

NIMHD

National Institute on Minority Health
and Health Disparities

NIMHD Science Visioning:

Report on the Results of RFI:
Soliciting Input into the NIH Science Vision for
Health Disparities Research (NOT-MD-15-006)

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National Institute
on Minority Health
and Health Disparities

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EXECUTIVE SUMMARY

To ensure that National Institutes of Health (NIH) remains a leader in addressing minority health issues and health disparities, the National Institute of Minority Health and Health Disparities (NIMHD) has embarked on a scientific planning process in collaboration with other NIH Institutes and Centers to define a vision that will guide health disparities research for the next decade. As part of efforts to engage scientific stakeholders and the general public in helping to shape this vision and agenda, NIMHD issued a Request for Information (RFI): Soliciting Input into the NIH Science Vision for Health Disparities Research (NOT-MD-15-006). Comments were accepted from April 17, 2015 to July 31, 2015. A total of 88 responses were received from a range of individuals, professional associations, and research networks and organizations.

The comments provided by respondents represented a wide array of perspectives. Most respondents identified research areas, essential steps, and strategies that NIMHD and NIH should undertake. Based on the analysis of responses, certain scientific areas of future research opportunities emerged. Better understanding of how multiple determinants of health interact was noted as most crucial for addressing the causes or etiology of health disparities. Using innovative methods and analyses as well as valid and consistent measures to identify and track the disparities was strongly encouraged. Respondents also commented on the need to better understand how effective interventions that reduce health disparities work and how they can be successfully disseminated. In addition, respondents commented on the resources and infrastructure needed to advance the science of health disparities research, with most comments centering on funding mechanisms/grant review and workforce development. Finally, respondents provided suggestions on research areas that should be the focus of health disparities research in the upcoming decade.

REPORT ON THE FINDINGS OF THE RFI

Introduction

In pursuit of its mission, the National Institute on Minority Health and Health Disparities (NIMHD) promotes and supports research to improve minority health and eliminate health disparities. NIMHD also plans, leads, coordinates, and assesses the efforts of the National Institutes of Health (NIH), as a whole, to reduce and eliminate health disparities. To ensure that NIH remains a leader in addressing minority health issues and health disparities, NIMHD has embarked on a scientific planning process in collaboration with other NIH Institutes and Centers to define a vision that will guide health disparities research for the next decade. It is expected that this planning process will result in a transformational agenda for health disparities science that builds on current technological advances and scientific knowledge. Further, this visioning process will identify key research areas that should be given high priority because knowledge in those areas might inform translational efforts that could have a significant impact on reducing health disparities.

To ensure active participation in shaping this transformational agenda from scientific stakeholders and the general public, input was solicited through a Request for Information (RFI): Soliciting Input into the NIH Science Vision for Health Disparities Research (NOT-MD-15-006). The RFI sought conceptual input regarding the science vision for health disparities

research to ensure that NIMHD and NIH remain global leaders in addressing health disparities. This RFI was widely distributed and was made publicly available via Grants.gov. Comments were accepted from April 17, 2015 to July 31, 2015. NIMHD invited comments on several aspects of health disparities science, including foundational areas to better characterize the state of the field. Respondents were asked to comment on several specific areas:

- 1) The etiology of health disparities
- 2) Measurement and analytical science methods
- 3) Intervention science
- 4) Implementation and dissemination science
- 5) Scientific resources and infrastructure needed
- 6) Future research priorities and emerging research needs

Respondent Characteristics

A total of 88 responses to the RFI were received. The majority of respondents, 43 (49 percent), were individuals associated with academic institutions. Of the remaining respondents, 11 (13 percent) came from professional organizations/societies, 10 (11 percent) from advocacy organizations, 6 (7 percent) from healthcare/hospital settings, 5 (6 percent) from federal and state government agencies, 3 (3 percent) from research organizations, and 1 (1 percent) from a foundation. A total of 8 respondents (9 percent) provided no indication of an affiliation.

Analysis of Results

Staff from NIMHD analyzed the responses provided by respondents. Respondents provided responses to each question asked in the RFI, a select subset, or provided a narrative that may or may not have corresponded to RFI questions. All types of written submissions were analyzed similarly. Staff used a standardized coding system. Codes were not mutually exclusive and multiple codes were assigned to responses. Each submission provided was read by staff members and coded independently. Differences between coders were reconciled, and final codes were assigned to all responses provided. Once codes were assigned, coded statements were grouped.

SCIENCE VISION COMMENTS

Findings

This RFI sought conceptual input regarding the science vision to promote involvement of all communities in the visioning effort and to ensure a process and outcomes that reflect the diversity of the field of health disparities research. In particular, comments were being sought regarding key research areas that might address the complexity of multiple, interacting factors that often generate and perpetuate health disparities. The comments could include, but were not limited to, the following topic areas:

- 1) Etiology and causal inferences in health disparities research
- 2) Methods, measurement, and analytical approaches
- 3) Intervention science
- 4) Dissemination and implementation science

5) Topic areas that respondents felt would be of most value, or least value, to support a transformational agenda

Most respondents identified research areas, needed steps, and strategies that NIMHD and NIH should undertake for the visioning process. Fewer respondents provided direct input on what is currently known and attributable to causing health disparities, and the principles that should be incorporated into the science visioning process. Overall, responses were unique, with few statements reoccurring or being widely supported. Findings are organized to correspond with the key areas outlined in the RFI. Abstracted statements are presented in Appendix A.

