Disparities in Healthcare and Health Outcomes in Selected Conditions

NATIONAL QUALITY FORUM

CONTENTS

EXECUTIVE SUMMARY

Despite overall improvements in the healthcare system, disparities based on social risk factors continue to persist. In 2015, the Center for Disease Control and Prevention reported significant health and healthcare disparities in leading causes of death. For example, African Americans are more likely to die prematurely from heart disease; the prevalence of heart disease is higher for individuals with lower incomes and lower educational attainment; and men have higher suicide rates than women. In the same year, the Agency for Healthcare Research and Quality reported significant disparities in healthcare quality. Racial and ethnic minorities as well as individuals who have low incomes are far more likely to receive lower quality care. Eliminating these disparities has become the priority of the U.S. Department of Health and Human Services and many other stakeholder groups. These groups have begun to implement strategies to reduce disparities.

Measurement is a critical tool that can be leveraged to reduce disparities. Performance measures can be used for public reporting, tied to accountability programs, and allow stakeholders to assess the impact of interventions. Therefore, the National Quality Forum has convened a multistakeholder Committee, with funding from the Department of Health and Human Services, to provide recommendations on how performance measurement and its associated policy levers can be used to eliminate disparities in health and healthcare. The Disparities Standing Committee will develop its recommendations by focusing on selected conditions that include cardiovascular disease, cancer, diabetes and chronic kidney disease, infant mortality/low birthweight, and mental illness. Disparities within these conditions will be reviewed based on the social risk factors outlined in the 2016 National Academy of Medicine (NAM) report, *Accounting for Social Risk Factors in Medicare Payment: Identifying Social Risk Factors*. A separate report will document each of four phases of the project:

- report 1: review the evidence that describes disparities in health and healthcare outcomes;

- report 2: review the evidence of interventions that have been effective in reducing disparities;

- report 3: develop a conceptual framework to guide performance measurement to reduce disparities and perform an environmental scan of performance measures and assess gaps in measures that can be used to assess the extent to which stakeholders are deploying effective interventions to reduce disparities; and

- report 4: provide recommendations to reduce disparities through performance measurement.

This first report includes a review of the literature related to disparities and health and healthcare in the selected conditions. It also presents the Disparities Standing Committee's draft conceptual framework that illustrates a high-level approach to reduce disparities through measurement. The Committee has identified five steps to eliminate disparities:

1. Prioritize reducing disparities

2. Develop valid, reliable performance measures

3. Ensure scientific integrity of measures and recommend measures for use

4. Incentivize reduction of disparities

5. Implement quality improvement and care transformation

The Committee will continue to develop and refine the framework over the life of the project as the basis of a roadmap for how performance measurement can be used to eliminate disparities.

NQF found significant disparities across all of the selected conditions based on its review of the evidence: This confirms the urgent need for a systematic approach to eliminating health disparities through measurement. The review also notes several ways in which disparities have been reduced.

BACKGROUND AND CONTEXT

The World Health Organization (WHO) defines health as a "state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity." The WHO notes that "health is a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities." The WHO constitution stresses that attainment of the highest possible standard of health is a fundamental right of every human being, regardless of race or socioeconomic status. The WHO also stresses the importance of healthcare in achieving health, noting that "the extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health." However, the current reality falls short of this ideal and many Americans face disparities in both health and healthcare because of factors like their race, socioeconomic status, or where they live.

Addressing these disparities is a priority for both public- and private-sector stakeholders. In recent years, progress has been made towards addressing disparities in health and healthcare. The passage of the Patient Protection and Affordable Care Act (ACA) helped to close disparities in health insurance coverage. For example, the rate of uninsured African Americans dropped 9.2 percent while the uninsured rate among Hispanics dropped 12.3 percent, helping to reduce disparities in coverage among these populations when compared to whites. African

Americans and Hispanics have also historically been less likely than whites to have a usual source of medical care. However, these gaps narrowed significantly between 2010 and 2015. Addressing these access disparities is a crucial first step to reducing disparities in health and healthcare broadly. Despite these gains, the *2015 National Healthcare Quality and Disparities Report* found that disparities in care related to race, ethnicity, and socioeconomic status (SES) continue to persist across all National Quality Strategy (NQS) priorities. Key findings from that report show that people in poor households received worse care than people in high-income households for about 60 percent of quality measures, and that blacks, Hispanics, and American Indians and Alaska Natives received worse care than whites for about 40 percent of quality measures.[1] Many disparities also exist in the prevalence of and risk factors for disease.

A 2013 report from the Centers for Disease Control and Prevention (CDC), *CDC Health Disparities and Inequalities Report-United States, 2013,* highlighted disparities in the morbidity and mortality of key conditions that may be disproportionately affected by social risk factors, for example:

• African American adults are at least 50 percent more likely to die of heart disease or stroke prematurely (i.e., before age 75 years) than their white counterparts;

- the prevalence of adult diabetes is higher among adults without college degrees and those with lower household incomes;

- the rates of infant mortality vary geographically, with higher rates in the South and Midwest than in other parts of the country;

- men are far more likely to commit suicide than women, regardless of age or race/ethnicity, with overall rates nearly four times those of women;

- blacks had higher colorectal cancer incidence and death rates than whites, Asians/Pacific Islanders, and American Indians/Alaska Natives.[2]

Measurement science and performance measurement are powerful tools that can be used to drive improvements in health equity. Measurement can help to identify disparities in health and healthcare as well as highlight the use of successful interventions to eliminate them. The U.S. Department of Health and Human Services (HHS) Action Plan to Reduce Racial and Ethnic Health Disparities established a Secretarial Priority to measure and provide incentives for better healthcare quality for minority populations.[3] The

National Academy of Sciences and the Secretary's Advisory Committee have provided HHS with recommendations for 'Leading Health Indicators' to assess the nation's progress toward meeting the National Health Promotion and Disease Prevention Objectives for 2020, some of which address the social determinants of health.[4] The CMS Equity Plan, which focuses on reducing disparities in Medicare populations, also includes specific performance metrics to assess progress across its priorities and activities.[5] Increasingly, performance measurement is being tied to powerful incentives to change behaviors such as value-based purchasing and quality reporting. Leveraging measurement and its associated incentives can help to reduce and eventually eliminate disparities in health and healthcare. First, performance measurement can be used to identify disparities and their drivers. Secondly, performance measures can be used to assess the effectiveness of interventions to reduce disparities across common causes of morbidity and mortality to understand which measures can best be employed to eliminate health and healthcare disparities. Finally, measurement can be used to incentivize the reduction of disparities through payment and reporting.

PROJECT OVERVIEW

The National Quality Forum (NQF) has a long history of addressing the measurement of healthcare disparities, including establishing criteria to identify "disparities sensitive" measures, developing a framework and identifying practices for measurement and reporting cultural competency, and endorsing performance measures related to disparities and cultural competency. Recognizing the significant impact that disparities can have on outcomes of care, NQF has seated a Standing Committee

to make recommendations on how to address healthcare disparities. This Disparities Standing Committee is a permanent multistakeholder group of experts charged with providing recommendations on using measurement to eliminate disparities across NQF's work.

In this project, with funding from HHS, NQF will convene the Disparities Standing Committee to develop a roadmap to show how performance measurement and its associated policy levers can be used to eliminate disparities in health and

healthcare. The project will examine disparities in five target conditions that are among the leading causes of morbidity and mortality. These target conditions include cardiovascular disease, cancer, diabetes and chronic kidney disease, infant mortality/low birthweight, and mental illness. The Committee's work will focus on these conditions, but its recommendations will likely apply to disparities within conditions beyond the scope of this project. A separate report will document each of four phases of the project:

- report 1: review the evidence that describes disparities in health and healthcare outcomes;

- report 2: review the evidence of interventions that have been effective in reducing disparities;

- report 3: develop a conceptual framework to guide performance measurement to reduce disparities and perform an environmental scan of performance measures and assess gaps in measures that can be used to assess the extent to which stakeholders are deploying effective interventions to reduce disparities; and

- report 4: provide recommendations to reduce disparities through performance measurement.

This is the first of three interim reports that will culminate in a final report which will be released in September 2017. This interim report describes a review of the literature on disparities in health and healthcare related to the target conditions listed above based on the social risk factors identified in the NAM report, *Accounting for Social Risk Factors in Medicare Payment: Identifying Social Risk Factors.* The findings from this interim report will inform the first phase of the Committee's work to develop a roadmap and conceptual framework for how performance measurement can be leveraged to eliminate disparities in health and healthcare.

