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# Improving Access and Utilization of Data to Support Research and Programs Intended to Eliminate Disparities and Promote Health Equity

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## Abstract

Numerous Federal initiatives are addressing health and health care disparities. The ultimate goal is to achieve "a nation free of disparities in health and health care." Social determinants of health remain mostly responsible for health/health care disparities among population groups within and between countries. In the United States, there is little evidence that disparities associated with such determinants are decreasing, with only 10% of those associated with race/ethnicity and income having demonstrated improvement in recent years. A variety of data sources are available from the Federal and private sectors to support research on disparities, but no single national survey seems to provide information that allows comprehensive analyses of health/health care disparities. With the Health Data and Big Data Initiatives, much progress has been made in making data more accessible, but the linkage of large databases results in complexity and yet unavailable tools to facilitate these analyses. The limited training of professionals and researchers in data science methods particularly affects their ability to translate findings into policies. New resources are available to promote increased data access and utilization, facilitate research planning and development of quality improvement strategies. Further work is needed to maximize and accelerate the integration of big data and data science to expand opportunities in biomedical and health services research targeting the elimination of health/health care disparities.

## Keywords

health disparities; health care disparities; health equity; race/ethnicity; social determinants of health; databases; survey data; big data; health data; data sharing; Federal government

## Cover Page Footnote

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**ABSTRACT**

Numerous Federal initiatives are addressing health and health care disparities. The ultimate goal is to achieve "a nation free of disparities in health and health care." Social determinants of health remain mostly responsible for health/health care disparities among population groups within and between countries. In the United States, there is little evidence that disparities associated with such determinants are decreasing, with only 10% of those associated with race/ethnicity and income having demonstrated improvement in recent years. A variety of data sources are available from the Federal and private sectors to support research on disparities, but no single national survey seems to provide information that allows comprehensive analyses of health/health care disparities. With the Health Data and Big Data Initiatives, much progress has been made in making data more accessible, but the linkage of large databases results in complexity and yet unavailable tools to facilitate these analyses. The limited training of professionals and researchers in data science methods particularly affects their ability to translate findings into policies. New resources are available to promote increased data access and utilization, facilitate research planning and development of quality improvement strategies. Further work is needed to maximize and accelerate the integration of big data and data science to expand opportunities in biomedical and health services research targeting the elimination of health/health care disparities.

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## INTRODUCTION

In the United States, numerous Federal initiatives are in place to address health and health care disparities. The National Partnership for Action to End Disparities (NPA), the first national, multi-sector, community- and partnership-driven effort on behalf of health equity, developed the National Stakeholder Strategy for Achieving Equity, which includes goals and objectives for both public and private sectors and calls for increased awareness of health disparities, stronger leadership to address these disparities, better health outcomes for underserved populations, improved health care workforce diversity, cultural and linguistic competency, and enhanced data and research in disparities. Its key principles are based on increasing local awareness of health disparities, enhancing local data collection, and emphasizing public-private partnerships to improve access to care. These principles are extremely relevant because the vast majority of actions to overcome disparities in health and health care has to be taken at local levels. These goals and objectives also give communities some level of flexibility to tailor strategies to their needs. (National Partnership for Action to End Health Disparities, 2011).

The U.S. Department of Health and Human Services (HHS) Action Plan to Reduce Racial and Ethnic Disparities reflects suggestions from stakeholders throughout the nation and takes advantage of opportunities in the Patient Protection Affordable Care Act of 2010 (ACA) to help diverse communities and to improve data collection. The HHS plan ultimately targets to achieve "a nation free of disparities in health and health care." (Koh et al., 2011) The Agency for Healthcare Research and Quality (AHRQ) National Healthcare Quality and Disparities Reports track disparities in health care particularly related to income, education, and insurance coverage. Disparities in measures of access to and quality of health care related to social determinants of health are well documented in these reports. While disparities related to race/ethnicity are commonly observed (25%-42% of measures), disparities associated with income are much more prevalent (50% of measures). There remains, however, little evidence that disparities associated with social determinants of health are decreasing, with only 10% of health care disparities linked to race/ethnicity or income having demonstrated improvement in recent years (Moy & Freeman, 2014).

