

# NIMHD Science Visioning Research Strategies

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Health disparities are a substantial burden to society in terms of healthcare costs, lost productivity, and general societal well-being. In 2015, NIMHD began a visioning process to create a scientific vision that will transform minority health and health disparities research. Thirty specific research strategies across the three pillars that guided the science visioning: methods and measurement, etiology, and interventions establish a new paradigm to stimulate research for improving minority health and closing the gaps in health disparities. The visioning strategies are endorsed by the NIMHD Director, the National Advisory Council on Minority Health and Health Disparities, and many in the extramural scientific community. The following pages include the 30 strategies with rationale.





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## Methods and Measurement Science in Minority Health and Health Disparities Research Strategies



#### Indicators for Measuring Health Disparities

#### Promote adoption of common outcomes to quantify health disparities processes across different diseases and conditions and develop sentinel indicators.

Rationale: NIMHD proposes five health disparities outcomes: 1) higher incidence or prevalence, including earlier onset or more aggressive progression, 2) premature or excessive mortality from specific conditions, 3) greater global burden as indicated by population health measures, 4) poorer health behaviors and clinical outcomes (related to above), and 5) worse self-reported outcomes measures that reflect daily functioning or symptoms from specific conditions (Duran and Perez-Stables, 2019). The ultimate goal of investment in health disparities research is to reduce or eliminate health disparities. Measuring overall progress requires the ability to compare patterns and trends across different diseases, conditions, and populations. Using common outcomes across studies would make it possible to pool samples, compare results across different studies, conduct meta-analyses, and model results. Common outcomes are especially important for small populations because these data often need to be pooled over time to be adequately powered for analysis. Adopting common outcomes does not preclude use of additional outcomes.

"Sentinel" (early warning) indicators for health disparities would not measure outcomes but would identify when a health disparity is emerging within a complex system. A health disparity sentinel indicator should be easy to communicate and signal the need for further investigation. A successful indicator depends on close collaboration between researchers and communities. Disparities in income, race and geography may be sentinel indicators of disparities in common risk factors. Other potential sentinel indicators are disparities in obesity for disparities in diabetes, or disparities in excess tobacco use for disparities in heart disease and lung cancer.

## 2. Develop a set of indicators that reflects the complexity of population characteristics and that can be adjusted to capture changing U.S. demographics.

Rationale: When developing data on race, ethnicity, class, immigration, gender, sexual orientation, and other population characteristics that are integral to quantifying and characterizing disparities, standard measures for widely recognized health determinants (e.g., Census or NHIS variables for racism, income, education, poverty, and health insurance coverage) should be considered before developing new measures. In addition, standard ways of collecting population characteristics across data systems are needed. A special challenge will be to standardize collection of race, ethnicity, SES, and other measures in Big Data collection, starting with the precedent-setting NIH Precision Medicine Initiative. NIMHD is developing a set of common data elements (CDE) on structural social determinants to complement a wide range of CDE in the NIH PhenX Toolkit (https://www.phenxtoolkit.org).

Moreover, it can be challenging to characterize the complexity of groups and populations because characteristics are often considered in isolation. Systematic approaches for examining the complex set that characterize population subgroups—i.e., their "intersectionality"—need to be developed. In developing these approaches, it must be noted that population characteristics may change over time due to changes in socio-demographics, policy, and cultural norms. In addition, the current categories that are used to designate populations (e.g., Hispanic or Asian without associated nationality) may be insufficient or change over time (e.g., gender). An adaptable system of robust indicators is needed that can capture emerging disparities, intersectionality, and evolving individual and population identities.



## 3. Make explicit the assumptions and values that may be implicit in health disparity outcomes.

Rationale: It is generally assumed that determining the magnitude, direction, and rate of change of health disparities is a technical process that produces accurate, unbiased, and value-neutral estimates. However, research on health disparity outcomes comes from many disciplines and can have different meanings, assumptions, and implicit values. For example, measuring survival without measuring quality of life is making an implicit value judgment that may vary among populations and fields of study. Because the values implicit in health inequality measures may lead to different results using the same underlying data, it is important for researchers to explicitly consider and transparently discuss the normative judgments underlying their outcomes. For example, computing a change over time will yield a different result depending on whether the reference group is the "best" group or the population average. Specifying assumptions and explaining why a variable or outcome was chosen or a population was selected for study needs to be consistently reported in health disparities research.