Etiology

Responses describing current knowledge or understanding of the etiology of health disparities were diverse in perspectives, although consistent with current science about the complexities of the determinants. Respondents provided input on either specific causes/pathways, or they described research areas that are needed to better understand the etiology of health disparities. Comments focused on the need to better understand basic, environmental, and socio-cultural pathways, since it is not clear how these operate independently. In addition, respondents provided statements that health disparities result from a confluence of factors, and that this interaction is not well understood. Respondents indicated that research must focus on understanding the interaction of the socio-cultural, ecological, environmental, and behavioral pathways. Several additional respondents indicated that the health disparities field lacks a theoretical framework or model, an absence that has hindered explanations for and understanding of the causes of health disparities. In their submissions, several respondents encouraged the development of a comprehensive framework. Other respondents provided recommendations on specific frameworks or components that should be part of a comprehensive framework. Respondents recommended the use of a socio-ecological framework, social determinant, exposome, or biopsychosocial framework to ground the science of health disparities.

Methods and Measurement

Respondents described the need for a conceptual definition for minority health and health disparities. An agreement on how to define minority health and health disparities is essential for setting direction within the field. Further, several respondents indicated that health equity must be a central part of the definition for health disparities in order to guide measurements and methods for addressing and assessing the magnitude of disparities. Respondents also noted that Institutes and Centers within NIH all define health disparities differently and that a common definition is needed to guide the science.

A large number of respondents answered the question of how health disparities should be measured. Individuals agreed that health disparities could be measured in terms of physical health, mental/psychosocial health, and general well-being. Regardless of how the health disparity is measured, the measure must be valid. Respondents indicated that more emphasis needs to be placed on developing a consistent core of valid measures that can be used within the field. Some of the suggestions included ensuring greater rigor and consistency in metrics for identifying or quantifying the influence of race/ethnicity, socioeconomic status, education, generation, immigrant status, and geography in health disparities research.

Next, respondents provided input on how the reference population should be selected in health disparities research. Responses varied, with most respondents indicating that there should be some flexibility on which reference group is selected. A large number of respondents indicated that non-Hispanic Whites should not be the default group. Reference populations should be selected based on the desired outcome. Expanding the reference population to include socioeconomic status and rural/urban referents also emerged as an alternative to using race.

Respondents were asked to discuss analytic approaches and research methods that have advanced the field or have the potential to advance the field. Several respondents suggested that qualitative and mixed methods research were essential and have been useful in elucidating the causes of health disparities. Other respondents acknowledged the importance of community-based participatory research methods. Respondents felt that the inclusion of the community in the research process was a strong approach and would advance the state of the science. Respondents also mentioned the need for innovative study designs to identify the causes of health disparities and to avoid the exclusive use of the randomized designs to assess trial effectiveness. Some respondents mentioned that randomized control trials were barriers within certain populations and that a balance between other quasi-experimental designs needs to be taken into account when considering the unique structures of a community. Other responses mentioned the use of multi-level approaches and analyses as a strategy that can help yield better understanding and outcomes. Advancing the science of health disparities will require understanding and intervening at the individual, family, social, community/organization, and policy levels. Finally, big data was emphasized as an analytic approach that could be useful to resolving health disparities. The need for a national database that collects meaningful health disparities data was a common theme. Respondents mentioned the importance of a central hub for the development and storage of relevant disparities data, as well as the need to promote the use of computational analytics for larger data sets.

Interventions

Respondents generally provided input on the need for more intervention research that targets the drivers of health disparities. They also cited the need to align interventions with racial and ethnic minorities and other health populations and their health needs. Other respondents indicated the need to focus on identifying cost-effective intervention strategies and suggested the need to undertake comparative effectiveness research to identify the most effective intervention approaches.

In terms of promising interventions for addressing health disparities, community-based participatory research overwhelmingly emerged as the only promising model. Respondents indicated that involving the community was essential in developing effective interventions. They recommended working with those who are affected to develop the intervention, determine meaningful clinical and community outcomes, and assist with data collection protocols. However, several respondents mentioned that there was a need to develop quality assurances to ensure that the community is actually involved and fully integrated in the process.

Suggestions were also made in terms of the period of the life cycle that appear most promising as targets for interventions to address health disparities along the life course. The majority of comments suggested that prenatal or early childhood interventions would be the most effective. Other comments suggested that interventions need to be aligned with the

lifespan development perspective. Interventions are most effective if synchronized with the periods of the lifespan that place individuals at greatest risk.

Dissemination and Implementation

Respondents commented on dissemination and implementation science approaches that could inform the science vision. When identifying criteria to establish when an intervention is ready for dissemination, nearly all respondents believed that the community and community stakeholders are in the best position to make this determination. Respondents commented on the need to better understand how interventions can be translated to other settings and with other populations. A consistent comment was that interventions could be disseminated only if they are culturally appropriate. A one-size-fits-all approach does not work well when the unique characteristics of a population are not taken into account. Interventions should be tailored to the unique characteristics of a community. Additional comments centered on the need for a resource/clearinghouse that interested parties could access to identify effective intervention approaches.

OTHER COMMENTS

Infrastructure and Resources

The RFI solicited comments on infrastructure and resources needed by the scientific community. Comments could be grouped mainly into funding mechanisms/grant review and workforce development. Several respondents commented on the need for a clearinghouse that researchers and the community could use to identify resources about health disparities. Further, this clearinghouse should provide an overview of health disparities research at NIH.

There were numerous comments about funding mechanisms and peer review. Comments centered on the need to develop funding mechanisms that will allow for innovative research within populations experiencing some of the highest rates of health disparities. Respondents mentioned the need to allow funding for nontraditional research designs. Next, respondents discussed the need to better understand the impact of intervention efforts on eliminating health disparities. Respondents encouraged more long-term funding of projects. Others commented on who should receive the funding. Some respondents made statements about funding institutions, rather than individual investigators, to build institutional infrastructure. Along a similar line, they mentioned ensuring that more community-based agencies receive more of the research money and funding support. Ensuring that community-based agencies are funded appropriately could increase the likelihood of long-term adoption of interventions. Respondents also made statements about ensuring that underrepresented minority researchers are funded. Respondents discussed the importance of and need for individuals with similar cultural backgrounds to those being studied to lead health disparities investigations. Finally, comments about the grant review process mentioned the difficulty respondents have had with scientific review panels undervaluing the research they are proposing and not taking into account the unique study population and the specific barriers that prevent the use of more traditional research designs. Further, respondents encouraged NIMHD to ensure appropriate membership on study sections.