A variety of data sources is available from the Federal and private sectors to support research on disparities in health and health care (Moy & Freeman, 2014; Johnson et al., 2010; Sequist & Schneider, 2006). While national surveys are major sources of annual and periodic data for assessing population-based disparities in health care coverage, access and quality, limitations with information on race, ethnicity, sex, primary language, and disability status prevent investigators from conducting comprehensive analyses of health care disparities (Johnson et al., 2010; Sequist & Schneider, 2006). No single survey seems to provide detailed race, ethnicity or immigrant group identifiers, comprehensive measures of health care coverage and access, and geographic identifiers to allow comprehensive analyses (Johnson et al., 2010).

Despite the Health Data and Big Data Initiatives, limitations still exist with restricted data accessibility, the availability of appropriate tools to facilitate data analyses and use, and training of health care professionals and researchers in data science methods including the translation of findings into practices and policies (Brennan et al., 2014). It is well known that disparities in health care can lead to unequal treatments for similar symptoms or conditions, unequal access to

health services, and considerable variations in health outcomes including poor health outcomes. Because very large databases are now being combined within electronic health record systems (EHRs) and related data repositories, information becomes more complex and may make it difficult to ascertain all factors responsible for disparities in health outcomes. (Correa-de-Araujo, In Press)

Under the Health Data Initiative, *healthdata.gov* is the HHS public-facing portal for making high value health data (over 1,000 datasets) more accessible to entrepreneurs, researchers, and policy makers in the hopes of better health outcomes for all. Through this initiative, HHS is disseminating clinical care provider quality information, nationwide health service provider directories, databases of the latest medical and scientific knowledge, consumer product data, community health performance information, and government spending data. While continuing to protect privacy and confidentiality, it is also the initiative's goal to make existing data machine readable, downloadable, and accessible via application and programming interfaces. (See www.healthdata.gov)

At the National Institutes of Health (NIH), the main vision of the Big Data Initiative is to achieve efficiency in biomedical research by making it easier for researchers to locate and manipulate data and software. The Big Data to Knowledge (BD2K) is a trans-NIH initiative aiming to enable biomedical research as a digital research enterprise, to facilitate discovery and support new knowledge, and to maximize community engagement. One example of impact from such initiative includes a virtual cohort built by linking phenotypic information from de-identified EHRs to a DNA repository to provide real-world clinical data that can be used to study disease and drug response in diverse populations (See https://emerge.mc.vanderbilt.edu/). In its continued effort to increase access to biomedical data, NIH made 64 data sharing repositories viewable to the public on *healthdata.gov*. Another example of a data sharing repository is the 1000 Functional Connectomes Project/International Neuroimaging Data-Sharing Initiative-INDI (See http://fcon_1000.projects.nitrc.org/), which contains imaging data of all types, and in some cases its related phenotype data can be deposited in the repository by an interested investigator. Over 5,000 resting state functional magnetic resonance imaging (fMRI) datasets are available as well as a growing number of diffusion MRI data. (See https://datascience.nih.gov/sites/default/files/bd2k/docs/fmri.pdf)

Numerous other efforts are underway at HHS and across the federal government, to increase access to the results of federally funded research. It is anticipated that in the coming years all federally funded researchers will make their scientific data available in publically accessible data sharing repositories. This is part of a large White House initiative to promote open data and open science across all the U.S. Government departments and agencies. (See https://obamawhitehouse.archives.gov/sites/default/files/microsites/ostp/NSTC/bigdatardstrategicplan-nitrd_final-051916.pdf)

The main purpose of this paper is to provide an overview of key initiatives addressing health and health care disparities, particularly those targeting the improvement of data collection and related research, and to introduce resources such as the new *Compendium of Federal Data Sources to Support Research and Programs Intended to Eliminate Disparities,* developed to help facilitate the planning of research and programs aiming to eliminate disparities and promote health equity.