#### Methods for Analyzing Health Determinants Contributing to Health Disparities

## 4. Strengthen and promote analytic methods, particularly models, that will enable a better understanding of causes of health disparities.

Rationale: Causes of health disparities are complex, making a complementarity of methods needed to identify and understand health disparities. A rich array of discipline-specific methods is available, not all of which are widely used in public health. Specifying best practices for analytic methods would help researchers select the most appropriate methods for their research question and data and lay the groundwork for adapting, refining, and developing the next generation of methods. A pressing need is to identify the causal pathways that connect the etiology (i.e., health determinants) with the effect (i.e., health disparities) because these are where interventions are likely to be most effective in reducing health disparities. Large representative studies that prospectively track socioeconomic status (SES), behaviors, health status, risk factors, and disease longitudinally (e.g., the million-person cohort planned for the NIH Precision Medicine Initiative [PMI/All of US]), will allow researchers to identify causes of health disparities. However, because longitudinal studies are rare and because most data are observational in health disparities research, other approaches to rule out counterfactual and alternative explanations are needed to establish likely causation. Regression and other analytic methods provide the initial direction for understanding complex etiological pathways. For example, regression models and non-parametric methods can quantify potential associations and test whether associations are statistically significant. This makes it important to establish criteria for what constitutes a sufficient level of evidence for intervention. Do consistent findings across multiple studies provide sufficient evidence to take action? Should criteria be the same for evidence derived from all types of intervention designs (e.g., pragmatic, adaptive designs, or community-level interventions or multi-modal studies)? A related set of questions focus on: what evidence and methods are needed to move a successful intervention from one setting to another, especially from one public health or community setting to another? How can exploratory and qualitative analyses inform quantitative findings and identify the need for future studies? When can action be taken even when cause is not fully established?



## 5. Push the limits of systems modeling to increase its ability to predict relationships between health disparities and health determinants, and to assess health disparities interventions.

Rationale: The etiology of health disparities is complex and dynamic because it involves multiple factors and levels that can change over time, including genetic factors, life course processes, place effects, and policies. Therefore, models of health disparities need to be complex and address multiple factors and levels over time. Broadly speaking, the purpose of modeling variables is to identify and explore causal pathways. All types of models may need to be used, from basic regression models to complex systems models, to understand the multiple causal pathways that shape health disparities. Complex systems modeling is designed to explore multiple complex pathways and, therefore, may be especially useful for assessing how interventions work to reduce health disparities. Systems modeling has the capacity to simulate short-term and long-term intervention effects; identify pathways and critical leverage points; test effective intervention approaches; and ascertain components that are critical to the scalability and successful implementation of evidence-based interventions. A key feature of systems modeling is its ability to capture spatial variability of exposures (i.e., where various concentrations of exposures are unevenly distributed across an area or a population) flexibly and dynamically, and this is needed for understanding the importance of place in health disparities and for appropriately targeting health disparity interventions. Importantly, because systems modeling requires data to support specific parameters, development of systems models can inform data collection needs.

### 6. Identify and strengthen rigorous quantitative and qualitative methods to enable analysis on small populations and sub-populations.

Rationale: It is important to acknowledge that health disparities can exist or emerge among populations even when data are not available to quantify the disparities. Thurs health disparities experienced by small populations may be overlooked because data are insufficient. Some populations that shoulder a significant proportion of health disparity burden are not adequately represented in data collection, analysis, and reporting. Examples include incarcerated or previously incarcerated populations, sexual and gender minorities, American Indians and Alaska Natives, Asians, Native Hawaiians and Pacific Islanders, and immigrants. In addition, most interventions are not powered to examine subpopulations that are included in studies, which makes it difficult to draw conclusions about health disparities they may be experiencing. Methods are needed to analyze and interpret studies with large differences in population sample sizes (e.g., 100 vs 10,000). Methods also need to be developed that can consider unique characteristics of subpopulations and within group heterogeneity. These methods could be applied to achieve a vision in which different types of data from different sources are matched, linked, and geocoded into a coherent picture so that health disparities can be addressed systematically and efficiently. These sources of data include electronic medical records (EMR), public health surveillance data systems, insurance records, and epidemiological surveys.