Others commented on the need for workforce development. Statements made by respondents focused on training for students as well as early and mid-career scientists. Respondents made statements about the need to train students in fields that will position

them to conduct research to eliminate health disparities. Respondents also noted the need to ensure that there is sufficient support and training of early and mid-career underrepresented scientists.

Research Areas

This RFI also provided respondents with the opportunity to discuss research areas that should be the focus of health disparities research in the upcoming decade. The responses were broad, and are abstracted in Appendixes A and B. Respondents suggested the need for more research on the etiology of health disparities, specific diseases and outcomes, health behaviors, and specific populations.

SUMMARY

This RFI allowed diverse stakeholders to provide input on a scientific planning process that will define a vision to guide health disparities research at NIH for the next decade. Respondents represented a broad range of stakeholders, including the general public, research scientists, and professional and advocacy groups. Overall, respondents endorsed the need for a science vision on health disparities. Comments provided a wealth of information that identified future areas of opportunity and need, as well as scientific advances to date that have helped improve minority health and reduce health disparities. These comments will help inform priorities as NIMHD and NIH work to improve minority health and eliminate health disparities.

Appendix A: Abstracted Statements

1. What are the causes of health disparities?

NIH must address health inequities the true root causes of health disparities. These are often deeply rooted, historically-based inequities that research could address to better inform policy making. Can we truly eliminate health disparities without address health inequities? No. I would argue that several great funded projects have not translated to change in practice or community settings because of this.

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Another very important area would be “Social Determinants of Health” as this now appears to be the most significant factor in the development of health disparities – would not like to see this moved to Etiology as this is so important as a stand-alone.

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One of the questions posed in the RFI was what are the causes of health disparities. As far as oral health is concerned, the Centers for Disease Control and Prevention estimates that more than 108 million American children, adults and seniors lack dental insurance and thus access to dental care. Access to basic dental care is unattainable for so many of our citizens, leading to poor oral health conditions that affect work and school productivity, employability, self-esteem, quality of life, and can even lead to death. Research has proven that oral health is inextricably linked to overall health and must be accessible to ensure that all populations have an equal opportunity to live long, healthy and productive lives. A scientific agenda that includes oral health disparities research, capacity building and outreach would address a critical area of need for millions of Americans and, more importantly, can contribute to scientific gains that inform interventions, create policy and enhance practice that promotes overall health and well-being.

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Historical trauma/dispossession and its intergenerational effects.

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We believe that the next critical phase in health disparities research will come at the intersection of biologic, environmental, behavioral, and social factors. Therefore, we believe it would be valuable for the NIMHD portfolio to cover the spectrum of research studies that span from the basic science of health disparities to studies that focus on intervention, implementation, and dissemination. Additionally, we strongly believe that the view of basic science can include not only basic science of biologic components but also basic science in the areas of health behavior change and social forces such as racism. A spectrum of research will support understanding the root causes of disparities and then translating these root causes into multi-level interventions.

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Oral health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their social and economic position, racial

or ethnic group, religion, gender, age, mental health, cognitive, sensory or physical disability, sexual orientation, gender, identity geographic location or other characteristics historically linked to discrimination or inclusion.

Oral health disparities are often conceptualized in terms of social determinants of health, with several factors such as income and education being involved across the social gradient.⁶⁷ Individual and group behaviors are crucial parts of the equation of addressing health disparities, but must be understood in the context of access to resources, particularly economic ones and in the context of poverty including intergenerational poverty, generally.

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Health disparities are the result of multiple causal factors. Poverty and the intergenerational transmission of poverty – one’s zip code determines, to a great extent, one’s life chances, one’s earnings, and most importantly, one’s health outcomes. Moreover, where people live should also be included as a contributing factor. Communities in which pollution, lack of access to a space for exercise and leisure, food deserts, fast food swamps, poor education, poor educational resources, poor or inadequate public and private transportation, violence, consistent and disproportionately high unemployment rates, inadequate housing, alcohol and substance abuse, limited and or non-existent social supports, and lack of political power are more likely to evidence health disparities. Other significant contributing factors are institutional, individual, and community based including behavior, political determinants of health (policy – lack of access to political power and policy makers), racism/discrimination, lack of access to quality health care, lack of culturally competent providers, absence of culture-informed health literacy (provider/patient/client), and inadequate or lack of a productive collaborative partnership between the client/patient and the provider that builds and maintains a trusting relationship.

People are the products of their environments and the sum total of their inherited and lived experiences. Moreover, they are members of various systems that interconnect in ways that impact each other. Any negative effect in one system has the potential to have an adverse long term effect on all. History and research demonstrates the intractability and pervasiveness of the adverse consequences of these and other social determinants of health. People need to believe they are valued, have worth, possess dignity, and, most importantly, that they have the opportunity to build trusting relationships with care providers. Moreover, they need to feel that they have and enjoy a right to self-determination. When impediments to realizing these human needs occur, including the causes listed in the first bullet, health disparities emerge and are sustained across generations.

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Causes of health disparities are:

- 1) Public policy discriminatory to the poor, especially to but not limited to African Americans;
- 2) Geographic remoteness;
- 3) Historic factors related to the Tuskegee Syphilis Study;
- 4) Historic irresponsibility of the US medical care system;
- 5) Lack of trust in the medical establishment;
- 6) Poor access to Web-based educational and patient monitoring resources;
- 7) Lack of local industry and other employment opportunities;

- 8) Poor nutrition practices and poor access to nutritious food;
- 9) Limited enrollment in the Affordable Care Act.

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We urgently need a better understanding of how racism shapes health and interacts with other environmental and biologic factors.

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We are likely to find that community stress is a common pathway for multiple types of population–level disparities, providing implications for targeting community-level interventions.

