Health Equity and Social Determinants of Health in HEDIS: Data for Measurement

NCQA

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Improving health care.
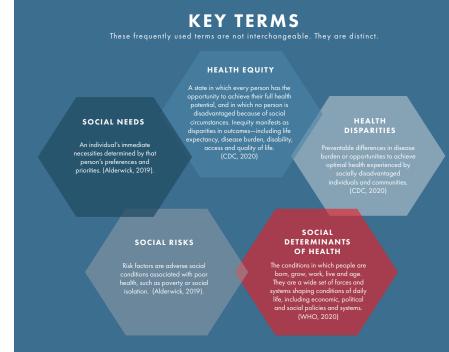
INTRODUCTION

NCQA strives to:

- Address inequities in health care and promote health equity through performance measurement.
- Shed light on health care disparities, advance health equity and ensure that factors beyond clinical determinants are considered in the Healthcare Effectiveness Data and Information Set (HEDIS®).

As a part of this effort, NCQA is exploring several approaches, including stratification of HEDIS measures by race, ethnicity and socioeconomic status, to highlight disparities in care and hold plans accountable for implementing interventions to reduce those disparities. NCQA is also considering potential new measures aimed at explicitly addressing social determinants of health (SDOH), such as assessing social risk or needs. This issue brief reports on the results of an environmental scan conducted by NCQA to inform future directions in health equity measurement. The report also describes challenges and opportunities related to race, ethnicity and social needs data sources to support these efforts.

❯ Background

The World Health Organization (WHO) defines social determinants of health as "the conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the conditions of daily life," including economic policies and systems, development agendas, social norms and political systems (WHO 2020). Several other leading health organizations have developed similar definitions to use when working to achieve health equity (CDC, 2020; Healthy People 2030, 2020). Equally important terms often referred to in the health equity domain include "social risk factors," "social needs," "behavioral risk factors" and "disparities." Such language is often employed to highlight the influence of various factors on health care access as well as outcomes (Alderwick, 2019). Factors cited as considerably impacting health inequity include access to nutritious food, neighborhood safety, distance to public transportation and adequate housing (AMA, 2019; AAFP, 2019).

KEY TERMS

These frequently used terms are not interchangeable. They are distinct.

HEALTH EQUITY

A state in which every person has the opportunity to achieve their full health potential, and in which no person is disadvantaged because of social circumstances. Inequity manifests as disparities in outcomes—including life expectancy, disease burden, disability, access and quality of life. (CDC, 2020)

SOCIAL NEEDS

An individual's immediate necessities determined by that person's preferences and priorities. (Alderwick, 2019).

HEALTH DISPARITIES

Preventable differences in disease burden or opportunities to achieve optimal health experienced by socially disadvantaged individuals and communities. (CDC, 2020)

SOCIAL RISKS

Risk factors are adverse social conditions associated with poor health, such as poverty or social isolation. (Alderwick, 2019).

SOCIAL DETERMINANTS OF HEALTH

The conditions in which people are born, grow, work, live and age. They are a wide set of forces and systems shaping conditions of daily life, including economic, political and social policies and systems. (WHO, 2020)

Disparities in morbidity and mortality across multiple factors have been well documented over the last few decades as leading health organizations increasingly elevate health equity as a priority (Baciu, 2017; Penman-Aguilar, 2016). Organizations such as the Centers for Disease Control and Prevention (CDC) and the WHO, and policy initiatives like Healthy People 2030, have indicated the need to pursue health equity in the face of widening disparities between various subgroups in the United States (CDC, 2020; CSDH 2008; Pendo, 2020). Health care disparities occur across many dimensions, including race and ethnicity, gender, sexual orientation, socioeconomic status (SES), disability status and geographic location (KFF, 2020).

