

Data Needs and Challenges to Advance Health Equity for American Indians and Alaska Natives

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The Kaiser Family Foundation

- **Non-profit, private organization dedicated to providing information and analysis on health care issues to policymakers, the media, the health care community, and the general public**
- **Not associated with Kaiser Permanente or Kaiser Industries**
- **Essential roles**
 - Producer of policy analysis and research
 - Clearinghouse of news and information for the health policy community
 - Public health information campaigns
- **Recent publications**
 - Health Coverage and Care for American Indians and Alaska Natives, October 2013
 - The Role of Medicare and the Indian Health Service for American Indians and Alaska Natives: Health, Access and Coverage, December 2014

American Indians and Alaska Natives face persistent disparities in health coverage, access, and outcomes.

- Non-elderly American Indians and Alaska Natives are more likely to be uninsured than the overall US non-elderly population.
- American Indians and Alaska Natives have higher rates of physical and mental health problems.
 - More likely than overall population to report fair or poor health, being overweight or obese, having diabetes or cardiovascular disease, and frequent mental distress.
 - Disparities exist across the age spectrum.
- Disparities reflect a complex and interrelated set of individual, provider, health system, societal, and environmental factors.

Data are essential for advancing health equity efforts.

- Identifying disparities and the circumstances in which they occur
- Understanding the factors driving disparities
- Developing and targeting interventions and innovations
- Measuring progress and the impact of policy changes and interventions
- Enforcing civil rights protections

“Effective data collection is the linchpin of any comprehensive strategy to eliminate racial and ethnic disparities in health.”

-Tom Perez, Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare, March 2002

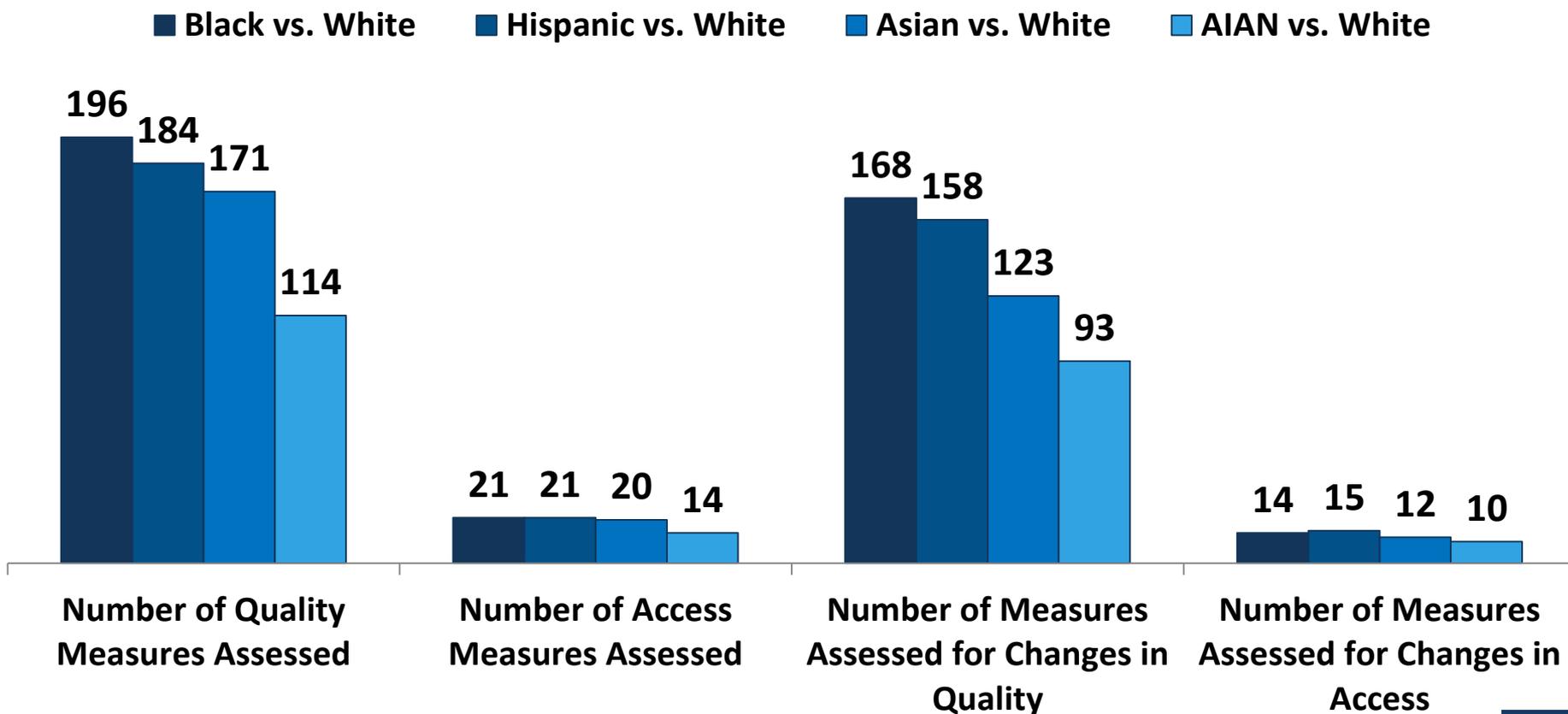
Data are key for informing current policy questions.