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Health disparities are recognized as involving multilevel causal factors whose effects on health can unfold over time (including across generations) and through complex interactions (168). Recognizing greater levels of chronic and cumulative stress experienced by racial/ethnic minorities and low SES groups (169, 170), research has increasingly investigated biological mechanisms by which adverse environments “get under the skin” to affect health (171); hence, the growth of research on allostatic load (172-174) and a recent colloquium of the National Academy of Sciences on the biology of social adversity which addressed a range of potential mechanisms, including gene-by-environment interactions, epigenetics, the HPA axis (the body’s stress response system), and neurological changes (175, 176).

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Many Health Disparities are linked to the historical antecedents of a community, society, individual. A scientific vision must have access to these historical narratives, accounts or have mechanisms in which these are factored when developing a science based intervention to address them. This is a very difficult process as gaining access to the real narrative is a complex exercise. Further power places an important role here in privileging whose narrative is accurate. In many case, we are unable to address historical determinants behind health disparities (or address the wrong ones) as we are not in possession of the correct narrative.

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I would make the focus on ‘the social gradient’ rather than ‘health disparity populations’ both because of the evidence that health status exists on a gradient, and because it effectively makes health inequalities everyone’s business.

A. *What are the social, ecological, environmental and behavioral pathways, and the biological mechanisms that determinants of health operate upon to influence the health status of health disparity populations?*

- I. Social

Examining cultural determinants of health (e.g., cultural trauma, cultural safety, cultural stereotypes) for indigenous populations, and their interplay with biological, behavioral, and social determinants of health, would shed light on possible causes.

II. Ecological

Community level factors are also likely to impact the levels and trends in leading risks such as obesity and smoking. Identifying and quantifying the impact of these underlying factors are the key to driving change through program implementation, policy selection, and knowledge building.

III. Environmental

The lack of distinction between the causes of poor health outcomes among minority and other underrepresented populations and the causes of population level disparities has perpetuated research that has failed to distinguish between minority health and health disparities. The result has been too much funding of basic science research that has tried to explain disparities in terms of genetics as well as social/behavioral research that seeks to identify the causes of disparities as individual behavior, while ignoring the role of environment including chemical and non-chemical exposures and lack of availability and access to resources and opportunities.

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Health disparities are measures of population level health outcomes and need to take into consideration the effects of place on health. Research that fails to take into account the effects of environment are unlikely to have much impact on reducing disparities.

IV. Behavioral Pathways

No responses

V. Biological

The etiology of health disparities continues to be a very important area of research with tremendous potential for benefits to the nation's public health, and to global health. In this regard, an understanding of biological mechanisms is almost non-existent for most of the diseases with significant health disparities. Therefore, I strongly believe that research that seeks to understand biological mechanisms of health disparities is vitally important. Consequently, basic science, as well as translational science methodologies will continue to be important if we are to understand the mechanisms underlying health disparities, and how to exploit these mechanisms for beneficial clinical applications.

B. How do different health determinants interact to produce health disparities? How can the complexity be captured while producing scientific information useful to guide policies and practice?

The causes of health disparities are complex. While some vary by disease, others are likely to have common cross-cutting origins. We need to move away from simplistic cause-effect models of health disparities and away from interventions that don't reflect the complex real world.

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This growing gap in health outcomes demonstrates a need to understand the relative contribution of key health drivers to increases in health inequalities. Health disparities in the US and beyond are multidimensional and can be affected by various influences. To understand health disparities IHME focuses on some of the more distal influences on health, such as poverty, education, and climate. This includes understanding the risk factors, behaviors, and social and economic determinants that contribute to poor health outcomes, such as economic status, tobacco use, obesity, and other significant risk factors including diet, physical activity, drug and alcohol use, and so forth. However, quantifying the relative impact of risk factors, behaviors, and socioeconomic determinants on health outcomes in a meaningful way at the population level is challenging due to insufficient data of the aforementioned factors.

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Disparities in health cannot be understood or effectively addressed as discrete phenomena in the manner of research on specific biological processes, mechanisms, or particular disease etiologies. Health disparities are complex phenomena that result from the interaction of multiple contributing factors over time, to create trajectories of health vulnerability for certain groups of people that vary from the majority norm. As has been documented to varying degrees (Meyer, Yoon & Kaufmann 2013; Gaskin et al. 2013; Edberg, Cleary & Vyas 2010; Starfield 2007; Braveman et al. 2011, 2010; AHRQ 2011; Kawachi, Daniels & Robinson 2005; LaVeist & Issac 2012; Lillie-Blanton & Lewis 2005; Smedley, Stith & Nelson 2003; Edberg, Cleary et al. 2010), these contributing factors are most often associated with social, economic, racial and political marginalization, and may include:

- Lack of access to health care;
- Lack of access to social and support services in general;
- Living in community environments that are not health-supportive – where adequate food/nutrition, recreation space and safety are limited, and where exposure to environmental risks (pollutants, lead paint, etc.) is high;
- Having limited economic opportunities, such that health in the optimal sense cannot be prioritized in the face of more immediate needs;
- Experiencing higher stress levels because of the lack of income, community safety concerns, and reduced ability to control one's circumstances;
- Low levels of community efficacy – that is, the shared belief among community members that the community can and will act to resolve problems that the community faces;
- Lower levels of education and educational opportunity, resulting in gaps in information about prevention and health;
- Cultural differences between specific groups and the biomedical health system, such that health and disease are understood, and treated differently;

- Discrimination, resulting in actual differences in health care quality, differences in economic and social opportunity, individual beliefs about opportunities and about future expectations, a sense of alienation, depression, anger, and different calculations regarding what is and is not a health risk of concern.

Most importantly, the above kinds of contributing factors do not operate in isolation, but are interactive, as an aggregate syndrome. They function together to create patterns of living that are more or less health-vulnerable. Because that is the case, the science of health disparities faces a unique task of advancing knowledge about interactive and cumulative effects, within the context of communities and communities nested within broader domains of influence.