Disparities

Racial, ethnic and socioeconomic disparities call attention to a striking need for targeted interventions to improve health outcomes. While socially constructed categories of race and ethnicity do not cause health disparities, they often link directly to other dimensions that impact health, including, but not limited to, geographic location, SES, access to health care insurance and systemic racism (CDC, 2020; Cogburn, 2019). When compared with White Americans, for instance, racial and ethnic minorities often fare significantly worse in terms of health outcomes. A review of health status across racial groups in 2019 found that while policy and program efforts such as the Affordable Care Act have begun to narrow disparities, notable differences in health outcomes persist. For example, Blacks and Native Americans experience infant mortality rates approximately two times higher than that of Whites (Artiga, 2019). The Office of Minority Health found that Hispanics are 60% more likely to die from viral hepatitis than Whites, despite having lower rates of hepatitis C (OMH, 2020). In 2014, the CDC reported that about 18% of Black adults and 16.8% of Hispanic adults had a diabetes diagnosis, while the prevalence in White adults was 9.6%. Each statistic is striking, given that in 2014, all racial and ethnic minority groups combined made up 37.9% of the United States population (over 120,000,000 people) (Baciu, 2017; NCHS, 2016).
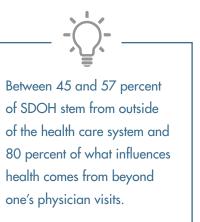
Literature indicates that disparities exist on different axes, such as environmental and social exposures, access to health care and health services, completion of treatment and quality of care, in addition to disparities in health outcomes across populations. From 2000–2017 approximately one third of performance measures assessing individuals' access to health care services showed no improvement; about 40% of access measures revealed that Blacks, Native Americans and Native Hawaiians received worse care than Whites (AHRQ, 2019).

Recent studies have found that individuals with lower economic and educational status are less likely to begin and/or complete engagement with health care services. A Minneapolis-based study indicated that while 69% of White patients who qualified for colorectal cancer screening completed screens, just 43% of all patients of color completed them (Kottke, 2014; Hostetter, 2018). Of note, Latinos are less likely than the majority of the population to seek and receive health care services, due to discrimination, lower insurance rates (76% compared to 91% nationwide) and, in some cases, a lack of Spanish translation services in the health care setting (Vega, 2009; Steinberg, 2016).

Studies also show that environment plays an important role in health disparities. Due to racist segregation practices, disadvantaged populations such as ethnic minorities (particularly Blacks and Native Americans), immigrants, people with lower incomes and beneficiaries with Medicaid insurance are more likely to live and work in areas with greater exposure to toxic environments (Gee, 2004; Institute of Medicine, 2003; Lewis, 2017). Chemical waste plants and other high-pollutant sources make certain groups more vulnerable to conditions such as asthma, cancer and chemical poisoning. The American Lung Association finds that the burden of air pollution is unevenly shared and may deeply affect populations with greater exposure to stress and discrimination (ALA, 2020). Studies underscore strong associations between constant exposure to air pollution and increased asthma diagnoses in children from economically deprived areas.

❯ Importance

Public health leaders have increasingly called for collaborative, coordinated approaches across disciplines to close the gaps in health disparities. It is estimated that between 45% and 57% of SDOH stem from outside the health care system and 80% of influences on health come from outside physician visits; calls for response to health disparities have echoed a need to implement interdisciplinary approaches (APHA, 2019; Daniel, 2018; AMA, 2019). Some SDOH that stem from within the health care system are health literacy and sociobehavioral SDOH screening, as well as treatment from interdisciplinary clinical teams (Mogford, 2011; Daniel, 2018; NAS, 2019).

> Between 45 and 57 percent of SDOH stem from outside of the health care system and 80 percent of what influences health comes from beyond one's physician visits.

The American College of Physicians published a set of policy recommendations on SDOH, expressing support for cross-agency collaboration to maximize the impact of changes in policy. The American Public Health Association (APHA) similarly indicated that cross-cutting interventions must be employed by organizations at the national, local and individual levels, in addition to work implemented through nongovernmental organizations (Chisolm, 2019). The need for the implementation and maintenance of measurable objectives when assessing disparities and health equity-driven goals is another topic in which many leading health care organizations are invested.

