EDITORIAL

Addressing Disparities in the Health of American Indian and Alaska Native People: The Importance of Improved Public Health Data

Chronic diseases and injuries are now the greatest threat to health in the 21st century.[1] Racial and ethnic disparities in health status, largely attributable to chronic diseases, are widely recognized as a priority public health and civil rights challenge.[2] The articles in this supplement of the *American Journal of Public Health* document the substantial burden of disease borne by American Indian and Alaska Native (AI/AN) people. Addressing these issues should continue to be a major priority for public health, amplified in urgency by the legacy of social, environmental and cultural injustices that have been inflicted on these populations.

Accurate, complete population-based health data drive public health decision-making, priority setting, and deployment of resources. Surveillance, program evaluation, and research data provide the scientific basis for action at every level of the public health system; each of the three core functions and 10 essential services of public health rely on these data to drive their performance and meet their objectives.[3] Recent data linkages and information technology advances have improved the scope and quality of public health data sources. However, accurate documentation of race and ethnicity has been a persistent problem across many data sets.[4,5]

The articles in this supplement employ linkages to Indian Health Service (IHS) patient registration records to reduce the misclassification of AI/AN race as other than AI/AN and thus make

Sergio Morales, Kurtis Holiday, and Kevin Bedonie watch YouTube videos on an iPad after school at Monument Valley High School in Monument Valley, UT, amid the Navajo Nation's iconic red mesas. While students must be prepared for success in the wider world, they must also be taught the Navajo language and traditions, the latter the result of federal lawsuits that accused the district of unequal treatment of American Indian students. Photograph by Rick Egan. Printed with permission of AP Images.

important contributions to understanding the health issues and disparities facing AI/AN populations. These analyses highlight the fact that non-Hispanic AI/AN men and women have not experienced the decreases in mortality that have been documented and widely heralded for the US population overall. Rates of mortality from tobacco-related illnesses are particularly concerning. While heart disease and lung cancer mortality among non-Hispanic White persons has decreased for both males and females, the rates have plateaued for non-Hispanic AI/AN males and are still increasing for females.[6] Overall, non-Hispanic AI/AN people have almost a 50% higher death rate than non-Hispanic White people, and the leading causes of death are distinctly different, with

diabetes, intentional and unintentional injury, and chronic liver disease taking a particularly devastating toll.[7]

Linking mortality and central cancer registry data with IHS patient registration records has substantially improved the accurate classification of race for members of federally recognized tribes in these two data sets.[8] These linkages are useful because self-identification of race generally does not occur with the medical records used for cancer registry data nor with funeral directors who provide information on death certificates. However, there are significant shortcomings to this approach. Because of the complexities of addressing race classification, the articles in this issue are only able to look at a subgroup of AI/AN people who are not of Hispanic ethnicity. In addition,

linkages to IHS patient registration records identify only those eligible for services through federally recognized tribes. The data do not represent the entire AI/AN population because many tribes are not federally recognized. The problems of racial classification that have plagued surveillance and research on incidence and mortality in AI/AN people continue to be a significant challenge. Nonetheless, the work in this issue represents an important step toward more accurate estimates of morbidity and mortality in this population.

Mortality data are a compelling resource for documenting health disparities. However, other public health data sets must also be used to better understand the causes and potential solutions to pervasive disparities. Recent national efforts will improve documentation of race and ethnicity in a number of public health data sets. Section 4301 in the Patient Protection and Affordable Care Act requires that all federal data collection efforts include collection of self-reported information on race, ethnicity, gender, primary language, and disability status.[9] With assistance from federal grants, central cancer registries are exploring methods to more accurately collect data on race and ethnicity.

Some of the most immediate progress toward eliminating racial and ethnic disparities may result from addressing differences in the quality of medical care.[2] Historically, medical settings have been inconsistent in collecting self-reported race and ethnicity data, and these data are not routinely used to improve care and outcomes.[4,5] For this reason, better collection of accurate race and

ethnicity data are increasingly important in medical practices, hospitals, health care systems, and health insurance plans. These data can be used to assess, identify, and address differences in incidence, morbidity, and quality of care for a variety of important health conditions.[4,5,10]

In addition to improving the accuracy of race and ethnic classifications, additional steps can be taken to expand and improve data from medical settings to help better understand and address health disparities. Electronic health records (EHRs) represent an interconnected system of electronic health care information encompassing medical records of care from multiple providers and facilities. The IHS and tribal health systems have been national leaders in implementing EHRs across their clinical sites,[11] and these systems have been invaluable in providing continuity of care across geographically isolated populations with limited specialty care facilities. EHRs contain data essential for public health practice: notifiable diseases and conditions, chronic disease management, and preventive measures such as screenings and immunizations. The Centers for Medicaid and Medicare Services and Office of the National Coordinator for Health IT final rule for Stage 2 of Meaningful Use mandates submission of data to immunization registries. It also provides incentives for practices to submit electronic syndromic surveillance data to public health agencies and to identify and report cases to a state cancer registry or other specialized registry. This exchange of health information between the EHRs and public health data systems provides opportunities to better quantify

morbidity and mortality and to measure, benchmark, and drive quality improvement across clinical services.