## SOCIAL DETERMINANTS OF HEALTH AND DISPARITIES

Health is impacted by a number of interacting factors including genes and biology, the social and physical environments, health behaviors, and health care. According to the World Health Organization (WHO) the social determinants of health are mostly responsible for health inequities and differences in health status among population groups within and between countries. Understanding the impact of social determinants of health helps us develop strategies to improve health, decrease health disparities, and advance health equity at both individual and population levels (WHO, available from http://www.who.int/social_determinants/en/) Translation of social determinants of health into policies and practices, however, is jeopardized by the challenges associated with linking health policy with public health. Therefore, work is still needed on how to properly use, interpret and implement quality improvement strategies or interventions based on the impact of these determinants on health outcomes. Improving and sustaining policy changes at the system level and empowering communities will likely result in long-term impact in population health. (Russel et al., 2013)

A conceptual framework illustrates how disparities in health care relates to social determinants of health and health disparities. Essentially, the availability of resources to support health at the family and community levels influences the length and quality of life. Health disparities also have direct mutual effects on social determinants of health, therefore creating a cycle that reinforces the association of poverty, low educational levels, and poor health. Social determinants of health have a much stronger impact on health care disparities as family and community financial resources largely influence access to health services. Strategies that remove barriers to accessing quality health services can effectively mitigate the impact of the social determinants on health. (Moy & Freeman, 2014; Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020).

A dataset directory of social determinants of health at the local level is available from the Centers for Disease Control and Prevention (CDC). It contains an extensive list of existing datasets that can be used to investigate these social determinants, with primary focus on datasets displaying information for Metropolitan Statistical Areas (MSAs). A broad range of data for MSAs is collected and geographically coded, but it is thought that by using more localized units (e.g., county, zip code, census tract, and census block), the likelihood of measuring individuals' experiences with certain aspects of the social and physical environment is enhanced. (Hillemeir et al, 2004). The CDC also offers public health practitioners and interested partners a resource to help communities address social determinants of health to promote health and achieve health equity. Interesting case studies illustrate and facilitate the use of the information to plan for future interventions or programs (Brennan Ramirez et al., 2008).

A *Compendium of Public Health Data Sources & Assessment Tools* (updated in 2009) is available to support a state or community wide assessment of current health status, barriers to access, and help develop interventions or programs toward improving access to services and reducing health disparities. This compendium includes links to state and local data sources that are available online. Public health agencies' critical core function is frequently carried out through partnerships at the national, state, and local levels, with state and territorial health departments playing a vital role in mobilizing partners and working with others to support health improvement strategies. The Health Resources and Services Administration (HRSA)-supported State Access Planning Grants and Community Health Center Expansion are examples of such

partnerships.     (See     http://www.astho.org/Programs/Access/Public-Health-Data-Sources---Assessment-Tools/).

## HEALTH CARE SYSTEMS, HEALTH CARE WORKFORCE, AND DISPARITIES

Because of the relevant interactions between health care and the numerous determinants of health, the health care system and the health care workforce represent key areas for which strategies to reduce disparities and enhance data collection should be in place to support monitoring our progress (Moy & Freeman, 2014).  Enhanced access to the health care system via insurance coverage does not guarantee that all patients will receive equal benefits from health care services. Disparities in the quality of specific health-care services have been documented in the literature and can lead to disparities in health. Unconscious bias, for example, may result in providers managing differently the same condition in populations of diverse backgrounds and lead to unintentional poor health outcomes. The issue of patient/provider communication is also a factor and may considerably affect disadvantaged populations due to their limited health literacy and/or language barriers. Poor communication between patients and providers can result in reduced efficacy and increased risk of failure with prescribed treatments. The 2011 National Healthcare Disparities Report revealed that about 10% of adults report poor communication with their providers and about 15% indicate that their usual provider sometimes or never solicits their involvement in treatment decisionmaking. Disadvantaged populations are frequently affected, including in measures of patient centeredness (e.g., patient perceptions of care, involvement in decisionmaking, and ability to get language assistance). In these measures, disparities related to income are observed. (U.S. Department of Health and Human Services, 2012)