Literature Review Methods

The literature review provides the Committee with a snapshot of some of the evidence related to health and healthcare disparities in the selected conditions. To support this goal, NQF conducted a search for information sources relevant to the disparities in the five target conditions associated with the social risk factors identified in the NAM report. The Disparities Standing Committee provided key information sources and provided preliminary guidance on where to collect sources. Databases for the literature review included Academic Search Premier, PubMed/Medline, Google Scholar, PsychINFO, PAIS International, Ageline, Cochrane Collaboration, and Campbell Collaboration. NQF conducted a targeted search within these databases using various combinations of keywords that were derived terms related to the target conditions and social risk factors as well as general terms to capture broader work that may include relevant information. NQF also searched by population types including ethnic and racial minorities according to the Office of Management and Budget definitions. The search was confined to U.S. based work published between 2010 and 2016. Over 600 sources were identified. After a review of abstracts, around 250 sources were identified as highly relevant and subsequently used to inform the findings of this report. The literature review is not meant to be exhaustive nor does it include all populations affected by health and healthcare disparities. Rather, it highlights examples of disparities within the selected conditions and illustrates the associations found between social risk factors and health and healthcare outcomes with the goal of informing the development of the roadmap.

HEALTH AND HEALTHCARE DISPARITIES

The terms 'health disparity' and 'healthcare disparity' are defined differently throughout the literature. These terms are often used interchangeably with similar terms like health inequity, health inequality, and racial/ethnic differences. All of these terms vary in scope as to what is considered a disparity. The World Health Organization defines disparities in health as avoidable differences that arise from social and economic conditions which determine an individuals' risk of illness and the actions taken to prevent them from becoming ill or treat their illness when it occurs.[6] The HHS Office of Minority Health describes a health disparity as "a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage" (based on individual's gender, age, race and/or ethnic group, etc.). Healthcare disparities are related to "differences in the quality of care that are not due to access-related factors or clinical needs, preferences, and appropriateness of interventions" (i.e., differences based on discrimination and stereotyping, institutional, and health systems level).[7] Although these terms have been defined differently, the common thread is that they are differences based on modifiable, socially determined and cultural factors.

The Committee recognized the multifaceted nature of disparities in health and healthcare and the numerous drivers identified in the literature. Disparities in health and healthcare can be driven by factors both within and outside of the control of the person and the healthcare system. Disparities can be caused by personal, financial, structural, social-political, cultural, community,

and healthcare system factors. However, a number of interventions have proven to contribute to better outcomes. As a starting point for showing the relationship between drivers of disparities, mediators, and outcomes, the Committee developed a conceptual framework based on the work of Cooper et al.

Recent research has focused on the role of social determinants of health on disparities in health and healthcare. Social determinants of health, which include the social environment, physical environment, health services, and structural and societal factors, significantly affect health and healthcare outcomes. These determinants are influenced by the distribution of power, money, and resources throughout society.[8] A large body of research has measured the positive and negative effects of social determinants ranging from working conditions to social networks. The NAM report, Accounting for Social Risk Factors in Medicare: Identifying Social Risk Factors, highlights key social risk factors that include socioeconomic position; race, ethnicity, and cultural context; gender; social relationships; and residential and community context. A description of these social risk factors is excerpted from the NAM report and included in Exhibit 2. The NAM report describes the conceptual relationships between these social risk factors and health and healthcare outcomes. These risk factors are known to be associated with and sometimes cause health and healthcare disparities. Significant disparities have been observed in access to care and the quality of care as well as health outcomes across a wide range of conditions.

EXHIBIT 1. DRIVERS, MEDIATORS, AND INTERVENTIONS TO ACHIEVING EQUITABLE HEALTH CARE

Drivers of Disparities	Mediators	Interventions	Outcomes
Personal/Family • Acceptability • Cultural • Language/literacy • Attitudes, beliefs • Preferences • Involvement in care • Health behavior and health literacy • Socioeconomic status, education, income • Race and ethnicity • Disability • Healthcare need **Structural** • Availability • Appointments • How organized • Transportation **Financial** • Insurance coverage • Reimbursement levels • Public support **Social-Political** • Laws, regulations, policies • Income inequality • Social mobility • Level of segregation **Cultural** • Norms • Beliefs • Behavioral practices • Social exclusion • Discrimination, racism, and biases **Community Factors** • Environment • Public services • Education system • Urbanicity **Life Course Effects** • Adverse childhood events • Cumulative allostatic load **Healthcare System** • Limited Access • Lower Quality Care	**Resilience Factors** • Family • Spirituality **Quality of providers** • Cultural competence • Communication skills • Medical knowledge • Technical skills • Bias/stereotyping Appropriateness of care Efficacy of treatment Patient adherence	Improve quality Incentivize primary care Address social determinants of health Assist safety-net organizations Implement payment and delivery system reform interventions	**Health Status** • Mortality • Morbidity • Well-being • Functioning Equity of Services Patient Views of Care

Source: Adopted from Cooper et al., 2002

EXHIBIT 2. NATIONAL ACADEMY OF MEDICINE'S SOCIAL RISK FACTOR DESCRIPTIONS

Social Risk Factor	Description	Common Indicators
Socioeconomic Position (SEP)	SEP describes an individual's absolute and relative position in a society's stratification system. SEP captures a combination of access to material and social resources as well as relative status—prestige or rank-related characteristics.	• Income • Wealth • Dual eligibility • Occupation • Education
Race and Ethnicity	Race and ethnicity are social categories that represent a society's stratification system by which resources, risks, and rewards are distributed.	• Language • Nativity, immigration history, and acculturation
Gender	The social dimensions of gender distinguished from the biological effects of sex. It includes both normative gender identity and gender minorities, including individuals who identify as transgender, intersex, or otherwise nonconforming gender.	• Gender identity • Sexual orientation
Social Relationships	Social relationships include access to social networks that can provide access to resources, including material resources and instrumental social support.	• Marital/partnership status • Living alone • Emotional and instrumental social support

Residential and Community Context	The residential and community context includes compositional characteristics of neighborhood residents, characteristics of physical and social environments, as well as policies, infrastructural resources, and opportunity structures that influence individuals' everyday lives.	• Compositional characteristics
		• Environmental measures
		   – Urbanicity
		   – Housing

In developing the roadmap, the Committee seeks to build on the work of NAM. The Committee adopted some modifications to the risk factors put forward by NAM. Specifically, the Committee chose to include disability as a social risk factor. The Committee also expressed a desire to look beyond social risk factors to include behavioral risk factors, environmental exposures and access to green space, healthcare access, and cultural considerations.

These risk factors are strongly associated with disparities in health and healthcare. Socioeconomic positon, for example, is frequently linked to differences in health and healthcare. Occupying a higher level on the socioeconomic ladder is associated with better outcomes. The 2015 National Healthcare Quality Report showed that people who are uninsured or live in low-income households have lower access to care and receive poorer quality of care across a variety of measures. Similarly, the likelihood of premature death increases as the income decreases.[9] The 2015 American Community Survey reported increased income inequality across the country with far less growth in the median income for nonmetropolitan areas.[10] Growing income inequality creates an imbalance in the distribution of resources which can contribute to wider disparities in health and healthcare. Disparities are also seen in educational attainment which is associated with income. The 2015 Current Population Survey reported that

adults with a disability are less likely to hold a bachelor's degree than those without a disability.[11] Asians and whites were more likely to hold a bachelor's degree or higher as compared to African Americans and Hispanics.[12] These differences have persisted for decades.

Racial and ethnic minority groups experience increased marginalization and discrimination which has negative health repercussions.[13] A 2009 meta analytic review found that perceived discrimination can produce heightened stress responses which are related to participation in unhealthy behaviors and nonparticipation in healthy behaviors.[14] In June 2016, The Kaiser Family Foundation reported that African Americans, American Indians, and Alaska Natives fare far worse on health outcome measures than whites and, despite increases in insurance coverage through the Affordable Care Act, they remain significantly more likely to be uninsured.[15] The Kaiser Family Foundation also found significant disparities in access to and use of care.[16] Racial and ethnic minorities disproportionately receive lower quality care compared to whites.[17] Asian Americans, for example, received worse care than whites for about 20 percent of quality measures.[18] Many health conditions such as heart disease, asthma, obesity, diabetes, HIV/AIDS, viral hepatitis B and C, infant mortality, and violence, disproportionately affect minority populations.[19]

While many studies have identified disparities in racial and ethnic minorities, disparities have also been documented among women, children, older adults, and many other groups. A 2014 study in the *American Journal of Public Health,* showed that people with disabilities are more likely to be obese, be a current smoker, engage in no leisure time physical activity, and were less likely to have access to care.[20] Women are twice as likely to experience depression than men, but more women likely seek treatment for mental health issues than men.[21] Sexual and gender minorities have a higher prevalence of poor health behaviors and outcomes (e.g., report heaving drinking, higher prevalence

of obesity and hypertension, etc.).[22] They are also more likely to attempt suicide, less likely to get preventive services for cancer, and face barriers to accessing social services.[23] The LGBT community experiences legal discrimination in access to health insurance, employment, housing, marriage, adoption, and retirement benefits.[24]

The Disability Rights Education & Defense Fund (DREDF) has reported similar disparities amongst individuals living with disabilities. Having a disability has been shown to lead to lower quality of care, poorer health, institutionalization, and premature death.[25] The DREDF also reported that 31 percent of people with disabilities report having fair to poor health compared to 6 percent in the general population.[26] Healthy People 2020, a national health promotion and disease prevention initiative, also reports disparities in preventive healthcare services like cancer screenings and teeth cleaning.[27] These disparities have been attributed to factors such as inaccessible physical environments and discrimination. Other barriers include lack of provider training and inadequate research and monitoring.[28]

Disparities have also been found in the types and breadth of social relationships across many populations. Studies have found that inadequate social support is associated with higher rates of mental and physical disorders.[29,30] Social relationships have a cumulative advantage on health over the course of the individual's life. Fostering relationships that provide emotional and instrumental support is essential for healthy living. Having close connections with others shapes daily health choices, and the characteristics of people within a person's social network can predict health outcomes.[31] Having large social networks has been associated with better outcomes and improved health.[32] Social networks are important for people of all ages and backgrounds. Many people don't have regular, meaningful social interactions. U.S. population studies have shown that up to 20 percent of the population lives alone.[33] Older adults may be particularly at risk for social

isolation. Individuals' social positon in society, their health status, or even where they live can significantly affect their social relationships.