#### **Evaluating Health Disparities Research**

## 7. Evaluate health disparities programs and research, including policy interventions and natural experiments.

Rationale: Opportunities to evaluate policy (i.e., regulations, laws, policymaking actions or formal or informal rules established by organizations or governmental units) are rarely leveraged and the full range of evaluation methods are underused in health disparities research. Health disparities research needs to include an evaluation component to the maximum extent practicable, starting with research planning. Lack of data on



process and economic costs leads to missed opportunities in health disparities research because, if these data are not collected, evaluations of interventions cannot be performed. Evaluations of policy and other interventions and natural experiments provide insights into how such interventions may lead to a reduction in health disparities. Furthermore, testing the impact of policy interventions as they occur amid the complexities of the real world is a useful way to test assumptions underlying an intervention.

8. Clarify whether the intent of the evaluation is process or summative, and ensure the evaluation design is relevant to the diversity of the population being assessed.

Rationale: To determine the best approach in assessing need and implementation, unique aspects relevant to the health disparity populations under study must be considered. The experiences and perceptions of health disparities populations may differ from those experienced and expressed by mainstream populations, influence behaviors and attitudes, and frequently take considerable time to manage in real-world applied community research. These factors must weigh into every aspect of the process evaluation so that decision-makers receive useful information and harm is not generated by misinterpretation through using a mainstream framework. Researchers outside of a community may not know or understand the nuances of the culture, life experiences, system discrimination, and protective coping skills embodied by the population. These researchers may never penetrate the community defenses to engage the population in research or to conduct evaluations. Without gatekeeper and stakeholder engagement, important population and sociocultural elements of an evaluation may be underappreciated or missed, and important challenges may not be addressed as well as harmful misinterpretations generated.

#### Health Disparities Research in the Era of Big Data

 Leverage and foster linkages between existing and emerging data sources, including big data, to magnify the data's analytic capacity and to more swiftly translate health disparities findings into health disparities reductions.

Rationale: Different sources, types, and complexity of data can be mobilized to identify where interventions are likely to be effective in reducing health disparities. The challenge is to store, manage, and retrieve data throughout their life cycle so the different data types can be accessed as a coherent holistic data system that can be used to identify health disparities and analyze causes. What is new about this challenge is the volume, types, and complexity of available data. Although "big data" are commonly cited as the wave of the information future, a vision of how to use big data in health disparities research is lacking. In terms of data collection, a focus on "well-annotated" clinical samples (samples with associated clinical and sociodemographic data, including tissue samples) is still needed. To rectify this, the rapidly developing field of "data science" needs to be applied to health disparities research. Social media data, personal monitoring data for health and biomedical purposes, and genomic data are relatively new data sources that already show geographic patterns in health disparities. Census and other survey data and traditional medical data—ranging from Medicare to hospital records—combined with new data sources offer researchers a mosaic of sometimes inconsistent information, leading to an incomplete understanding of health disparities. To connect the pieces into a coherent picture, and to add an understanding of social determinants, new approaches for managing and analyzing big data for understanding health disparities are needed. Application of data science approaches would make data Findable, Accessible, Interoperable, and Reusable (FAIR) as a first step, followed by the application of new analytical techniques, some of which would be hypothesis driven but others not. Because personally identifiable information (PII) may be key to linking different types and sources of data, a strategic plan for the application of data science needs to address ethical, legal, and social



implications (ELSI). Finally, data science would contribute new modes of dissemination and comprehension of big data so that these data could be understood and used widely by all stakeholders, from researchers to care providers to members of the public most affected.

## 10. Develop and define best practices for incorporating and using geographic identifiers in health disparities research to promote place-based research.