The Affordable Care Act provides additional opportunities to expand and improve data sources. Section 9007 will require hospitals and health systems to develop regular health assessments of the communities they serve and use these to improve population health measures and address dispariteis.[9] Geographically based demographic and health status data will be needed for hospitals and health facilities that serve urban, suburban, and rural communities. These data are particularly important to IHS and tribally run health programs that target the medically underserved across multiple geographic boundaries. Data are often available by zip codes or other geographic units, but analyses within and across these arbitrary boundaries are often necessary.

Geographic data and spatial analyses provide contextual approaches to the study of health and health inequities, and are particularly well suited to address questions regarding access to health care. Geographic information systems have been used increasingly to understand the needs of urban and rural areas and better examine social determinants of health.[12] At the most detailed level, geographic information systems use physical addresses of locations that are frequently not included in public health data sets. In order for community health assessments to fully document and meet the needs of underserved and special populations, public health data systems must expand the collection of data for small area analyses without violating individual privacy and confidentiality. Currently,

the National Health Interview Survey permits analysis of location data by special data request, and location data are collected and controlled by individual states for the Behavioral Risk Factor Surveillance System. These approaches could be expanded and applied to other data sets.

Ultimately, what a society chooses to measure, and how well, speaks to its values and what it aspires to become. Efforts under way and reflected in the articles contained in this supplement demonstrate renewed attention to the health status of American Indian and Alaska Native peoples, and, potentially, a shift in values as society makes further progress toward health for all. Disparities in health outcomes are not intractable, and an evidence base is emerging for effective interventions.[13] We must use accurate public health data to monitor our progress, drive future change, and eliminate disparities in the health and health care of AI/AN people and other racial and ethnic minorities. ∎

Ursula E. Bauer, PhD, MPH
Marcus Plescia, MD, MPH

About the Authors

Ursula E. Bauer is the director of the National Center for Chronic Disease Prevention and Health Promotion, US Centers for Disease Control and Prevention (CDC), Atlanta, GA. Marcus Plescia is the director of the Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion.

Correspondence should be sent to Ursula E. Bauer, 4770 Buford Hwy NE MS F-80, Atlanta GA 30341 (e-mail: ubauer@cdc.gov). Reprints can be ordered at http://www.ajph.org by clicking the "Reprints" link.

References

1. Mokdad AH, Marbo JS, Stroup DF, Gerberding JL. Actual causes of death in the United States, 2000. *JAMA*. 2004; 291(10):1238–1245.

2. Smedley BD, Stith AY, Nelson AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. Washington, DC: National Academies Press; 2003.

3. Centers for Disease Control and Prevention. National public health performance standards program. Available at: http://www.cdc.gov/od/ocphp/nphpsp/EssentialPH Services.htm. Accessed July 12, 2013.

4. Institute of Medicine. *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. Washington, DC: The National Academies Press; 2009.

5. Disparities Toolkit HRET. Health Research & Educational Trust http://www.hretdisparities.org/Prin-4347.php. Accessed: July 12, 2013.

6. White MC, Espey DK, Swan J, Wiggins CL, Eheman C, Kaur JS. Disparities in cancer mortality and incidence among American Indians and Alaska Natives in the United States. *Am J Public Health*. 2014;104(6 suppl 3): S377–S387.

7. Espey DK, Jim MA, Cobb N, et al. Leading causes of death and all-cause mortality in American Indians and Alaska Natives. *Am J Public Health*. 2014;104 (6 suppl 3):S303–S311.

8. Anderson RN, Copeland G, Hayes MH. Linkages to improve mortality data for American Indians and Alaskan Natives: a new model for death reporting? *Am J Public Health*. 2014;104(6 suppl 3): S258–S262.

9. Patient Protection and Affordable Care Act, Pub L No. 111-148.

10. Pathman DE, Teal R. Use of Data by Hospitals in North Carolina to Identify Disparities in the Care and Outcomes of Minority Patients. *NCMJ*. 2011;72(3): 177–182.

11. Sequist TD, Cullen T, Ayanian JZ. Information technology as a tool to improve the quality of American Indian health care. *Am J Public Health*. 2005; 95(12):2173–2179.

12. Ricketts TC, Savitz LA, Gesler WM, Osborne DN. *Geographic Methods for Health Services Research: A Focus on the Rural-Urban Continuum*. Lanham, MD: University Press of America; 1994.

13. Agency for Healthcare Research and Quality. National Healthcare Disparities Report, 2009. AHRQ publication no. 10-004. 2010. Available at: http://www.ahrq.gov/research/findings/nhqrdr/nhqrdr10/qrdr10.html. Accessed July 24, 2013.