Health and healthcare outcomes also vary greatly by geography. Geographic regions differ by their levels of urbanization as well as their economic, environmental, and social characteristics.[34] As a result, there are disparities in healthcare access, unhealthy behaviors, and chronic conditions based on where people live. The Rural Health Reform Policy Research Center, for instance, found that adolescents and adults living in rural and nonmetropolitan counties are more likely to smoke.[35] They also found that the availability of physicians and dentists decreases as areas become more rural with the greatest deficit in specialty care. Children in rural areas are less likely to receive preventive medical visits in rural areas.[36] There are also many differences in environmental exposures between urban and rural settings.

These are only a few of many findings that demonstrate the ways in which social risk factors influence health and healthcare outcomes. Each social risk factor has independent effects on health and healthcare, but more often, social risk factors interact and have cumulative effects on an individual. Many social risk factors have a cascading effect. For example, where people live can determine their educational opportunities; educational opportunities can determine their future employment opportunities; and their future employment opportunities influence their ability to earn income and influence their levels of access to consistent, high-quality healthcare. Further, all individuals occupy multiple social identities. The

term 'intersectionality' has been used to describe the effects of multiple social risk factors on a single individual.[37] U.S. Census Bureau reports show that racial and ethnic minorities disproportionately occupy a lower position of the socioeconomic spectrum based on common indicators (e.g., income and education).[38] Compared to the general population, sexual and gender minorities are disproportionately poor.[39] The intersection of multiple social identities and its impact on health play out over and over again throughout the literature.

When groups are marginalized, they struggle to obtain the resources that are critical to improving and maintaining health. Although many disparities persist, some progress has been made in reducing them. The National Healthcare Quality and Disparities Report shows that differences based on childhood immunization and the rates of adverse events have been eliminated.[40] There are also only a few disparities found in patient safety. These promising findings show that reducing and eliminating disparities is possible.[41] However, measurement will be critical to tracking the healthcare system's progress and creating accountability for reducing and eliminating disparities. Targeting measurement efforts towards conditions that have the greatest disparities and highest rates of morbidity and mortality across various populations is one way to improve. The following sections describe the health and healthcare disparities specific to each target condition.

A ROADMAP TO ELIMINATE DISPARITIES IN HEALTH AND HEALTHCARE THROUGH MEASUREMENT AND ASSOCIATED POLICY LEVERS

The reduction of disparities and promotion of health equity is a primary goal of healthcare quality improvement. In *Crossing the Quality Chasm,* the National Academy of Medicine (NAM) established equity as an essential aspect of healthcare quality noting that equitable care does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status (SES).[42] Other seminal reports like *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* demonstrated that racial and ethnic minorities often receive lower quality care than their white counterparts, even after controlling for factors such as insurance, SES, comorbidities, and stage of presentation.[43]

The Committee recognizes that many frameworks have been developed to demonstrate why disparities exist and how they can be reduced. Specifically, NQF has engaged in extensive work to better understand the role quality measurement can play in reducing disparities. The Disparities Standing Committee (DSC) seeks to build on this work by developing a roadmap with the unique goal of demonstrating how quality measurement can be used to identify and eliminate disparities. The roadmap sets an aspirational goal of eliminating disparities in health and healthcare as well as laying out shorter term goals to achieve this aspirational goal. The roadmap will describe a path to achieving these goals by outlining the actions needed to eliminate disparities and highlighting stakeholders and their responsibilities.

The Committee developed a series of principles to guide the development of the roadmap. These principles are meant to describe what the final roadmap *should* include:

1. Disparities in health and healthcare should be identified and eliminated.

2. Elimination of disparities is an integral component of quality improvement.

3. The roadmap must be transparent, and the DSC will be open about its goals and plans.

4. The DSC and NQF must have accountability and commit to follow-through, progress, and monitoring of the roadmap.

5. All stakeholders must engage and work to eliminate disparities.

6. The roadmap should be data driven.

7. Initiatives to eliminate disparities in healthcare quality should be based on the clearest possible understanding of underlying causes of those disparities, and on a clear understanding of which agents or actors are best able to modify those causal factors.

8. Recommendations must be feasible to implement within current system.

9. Support efforts should focus on translating scientific evidence into everyday medical practice, and promote the identification and rapid adoption of best practices proven to reduce disparities.

10. Promote transparency of cost, outcomes, and patient experience through availability of timely, actionable, and culturally and linguistically appropriate information for patients and providers; this includes standardization of consumer tools to allow the healthcare consumer greater ease in comparing across diverse populations.

The roadmap will emphasize that equity is an essential part of quality and will encourage the elimination of disparities across the three aims of the National Quality Strategy: better care, healthy people/healthy communities, and affordable care. The Committee also noted that the roadmap will apply to a wide breadth of populations experiencing disparities, for example social stratification including race, ethnicity, age, gender, sexuality, disability, and geographic location. The roadmap will emphasize the role of the community and the importance of building cross-sector partnerships. In particular, the Committee noted that measurement should extend beyond clinical settings and structures and processes of care. The roadmap will also strive to help stakeholders develop better connections between health and healthcare.

The roadmap will feature potential interventions or pathways to reduce disparities. For example, the roadmap could highlight the use of alternative payment and delivery models to address social determinants of health, align reimbursements with actions to eliminate disparities, and identify accountable entities. The roadmap will also stress the need to address population health and community-oriented drivers of disparities as the system increasingly shifts to global payments. The Committee noted the need to encourage investments in the health of underserved communities and address underlying issues of affordability. Factors within and outside of the control of the healthcare system drive disparities. The roadmap will focus on factors within the healthcare system and identify relevant performance measures that can help drive uptake of evidence-based interventions.

Draft Roadmap

To develop the roadmap, the Committee will draw on existing frameworks. As a starting point, the Committee recognized the role that both access and quality can have on healthcare disparities. The Committee noted the need to drive improvements

among the five A's of access to care defined by Penchansky and Thomas: affordability, availability, accessibility, accommodation, and acceptability.[44] Similarly, the Committee adopted the domains of quality put forth by the NAM: safety, effectiveness, patient-centered, timely, efficient, and equitable.

The Committee began by outlining five steps to using measurement to eliminate disparities:

1. Prioritize reducing disparities

2. Develop valid, reliable performance measures

3. Ensure scientific integrity of measures and recommend measures for use

4. Incentivize reduction of disparities

5. Implement quality improvement and care transformation

The Committee recognized the need to continually track disparities in health and healthcare and that measurement and its associated levers will need to evolve with changes in the healthcare system and as new evidence becomes available. The Committee also cautioned that there is no global solution to eliminating disparities; rather, stakeholders must take individualized actions across the system. To facilitate this process, the roadmap will identify measures and interventions at both a population and an individual level. Additionally, the roadmap will identify measures and interventions that can be used by stakeholders across the system: patients, clinicians, facilities, systems, payers, and purchasers.

The Committee also noted the intertwined yet distinct challenges of eliminating disparities in health and healthcare. Healthcare contributes to a person's health, but health is influenced by factors beyond the control of the healthcare system. As a starting point for determining areas that could be most amenable to change through measurement, the Committee will build from the NAM's Conceptual Framework of Social Risk Factors for Healthcare Use, Outcomes, and Cost.