Rationale: Numerous studies have shown a strong association between location and health disparities. Only in the past decade or two has geocoding become a widespread option to provide context for other data and to allow linking of different data sources. Disparities in racial justice, environmental justice, poverty, and health disparities are often associated with location. Differences in neighborhoods, activity space, environmental hazards, and work environments all contribute to the etiology of health disparities. Understanding these differences to reduce disparities requires sharing, linking, analyzing, and interpreting data to understand health disparities in the context of home, work, school, and other locations. Multi-level data sets for appropriate geographic units are needed to understand the complex etiology of health disparities and to intervene appropriately. New technology is facilitating community participation, crowdsourcing, and data collection from citizens and citizen scientists. Group analysis methods allow community members to express their points of view through photographs, which are then analyzed and interpreted in collaboration with population scientists to develop research themes for social action. However, access to such detailed information increases the risk of research participants being identified. The development of best practices, masking techniques, and data enclaves is critical because it will allow access to multilevel spatial data while protecting the privacy of study participants. How to define place also must be addressed as new research methods emerge to optimally use geocoded data.



## **Etiology of Health Disparities Research Strategies**



#### Social Determinants

### 11. Advance identification and understanding of how protective factors and resilience promote health at the individual, community, and population levels.

<u>Rationale</u>: Despite the presence of risk factors, not all individuals, families, communities, and/or populations experience worse health outcomes. Protective factors and factors that promote resiliency may explain why some groups withstand adversity. It is hypothesized that protective factors and resiliency operate at both the individual (e.g., personality traits, psychological resources, behavioral skills) and contextual levels (e.g., interpersonal, social networks, physical resources). However, a better understanding of the mechanism(s) by which these protective factors operate, how they work in and across different populations, and to what extent they provide protection is needed. If protective factors can be modified and enhanced, they could offer strategies to reduce health disparities.

## 12. Strengthen the understanding of how racism and discrimination are conceptualized, measured, and contribute to health disparities, with emphasis on internalized and structural racism.

Rationale: Further understanding of how racism and discrimination operate and contribute to health disparities is needed. Knowledge about the cumulative effects of different types of racism on health, such as interpersonal, internalized and structural, is limited. Better conceptual and analytic models and measures that account for how racism and discrimination operate are needed. Although the available literature has examined interpersonal racism and discrimination, a better understanding of how structural and internalized racism provide pathways that lead to health disparities is needed. Several issues related to structural racism need to be examined, such as how inequities in power, access, opportunities, treatment, and policy create structures and practices in society that contribute to inequities in health outcomes. For internalized racism, issues to examine include why some individuals internalize racism and conform to stereotypes (i.e., stereotype threat), while others are resilient from imposed racist attitudes and stereotypes. The ways in which internalized racism contribute to health disparities is a priority for research.

## 13. Elucidate mechanisms for how social determinants influence health behaviors that lead to health disparities.

Rationale: A consensus exists that social determinants influence an individual's participation in health behaviors that harm health (i.e., tobacco use, lack of exercise, lack of health care seeking) or promote health (i.e., exercise, health care screening, proper nutrition). Social determinants may exert influence through altering brain morphology, which leads to neurodevelopment and neurocognition deficits that increase the likelihood of engaging in health behaviors that lead to worse health and contribute to creating health disparities. Given that a considerable amount of excess morbidity and mortality is explained by high-risk health behaviors and practices, understanding how social determinants influence these behaviors will provide insight on how to modify and improve individual and population health. Little is known about the pathways that lead to establishing and maintaining these behaviors and practices. Consequently, a better understanding of how social determinants lead to health behaviors and practices, both at an individual and community levels, is needed. Newer models explore behaviors beyond social cognition (e.g., behaviors that result from cognitive processing and executive functioning). For example, newer models incorporate the fact that much behavior is also influenced by non-rational decision-making or impulsivity as well as deficits within neurodevelopment or neurocognition.



#### Environmental Exposures, Biological Pathways and Mechanisms

#### 14. Assess how place and neighborhoods structure health disparities geographically.

Rationale: Health outcomes vary geographically. Neighborhoods, a place where people live, play, work, and receive health care, are understood as a convergence between the physical, built, and social environments and contribute independently to overall mortality. Minorities and low SES populations disproportionately live in resource poor communities, but life expectancy can vary substantially across local areas. Several mechanisms have been proposed to account for geographically clustered health disparities, such as differential exposures to environmental toxins, low material and social support (e.g., limited health-promoting resources, inadequate quality and access to healthcare), higher concentrations of social stressors (e.g., violence, discrimination, neighborhood and economic instability), built and social environment-induced or constrained lifestyles (e.g., high density of tobacco outlets or food deserts) and/or shared psychosocial mechanisms that influence health behaviors. An understanding of the pathways and mechanisms that explain how exposures and policies cause a concentration of health disparities for different places is needed.