The AHRQ's Consumer Assessment of Healthcare Providers and Systems program is a great source of information about patients' surveys to measure their perceptions of care and to advance patient-centered care. The quality of patient-provider communication and overall ratings of care administered in a variety of settings (health plans, hospitals, dialysis centers, provider's offices, home health settings) are captured in these surveys with some specific questions that address cultural competency and health literacy. (See http://www.ahrq.gov/cahps/index.html; Au et al., 2009; U.S. Department of Health and Human Services, 2003 and 2001).

To continue to improve patient-provider understanding, HHS revised its National Standards for Culturally and Linguistically Appropriate Services in health care (CLAS Standards).  The CLAS Standards outline language access services that must be provided by recipients of federal funds and make recommendations for culturally competent care and organizational supports for cultural competence. To help managed care plans understand and meet these standards, AHRQ supported the development of two guides: Providing Oral Linguistic Services and Planning Culturally and Linguistically Appropriate Services. AHRQ has also supported work to identify cutting-edge state initiatives that improve access to language services in health care. (U.S. Department of Health and Human Services, 2003)

The critical role of the health-care workforce in improving quality and reducing disparities is widely recognized in HHS.  Increasing the diversity of both health care and public health workforces and promoting community health workers are elements of the HHS Disparities Action Plan (U.S. Department of Health and Human Services, 2011). Workforce diversity can reduce health care disparities and their impact on health and mitigate social determinants of health that lead to health and health care disparities. Workforce at the community level can considerably contribute to increasing knowledge of screening, prevention, and self-management,

potentially leading to better use of health services and improved outcomes across a wide range of diseases and conditions (Viswanathan et al., 2009).

The National Healthcare Quality and Disparities Reports have tracked the diversity of U.S. nurses, physicians, dental professionals, pharmacists, and physical, occupational, and speech therapists and found inequities in all health-care professions, with under or overrepresentation of certain racial/ethnic groups. While these reports will continue to monitor such diversity, a compendium of data sources to support health workforce analyses is also available from the HRSA and can be downloaded from https://bhw.hrsa.gov/sites/default/files/bhw/nchwa/compendiumfederaldatasources.pdf .

The HHS National Strategy for Quality Improvement in Health Care (2011) aims to achieving high-quality, affordable care for all Americans; identifying and placing providers in workforce shortage areas; and, training health-care professionals in quality improvement and patient safety principles, as essential elements for realizing its goals (See http://www.ahrq.gov/workingforquality/nqs/nqs2011annlrpt.pdf ). In addition, Healthy People 2020 includes increasing the numbers of practicing primary care providers and training providers about cultural diversity as important objectives. (Healthy People 2020 Objectives, available from https://www.healthypeople.gov/2020/topics-objectives)