EXHIBIT 3. SOCIAL RISK FACTORS FOR HEALTHCARE USE, OUTCOMES, AND COST
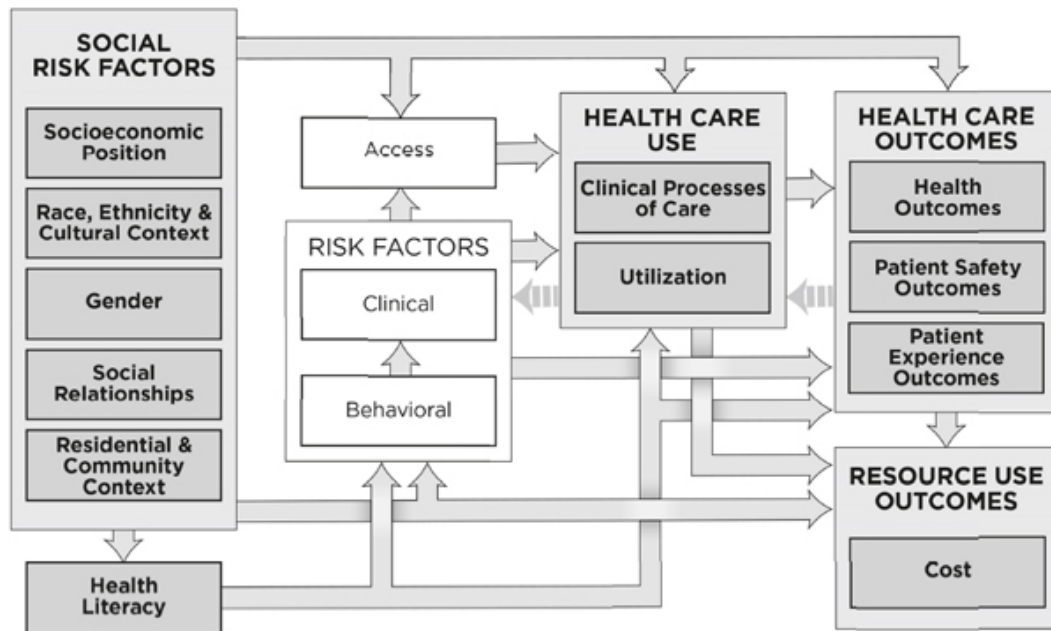
Source: National Academies of Sciences, Engineering, and Medicine, 2016.

Throughout this work the Committee will refine its recommendations about potential actions that stakeholders can take to use measurement to ensure effective interventions to reduce disparities. The Committee began it first attempt to illustrate the roadmap in Exhibit 4. The illustration includes key concepts and actions to be taken to drive improvement. The roadmap and illustration will evolve over the life of the project.

This model aims to identify the role of measurement and the continuous nature of quality improvement. The disparities measurement cycle mirrors the typical measure development life cycle but focuses on measures that reduce disparities. Included are actions that stakeholders can take to identify disparities, incentivize their reduction, and implement effective inventions.

The Committee recognized that reducing disparities will require measures that are condition and population specific to ensure improvements in areas that have the largest disparities. It will also require measures that apply across multiple conditions, populations, and settings to allow for better comparisons and to drive improvements for all. The Committee will develop example use cases to make the roadmap more concrete, showcase effective interventions, and provide example measures that could help facilitate the use of effective interventions. This report presents a high-level literature review to identify disparities in these key areas. Similarly, the Committee will focus on these key areas to identify effective intervention, existing measures, and measurement gaps.

EXHIBIT 4. A ROADMAP FOR THE ELIMINATION OF HEALTH DISPARITIES THROUGH MEASUREMENT

Identify disparities by stratifying data

Priortize areas for measurement that can reduce disparities
ALL STAKEHOLDERS

Identify gaps in measurement and performance
CLINICIANS AND PROVIDERS

Develop valid, reliable performance measures
MEASURE DEVELOPERS

Disparities Measurement Life Cycle

Implement quality improvement strategies and care transformation
CONSUMERS, PAYERS, PURCHASERS, POLICYMAKERS

Ensure scientific integrity of measures and recommend measures for use
NQF

Incentivize the reduction of disparities through measurement

Incorporate equity accountability measures into payment and reporting programs	Align equity accountability measures across payers	Incentivize preventive care, primary care, and addressing the social determinants of health	Assist safety-net organizations serving vulnerable populations	Conduct and fund demonstration projects to test payment and delivery system reform interventions to reduce disparities

Disparities in health and healthcare are identified and eliminated

REVIEW OF DISPARITIES IN SELECTED CONDITIONS

Cardiovascular Disease

Cardiovascular disease (CVD) is the leading cause of mortality and morbidity in the U.S., accounting for over 600,000 deaths in 2014 alone. The four categories of CVD include coronary heart disease (CHD), cerebrovascular disease, peripheral artery disease, and aortic atherosclerosis. The most common clinical risk factor is related to a process called atherosclerosis (the buildup of plaque in the walls of arteries), but there are many other risk factors including high blood pressure, cholesterol, poor diet, obesity, physical inactivity, and smoking/ tobacco use. CVD often manifests in heart failure, stroke, arrhythmia, and valve problems. Lifestyle factors also influence the likelihood of developing CVD. There are significant disparities found in the prevalence and incidence of CVD based on social risk factors.

The Framingham study documents the clinical and social risk factors of CVD. The study began in 1948 and is now in its third generation of participants. Tools and data from this study have been used to examine the relationship between social risk factors and CVD disparities. One study used Framingham risk scores to examine the relationship between subjective socioeconomic status (an individual's perceived position in the SES hierarchy) and risk for CVD. The study found higher risk for individuals who had lower subjective SES.[45] This relationship has also been found with more objective measures. Individuals who earn less than $35,000 per year are more likely to have all forms of heart disease than individuals who earn more.[46] Another study found that people of lower SES were more likely to experience delays in care and were less likely to receive preventive treatments for CVD related events.[47] Having public insurance rather than private insurance has been associated with a lower of likelihood receiving treatment for anarrhythmia.[48] SES factors also influence disease progression,

treatment compliance, and readmission rates for CVD.[49] Even after controlling for SES many disparities still remain, especially those based on race and ethnicity.

The American Heart Association (AHA) reports that the average rate of death attributable to CVD was 222.9 per 100,000 Americans, with 270.6 for white males, 356.7 for African American males, 246.6 for African American females, 197.4 for Hispanic males, 183.8 for white females, and 136.4 for Hispanic females.[50] These findings are consistent with the literature, with the majority of studies finding wide gaps between the prevalence and risk for CVD between whites and African Americans. The Jackson Heart Study documents disparities in the African American Community. The most recent cohort included over 5,000 African American men and women and found significant differences in CVD risk, morbidity, and mortality between individuals in the study and the general population. The AHA also reported that CVD age-adjusted death rates were over 30 percent higher for African Americans than for the overall U.S. population.[51] African Americans are also nearly twice as likely to die from a stroke.[52] The literature is replete with examples of African Americans having less access and receiving lower quality care for CVD-related events. Studies have found that they receive less lifesaving treatment like coronary revascularization (30 percent less) than whites.[53] Disparities are also found in most other racial and ethnic minority groups. Hispanics report hypertension at higher rates and lower knowledge of CVD risks.[54] There are also many studies that have documented disparities in Asian American subgroups. A literature review from the AHA found that Asian Indians have significantly higher mortality related to coronary heart disease than other racial/ethnic groups and that other Asian American subgroups have a higher incidence of hemorrhagic stroke than whites.[55]

These disparities may be attributed to factors like discrimination within the healthcare system. One study looked at the relationship between perceived discrimination and medication adherence amongst African Americans with hypertension and found a significant relationship between increased perceived discrimination and lower medication adherence for those with CVD.[56] Another study examined the relationship between structural racism (state level indicators: political participation, employment, and job status) and myocardial infarction (MI). Researchers found that African Americans living in states with high levels of structural racism were more likely to report an MI in the last year.[57] Discrimination may affect health outcomes through stress which has been linked to a variety of adverse effects.

Most studies include a racial and ethnic dimension in their analysis and look at the partial effects as well as the interactions between other social risk factors. One study, for instance, used Framingham risk scores for stroke and CVD to examine its relationship with race and other factors like geography.[58] They found CVD-related mortality rates were higher for African Americans than their white counterparts in middle states, high-risk urban areas, and low-income southern areas.[59] These findings are consistent with other studies.[60] Overall, heart disease related mortality rates are higher in southern states than in in western states.[61] One study specifically looked at risk for hypertension and found that African Americans born in southern states were 1.11 times more likely to be hypertensive than whites.[62]

Fewer studies have examined the effect of disability, social support, and gender on CVD disparities. One study that found that 34 percent of adults with disabilities had hypertension compared to 27 percent for adults without disabilities.[63] People with disabilities also are more likely to smoke, not engage in physical activities, and have high blood pressure.[64,65] Individuals who are widowed or divorced are more likely to have all forms of heart disease than individuals

who are married.[66] Similar lifestyle-related CVD disparities are seen in LBGT populations. A 2015 AHA report describes the LBGT population as having the highest rates of tobacco, alcohol, and other drug use.[67] These lifestyle factors have been attributed to depression, having other chronic conditions, as well as negative social influences. Social relationships play a similar role in predicting CVD risk and outcomes as with other chronic illnesses. A 2016 systematic review that included 16 longitudinal data sets found that deficiencies in social relationships are associated with increased risk for CVD.[68] Other studies have also found the that supportive social relationships can reduce the incidence of CVD.[69]