Healthy People 2030 has expressed interest in strengthening the link between performance measurement and addressing social risks (APHA, 2019). The APHA also highlights the importance of measurement-oriented initiatives in decreasing health disparities. Researchers find that creating approaches with operational objectives can help health care organizations assess whether they are on track to meet health equity goals at the individual, community, state and national levels.

In 2017 the Health and Public Policy Committee at the American College of Physicians recommended that health care organizations adjust performance measures to reflect risks in caring for disadvantaged populations (Daniel, 2018).

COVID-19

The COVID-19 pandemic accentuates the need to address health disparities. This pandemic underscores the fact that living in an underserved environment and facing social adversity is directly correlated with biased rates of infection and poor health outcomes (Holuka, 2020).

Early studies show that several groups are at increased risk of contracting COVID-19 and dying from the coronavirus, including individuals aged 65 and older, racial and ethnic minorities, and groups from economically depressed communities (Hatcher, 2020; Kim, 2020).

The pandemic has also shed light on disparities in utilization of the emergency department (ED). In a study of individuals who tested positive for COVID-19 in the ED, 65.3 percent of Black patients tested positive while 38.0 percent of white patients tested positive in the ED (Price-Haywood, 2020). Additionally, data gathered from the California Department of Public Health reveals that racial and ethnic minorities are disproportionately diagnosed with COVID. Latinos make up 39 percent of California's population but account for 61 percent of the state's COVID-19 cases while whites make up 38 percent of the state's population despite accounting for just 18 percent of cases (CDPH, 2020).

A coordinated response to COVID-19 may help reduce these inequities.

The Cost of Inequity

Health disparities place a considerable economic burden on society. Total overall costs of health inequities and premature deaths between 2003 and 2006 amounted to $1.24 trillion (AHPA, 2019). Experts estimate that eliminating health disparities during this time frame would have reduced this number by $229.4 billion (LaVeist, 2009).

State and local-level analyses similarly reveal the potential economic impact of eliminating disparities. Researchers found that of the $525 million spent on diabetes-related services by North Carolina's state Medicaid program in 2008, approximately $225 million in costs linked to diabetes services could have been saved if racial and economic disparities were eliminated (Buescher, 2010).

Health disparities also have a direct impact on the economy due to the disruption to daily lives, loss in labor productivity and premature death (Thornton, 2016). The Government Accountability Office found that an increased prevalence of chronic conditions such as heart disease and cancer among Blacks and Hispanics has led to notable decreases in average household earnings, in addition to a weakened ability to afford health care (Suthers, 2008).

Impact on the Individual

Constant interaction with adverse social risk factors can take a considerable toll on well-being. A national geographic analysis of life expectancy by ZIP code found that in the city of Chicago, life expectancy differed by as much as 30 years, depending on the neighborhoods reviewed (Gourevitch, 2018; Healthy Chicago 2.0, 2020; Cohen, 2016). Similar life expectancy differences were found in cities across the United States: Residents living mere miles apart were found to have vastly different socioeconomic experiences, which mapped onto health disparities and life expectancy trends. Individuals living in neighborhoods with higher life expectancies were more likely to have higher average incomes, access to transportation, successful schools, high-quality medical facilities, access to nutritious food and clean water sources, and to live in communities that invested in social services (Chetty, 2016; Hacke, 2017; Gourevitch, 2018). Several studies have noted that areas with a deep investment in these services tend to coincide with better access to health care services and better individual and public health outcomes (Dwyer-Lindgren, 2017).
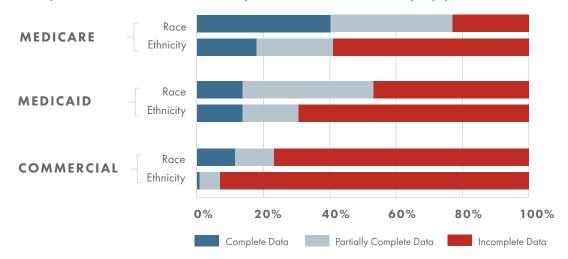
MEASURING EQUITY IN HEDIS

Race and Ethnicity: While the HEDIS measure set does not currently require reporting by race/ethnicity, it does include two measures that assess diversity of health plan membership. Their intent is to assess the level of completeness of language, race and ethnicity data among health plans.