## HEALTH INFORMATION TECHNOLOGY AND DISPARITIES

The adoption of health informatics can increase local health departments' ability to collect, disseminate, and compare health disparities-related data. This facilitates the identification of gap areas and the development of partnerships to implement strategies, activities, or programs that modify and eliminate institutional policies and practices that result in inequities. Focusing on social determinants of health is very relevant to the identification of upstream root-causes of public health issues such as health disparities due to marked differences between demographic and social groups. Data from the National Association of County and City Health Officials' 2013 National Profile of Local Health Departments demonstrate that many of them lack health informatics capacity, particularly in smaller or rural areas. (Shah et al., 2016). While approximately 83.8%, 73%, and 47.5 % of the local health departments had implemented, respectively, an immunization registry, an electronic disease reporting system, and an electronic laboratory reporting system, only 22.2% of them had EHRs and 13.5% had health information exchanges. Health informatics adoption was associated with numerous factors including being in a metropolitan area, covering a larger population size with provision of a greater number of clinical services and incurring greater per capita public health expenditures. Having health information systems specialist(s) on staff and a decentralized governance system with one or more local boards of health and level of experience of top executives were other significant factors affecting the health informatics adoption (Shah et al., 2016). Shortage in resources including budget cuts and staff reductions have impacted the local health departments' ability to conduct activities that address health disparities. Increase in their ability to engage in activities to reduce health disparities in association with their informatics capacity is among the benefits introduced by the health information technology (Shat et al., 2016). The AHRQ has supported the development of a guide for developers and purchasers of health information technology to ensure such technology can be used by patients with limited literacy. (Eichner & Dullabh, 2007).

**OTHER OPPORTUNITIES TO IMPROVE DATA COLLECTION AND ACCESS TO DATA TO ELIMINATE DISPARITIES**

Patient Protection Affordable Care Act of 2010 (ACA).
        The ACA greatly contributes to the cause of reducing or eliminating disparities in health and health care. To begin with, expanded health coverage through employers' provision of health insurance, the availability of credits to uninsured families to help them buy coverage through health insurance market places, and the expanded eligibility for Medicaid are some of the strong contributing features of this law. Young adults aged 19-25 years can now receive coverage under their parents' policies. In addition, provisions that lessen the cost of prescription drugs and make preventive services free to Medicare beneficiaries have enhanced affordability.
        A number of additional provisions address disparities related to community health, workforce, and data collection. The ACA's Section 4302 (Understanding Health Disparities: Data Collection and Analysis) calls for standardization, collection, analysis and reporting of health disparities data. It requires that data collection standards for race, ethnicity, sex, primary language and disability status be used and included on all population health surveys sponsored by HHS to the extent applicable. Respondents to these surveys either self-report information or a knowledgeable person responds for all members of a household. The law also requires any data standards published by HHS to comply with standards created by the Office of Management and Budget (OMB). HHS is implementing these data standards in all new surveys and at the time of major revisions to current surveys. The final standards were announced by the U.S. Secretary of Health in October 2011 and are available from https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=23. Further, Section 4203 (Removing Barriers and Improving Access to Wellness for Individuals with Disability) specifically addresses the issue of accessibility standards for the design of medical diagnostic equipment for individuals with disability. New related data may become available on how health care organizations are responding to the need for improving access to safe care and potentially better health outcomes for this population. (See https://www.access-board.gov/news/203-access-board-to-set-standards-for-medical-diagnostic-equipment-under-health-care-reform-law).
        The ACA elevated the NIH National Center on Minority Health and Health Disparities (NIMHD) from center to a full institute, reflecting its major concern with addressing disparities. Moreover, it codified into the law the HHS Office of Minority Health and a network of minority health offices within HHS. Each of the 50 states currently have a minority health or health equity office or entity (See http://www.ncsl.org/research/health/2012-health-disparities-legislation.aspx), with these offices sharing a common goal of improving health disparities within their state through the following core competencies: monitor health status; inform, educate, and empower people; mobilize community partnerships and action; and, develop policies and plans to support health efforts.
        The Centers for Medicare and Medicaid services (CMS) Office of Minority Health earliest in its activities focused on supporting outreach and enrollment, particularly for those eligible for coverage through the health insurance marketplaces; and, in launching the national initiative "From Coverage to Care (C2C)" to assist the newly insured individuals through guiding community partners ("roadmap" to better care and health) and explaining the basics of health insurance (network, co-insurance, deductibles, obtaining insurance, navigating the system; information on preventive health). The impact of the ACA in improving access to care and