The lack of an appropriate theoretical framework of the causes of health disparities has limited the shaping and support of a research agenda that addresses the underlying causes of population disparities rather than the causes of poor health in minority and other underrepresented populations. Exposure science provides a model and tools that can be readily adapted to address health disparities.

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The exposome provides an excellent theoretical model for conceptualizing the links between external and internal pathways and mechanisms through which environment affects health and leads to population level disparities. The exposome framework supports translational research and transdisciplinary team science. Juarez, et al., (2014) operationalized external exposures in four broad domains: natural, built, social and policy environments and have developed a national, county level database that supports this approach. The exposome incorporates a lifecourse perspective recognizing the importance of life stage in the development and progression of disease.

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It must be noted however that several of the social determinants of health tend to cluster and co-vary so that an 'eco-social' framework is best.

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It is critically important to focus significant attention on the interaction of social determinants, including culture, environmental and occupational determinants, and biological pathways. Using the perspective of cumulative risk science would yield more nuanced and complex understanding of the drivers of disparities and the potential interventions necessary to address them. Of particular importance are the research questions related to the impact of social and income inequality, and its impact on health across the lifespan.

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A community-based ecological approach to understanding the nature and causes of health disparities and human behavior, as determined by the environment, is critical to achieving success in research, policy informed by research and practice, and creation of population determined interventions strategies.

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We suggest that for health disparities research, NIMHD employ an ecological approach that will, of necessity, include all social determinants including individual behavior and conduct.

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Studying vulnerable populations using longitudinal biopsychosocial approaches and a family lens will produce new knowledge about both vulnerability and resilience. Hence, any comprehensive model to examine health disparities must incorporate a multilevel perspective and advanced methodologies.

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Whether using the frameworks and terminology of “social determinants of health,” “environmental determinants,” or “intersectionality theory,” we believe a systems perspective is needed to appreciate and address the health problems created by resource inequities, discriminatory practices, and institutional bias and racism. Thus, NIMHD deliberations may be informed by including researchers and policy experts in housing, education, employment, transportation, urban planning, criminal justice, banking, and other fields that have a direct impact on the lived experiences of disparity populations and in particular communities of color.

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The exposome is an alternative approach that offers significant potential for creating a science of health disparities. It supports translational team science in which basic, clinical and population health scientists work together with community partners. This approach is likely to spur innovation and interventions that are based in real world knowledge and help us develop an understanding of complete exposure pathways: the pathways and mechanisms through which exposures in the external world are internalized by the body and how these lead to increased susceptibility of disease which can affect segments of communities.

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Cumulative inequality perspective is crucial. Applications of fundamental social causes models and epigenetic models. Additionally, biomarker research in general, including integrative biopsychosocial perspectives.

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The science of health disparities research should include a philosophy built on a model that includes a biopsychosocial-ecological approach that upholds a life course perspective.

2. What are the best methods and metrics to study health disparities, their causes and promising solutions? What measures, analytic approaches and other methods will advance health disparities science?

Need For a Common Definition

A health disparity is a difference in health outcomes across subgroups of the population. Health outcomes are the result of a complex confluence of factors which include not only biological or genetic causes but also race, ethnicity, gender, sexual orientation, geography, socioeconomic status, education level, mental health, etc. Further, social, economic, and environmental disadvantages contribute to differences in access to care and, ultimately, the health and well-being of groups and communities.

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We believe that NIMHD and the health disparities research community needs to agree on a common definition of “health equity” in order for our field to progress.

Develop Common Definitions

Foundational to the development of a cross-IC vision for health disparities research are common, guiding definitions of “health disparity/inequity” and “health equity/disparities research”. Without consensus regarding the target of health disparities research, it will be impossible to craft a cohesive vision comprehensive in terms of the outcomes and populations considered to be in scope. While no explicit definition of “health disparity” is currently provided on NIMHD’s website, it does note, “Many populations in America, whether defined by race, ethnicity, immigrant status, disability, sex, gender, or geography, experience higher rates of certain diseases and more deaths and suffering from them compared with the general population.” Other ICs offer distinct definitions of “health disparities” on their websites. For example, NIAID focuses on gaps in quality of health or health care that mirror differences in “socioeconomic status, racial and ethnic background, and education level”. NCI’s definition of health disparities populations is more inclusive: “These population groups may be characterized by age, disability, education, ethnicity, gender, geographic location, income, or race.” Finally, NIDA limits its health disparities research to minorities, rural groups, and socioeconomically disadvantaged urban populations. Of note is the universal exclusion of LGBTQ populations from these definitions. Given the health and healthcare inequities faced by sexual minorities AAMC encourages NIMHD to explicitly note LGBTQ populations in their definition of “health disparities” and “health disparities research” alongside other vulnerable populations.

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We believe that NIMHD and the health disparities research community needs to agree on a common definition of “health equity” in order for our field to progress. Specifically, there is a key question in our field: who should the reference group be in studies of health disparities? While majority “best-performing” populations provide a framework for understanding the potential of individuals or communities (the “best health” possible), studies focused within specific populations may best facilitate understanding of root causes and contribute to meaningful interventions for greater impact. These are complementary approaches: comparisons allow researchers to identify the disparities that exist, while within-group studies are needed to understand the specific targets of interventions.

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A common definition will also aid in the identification of gaps in NIH's current and historical health equity research portfolio.

A. How should health disparities be measured- in general, in physical health, in mental/psychosocial health, and in social health and wellbeing?

In terms of social isolation and stress.

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Cultural determinants of health and socio-cultural factors should be included (not mainstream, cultural practices, especially for indigenous of people who are struggling to keep identity).

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I would be recommend considering mental/psychosocial health, self-reported health, and measures such as life expectancy and disability-free life years. The latter is good particularly in terms of workforce planning, as we need a healthy workforce into the mid-60s given the demographic pyramid, and the demand for labour. It is useful in general to pick metrics which chime with state, or municipal policy.

