oversample are complex, since there are 562 tribes representing over 300 distinct languages and cultures. The diversity of the AIAN population and the diversity of its potential sources of health care make any studies of health care quality a challenge in both design and interpretation. Methodological challenges can also include defining the exact AIAN population of reference or sample due to the significant diversity among AIANs and their health care settings. Researchers must carefully try to define and understand their population of reference, especially when calculating rates or comparing results with other populations. For example, in a single community, the population of reference for a study could be the clinic user population, the tribal membership count, or census estimates of the population in that particular area or county. Researchers must also carefully consider if their measures are appropriate, both scientifically and culturally. Some surveys may require adaptation to the local culture and/or translation, and some may need to ask additional questions about IHS services. The issue of multiple potential sources of care must be addressed as well.

#### **SUMMARY**

There clearly is a need for more data on the quality of health care for AIANs and, in particular, information beyond just a simple description of care. More studies are needed that can directly test improvements in care or interventions and that measure specific outcomes of care. The health disparities in the AIAN population compared to other groups have been clearly demonstrated, and improvements in the quality of care are needed urgently.

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**#753** *Disparities in Patient Experiences, Health Care Processes, and Outcomes: The Role of Patient–Provider Racial, Ethnic, and Language Concordance* (July 2004). Lisa A. Cooper and Neil R. Powe. According to the authors, patients treated by doctors of the same racial or ethnic background generally experience greater satisfaction with their care and, in many cases, better outcomes, a new report concludes. The findings highlight the need for greater minority representation within the health care workforce.

**#746** *A State Policy Agenda to Eliminate Racial and Ethnic Health Disparities* (June 2004). John E. McDonough, Brian K. Gibbs, Janet L. Scott-Harris, Karl Kronebusch, Amanda M. Navarro, and Kimá Taylor. The authors of this report detail a wide range of state initiatives to reduce racial and ethnic disparities in health and health care, along with practical strategies for improving insurance coverage, access to care, and medical outcomes for minority Americans.

**#726** *Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals* (May 2004). Romana Hasnain-Wynia, Debra Pierce, and Mary A. Pittman. The authors of this study find that, although the majority of hospitals are now collecting information on patients' race, ethnicity, and primary language, many say there are drawbacks, including problems with accuracy and confidentiality. The authors recommend standardizing the data collection process—relying on patients to provide information and giving them a uniform rationale for doing so.