reducing disparities may be reflected in future findings of the National Health Care Quality and Disparities Reports (Moy & Freeman, 2014). The CMS Office of Minority Health is also improving data collection/availability on race, ethnicity, and primary language, by working across the agency to implement the enhanced data collection standards (Section 4302) and incorporate many of them in the streamlined application for the marketplace, Medicare Health Outcomes Survey, and Transformed Medicaid Statistical Information System. The office also emphasizes the provision of more culturally and linguistically appropriate services for CMS beneficiaries and addressing diabetes-related disparities (See https://www.cms.gov/about-cms/agency-information/omh/index.html). The CMS Office of Minority Health made publically available the national and contract level data showing racial and ethnic disparities in health care in Medicare Advantage. These data are of particular relevance to evaluate disparities in a more controlled environment (See https://www.cms.gov/About-CMS/Agency-Information/OMH/research-and-data/index.html).

The Food and Drug Administration (FDA) Office of Minority Health main activities include communication and dissemination of information to vulnerable populations; increasing diversity in its health care workforce to strengthen its capacity to address health disparities; and, advocating for participation of minorities in clinical trials and analysis of subpopulation data. The latter is an important area for the NIH National Institute on Aging (NIA) due to frequent exclusion of older adults, including older minorities, from clinical trials. It is in fact, an area of relevance to all populations as knowledge is evolving on race/ethnicity differences in response to drug therapy, which can impact personalized medicine (See http://www.fda.gov/AboutFDA/CentersOffices/OC/OfficeofMinorityHealth/default.htm).

Federal Interagency Health Equity Team

The NPA continues to contribute to the increasing effectiveness of programs and mobilization of partners, leaders, and stakeholders toward eliminating health disparities. Government agencies are involved in this effort through the Federal Interagency Health Equity Team (FIHET), which offers leadership and guidance for national, regional, state, and local efforts that address health equity. In addition, ten Regional Health Equity Councils (RHECs) comprised of practitioners from various sectors (health care, education, transportation, technology, and business) engage HHS regional directors or administrators. (See http://minorityhealth.hhs.gov/npa/).

The NPA and ACA's call to better understanding of health disparities through data collection and analysis and the Health Data and Big Data Initiatives stimulated the FIHET's Data, Research and Evaluation Workgroup to developed the first compendium of publically available federal data sources relevant to health disparities research and programs. This resource is intended to facilitate identification and use of such data sources; stimulate research that connects information from different sources and support work addressing health and social disparities in a meaningful way; provide easy access to these publicly available data through a single resource, update and build on ongoing federal data sharing and big data efforts; encourage data collection to fulfil data gaps in support of the development of quality improvement strategies and monitoring activities; inform programs and strategies, and alert health care, public health professionals, and policymakers on populations in need of attention. The inclusion of datasets from Federal agencies beyond HHS is a major feature of the compendium, which is seen as a work in progress. The potential for adding new data to this resource, identifying new uses,

linking data and expanding research areas also serve the purpose of the overall Health Data and Big Data Initiatives. The challenge remains in eliminating barriers to making all information machine readable and accelerate translational impact, but work is ongoing. The compendium is available from https://www.minorityhealth.hhs.gov/npa/templates/browse.aspx?lvl=1&lvlid=46. *Figure 1* provides a snapshot of the compendium and how the information is displayed to help individuals looking for relevant data sources as they prepare their research plan or seek information that may help improve their programs. By knowing, for example, that publically available files from the CDC's National Health and Nutrition Examination Survey contain information on specific social determinants of health, that starting in 1999 these datasets have capability for linking to other databases (e.g., mortality, Medicare) and, that periodic reports are made available online, may significantly facilitate research planning.