- **Language Diversity of Membership (LDM)** assesses the count and percentage of members enrolled any time during the measurement year by spoken language preferred for health care and for written materials.

- **Race/Ethnicity Diversity of Membership (RDM)** assesses the count and percentage of members enrolled any time during the measurement year by race and ethnicity. The measure categorizes members using the designations provided by the Office of Management and Budget. Racial categories included in this measure are White, Black or African American, American Indian and Alaska Native, Native Hawaiian and Other Pacific Islander, Some Other Race, Two or More Races, Unknown and Declined. The measure also allows ethnicity reporting by the Hispanic or Latino category.

Both measures are specified for the commercial, Medicaid and Medicare product lines and were introduced into HEDIS in 2010. Reporting on these measures is required for health plans or other entities seeking NCQA's Distinction in Multicultural Health Care (NCQA, 2020).

For the purposes of HEDIS data collection, NCQA considers data to be "complete" when greater than 95% of data is known; "incomplete" data refers to instances where less than 50% of data is known or the data is missing. In recent years, the RDM measure has indicated a lack of complete race and ethnicity data. In Measurement Year 2019, approximately 76% of racial data and 94% of ethnicity data was incomplete for the commercial product line. For Medicaid plans, 50% of racial data and 70% of ethnicity data was incomplete. Medicare plans demonstrated the greatest ability to collect complete data: 26% of racial data and 60% of ethnicity data was incomplete.

To further address racial and ethnic disparities in care, NCQA seeks to implement a required stratification by race/ethnicity to a selection of HEDIS measures in order to encourage health plans to integrate equity into quality measurement efforts. This approach will help identify plans that successfully eliminate disparities in performance.

Completeness of race and ethnicity data varies substantially by product line.

Socioeconomic Status and Disability: Currently, HEDIS requires an SES and disability stratification for four measures: Breast Cancer Screening, Colorectal Cancer Screening, Comprehensive Diabetes Care—Eye Exam and Plan All-Cause Readmission. The decision to apply stratification was based on consultation with an expert panel and analysis of health plan performance when adjusting for disparity in performance between low- and high-SES populations (NCQA, n.d.). Stratification leverages Medicare-specific eligibility criteria and applies to the Medicare product line only. For these measures, performance is stratified into one of six categories capturing low-income status (LIS)/Dual Medicaid and Medicare eligibility (DE) only, Disability status only, LIS/DE and Disability, Neither LIS/DE nor Disability, Other or Unknown. "Other" represents members who have end-stage renal disease or who fall into no alternative categories. DE status remains one of the strongest predictors of outcome, even after accounting for other social and functional risks. The intent of stratifying SES and disability is to shed light on disparities in care by SES. NCQA is interested in potentially expanding this stratification to additional HEDIS measures.

SDOH in HEDIS: There is broad acknowledgment that social factors such as employment status, physical environment and access to food contribute significantly to health outcomes. HEDIS does not yet require stratifications by SDOH other than SES and does not include any SDOH-specific measures. NCQA sees this as an opportunity to expand the scope of HEDIS quality measurement and encourage health plan accountability for acknowledging members' social needs, as well as clinical needs.

DATA AVAILABILITY AND USE
(RACE, ETHNICITY AND SOCIAL NEEDS)

While the importance of addressing health disparities is apparent, challenges remain, including how to accurately and feasibly identify race, ethnicity and social needs for the purposes of equitable quality measurement. Some data elements may be more readily available than others; some data sources may demonstrate greater accuracy than others. Below is a review of the availability of race, ethnicity and social needs data in administrative claims and electronic health records and via geographic proxy and imputation.

ADMINISTRATIVE CLAIMS AND ELECTRONIC HEALTH RECORDS

Race and Ethnicity

It is not surprising that evidence indicates race and ethnicity in administrative data is largely incomplete. There are a number of challenges associated with collecting complete and accurate race and ethnicity data.