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Terms such as "income inequality" and "annual income below poverty" may fail to capture the information needed to understand the complexity of how health is determined. In part, this is because such terms are externally defined rather than internally defined. We have observed, for example, that among women who are defined as living in, "poverty" (annual income less than \$12,000 in this case), those who worried about paying monthly bills were three times less likely to obtain repeat screening mammography than those who were not worried about paying monthly bills. To better understand internal definitions, one might turn to the writings of Nobel Prize laureate, Amartya Sen. Sen has developed economic theories based on capacities and functionings. People living in poverty may succeed, in part, because they have, "Effective opportunities to undertake actions and activities that they have reason to value, and be the person that they have reason to want to be." Robeyns I. "The Capability Approach", The Stanford Encyclopedia of Philosophy (Summer 2011 Edition), Edward N. Zalta (ed.), URL = <http://plato.stanford.edu/archives/sum2011/entries/capability-approach/>. Studies based solely on externally defined context will likely miss the mark. Researchers have to get out into the field and actually communicate with people.

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Research on mental health disparities should benefit from zip code data to measure residential/racial segregation indices and neighborhood deprivation indices to help investigate whether these geographically based factors can explain mental health disparities.

There should be more research into designing mental health measures that are culturally sensitive to different racial/ethnic groups. For example, the Edinburgh Postnatal Depression

Scale which measures mothers' depressive symptoms after childbirth has been criticized for being mainly appropriate for western populations and does not capture the somatic symptoms that are important to detect depression among women from non-western cultures.

Additionally a focus on mood disorders and neurophysiological mechanisms that lead to disparate outcomes not only in depressive symptomatology but also anxiety, PTSD, etc.

There should be more research that investigates the race paradox in mental health (African American/black compared to white populations) and the Latino paradox in mental health (Latino compared to white populations).

These studies should figure out whether there is indeed a paradox or are we using the wrong measures of mental health that may not be culturally appropriate to how minorities experience mental health disorders. Moreover, these studies should differentiate within race and within ethnicity differences by country of origin and time of residency in the United States.

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Given that the 59 measures selected by AMCHP were reviewed and approved by a national expert panel and can be obtained from existing data sources, we propose to use these measures as the foundation of the science of health disparity research. A complete list of measures and related data sources can be found online at <http://link.springer.com/article/10.1007/s10995-015-1767-1>

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Encourage studies reporting on disparities to include explicit definitions of disparities and use valid measures. Measure health across domains (general, physical, mental/psychosocial health, etc.) with more attention on quality of life and wellness.

B. Who should be the "reference" population in determining health disparities? Who should be compared with whom, to measure health disparities? Should the criteria change over time in relation to demographic and contextual changes and if so, how?

For cancer in HI we sometimes reference Japanese who along with Chinese in HI have the lowest mortality rates for breast cancer and higher screening rates.

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Who should be the "reference" population might depend on the issue and populations involved. There should be flexibility on what groups serves as the reference and based on empirical evidence (e.g., bae rate of a disease) and not on the idea that Caucasians are the default comparison population.

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Ideal "reference" populations are in the 'Blue Zones,' a trademarked concept that describes places on earth with the highest populations of centenarians, such as Okinawa, Japan & Ikaria, Greece.

The reference group ought to be something akin to the top income decile, on the basis that we should all be able to achieve the same health as the best-off, under similar conditions. One then compares the difference for each income decile, and similarly one can compare areas by some measure of income deprivation.

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Models provided by Amartya Sen are instructive. One of his insights was to choose a referent population that was completely outside the study population – noting, for example, that mortality of women in the then impoverished Indian State of Kerala approximated that of European women. Using reference populations within a community may blind researchers to potential success since within-community socio-economic gradients may still prevail. Also, there should be at least some attention to reference populations who are culturally comparable and successful, not necessarily “black-white”.

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Recent changes in the demographic composition of the United States demonstrate that the population is becoming more diverse while staggering health disparities grow more problematic. Hispanics will constitute 30 percent of the nation's population by the year 2050 (Ennis, Ríos-Vargas, and Albert 2011). Mexicans are by far the largest Hispanic-origin population in the United States, accounting for nearly two-thirds of the U.S. Hispanic population in 2011 and 11 percent overall of the U.S. population (Gonzalez-Barrera and Lopez 2013). Latino populations are heterogeneous with several distinct ethnic backgrounds. The majority of all Latinos in the United States, 64.1 percent, are Mexican American; 9.5 percent are Puerto Rican; 8.3 percent are Central American; 7.9 percent are South American; 3.7 percent are Cuban American; 3.3 percent are Dominican; and 3.1 percent are all other self-identified subgroups (Pew Research Center Hispanic Trends 2015).

With that being said, the Latino population and other underrepresented minority subpopulations must be included in all research studies, specifically those funded by the NIH. We submit that the criteria for the “reference” population be assessed every ten years following the model of the US DHHS’s Healthy People campaigns. In this vein, the demographic and contextual changes can be accurately and consistently assessed giving priority to underrepresented communities in research.

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Comparisons between underrepresented minority groups should receive more attention by the NIH without necessarily having a “white” reference group.

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Finally, the “reference” population should not be defined solely by race or ethnicity, but should also include demographic factors such as education level and socioeconomic position. For example, education level is an important benchmark for determining literacy, health literacy and English language proficiency. Subgroups differ by these important social determinants, and in turn also may differ by important behavioral factors, including tobacco

and alcohol use, physical activity, and sleep patterns – all of which are well-documented correlates of chronic health conditions, particularly CVD, diabetes, and obesity.

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While the traditional approach for reference has been whites, the consideration of income, socioeconomics, and rural vs urban would be important to investigate. AND do we compare disparate groups with each other so we know if they have similar disparities but different outcomes that might tell us where to intervene.