Cancer

Cancer is the second leading cause of death in the U.S. accounting for nearly 25 percent of all deaths. According to the American Cancer Society, cancer refers to group of diseases that are characterized by the growth and spread of abnormal cells.[70] While cancer survival rates are improving, more than half a million people in the U.S. die from cancer each year. Mortality can be reduced by screening, which detects abnormalities and allows for intervention at an early stage of the disease, and prevention, which focuses on modifying the environmental and lifestyle risk factors that increase the likelihood of cancer.[71] Some environmental and lifestyle risk factors include tobacco use, obesity, poor diet, lack of physical activity, exposure to excessive ultraviolet radiation without protection, infectious agents, excess alcohol consumption, and general exposure to carcinogenic agents.[72] There are also genetic risk factors. However, the most significant risk factor is tobacco use. Roughly 30 percent of all cancer deaths can be attributed to tobacco use.[73] Beyond these lifestyle and clinical factors, social risk factors also determine cancer risk and prevalence.[74]

African Americans have the highest mortality rate and shortest survival of any racial or ethnic

group for most cancers.[75] While racial disparities in incidences of cancer vary by the type of cancer, the literature shows that African Americans are more likely to experience worse health outcomes after diagnosis, including higher rates of mortality, across various types of cancer. For example, white women experience more incidences of breast cancer than African American women, yet African American women have significantly higher mortality rates due to breast cancer.[76] Additionally, African American men have the highest incidence of prostate cancer and also have higher mortality than white men.[77] Racial and ethnic disparities may be attributed to late stage diagnosis. According to the American Cancer Society, ethnic minorities are substantially more likely to be diagnosed with cancer at a later stage of the disease, which often leads to less successful treatment.[78] The later presentation has been attributed to differences in income, education, and health insurance status among African American and Hispanic populations.[79] Several studies point to cultural beliefs and poor patient-provider communication as a reason for later stage diagnosis. One study found a significant positive association between late stage presentation of lung cancer, fatalistic beliefs, and medical mistrust among minorities.[80] Racial and ethnic minorities are also affected by poor patient-provider communication even after diagnosis. Mott-Coles examined the providers' skills in communicating with African American and Latina women diagnosed with breast cancer and found that providers generally did not tailor their patient education to account for factors such as literacy level or cultural beliefs.[81]

In addition to later stage diagnosis and poor patient-provider communication, evidence also suggests that discrimination against minorities leads to worse care. The landmark report, *Unequal Treatment,* from the Institute of Medicine cites a study that showed that minority outpatients with cancer received inadequate analgesic medication.[82] Another study found that African American men and women with colorectal cancer received less aggressive treatment than whites

even after adjusting for comorbidities, hospital type, and insurance coverage status.[83] Additionally, in the case of non-small-cell lung cancer, a study of similar African American and white Medicare patients found that African American patients were only half as likely as whites to receive a surgery that substantially increases the likelihood of surviving five years or longer, even after controlling for age, sex, stage of disease, comorbidity, marital status, and income.[84]

Independent of race and ethnicity, SES is a significant predictor of health and healthcare outcomes for cancer. Uninsured status poses a significant barrier to patients receiving quality cancer care.[85] Many of the studies that examined racial factors in healthcare disparities have included SES in their analyses. Bilikisu, Thierry, and Miranda found that, when studying racial differences in receipt of mammograms, after controlling for race, disparities were explained by SES and limited access to care.[86] The same was found in a study examining colorectal screenings in Hispanic versus white populations.[87] Another study examined the racial disparities in survival of patients with cancer of the head and neck and found that analysis of insurance status was the only factor that showed a significant effect on disease-specific survival.[88]

Additionally, SES predicts disparities in personal health behaviors. For instance, people whose income is less than twice the poverty level are much more likely to be current smokers than those with higher incomes, and are therefore at a higher risk for lung and other cancers.[89] According to the CDC, people with low incomes are more likely to partake in behaviors that increase risk for cancer like tobacco use, unhealthy diet, sedentary lifestyle, and engaging in risky sexual behaviors.[90] A person's SES also affects a person's access to healthcare which lowers the likelihood of receiving cancer screenings. This leads to later stage diagnosis and lower chances of survival.[91]

There is contradictory evidence for cancer disparities based on geography. These

inconsistencies are possibly attributable to varying classifications of urbanicity.[92] Regardless, a common disparity is in access to care as well as stage of diagnosis. One study found that while survival rates for rural residents were lower than their urban counterparts, the differences cannot be solely attributed to their late stage of diagnosis. Rural patients expressed different treatment preferences, which may contribute to their higher mortality rates.[93] However, the same study found that mortality was affected even more by SES than rurality. Rural populations face a unique set of challenges including the distance to a quality healthcare facility, lack of specialized resources, and differences in health behaviors. One study found that while rural hospitals provide care comparable to urban hospitals, for many surgical oncological procedures, patients who required more complex procedures experienced poorer outcomes in rural areas.[94] The lack of social support, including nearby family to assist with the transportation of older patients, may also be a factor in the disparities based on urbanicity.[95] Rural residents are also more likely to present at a later stage of cancer, and rural patients were also more likely to forego treatment because of cost.[96]

One recent study found that marital status has a positive impact on the survival of cancer patients. The study found that patients with breast, lung, colorectal, kidney, and pancreatic cancers who are married, survive longer than their single counterparts. Previous research on marital status has found that unmarried women with breast cancer were more likely to be diagnosed at a later stage of the disease and were more likely to die from the disease.[97] The disparity that exists among married and unmarried people can possibly be explained by differences in health behaviors as well as the impact of support from a spouse. Married patients may have more reliable access to care as well as increased support in attending medical appointments, complying with medication regimen, and functional recovery from surgery. Additionally, married patients may reap the benefits of social connectedness, including limiting

depression, which may influence mortality.[98] Fewer studies have examined disparities by gender, social relationships, and disabilities. One study that looked at gender differences in lung cancer found that women experience greater survival rates than men regardless of stage, histology, treatment modality, or smoking status. The literature on disparities in social relationships focused on women and the heteronormative assumptions made by providers. One study found that providers' assumptions reduced patient-provider discussion about sexual health with lesbian, bisexual, and queer women.

Cancer disparities are also found within the disability community. One study found that women with disabilities were more likely to have cancer and to be diagnosed at a later stage of the disease. They were also less likely to receive regular breast and cervical cancer screenings and to adopt health-promoting behaviors.[99] Women with intellectual disabilities were significantly less likely to receive breast and cervical cancer screenings, 72 percent and 45 percent less likely, respectively.[100] Women in this population are at a greater risk for sexual assault. Those patients who have been assaulted are more likely to be fearful of the necessary exams and procedures required in routine cancer screenings.[101] Additionally, providers can often lack knowledge or training related to working with patients with intellectual disabilities.[102] Providers may also not recommend the necessary Pap test, which tests for changes in cervical cells that could lead to cancer, because they erroneously assume women with disabilities are not sexually active.[103]

Diabetes and Chronic Kidney Disease

Diabetes is characterized by above normal blood glucose levels caused by defects in insulin production, insulin action, or both. Complications of diabetes include heart disease, blindness, kidney failure, and lower-extremity amputations. Diabetes is a primary risk factor for chronic kidney

disease (CKD), which includes diseases that inhibit proper kidney function. The CDC estimates that 29.1 million Americans, about 9.3 percent of the population, have diabetes.[104] In 2015, diabetes led to 76,488 deaths in the United States. However, the burden of diabetes is distributed differently based on social risk factors.

Marked racial and ethnic disparities exist in the burden of diabetes in the adult population. Whites have the lowest rates of diabetes with 7.6 percent of adults aged 20 years or older diagnosed with diabetes. Comparatively, 9.0 percent of Asian American, 12.9 percent of Hispanic, 13.2 percent of African American, and 15.9 percent of American Indian and Alaska Native adults have been diagnosed with diabetes. Racial and ethnic minorities are also at greater risk of developing complications from diabetes. Studies have found that African Americans are more likely to suffer complications caused by diabetes such as end-stage renal disease and blindness. They are also more likely than whites to have lower extremity amputations.[105]

These disparities may have a number of causes. Biological factors such as varying glucose metabolic rates and insulin resistance across racial and ethnic groups may contribute.[106] Racial and ethnic minorities also experience higher rates of obesity, one of the main risk factors for diabetes. African Americans and Hispanics are more likely to have glycated hemoglobin (HbA1C) values that are higher than whites which may contribute to higher rates of diabetes-related complications. Health behaviors may also contribute to these disparities. Risk factors for diabetes such as smoking and physical activity vary by racial and ethnic groups. Some studies have found that minorities are more likely to have less access to healthy food and places to exercise. There is also evidence that suggests that self-monitoring of blood glucose may vary by racial and ethnic groups, while other evidence suggests a relationship between varying rates of depression and disease management.

Access to healthcare and healthcare quality may

also contribute disparities in diabetes treatment and care for racial and ethnic minorities. Racial and ethnic minorities are more likely to be uninsured or underinsured. Lack of adequate health insurance has been associated with underuse of preventive services for diabetes such as foot and eye examinations.