Data Linkage Development

The CDC National Center for Health Statistics (NCHS) is currently linking various NCHS surveys with administrative data. Examples of data linkage already available include the National Health Interview Survey (NHIS), Supplement on Aging (SOA), Second Longitudinal Study on Aging (LSOA II), National Health and Nutrition Examination Survey (NHANES), NHANES I Epidemiologic Follow-up Survey (NHEFS), NHANES II, NHANES III, National Nursing Home Survey (NNHS), and National Home and Hospice Care Survey (NHHCS) with data from the following: National Death Index, Medicare, Medicaid, Social Security Administration (SSA), and U.S. Department of Housing and Urban Development (HUD). Information on available linked data files including specific years of data linkage can be found at http://www.cdc.gov/nchs/data/datalinkage/linkagetable.pdf or at http://www.cdc.gov/nchs/data-linkage/index.htm. The NCHS record linkage program is a very promising initiative, intended to maximize the scientific value of its population-based surveys by enabling researchers to examine factors that affect disability, chronic conditions, health care utilization, morbidity, and mortality. These are critical for advancing disparities research and improving programs intended to eliminate disparities.

Interactive Data Tools Development

The National Institute on Minority Health and Health Disparities (NIMHD) plans to develop a website, *HD\*Connect*, that will be a resource for data that can be used to examine health disparities in states and counties, and for interventions proven to be effective in health disparities research. *HD\*Connect* proposes two sub-portals: 1) population data with applications for calculating and mapping the data and 2) proven (evidence-based) intervention research studies with accompanying tools and projects. The website likely will provide a link to the FIHET Compendium with hypertext links to each dataset included in the compendium, as well as links to other important tools, datasets and sources of information on health disparities.

*Figure 1*: Snapshot of the Compendium Displaying Relevant Information About CDC's National Health and Nutrition Examination Survey

Data Source: National Health and Nutrition Examination Survey (http://www.cdc.gov/nchs/nhanes.htm)

Brief Description: The National Health and Nutrition Examination Survey (NHANES) operates out of mobile examination centers that travel to randomly selected sites throughout the country to assess the health and nutritional status of Americans. This survey combines personal interviews with standardized physical examinations, diagnostic procedures and laboratory tests to obtain information about diagnosed and undiagnosed conditions; growth and development, including overweight and obesity; diet and nutrition; risk factors; and environmental exposures.

Examination Components: Personal interviews; physical examinations; laboratory tests; nutritional assessment; DNA repository.

| Target Population | Age | Race & Ethnicity | Socio-Economic Variables | Geographic Estimates (Lowest Geographic Unit) | Years of Data Collected | Available for Use | Periodic Reports |
|---|---|---|---|---|---|---|---|
| U.S. population | All ages | American Indian or Alaska Native; Asian; Black or African American; White; Other; Mexican American, Hispanic/Latino/Spanish Origin or Ancestry [11] | Income and poverty index; education; occupation; type of living quarters; social services | National | Periodic cross-sectional NHANES surveys 1971-1974; 1976-1980; 1982-1984 (Hispanic HANES); 1988-1994; Beginning 1999- collected annually, with capability for linking to other databases (i.e., mortality, Medicare) | Yes | http://www.cdc.gov/nchs/nhanes_products.htm |

[11] Other ethnicity variables include follow-up questions on race/ethnicity response categories by country of origin or ancestry.

**CONCLUSION**

The initiatives and related opportunities described in this paper are exciting and can result in future improvements in health and health care disparities and promotion of health equity. The AHRQ's National Healthcare Quality and Disparities Reports will continue to monitor the nation's progress in addressing health and health care disparities. Because these disparities are still very wide among diverse populations, major opportunities exist within the Health Data and Big Data Initiatives to improve data collection, make new data available to support studies, link relevant data sources, and enhance or develop new quality improvement strategies, prevention or treatment interventions, all of which could result in significant translational impact. Further work is needed to maximize and accelerate the integration of big data with data science to expand opportunities to eliminate health and health care disparities.

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