## 15. Determine the pathways and mechanisms through which environmental, economic, sociocultural, and behavioral factors influence biological systems and pathogenesis that leads to health disparities.

Rationale: While it is clear that social context affects health outcomes, the pathways and mechanisms for how this context transmits to biological processes needs further clarification. In other words, it is critical to understand how the macrosocial factors that shape health "get under the skin." Identifying common pathways and mechanisms that lead to disease or multiple diseases is critical. Potential mechanisms include: 1) dysregulation of physiological systems, such as the immune system, hypothalamic-pituitary adrenal (HPA)—cortisol axis, and neurobiological systems, 2) epigenetic modifications that affect gene expression, including DNA methylation, histone modification, and chromatin structure, 3) actions by the metabolome, microbiome, and immune systems, and 4) allostasis, weathering, and biological aging. Further, understanding is also needed on whether and how biological processes differ from "known" pathological processes at the individual and population levels, and their contribution to disability, disease, health, and well-being.

#### Life Course Approaches

## 16. Integrate life course into health disparities research, including research on biological pathways and mechanisms.

Rationale: Health disparities do not emerge suddenly in adulthood or at the time of disease onset. A life course perspective posits that cumulative and/or interactive exposures over the lifespan—including in utero exposures—influence the development of health disparities. Life course perspectives stress consideration of complex, adaptive, dynamic, and nonlinear relationships. Key scientific priorities include examining: (1) whether population-level adversity and protective factors cumulatively interact to increase or reduce the risk of health disparities, (2) whether differential exposures at sensitive periods explain higher rates and severity of disease, (3) the periods of greatest susceptibility and whether the biologic consequences are permanent or reversible, and (4) how exposures in prior period(s) affect responses and susceptibility during the current period. Measures are needed that assess the complexity of adversity and protection beyond a single exposure or exposure type and that consider other factors, such as intersectionality, sensitive periods, magnitude of exposure over time, and impact of cumulative adversity and protective factors across multiple



levels (e.g., individual, interpersonal, household, occupational, community, and societal). Further, research is needed to determine relevant biological markers of differential exposures and disease risk at each life stage so as to advance understanding of the mechanisms and consequences of adverse exposures during sensitive developmental periods.

## 17. Identify mechanisms of intergenerational transmission of disease leading to health disparities, which take into account biological, behavioral, social, cultural, and life course perspectives.

Rationale: Health disparities are transmitted across generations. Mechanisms and pathways of adverse exposures that occur during pre-conception (maternal and paternal), in utero (fetal), and sensitive developmental periods of childhood have been found to enhance vulnerability to diseases of adulthood and yield potential for transgenerational transmission. Understanding how diverse prenatal and postnatal stressors place individuals at higher risk of developing postnatal disorders may lead to targeted interventions that affect life course trajectories. Studies are needed to understand how societal forces influence the range and scope of interpersonal and individual transitions and trajectories and how these influences health. Advanced dynamic and complex models of multi-context, multi-population development are needed to understand how health disparities arise over the life course and are transmitted across generations. Further, an understanding of the potential for transgenerational exposures to differentially affect individuals and populations based on both biological and socioeconomic status is needed.

#### **Health Services**

#### 18. Examine the impact of delivery models on population health.

Rationale: The fragmented nature of how healthcare is delivered in the United States contributes to health disparities. Lack of access to healthcare and timely care are known factors that lead to health disparities. In response, the healthcare system has attempted to address these factors and improve the quality of care delivered while maintaining efficiency and cost. New models of delivery have emerged that hold promise to reduce health disparities and have been promoted by both providers and payors. Central to the success for these efforts is an understanding of how healthcare systems can provide patient-centered care for all patients. Evaluations of newly developed patient care models are needed to determine whether they are effective. Similarly, studies on whether payor-based changes lead to improved outcomes and patient satisfaction are needed. With healthcare financing and reimbursement policies at the state and national level undergoing continuously revision, efforts are needed to ensure that these policies are implemented in ways that decrease, rather than increase, health disparities and that do not result in unintended consequences. For example, studies examining how policies can be optimized to ensure high-quality care is delivered to disadvantaged patient populations, for whom optimal health outcomes may be difficult to achieve, could shed important light on this issue. Other research is needed on whether new policies disproportionately affect or improve outcomes for specific groups, for example, whether they make it more difficult to prevent hospital readmissions for patients who are homeless, or to achieve diabetes control in patients who live in communities with very limited access to healthy foods.