People living in rural areas are also more likely to have diabetes. The prevalence of diabetes is 8.6 percent higher in rural areas than in urban areas.[107] Patients with diabetes are also more likely to have underdiagnosed complications in rural areas and are at higher risk of major and minor amputation as well as inpatient death. Rural patients are less likely to receive a professional foot exam, are less likely to conduct adequate self-examinations of their feet, and experience a lack of communication across healthcare providers, which impedes patient engagement in self-management of the disease.[108] Additionally, rurality also reduces the chances that someone will receive diabetes self-care education. Further, rural racial and ethnic minorities show a distinct gap in knowledge about diabetes compared to racial and ethnic minorities living in urban areas.[109]

The CDC notes a high incidence of diabetes among Americans with disabilities.[110] Adults with developmental disabilities are more likely to have diabetes than those without developmental disabilities.[111] Balough et al. found that adults with intellectual and developmental disabilities had both higher prevalence and incidence of diabetes. These disparities were highest among women, younger adults, and those residing in rural or low-income neighborhoods. Adults with developmental disabilities are more likely to lead a sedentary lifestyle and have high-calorie diets, increasing their risk of obesity and type 2 diabetes.[112] One study found that adults with developmental disabilities who were enrolled in the Kansas Medicaid Program experienced lower quality of care.[113] Similarly, adults with physical disabilities are also at a higher risk of developing diabetes. Reichard et al. note the challenges

faced by this population that can contribute to their risk of developing diabetes including lack of transportation, inaccessibility of medical and fitness facilities, inadequate training on disabilities for medical staff, and underinsurance or lack of health insurance.[114] Froehlich-Grobe et al. found a high prevalence of obesity among people with disabilities, increasing their risk for diabetes.[115]

Diabetes is a primary cause of chronic kidney disease (CKD). Chronic kidney disease is a group disorder that affects the structure and function of the kidneys.[116] The leading causes of CKD are diabetes and high blood pressure.[117] The CDC estimates that more than 10 percent of adults in the U.S. may have CKD.[118] Social risk factors can have a significant impact on a person's risk of developing diabetes and/or CKD. Norris and Nissenson note disparities in the incidence, prevalence, and rate of complications of CKD by gender, race/ethnicity, and socioeconomic status.[119]

There are significant CKD disparities based on race and ethnicity. The widest gaps are found between African Americans and whites, but CKD disparities have been found across several minority groups. Disparities are also found in CKD care. One study, for instance, found that American Indians and Alaska Natives are less likely to receive kidney transplants.[120] Some studies attribute these disparities to differences in diet and health behaviors.[121,122] Others find these disparities persist even after controlling for these factors. For example, Evans et al. found that after adjusting for demographic, socioeconomic, lifestyle, and clinical factors, African Americans still had increased risk for CKD.[123] Another study found that compared with whites, African Americans had poorer access to care, were less likely to have a usual source of care, and had a higher incidence of CKD.[124]

Evidence suggests that CKD prevalence tends to be higher in women, but the disease is more severe in men. Women with diabetes tend to experience significantly greater burden of CKD risk factors compared to men; however, sex-specific differences in diabetic kidney disease (DKD) are not well defined. Although women

had greater prevalence of advanced CKD, they had decreased odds of having CKD compared to men; these disparities were most prominent amongst the elderly.[125] A study by Goldfarb-Rumyantzev et al. uses the social adaptability index (SAI), a composite indicator of SES and interaction with society, to evaluate the likelihood of patients being placed on the waiting list for kidney transplantation. The study notes that SAI was greater in men than in women with greater SAI being associated with increased likelihood of being placed on the waiting list.[126] A study that measured the gender disparity in access to renal transplantation supports the evidence that women are less likely than men to be put on the transplant list.[127] Although sex and gender differences are of fundamental importance in CKD, considering gender as a factor in the prevention and treatment of CKD and implementation of clinical practice guidelines has been largely neglected.

Infant Mortality and Low Birth Weight

Infant mortality is a critical indicator of population health. Infant mortality is defined as the death of a baby within the first year of life. The infant mortality rate is calculated as the number of infant deaths that occur for every 1,000 live births.[128] The Unites States has an infant mortality rate of 6.1 per 1,000 live births, higher than that of other developed countries.

The leading causes of infant death in the United States are:[129]

• Congenital malformations or chromosome abnormalities – 20 percent

• Low birth weight (BW) or prematurity – 18 percent

• Sudden infant death syndrome (SIDS) – 7 percent

• Neonatal death due to maternal complications – 7 percent

• Unintentional injuries – 5 percent

Two out of three infant deaths occur in the neonatal period (the first 28 days of life).[130] The March of Dimes notes that the most common causes of neonatal death are premature birth, low birth weight, and birth defects.[131] Among term infants, the major causes of neonatal death were asphyxia and infection, and in post neonatal infancy, SIDS.[132]

Low birth weight is used to describe infants who are born weighing less than 2,500 grams or 5 pounds, 8 ounces. As noted above, it is the second leading cause of infant mortality. Low birth weight can be caused by fetal growth restriction and prematurity.[133] In the United States, preterm birth is the cause of low birth weight in almost two-thirds of infants born weighing less than 5 pounds, 8 ounces.[134] Only 2 percent of infants are born before 32 weeks gestation in the United States; however, they represent one-third to one-half of infant deaths.[135] Preterm birth and low birth weight are also associated with short- and long-term health and developmental complications.[136] The exact causes of low birth weight and preterm birth are not known, but these conditions have been linked to maternal smoking and substance use, chronic conditions, and infections.[137]

Significant disparities exist across the causes of infant mortality, contributing to overall disparities in health. These disparities exist across social risk factors; however, racial and ethnic disparities in infant mortality are particularly large.[138] The Centers for Disease Control and Prevention found significant disparities in infant mortality rates by race and ethnicity. From 2006-2008, the infant mortality rate for the United States was 6.68 per 1,000 live births. The mortality rate for white infants was 5.58, and for Hispanic infants the rate was 5.50, while the rate for African American infants was 13.11.

Hauck et al. examined the disparities in infant mortality in both the neonatal and post neonatal period. During the neonatal period, the most common causes of death for white infants are congenital malformations (0.95 per 1,000 live births), disorders related to preterm birth and low birth weight (0.76 per 1,000 live births), and newborn affected by maternal complications of pregnancy (0.32 per 1,000 live births). African American infants are more likely to die from all of these causes. For African American infants, the three leading causes of neonatal death are disorders related to preterm birth and low birth weight not otherwise classified (2.99 per 1,000 live births), congenital malformations (1.20 per 1,000 live births), and newborn affected by maternal complications of pregnancy (0.90 per 1,000 live births).

Although the causes of infant mortality do not differ much across racial and ethnic groups, the risk of death is not equal.[139] African American and white infants share the same leading causes of death in the post-neonatal period: SIDS, congenital malformations, and accidents. However, African American infants are more likely to die from each of these causes. For SIDS, African American infants have a rate of 1.02 per 1,000 live births compared to 0.49 per 1,000 live births for white infants. African American infants have a mortality rate from congenital malformations of 0.60 per 1,000 compared to 0.34 per 1,000 live births for white infants. Similarly, African American infants are more likely to die from accidents than white infants (0.52 per 1,000 vs. 0.21 per 1,000 live births).

The CDC examined causes of mortality across racial and ethnic groups but did not separate out the neonatal and post-neonatal periods[140]. Infant mortality was higher for all causes for American Indian or Alaska Native infants compared to white infants as well. The CDC found that American Indian or Alaska Native infants had a mortality rate of 761 per 100,000 live births compared to a rate of 505.6 per 100,000 live births for white infants. The mortality rate for disorders related to short gestation and low birth weight was 95.7 per 100,000 for American Indian or Alaska Native infants compared to 74.4 per 100,000 for white infants. The rate of SIDS was 78.3 per 100,000

compared to 40.1 for white infants. The rate of fatal accidents was 47.8 per 100,000 compared to 27.4 per 100,000 for white infants.

For Hispanic infants the mortality rate from all causes was 500.2 per 100,000 compared to 505.6 per 100,000 for white infants. For congenital malformations, Hispanic infants had a mortality rate of 129.4 per 100,000 compared to 114.7 per 100,000 for white infants. The mortality rate for disorders related to short gestation and low birth weight was 88.1 compared to 74.4 for white infants. Hispanic infants had lower rates of SIDS and fatal accidents than white infants.

Asian or Pacific Islander infants had the lowest mortality rate of any racial or ethnic group. Rates were lower than white infants for all causes except newborn affected by maternal complications of pregnancy (36.5 per 100,000 compared to 29.8 per 100,000 for white infants).