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The reference population should be the population experiencing optimal health and the cohort (or target) population should evidence health disparities for comparative purposes. The criteria should change over time and should be verified by objective data. Moreover, it is crucial that all of these be included in any research because they are interconnected and make up the totality of the individual. For example, challenges or problems with one's mental/psycho-social health can lead to physical health problems which in turn can have a deleterious impact on social health and well-being.

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This really depends on the specific research question. In general, the population whose health is closest to the desired outcome should be the referent group; this pattern will differ depending on what a given agency is interested in learning about. One good way to choose a reference population might be to seek out a group with comparatively high levels of self-rated health on a given indicator, but this is limited as self-rated measures are relatively nonspecific. The answer to this question is complex, as comparing to a majority group may inadvertently perpetuate disparities or misrepresent the severity of the disparity.

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Specifically, there is a key question in our field: who should the reference group be in studies of health disparities? While majority “best-performing” populations provide a framework for understanding the potential of individuals or communities (the “best health” possible), studies focused within specific populations may best facilitate understanding of root causes and contribute to meaningful interventions for greater impact. These are complementary approaches: comparisons allow researchers to identify the disparities that exist, while within-group studies are needed to understand the specific targets of interventions.

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C. What analytic approaches and other research methods can advance health disparities research?

Since I have a graduate certificate in qualitative research from the University of Georgia, I would encourage qualitative methods to be included as standalone smaller research grant projects as well as formative/pilot research for larger projects. Should health disparities research always be hypothesis driven? I argue that researchers often may not understand

the full picture before creating an intervention or RCT. I found in my qualitative dissertation research on breastfeeding in African-American women (using the positive deviance approach) that most of the existing (quantitative) research focused on the lack of breastfeeding women, and did not examine successful women breastfeeding long term. To not address gaps such as these in the literature/field, would be a disservice.

Embodied research: Researcher looks at data through the lens of their own story/i.e. bias.
Grounded theory: research allows themes and findings to emerge from the data.

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Research that uses multi-level models and analytics which can account for the impact of environmental exposures at different levels are likely to yield better outcomes.

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Support of research that includes observational studies and integrates large secondary data are likely to increase our understanding of the underlying causes of health disparities. Once the causes have been identified, research is needed that can identify the biological pathways and mechanisms through which environmental exposures increase susceptibility for disease.

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The Burden Of Disease approach, which is currently applied to 188 countries world-wide in the Global Burden of Disease (GBD) Study^{10–15}, is a platform for comparative health assessments that provides a set of measurement tools to track changes in population health outcomes and risk factors by age, sex, and location. It tracks the morbidity and mortality for a detailed and collectively exhaustive list of more than 300 disease and injury categories and over 70 risk factors by age, sex, and geography over time. The framework, methods, and summary metrics used in the GBD approach ensure comparability of results. This enables users to benchmark and conduct trend and spatial analysis, as well as better measure the causal attribution of overall health outcomes to specific diseases, injuries, and risk factors. To date, the GBD has been applied at the national, regional, and global levels and is working on subnational level estimation. IHME has also estimated some quantities of interest at the US county level, such as all-cause mortality and smoking prevalence^{4,6}. Collectively, these studies provide resources and expertise that would facilitate the development of a similar comprehensive assessment of the gaps in health outcomes and drivers at the US county level.

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Selecting methods and measures for health equity research based on community input and acceptability is a guiding principle for making appropriate choices. Just as various kinds of science – from fundamental discovery to community-based participatory research – can help build the evidence base of solutions to health and health care disparities, various methods and metrics can be deployed in service of health equity research. AAMC strongly urges NIMHD to require adherence to principles of bidirectional, community engaged research whenever feasible.

This community input and partnership in research planning can include the identification of acceptable ways to phrase questions, to gather data, to enhance representativeness of study participants, to delineate outcomes of community import, and to develop study designs that include control groups without withholding potentially beneficial treatments from communities who stand the most to gain.

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We recommend considering innovative study designs and approaches. We encourage a balanced approach to evaluating study design that avoids an exclusive focus on the randomized controlled trial. For example, mixed methods that include qualitative and quantitative methods may be critical for identifying root causes of disparities, informing interventions to reduce them, and informing the interpretation of quantitative outcomes of trials. While RCTs are critical to the field, we believe that a balanced portfolio that includes other quasi-experimental and qualitative approaches can be equally as valuable depending on the research question.

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Methodologic rigor and innovation are both required to advance health disparities research generally and child health disparities research specifically including:

- 1) Ensure greater rigor and consistency in metrics for race and ethnicity, socioeconomic status, education, generation, immigrant status, and geography including how they are defined (parent or child determined, mixed race) and how they may change over development.
- 2) Create or make available measures that are developed and/or validated in diverse groups and across languages.
- 3) Create developmentally appropriate measures for children, including child self-report measures.

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- Developing and testing methodologies (quantitative, qualitative, mixed) to capture, integrate, and analyze multiple contributing factors.
- The standardization of health disparities metrics and development of generalizable measures of impact.
- Development and testing of theoretical models and constructs that address complex and community processes, and the linkages from broader social factors across ecological levels to individual behavior. There have already been some efforts in this regard, including, for example, the construct of community efficacy (Sampson, Morenoff & Raudenbush 2005; Sampson 2003; Sampson, Raudenbush & Earls 1997) and its relation to health outcomes; the continuing work on social and cultural capital (Kawachi, Subramanian & Kim 2008; Rocco & Suhrcke 2012; Abel 2008; Shim 2010); the construct of syndemics linking multiple, interacting health outcomes to shared social and structural determinants (Singer & Clair 2003); theoretical models that seek to trace impacts across ecological levels (e.g., Flay 2009, 1999); and intervention frameworks that account for complexity (see Trickett et al. 2011).