A lack of standardized race and ethnicity categories has been identified as a key barrier to widespread collection and utilization of this data, as noted in the Institute of Medicine's landmark report, Race, Ethnicity, and Language Data Standardization for Health Care Quality Improvement.

Additional barriers identified include technical challenges such as space on collection forms and accessibility of fields in electronic systems to collect such information, discomfort with asking or responding to questions of race and ethnicity and a lack of sufficiently descriptive categories for patient self-identification (Institute of Medicine, 2009).

Analysis of RDM measure data from 2012–2015 found that data was most complete for Medicare plans and was least complete for commercial plans. Roughly 40% of Medicare plans reported complete race data, compared to less than 20% for Medicaid and commercial plans.

All product lines reported less than 20% complete ethnicity data. The majority of Medicaid and Medicare plans reported using direct methods of collecting race and ethnicity data; commercial plans used indirect methods (Ng et al., 2017).

In 2020, CMS released an analysis of Medicaid and CHIP beneficiary enrollment data from 2016, which found that the majority of states had incomplete race and ethnicity data. Despite regulations requiring states to report race and ethnicity data on all (or almost all) beneficiaries, the analysis found that only 21 states reported having race and ethnicity data for more than 90% of beneficiaries (State Health Access Data Assistance Center, 2020).

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ADMINISTRATIVE CLAIMS AND ELECTRONIC HEALTH RECORDS

Beyond the issue of completeness, there is evidence to suggest variable accuracy of race and ethnicity in administrative data. Discrepancy in accuracy of data between racial and ethnic groups may limit the ability to correctly measure disparities in care. Analysis of race/ethnicity in Medicare administrative data, compared to self-reported race/ethnicity in the home health Outcome and Assessment Information Set, found that data was considerably more accurate for White and Black beneficiaries than for Hispanic, non-Hispanic Asian, Hawaiian Native, other Pacific Islander, American Indian or Alaskan Native.

The sensitivity of administrative data to accurately identify race and ethnicity among White and Black beneficiaries was between 96% and 98%. Among people who self-identified as Hispanic, the data had a sensitivity of just 36.2%; it was 62.6% for those identifying as non-Hispanic Asian, Hawaiian Native or other Pacific Islander and approximately 43% for those identifying as non-Hispanic American Indian or Alaskan Native (Jarrín et al., 2020). Multiple studies have observed a similar pattern of under-identification or misclassification of smaller racial and ethnic groups in Medicare administrative data (Filice & Joynt, 2017; Smith et al., 2010; Zaslavsky et al., 2012).

Social Needs

Documentation of social needs in administrative claims is increasing, but remains uncommon.

In 2016, Medicare introduced "z-codes," a set of ICD-10 diagnosis codes related to SDOH. Z-codes are designed to capture social factors that influence a patient's health status, including, but not limited to, socioeconomic and psychosocial circumstances (CMS, 2020).

Analysis of z-code utilization among Medicare fee-for-service (FFS) beneficiaries found that among 33.7 million total beneficiaries in 2017, approximately 1.4% had claims with documented z-codes. The most commonly used z-codes were for homelessness, problems related to living alone, disappearance or death of a family member, problems related to psychosocial circumstances and problems in relationships with a spouse or partner.

The analysis concluded that the data likely underestimates patient social needs among Medicare FFS beneficiaries and that although SDOH screening may occur, the extent to which patient social needs are being documented in claims is unclear (CMS, 2020).

Another study examining z-code utilization from 2016–2017 using the National Inpatient Sample, a large, publicly available, all-payer, inpatient care database, resulted in similar findings. Of over 14 million hospitalizations, just 1.9% included a z-code. While noting that the proportion of hospitals ever using a z-code increased from 41% in 2016 to 70% in 2017, the study concluded that z-codes are not an accurate representation of the true burden of social needs among hospitalized patients (Truong et al., 2020).