In addition to the disparities in the overall infant mortality rate, significant racial disparities exist in preterm birth and low birth weight. African American women, American Indian and Alaska Native women, and Puerto Rican women are more likely to give birth prematurely.[141] Hauck et al. note that African American women are twice as likely to give birth prematurely and that 54 percent of the disparity in mortality between African American and white infants can be attributed to the greater incidence of preterm birth among African American women.[142]

Racial and ethnic disparities exist in other causes of infant mortality as well. African American infants are 1.3 times and Hispanic infants are 1.1 times more likely to die from congenital malformations than white infants. Additionally, African American and American Indian or Alaskan Native infants have SIDS rates of two to three times the national average and experience higher rates of SIDS across socioeconomic levels.[143] African American and American Indian infants are also more likely to die from accidental deaths than white, Asian, or Hispanic infants.[144]

Infant mortality has also been found to be associated with socioeconomic status. Research has focused on the mother's age, marital status, and education as indicators of socioeconomic position. He et al. found that infants born to teenage mothers had a higher mortality rate than infants born to mothers in their twenties and thirties.[145] The mortality rate for mothers less than 15 years old was approximately three times higher than for mothers in lower risk age groups. Much of this increased risk is due to the high prevalence of low birth weight among infants born to teenage mothers.[146] He et al. also found that marital status may be associated with infant mortality and suggested that the infants of single mothers may be at increased risk, as the mortality rates of these infants were almost twice as high . The authors found that a mother's age, education level, and receipt of prenatal care were associated with marital status.[147] The Robert Wood Johnson Foundation Commission on Health found that babies born to mothers with less than 12 years of education were the most likely to die in their first year of life.[148] The Commission on Health also found that infants born to women with 13-15 years of education had a mortality rate almost 40 percent higher than those born to women with 16 or more years of education.

Other social risk factors also contribute to disparities in infant mortality and low birth weight. Disparities in the infant mortality rate exist between rural and urban areas. In Child Health USA 2012, HRSA notes that the infant mortality rate is 6.51 in urban areas compared to 7.1 in large rural areas and 7.31 in small rural areas.[149] The infant mortality rate is higher in rural counties in both the neonatal and post-neonatal periods; however, the disparities were only significant in the post-neonatal period.[150] Infants born in small rural counties were slightly more likely to be low birth weight (8.31 percent compared to 8.15 percent for urban counties and 8.16 for large rural counties).[151]

There has been more limited research on the impact of a mother's disability on the birth

outcomes of her child. One study found similar rates of very low birth weight between mothers with intellectual disabilities and those without.[152] However, this study found higher rates of babies with birth weights of 2000–2499 and 2500–2999 grams. Babies whose mothers had an intellectual disability were more likely to die, but the result was of borderline statistical significance.

Disparities in healthcare may contribute to these disparities in infant mortality and low birth weight. People with social risk factors may have more limited access to healthcare and effective interventions, may receive lower quality care, and may have behavioral risks that contribute to infant mortality and low birth weight. A review of the literature suggests that all of these factors may contribute to the risk of infant mortality and low birth weight.

Prenatal care is essential to a healthy birth. Women who delay or do not receive prenatal care are more likely to deliver a low birthweight infant or to have a preterm birth compared with women who receive early prenatal care. Additionally, inadequate prenatal care is associated with an increased risk for infant mortality. However, mothers with social risk factors may not receive recommended prenatal care.

One study found that African American mothers were less likely than white mothers to receive adequate prenatal care as defined by the number of clinician visits.[153] Access to prenatal care may also influence the racial and ethnic disparities in infant mortality related to congenital malformations. While the causes of these disparities are not known, the literature suggests there may be differences in the use of preventive measures such as folic acid supplementation, and access to and acceptance of antenatal screening and termination of pregnancy.[154]

Challenges in accessing healthcare may also contribute to higher infant mortality in rural areas.[155,156] Access to prenatal care is a particular concern for mothers living in rural regions. One study found that in Mississippi some mothers

may travel over an hour to the nearest provider or over 100 miles to see a specialist. The authors of this study note that all Mississippi counties have federally designated medically underserved areas, and some do not have a practicing physician or nurse practitioner.[157]

The literature suggests that quality measurement could play a role in reducing mortality and ensuring access to effective interventions for prematurity. Hauck et al. note the need to develop a more robust way to measure the quality of prenatal care, beyond just the number of visits, to help identify potential causes of disparities.[158]

The impact of access challenges on infant mortality is not limited to prenatal care. The literature suggests the potential impact of access on effective interventions and quality of care on the survival of low birth weight infants. Howell et al. analyzed data from New York City and found that African American infants with very low birth weight were more likely to be born in hospitals with higher risk-adjusted neonatal mortality rates than white infants with very low birth weight, suggesting a relationship between quality of care and access to effective interventions.[159]

Hauck et al. note that differing access to effective interventions may affect racial and ethnic disparities across other causes of infant mortality.[160] For example, access to treatment may also affect the racial and ethnic disparities in mortality for infants with congenital malformations.

Healthcare can also play a role in modifying behavioral risk factors that contribute to disparities in infant mortality. Research has shown the importance of behavioral risk factors on disparities in SIDS. Racial disparities in SIDS increased after the introduction of the successful "Back to Sleep" campaign by the U.S. Public Health Service.[161] The Back to Sleep campaign advocates that infants sleep in a supine position to prevent SIDS. Research has found that African American infants are twice as likely to be placed

on their stomach to sleep.[162] One study found that African American mothers are generally aware of the recommendations of the Back to Sleep campaign but believe prone sleeping is safer, more comfortable, and allows infants to sleep longer.[163] However, one study noted that African American mothers were less likely to receive recommendations to have infants sleep on their backs or are more likely be told to place infants on their stomachs for sleep, suggesting a potential need for increased measurement of the quality of care.[164]

Research also suggests other behavioral interventions that could reduce racial and ethnic disparities in SIDS. Increasing the rates of breastfeeding among African American mothers could help reduce the risk of SIDS for their infants.[165] Increased rates of SIDS among American Indian infants may be related to increased smoke exposure and rates of bed sharing.[166]

African American and American Indian infants are also more like to die from accidental deaths than white, Asian, or Hispanic infants.[167] Hauck et al. note that accidental suffocation and strangulation in bed is the most common cause of accidental deaths in infants and that these findings suggest cultural variations in bed sharing practices may contribute to this disparity.[168]

Racial and ethnic disparities exist in other causes of infant mortality as well. African American infants are 1.3 times and Hispanic infants are 1.1 times more likely to die from congenital malformations than white infants. Hauck et al. note that the causes of these disparities are not known but suggest there may be differences in use of preventive measures such as folic acid supplementation, and access to and acceptance of antenatal screening and termination of pregnancy, as well as access to treatment for infants with congenital malformations.[169]

Disparities in infant mortality and low birth weight show the complex interplay of social risk factors. Socioeconomic position, race and ethnicity, a mother's marital status and other social supports, and residential and community context can all influence birth outcomes. Access to prenatal care and nutrition, education, behavioral risks, and the quality of care received can all be affected by a mother's social risk factors.

Mental Illness

Mental illness is defined as a wide range of mental health disorders characterized by dysregulation of mood, thought, and/or behavior.[170] Mental illness can cause functional limitations and is a risk factor for other chronic diseases. The effects of mental illnesses include disruptions of daily function; incapacitating personal, social, and occupational impairment; and premature death.[171] The most common forms of mental illness in adults are anxiety and mood disorders, depression being one of the most common. The World Health Organization (WHO) estimates that nearly 50 percent of U.S. adults will develop at least one mental illness during their lifetime.[172] The 2014 National Survey on Drug Use and Health found that:

- 19 percent or approximately 1 in 5 adults in the U.S. experiences mental illness in a given year;

- 18 percent of adults in the U.S. experiences an anxiety disorder such as post-traumatic stress disorder, obsessive-compulsive disorder, and specific phobias;

- 4 percent or approximately 1 in 25 adults in the U.S. experiences a serious mental illness in a given year that substantially interferes with or limits one or more major life activities; and

- 7 percent of adults in the U.S. had at least one major depressive episode in the past year, and the prevalence of major depressive disorder (MDD) is 16 percent nationwide.[173]

Racial and ethnic disparities have been well documented for various types of mental illness. Depression diagnosis rates were 7.2 percent for Hispanics, 6.4 percent for whites, 4.2 percent for

African Americans, and 3.8 percent for others.[174] African Americans are 20 percent more likely than whites to experience high degrees of psychological distress due to poverty.[175] A study examining perceived quality of care found that parents of African American and Latino children with Autism Spectrum Disorders (ASD) were less likely to report that the provider spent enough time with their child compared to parents of white children.[176] African American children were also more likely than white children to be identified with greater severity of ASDs. One study found that among the elderly, significant racial and ethnic differences exist in the diagnosis and treatment of depression.

One study observed significant racial disparities in the perceived benefits and satisfaction with mental health services by geographic region. African Americans in the western part of the U.S. were significantly more likely to report higher satisfaction, whereas Hispanics/Latinos in the West were significantly less likely to do so.[177] Minority children were less likely than white children to be diagnosed with attention-deficit/hyperactivity disorder (ADHD), and among those that were diagnosed, racial and ethnic minorities were less likely than whites to be prescribed medication for the disorder.[178] Perceived racism and discrimination may be one of the factors influencing disparities in perceived quality of care, and more research is necessary to quantify the theory.