- To what extent are eligible AIANs enrolling in the ACA coverage expansions? How does this compare to other groups? What enrollment barriers do they face?
- Are eligible AIANs receiving the benefits and protections they are entitled to under Medicare, Medicaid and Marketplace coverage?
- How are the ACA coverage expansions impacting access to and utilization of care for AIANs? How do these experiences compare to other groups? What key access barriers do they face?
- How many AIANs are participating in the new delivery systems intended to improve the coordination of health care, including ACOs and the federal-state demonstrations for dual-eligibles?

Figure 5

There remain significant gaps in data to measure disparities for American Indians and Alaska Natives.

Number of quality and access measures assessed by group for 2013 National Healthcare Quality and Disparities Reports:



Data available today come from a range of sources and vary in their scope and comprehensiveness.

- Sources of data
 - Public population and health surveys (CPS, ACS, BRFSS, NHIS)
 - Federal and state administrative datasets
 - Private surveys and qualitative studies
 - Health plan/health system data
- Key characteristics of data
 - Accuracy and reliability
 - Representativeness
 - Timeliness
 - Comparability (across sources and over time)

Figure 7

Current Status of Data for American Indians and Alaska Natives: Population and Health Surveys

Survey	Identifies AIAN by race?	Identifies tribal affiliation?	Identifies IHS users?	Level of analysis supported for AIAN
American Community Survey	Yes	Yes	Yes (as coverage source)	National and most states
Current Population Survey	Yes	No	Yes (as coverage source)	National and limited number of states
National Health Interview Survey	Yes	No	Yes (as coverage source)	National
Behavioral Risk Factor Surveillance System	Yes	No	Yes (as coverage source, as of 2013)	National and some states
Medical Expenditure Panel Survey	Yes	No	Yes (as state health benefit program)	National
Survey of Income and Program Participation	No	No	No	N/A
Medicare Current Beneficiary Survey	Yes	No	No	National

Current Status of Data for American Indians and Alaska Natives: Population and Health Surveys

- Advantages

- Representative data for study population
- Self-reported racial/ethnic data
- Cover broad range of demographic, coverage, and health access and use topics
- Allows for examination of trends over time

- Limitations

- Small sample sizes restrict ability to conduct state and sub-state level and sub-group analyses for AIANs
- Few surveys provide information on tribal affiliation
- Lack of standardization in racial and ethnic categories across surveys
- Data are often lagged
- Potential gaps in data

Current Status of Data for American Indians and Alaska Natives: Administrative Data

- Medicaid/CHIP
 - States collect data on race/ethnicity; aggregated at federal level
 - Voluntary reporting contributes to gaps in data
 - Definitions, categories, and data collection timing and methods vary across states
- Medicare
 - Limited race/ethnicity data in enrollment files and has been found to not match self-identified race, particularly for Hispanics, Asians/Pacific Islanders, and AIANs
- Marketplaces
 - Federally-facilitated Marketplace requests race, tribal affiliation, use of IHS services
 - State-based Marketplaces vary in data collection
 - Voluntary reporting contributes to gaps in data

A variety of potential strategies could increase the strength of data for American Indians and Alaska Natives.

- Pooling multiple years of data to increase sample sizes
- Over-sampling of American Indians and Alaska Natives
- Improved self-reporting of race/ethnicity in administrative datasets
- Greater standardization of racial and ethnic categories across data sources and collection of tribal affiliation and IHS use
- Increases in private and/or qualitative studies focused on AIAN
- Enhanced efforts to report racial/ethnic data by health plans and health systems

There are several initiatives under way that may improve data availability, but key challenges remain.

- Initiatives to Strengthen Racial/Ethnic Data collection
 - Section 4302 of ACA: Requires Secretary of HHS to develop data-collection standards for race, ethnicity, sex, primary language and disability status
 - Transformed Medicaid Statistical Information System
 - Enhanced reporting of data by race/ethnicity through health care plans as part of quality and performance initiatives
- Key Challenges Remain
 - Costs
 - Resource limitations
 - Privacy concerns

Looking Ahead

- Data will remain essential for understanding disparities, developing and targeting initiatives and interventions, and measuring progress.
- Data collection will improve but it will take time.
- Targeted efforts will be needed to improve data availability for American Indians and Alaska Natives.
- Increased focus on quality and performance provides a key opportunity to strengthen data collection and reporting efforts.