While there are limited studies examining the validity of ICD-10 social codes, there are some important considerations in evaluating the appropriateness of relying on claims to identify, prioritize and address social needs across a population. The effort of Gottlieb and colleagues to map social screening tools to existing z-codes revealed challenges: There may not be a social code that appropriately matches to an identified need; multiple social codes may apply; meaning may be lost in selecting a particular social code (Gottlieb et al., 2017). For example, because "lack of adequate food or safe drinking water" collapses several distinct social needs, meaning may be lost when attempting to understand and address population-level needs.

Despite the low utilization and limitations of ICD-10 social codes, efforts are underway to increase utilization and usefulness of SDOH documentation in claims.

- In 2019, the American Hospital Association released ICD-10-CM Coding for Social Determinants of Health in an effort to increase utilization of z-codes (American Hospital Association, 2019).

- The American Medical Association, in partnership with UnitedHealthcare, announced the desire to expand the existing set of z-codes to increase specificity and allow more accurate documentation of patient social needs (American Medical Association, 2019).

GEOGRAPHIC PROXY AND IMPUTATION

Due to the limited availability of both race/ethnicity and social needs data in administrative claims, a common alternative approach is to identify demographic information and social needs using a geographic proxy, such as aggregated geographic-level data from national surveys or data sources like the U.S. Census Bureau. In this approach, community-level data (e.g., census block, ZIP code) may be used to attribute a characteristic to a patient who resides in that location. For example, each year, CMS releases a report of racial and ethnic health disparities in Medicare Advantage, using HEDIS and Consumer Assessment of Healthcare Providers and Systems (CAHPS®) data. Because HEDIS data is not currently available by race/ethnicity, CMS combines residential location and surname to indirectly estimate race and ethnicity (CMS, 2020; Elliott, 2008). The method has shown 93% concordance for White and Black beneficiaries, 94% for Asian/Pacific Islander and 95% for Hispanic beneficiaries (Martino et al., 2013).

In 2009, the Institute of Medicine recommended that in cases where race and ethnicity data is unavailable, organizations should use indirect estimation to support analyses of race and ethnic disparities (IOM, 2009).

The National Quality Forum recommends that organizations use proxy data from geocoding, surname analysis and Bayesian estimation when conducting community-level interventions, but notes that such data is limited when conducting individual-level interventions (NQF, 2008). Broad uptake of these methods of estimation is limited, but a growing body of work in recent years documents use of this approach.

Analysis of studies combining clinical and nonclinical determinants of health (e.g., SES, built environment, social circumstances) found a four-fold increase in the number of articles in this space between 2010 and 2018. Among studies included in the review, 50% measured nonclinical determinants at the aggregate (i.e., geographic) level. Analysis found that geographic areas smaller than a ZIP code were commonly used and the majority of studies (81.7%) relied on U.S. Census Bureau data (Golembiewski, 2019).

Researchers in this space have cited risks associated with relying on community-level data to impute an individual attribute; for example, community-level data is subject to ecological fallacy, whereby an individual in a particular neighborhood may not match the overall attributes of that neighborhood (Gottlieb, 2018). Further, there may be concerns with the timeliness of national data sources (Cantor et al., 2018; Boudreaux, 2015). Examples of studies illustrating the advantages and disadvantages of relying on community-level proxies to impute social needs are provided below.

Leveraging national survey data to assign demographic and social characteristics has shown to have high feasibility and utility (Hatef, 2019; ACS, 2018). The American Community Survey (ACS), a

GEOGRAPHIC PROXY AND IMPUTATION

national survey of 3.5 million households across the country, fielded by the U.S. Census Bureau, is the predominant source. ACS survey results are used to direct over $675 billion in federal and state funds each year.