### 19. Identify the mechanisms by which patient-clinician communication and biases affect disparities in health outcomes.

Rationale: Clinician attitudes and beliefs or the assumptions they make about a patient's personality, motivation, or level of understanding clearly have implications for the care they give. Similarly, patients' perceptions and beliefs influence goals for health, health decision-making, and adherence to treatment. Poor communication between providers and racial and ethnic minority patients, characterized by implicit physician bias, less patient-centered communication, less discussion of treatment goals and options, and less positive and more disengaged non-verbal behavior, is associated with lower satisfaction with care and poorer outcomes for chronic diseases and pain management. Although the impact of clinician bias on patient-provider communication and patient satisfaction has been shown, understanding of how to overcome clinician bias, which affects diagnostic, referral, and treatment practices and can lead to disparities in health outcomes, is limited. Knowledge is needed about the specific mechanisms through which communication patterns affect health outcomes. This knowledge would be amplified by studies of how complex healthcare-based communications occur, such as those between patients and a team of providers, or between patients, providers, and family members.

### 20. Determine how to improve diagnostic and medical guidelines, screening criteria, and standards of care through incorporating considerations of patient characteristics.

Rationale: Health disparities can result when standards of care are not optimally implemented or certain groups of patients are provided with treatment plans that are not efficacious. Further, diagnostic and/or screening criteria can fail to identify at-risk individuals, also contributing to health disparities. Medical guidelines historically have been established based on homogeneous populations, and thus, diagnostic and screening criteria and therapies often do not take into account genetic variation across racial and ethnic groups based on genetic ancestry. Obscuring physiological and therapeutic needs because of existing standards can contribute to health disparities. Similarly, inadequately tailored health care can lead to disparities in health outcomes. Priority topics for research in this area include developing ways to improve guidelines, screening, and criteria to take into account characteristics of diverse populations, and examining ways to ensure the transition toward personalized medicine approaches that adequately account for characteristics of populations and diverse individuals. More data on how clinicians make medical decisions based on guidelines for their patients can improve the understanding of when and how current standards of care may lead to perpetuating health disparities, how to implement standards of care for diverse populations, and why certain clinical procedures are under- or overuse by certain population groups.



## Intervention Science for Health Disparities Research Strategies



#### **Guiding Principles**

## 21. Promote multi-sectoral interventions that address the structural drivers of health disparities, as well as those that consider the interplay with behavioral and biological factors.

Rationale: Interventions need to address structural factors, such as poverty, racism, discrimination, residential segregation, unemployment, food deserts, and educational inequalities. Interventions also need to mitigate the negative impact of these factors and assess the mechanisms by which these factors exacerbate health disparities. Current interventions to reduce health disparities are focused mainly on individual-level factors addressing change in behavior. These efforts are probably not sufficient to show sustained effect in reducing health disparities. Effective interventions that target a broad array of behavioral, biological, systems, policies, and environmental factors, and their complex interplay can produce sustainable change across multiple health outcomes. Addressing these factors that are generally not in the health or healthcare domain requires developing long-term multisectoral collaborations between health and non-health sectors. Such collaborations will be important to implement multilevel interventions that may affect policy, systems, and community environments to promote health and reduce disparities. It should be noted that although racism and discrimination are recognized as structural drivers, these factors often are not sufficiently addressed in interventions. It is critically important that interventions address the mechanisms through which racism and discrimination create, influence, or sustain health disparities.

## 22. Support interventions that address common modifiable risk factors associated with multiple health conditions and disease outcomes to reduce health disparities.