Consensus in research findings across multiple studies suggests socioeconomic inequalities widen with increasing age. Lower SES was associated with higher rates of both anxiety and depression symptoms; results show that progression from anxiety to depression symptoms is more likely for those of disadvantaged SES.[179] For persons of lower SES status, the likelihood of reporting depression is roughly double.[180]In patients with postpartum depression (PPD), subjective SES was the most consistent predictor of symptoms, being significantly associated with minor-major

PPD; higher subjective SES indicated lower odds of PPD.[181] One study found that household income and unemployment predicted greater odds of having major depressive episodes (MDE). Another study found a negative relationship between education and 12-month MDE.[182] Prevalence data consistently suggests that higher rates of panic disorder, all types of phobias, generalized anxiety disorder, and schizophrenia are exhibited by patient groups with lower SES.[183] Schizophrenia is considered the most debilitating mental disorder; multiple studies have shown increased risk of schizophrenia for persons with lower SES.[184] Evidence suggests that interventions to prevent or treat symptoms among disadvantaged individuals at early ages could substantially reduce inequalities. Most children with mental health problems do not receive the mental health services that they need because of poor access.[185]

A systematic review by Reiss examined the relationships between various commonly used indicators of socioeconomic status (SES) and mental health outcomes for children and adolescents aged four to 18 years in 55 published studies. The review indicates an inverse relationship between socioeconomic status and mental health problems in children and adolescents; socioeconomically disadvantaged children and adolescents were two to three times more likely to develop a mental health condition.[186] SES not only affects the likelihood of acquiring a mental health disorder but can also affect an individual's adherence to treatment recommendations. Socioeconomically disadvantaged patients were independently associated with an increased risk of early antidepressant discontinuation.[187] Potential solutions to decrease these disparities and improve the quality of care for patients are the use of formal screening tools and additional physician training around diagnosing mental health conditions. These programs may also serve to regularize treatment across socioeconomic lines.[188]

Mental health disparities exist according to gender,

sexual orientation, and disability. Rates of major mental disorders have been examined extensively by gender. Compared with men, women have been shown to be at two times or more the risk of depression and anxiety disorders.[189] These finding were supported by various studies that also found major depression is approximately twice as common in females compared to males.[190] Social relationships play a major role in mental health; both quantity and quality of the relationship can affect health behavior, mental health, and mortality risk. Social support has been described as a protective factor against the onset of mental disorders.[191] Women tend to have larger social networks compared to men. A larger social network is associated with a decreased risk of depression and anxiety disorders.[192]

Studies have found that adverse childhood experience (ACEs) can affect later mental health outcomes. ACEs are stressful and traumatic events; they can include family neglect and household dysfunction, for example, growing up with family members who have substance use disorders. Exposure to ACEs has shown to increase the risk of experiencing depressive episodes, increase the risk of attempted suicide by two- to five-fold, and increase the likelihood of acquiring a substance use disorder.[193] A study on the mental health of transgender youth notes that transgender youth had a two-fold to three-fold increased risk of depression, anxiety disorder, suicidal ideation,

suicide attempt, and inpatient and outpatient mental health treatment.[194] The combination of discrimination based on sexual orientation and other risk factors like race was associated with higher risks of mental health disorder. Evidence suggests that lesbian, gay, and bisexual individuals face a disproportionate burden of poor mental health compared to heterosexuals and were more likely to report frequent mental distress.[195] People with disabilities experience worse health and poorer access to mental healthcare compared to people without disability.[196]

Mental healthcare differs from other forms of healthcare in its heavier reliance patient/provider communication. Mental health can be affected by gender, race, sexual orientation, socioeconomic status, and community level factors, and this makes culturally appropriate education for providers and patients vitally important to better understand mental illness and disease management. An important question is whether prevention and intervention efforts should target socially based adversities that foster mental illness (e.g., poverty) or focus on protecting persons with mental illness from downward social mobility through increasing access to treatment and services, reducing employment discrimination and social stigma, and favoring community integration.

NEXT STEPS

Significant disparities exist across leading causes of morbidity and mortality in the United States. A review of the literature shows disparities across the domains of healthcare quality. People with social risk factors are less likely to receive care that is safe, effective, patient-centered, timely, efficient, and equitable, contributing to these disparities in morbidity and mortality. A review of the literature reveals a need to improve access to care, quality of care, and cultural competency and communication.

While disparities in care are well-documented, they are still poorly understood. Increased use of measurement to identify disparities can help to ensure that all Americans receive quality healthcare regardless of their social risk factors. Measurement can help to pinpoint where people at social risk do not receive the care they need or receive care that is lower quality. Disparities in healthcare must be eliminated across the aims of the National Quality Strategy: healthier people, better care, and affordable care.

As noted above, the NQF Disparities Standing Committee will develop a roadmap for how performance measurement and its associated policy levers can be used to eliminate disparities in health and healthcare. Leveraging quality measurement and capitalizing on new delivery and payment models will help to incentivize the elimination of disparities across the target conditions highlighted in this report as well as increase health equity broadly. This first report is intended to provide the Committee with the background necessary to develop the roadmap.

The next step in developing the roadmap will be a second report highlighting interventions that have been effective in reducing and eliminating disparities. The third report will include an environmental scan for measures and identification of a core set of measures and gaps in measures. The final report will include the Committee's recommendations for measure development and policies for the adoption of measures that could help to eliminate health and healthcare disparities.

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APPENDIX A:
Disparities Standing Committee

Marshall Chin, MD, MPH, FACP (co-chair)
Richard Parrillo Family Professor of Healthcare Ethics,
University of Chicago
Chicago, Illinois

Ninez Ponce, MPP, PhD (co-chair)
Professor, UCLA Fielding School of Public Health,
UCLA Center for Health Policy Research
Los Angeles, California

Philip Alberti, PhD
Senior Director, Health Equity Research and Policy,
Association of American Medical Colleges
Washington, District of Columbia

Susannah Bernheim, MD, MHS
Director of Quality Measurement, Yale New Haven
Health System Center for Outcomes Research and
Evaluation (CORE)
New Haven, Connecticut

Michelle Cabrera
Director, Health Policy and Research, SEIU California
Washington, District of Columbia

Juan Emilio Carrillo, MD, MPH
Vice President of Community Health, NewYork-
Presbyterian; Associate Professor of Clinical Medicine,
Weill Cornell Medical College
New York, New York

Lisa Cooper, MD, MPH, FACP
James F. Fries Professor of Medicine and Director of
the Johns Hopkins Center to Eliminate Cardiovascular
Disparities, Johns Hopkins University School of Medicine
Baltimore, Maryland

Ronald Copeland, MD, FACS
Senior Vice President and Chief Diversity & Inclusion
Officer, Kaiser Permanente
Oakland, California

José Escarce, MD, PhD
Professor of medicine, David Geffen School of
Medicine, University of California at Los Angeles;
Professor of health policy and management, UCLA
Fielding School of Public Health.
Los Angeles, California

Traci Ferguson, MD, MBA, CPE
Vice President, Clinical Services Management,
WellCare Health Plans, Inc.
Tampa, Florida

Kevin Fiscella, MD
Tenured Professor Family Medicine, Public Health
Science, Community Health and Oncology, University
of Rochester
Rochester, New York

Nancy Garrett, PhD
Chief Analytics Officer, Hennepin County Medical
Center
Minneapolis, Minnesota

Romana Hasnain-Wynia, PhD
Director, Addressing Disparities Program, Patient
Centered Outcomes Research Institute
Washington, District of Columbia

Lisa Iezzoni, MD, MSc
Director, Mongan Institute for Health Policy; Professor
of Medicine, Harvard Medical School
Massachusetts General Hospital
Boston, Massachusetts

David Nerenz, PhD
Director, Center for Health Policy & Health Services
Research, Henry Ford Health System
Detroit, Michigan

Yolanda Ogbolu, PhD, CRNP-Neonatal
Director, Office of Global Health and Assistant
Professor, University of Maryland Baltimore, School of
Nursing
Baltimore, Maryland

Robert Rauner, MD, MPH, FAAFP
Director, Partnership for a Healthy Lincoln
Lincoln, Nebraska

Eduardo Sanchez, MD, MPH, FAAFP
Chief Medical Officer for Prevention, American Heart
Association
Dallas, Texas

Sarah Hudson Scholle, MPH, DrPH
Vice President, Research & Analysis, National
Committee for Quality Assurance
Washington, District of Columbia

Thomas Sequist, MD, MPH
Chief Quality and Safety Officer, Partners Healthcare
System
Boston, Massachusetts

Christie Teigland, PhD
Vice President, Advanced Analytics, Avalere Health |
An Inovalon Company
Arnold, Maryland

Mara Youdelman, JD, LLM
Managing Attorney (DC Office), National Health Law
Program
Washington, District of Columbia

NQF Staff

Helen Burstin
Chief Scientific Officer

Erin O'Rourke
Senior Director

Andrew Anderson
Senior Project Manager

Tara Rose Murphy
Project Manager

Mauricio Menendez
Project Analyst