In one study, data from the ACS, along with data from the National Vital Statistics System and Behavioral Risk Factor Surveillance System, was used to implement the City Health Dashboard. The Dashboard, developed by NYU Langone and the Robert Wood Johnson Foundation, used the census tract area (which was found to be the most consistent level of analysis across data sets) to display 35 measures of health and social factors in order to inform city health equity initiatives. The Dashboard included both stratification of clinical measures (by gender, geography and race/ethnicity) as well as direct measures of inequity (e.g., measuring racial/ethnic diversity and neighborhood racial/ethnic segregation). Initial user experience indicates the Dashboard addressed unmet needs for granular data within and across cities, with over 47,000 users in the first 8 months of launch (Gourevitch, 2019).

Another study documented the creation of an aggregated dataset of community-level SDOH derived from open-source data sets. Called the "Factors Affecting Communities and Enabling Targeted Services (FACETS)" database, the system was designed to map individual addresses to their corresponding census-tract level determinants. The ACS was the primary data source for FACETS. ACS-derived data included racial diversity, ethnic diversity, educational attainment and poverty rate, among other national and state-level data sources (Cantor, 2018).

While some projects point to the advantages of community-level proxies, researchers have also noted challenges to using national datasets for this purpose.

- Different data sources may link data elements at different geographic levels that may not align with each other or with policy-maker priorities (e.g., countywide metrics are not likely to align with municipal or city boundaries).

- National datasets refresh infrequently; consequently, indicators may lag behind population change.

- Estimates from national sources may lack precision at the community level, leading to uncertainty, which must be communicated clearly to avoid random variation being interpreted as meaningful signals (Gourevitch, 2019). In addition, researchers cautioned about challenges mapping between census years, when census tracts may change. They also note that mapping individual street addresses to geographic groupings presents challenges, noting that misspellings, or duplicate street addresses in different areas, can generate error.

- SDOH mapping at the community level has limitations, particularly in the context of the National Academy of Medicine and others emphasizing the importance of individual-level SDOH over community-level SDOH, which can have a significant impact on care because they function as the "back end" of the health care system (Cantor, 2018).

LOOKING FORWARD

Achieving health equity requires action across the different levels and stakeholders of health and health care, centering patients and communities whose lived experiences reflect the structural and systemic inequities that shape care and outcomes. Foundational to this work is the ability to target interventions towards, and hold organizations accountable for, addressing these inequities. Quality measurement has a central role to play in this effort by defining equity-focused targets for improvement and creating transparency in access to health care, the process of care, and resulting outcomes. A large part of creating equity-focused measurement in health care hinges on the ability to use readily available race, ethnicity and social determinants data that is accurate, feasible, and valid. The lack of consistently available and reliable data has been a barrier to measurement in the past. However, the environment has evolved considerably in recent years as more organizations underscore the need to focus on capturing these data to move towards health equity. Improvements in structured data collection and in the analytic methods for integrating these data into quality measures are encouraging, though complex decisions and challenges remain. Building the path forward for quality measurement will require collaboration and coordination to address these challenges but also presents a critical opportunity to evaluate how quality is defined and measured in context of a fundamental truth: high quality health care is, and must be, equitable health care.

Quality care is equitable care.

ACKNOWLEDGEMENTS

❯ NCQA Staff:

Numerous NCQA staff contributed to the development of this Issue Brief. We thank the following staff for their participation on this project:

Mary Barton, MD, MPP
Vice President, Performance Measurement

Rachel Harrington, PhD
Research Scientist, Performance Measurement

Judy Lacourciere
Editor, Product Design and Support

Sarah Paliani, MPH
Senior Health Care Analyst, Performance Measurement

Bob Rehm, MBA
Assistant Vice President, Performance Measurement

Andy Reynolds, MBA
Assistant Vice President, Communications and External Relations

Sarah Hudson Scholle, DrPH
Vice President, Research and Analysis

Keirsha Thompson, MA
Health Care Analyst, Performance Measurement

Deidre Washington, PhD
Research Scientist, Performance Measurement

Additional Thanks:

NCQA would also like to thank the members of our Equity in HEDIS Expert Work Group, HEDIS Measurement Advisory Panels, and the Committee on Performance Measurement for their insight and support. Finally, we would like to thank the numerous stakeholders and members of the public who offered their time, perspectives, and feedback through public comment.

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