Rationale: Common modifiable risk factors, such as unhealthy diet, physical inactivity, insufficient or poorquality sleep, exposure to violence, and tobacco use, contribute to disparities in multiple health outcomes. The distribution of these behavioral risk factors is influenced greatly by underlying socioeconomic, environmental, social, political and cultural determinants. Low socioeconomic status, stigma and discrimination, tobacco use, dietary risks, and obesity all contribute to disparities in cardiovascular disease, cancer, and other chronic conditions. Therefore, rather than developing and testing interventions that target only a single risk factor, interventions can maximize their potential impact and efficiency by addressing modifiable risk factors associated with multiple health conditions or outcomes.

# 23. Incorporate a life course perspective by intervening at critical windows of malleability and plasticity during the lifespan and determining opportunities for altering the intergenerational transmission of advantage/disadvantages to prevent and reduce health disparities.

Rationale: A life course perspective acknowledges that health status reflects cumulative life conditions. Rather than a one-size fits all approach, interventions embracing a life course perspective can be appropriately tailored to specific developmental stages that are malleable and take into account the impact of cumulative social and environmental exposures, both positive and negative factors, in order to maximize intervention appropriateness, acceptability, and effectiveness. Interventions designed with a life course perspective need to consider that poor health and many chronic conditions develop across generations. Similarly, interventions may have latent or cumulative effects on health, depending on their timing, frequency, and intensity. Thus, life course approaches that consider critical time periods of opportunity during the lifespan can inform the design and evaluation of interventions to reduce health disparities.



#### **Approaches**

# 24. Leverage electronic information and communication technologies to deliver and evaluate interventions that have the greatest potential to reduce health disparities by removing accessibility and health literacy barriers, facilitating tailoring and personalization, and decreasing cost.

Rationale: Electronic communication and information technologies can increase uptake of health interventions among populations who have historically experienced barriers related to the availability, accessibility, affordability, and acceptability of health or community services. These technologies can also reduce the burden of data collection required to evaluate interventions in health disparity populations through electronic health records, mobile devices, and activity monitors. Potential mechanisms by which technology-enabled interventions can improve minority health and reduce health disparities include: (1) changing awareness, knowledge, attitudes, and beliefs through information provision, sensing/monitoring strategies, and techniques such as motivational interviewing; (2) changing behaviors through alerts, reminders, and social support; (3) overcoming health literacy, (4) improving guideline-based screening, diagnosing, and treating; and (5) improving communication and coordination among members of the healthcare team, including patient and family. However, it is important for electronic communication and information technology approaches to be sensitive to socioeconomic and cultural differences in the use of technologies, in order to avoid interventions that actually increase health disparities due to differential uptake. Electronic communication and information technologies need to be designed and implemented in partnership with the intended communities in ways that are meaningful and relevant to health disparity populations.

## 25. Promote interventions that address the social determinants of health within health care systems.

Rationale: Social determinants of health, such as poverty, occupational opportunities, food insufficiency, neighborhood resources, and exposure to violence, play a significant role in how individuals and populations engage in and benefit from health care services, programs, and policies. Social determinants of health are now more commonly included as data elements in electronic health records, but it is less clear how health care providers and systems can effectively act upon this information. As there is a move towards value-based reimbursement of health care by private and federal payers, there are incentives for health care systems to address social determinants (e.g., literacy, numeracy) to improve outcomes for disadvantaged patient populations. Integrating community assets and organization resources within health care systems may be an avenue for addressing social determinants of health. Other examples include addressing social needs such as food and income security, employment, and housing stability, during primary care visits. The evidence base for these interventions and practices, such as assessment of implicit bias among providers and addressing of unmet psychosocial needs through patient navigation, linkage to services, co-location or integration of social and other human services, and outreach activities such as home and group visits, needs to be further developed.



#### Methods and Evaluation

### 26. Use study designs and intervention research approaches best suited to accommodate the complexity of health disparities research, while upholding principles of validity and rigor.

Rationale: Although individual randomized controlled trials (RCTs) are considered as the gold standard for clinical research, they may not always be the most appropriate design for evaluating interventions for health disparities research. Individual RCTs may not be methodologically appropriate for interventions that operate at the group, community, or population level, or acceptable to community stakeholders. Alternative intervention designs are needed in health disparity research that can retain scientific rigor for validity and generalizability. Possible alternative designs include cluster randomized trials, pragmatic trials, rigorous quasi-experimental designs, stepped wedge designs, adaptive trials, and the evaluation of natural experiments. Evaluation of public policy changes and their impact on health disparities can provide evidence of the contribution of non-health policies on health and health disparities. A better understanding of the mechanisms by which participatory research approaches may be effective in enhancing the relevance, feasibility, acceptability, and rigor of research designs to develop and evaluate community-based interventions also would be valuable.

## 27. Evaluate the effectiveness of community-derived and practice-derived interventions that maintain and improve health or prevent disease.

Rationale: Researchers often develop interventions guided by the theoretical or conceptual models that drive their research programs, with intervention structure, targeted populations and anticipated outcomes conceptualized accordingly. Such interventions may require substantial adaptation or modification before they can be successfully implemented in diverse community settings. In contrast, effective interventions initially developed in real-world settings already have built-in organizational and community feasibility and acceptability, and therefore, may have greater potential to be adopted and sustained in other settings. Thus, in addition to a "researcher-centric" model of intervention research, a collaborative, practice-based intervention model that originates from the community needs to be considered, as it has the potential to accelerate knowledge generation about effective and scalable health disparity interventions.

## 28. Assess the relative and interactive contributions of multilevel intervention components, as well as the mechanisms through which an intervention affects health outcomes.

Rationale: Evaluation of intervention effect has usually focused on determining changes in outcomes. However, there is a need to understand what parts of an intervention worked (evaluating components), how the intervention worked (mechanism), and whether the intervention was implemented as designed (process measures). Examining mechanisms, as well as dose, duration and timing of interventions, is especially important for interventions addressing health disparities as these interventions are often complex and multimodal. They tend to include multiple components and act at various social-ecological levels. Multilevel interventions are likely necessary to overcome the multidimensional and multifactorial challenges inherent in addressing social and physical determinants of heath to address disparities. However, these interventions are complex in nature, and their outcomes on multiple levels (individual, interpersonal, community, society etc.) are difficult to assess. The assessment for the relative, interactive and mechanistic effects of intervention components that span multiple socio-ecological level is important. Understanding the mechanisms of intervention effects can facilitate translation, scalability, and dissemination of best practices.



#### Dissemination and Implementation (Scalability)

29. Examine key dissemination and implementation issues during intervention design, development, and evaluation (e.g., cost, resources, fidelity, adaptation, feasibility, acceptability) to inform subsequent implementation and assist in scaling up in health disparities populations.

Rationale: Traditionally, intervention development/evaluation and implementation science have been considered as distinct phases of research. However, if interventions are designed under "ideal" conditions or in highly unique circumstances or settings, they may be unlikely to be implemented in other settings, as there would be a lack of information regarding the costs, resources, and other support needed for successful implementation. It is important that intervention developers consider and, if appropriate, identify the pathways to broad implementation across different populations and settings, including resource-poor settings, from the beginning, rather than after intervention efficacy has been established. It is important to enhance and evaluate implementation and dissemination frameworks for interventions that include complex processes, factors, and contexts that are relevant for health disparities populations.

## 30. Build the science of adapting interventions to different contexts including cultures, delivery systems, and social environments.

Rationale: Service providers who wish to implement evidence-based practices in their settings are often in the position of having to choose between offering an intervention "as is" to maintain fidelity, even if it is not completely suitable for the setting or intended population or make adaptations that have an unknown impact on intervention fidelity and outcomes. It has been recognized for decades that interventions that are culturally congruent (adapted/ tailored/sensitive) have been shown to increase engagement among identified groups of consumers or participants and have had the most uptake. Although adaptation frameworks and tools exist, there remains a need for empirically-supported guidance on effective methods of adapting existing evidence-based interventions, including processes for ensuring cultural adaptation, obtaining community and other stakeholder input to enhance acceptability, and modifying interventions to be feasible for resource-poor settings. To develop this empirically supported guidance, more research is needed that examines the feasibility, acceptability, fidelity, and effectiveness of different types of adapted interventions relative to the original interventions.