- Following on the previous point, research that seeks to link ecological factors already integrated at the community level (e.g., community efficacy, socioeconomic opportunity, safety, neighborhood attachment, culture, access to health and health-supportive services) to health behaviors, attitudes. The results of a 2009 interdisciplinary conference on community interventions resulted in key recommendations in this area (Trickett et al. 2011).
- Research that builds the evidence and methodological base with respect to community based participatory research (CBPR). The Affordable Care Act (ACA) calls for developing and evaluating activities to reduce racial/ethnic health disparities through beneficial investment in community organization. Effective interventions must draw on the expertise and knowledge of the affected communities (especially communities and population groups that are marginalized) as well as researchers. At the same time, drawing from Adler (2006), there is a need for: 1) a strong scientific foundation upon which targeted culturally (and linguistically)-relevant interventions can be developed and evaluated; 2) the widespread adoption of interventions by community partners; and 3) an ongoing assessment of changes in health that result from these interventions and from other societal changes. CBPR is an increasingly recognized methodology in which public health researchers (Wallerstein et al. 2010) partner with “disparity communities” to develop, implement and evaluate health promotion/disease prevention interventions.

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a. Reliance on large samples. There appears to be a great emphasis on projects involving large samples. This seems to be rationalized as the best way to assure generalizability of results. Unfortunately, not all health disparities are resolved by the same general approaches that work on the dominant population. While more focal studies directly involving populations experiencing disparities would seem to be the answer, it is rarely possible recruit a large sample from comparatively tiny American Indian and Alaska Native populations. We believe that the significance of a disparity on a given population should be weighted more highly than sample size if the intent is to eliminate disparities. While we understand that no NIH Institute wants to fund studies with statistically insignificant results, we also believe that reliance of very large sample sizes can easily contribute the studies producing statistically significant results with effects so small they are meaningless in practice.

b. Reliance on randomized clinical trials (RCT). NIH appears to place near exclusive reliance on RCT. Once again, while we recognize that this can be the “gold standard” for establishing efficacy, excessive reliance on this methodology can effectively shut out exploration of other promising research avenues and do nothing to address or close the gap between efficacy obtained under “ideal” circumstances and effectiveness in actual clinical practice. This is particularly true for investigating disparities in minority communities. We would recommend that much more consideration be given to other methods when the intent is to find promising approaches to reduce disparities.

c. Community-based participatory research (CBPR). While there appears to be a great deal of interest in CBPR and it may have great promise in reducing disparities, it does not appear that NIH has found a way to integrate this approach into its system of Institutes, Centers and Offices. Our experience is that too many projects are returned unscored or with scores too low to justify funding because the reviewers wanted to see a traditional research proposal that would be accomplished in a short period of time. This is, of course, just the opposite of the requisites necessary for CBPR where only a general statement of the research issue

can be proposed and time taken to recruit and inform a representative panel of people from the community. It is recommended that NIH establish research review processes that truly reflect a goal of supporting true CBPR.

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Research on mental health disparities would benefit from using the statistical methods of decomposition analysis such as the Blinder-Oaxaca decomposition technique for linear regression and the Fairlie decomposition method for non-linear models. Decomposition analysis helps identify the factors that explain mental health disparities between two groups (e.g., African American/black and white populations, Hispanic and white populations, etc.) and quantify the percentage that these factors explain in the disparities.

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Consider meta analyses, comparative effectiveness reviews, etc. of what we know from completed research with specific disparity populations and conditions.

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Historically, health disparities were measured as pair-wise weighted comparisons between subsets of populations. Developing an index measure that can be summarized into one number ("health disparity index") could be useful; however, such an index measure will require tremendous data collection and lengthy validation.

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Although measurement is fundamental to knowledge of health disparities (and to the public health decisions based on that knowledge), there is little basic measurement research and almost no comparisons of different measures or methodologies. For example, a few recent studies found that some health disparities (those based on self-reports) are primarily a function of how the questions are asked and can be eliminated by asking questions in a manner that is more sensitive to ethnic-minority cognitive styles. Likewise, my own studies found that random sampling of racial-ethnic minorities door to door, instead of by telephone, yields samples that are more representative of their populations. Such samples also exhibit significantly higher problematic health behaviors (health behavioral disparities are worse than is generally known) and lower chronic disease rates than similarly-random telephone samples. Moreover, the standard measures of socioeconomic status, residential segregation, and similar social factors are quite limited and even flawed, as several publications (my own included) have shown, yet there is little research to improve them. Likewise, there isn't enough research on rural populations (e.g., the farmers who constitute a large population of some states) to understand their specific health disparities or how to reduce them despite their social isolation and limited literacy and access to care. Worse, there is a widespread belief that informing disparities-populations of their health disparities (dissemination of disparities data) motivates behavioral changes. Yet the two studies testing this (Nicholson's and my own) both found that such information has the opposite effect, i.e., disparities-populations reject the data, feel discouraged by it, and may subsequently decrease health promoting behaviors. Basic research on communicating health information to disparities populations/communities is needed and is lacking. These are just a few

examples of the importance of studies of measurement and methodology and the need to fund them.

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Physical health, mental/psychosocial, and social health and well-being should be measured, comparably, with the highest standards in the state and, when appropriate, national and world standards.

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Health disparities research can be advanced most effectively and efficiently by employing methods and analytics that use community based participatory and community directed research that shows promise of collective impact.

The research process should include methods that are objective and that incorporate multicultural priorities and concerns.

Health disparities research should also combine “snapshot” and longitudinal research to determine and document change, both positive and negative, in the targeted communities and among individual members in the targeted community (single disease focused or social determinant(s) focused)

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Over more than two decades a tremendous amount of work has been done to identify standard indicators of community health, both to set population health goals and to help benchmark progress toward those goals. For example, the Healthy People 2020 national health promotion and disease prevention goals have framed the national agenda and include more than 1,200 objectives to monitor and improve population health both by developing new indicators and defining existing measures. Public reporting on disparities has been done for more than 12 years by the Agency for Healthcare Research and Quality (AHRQ), focusing on the role of health care access and quality in improving community health. The Health Indicators Warehouse

(<http://www.healthindicators.gov/>) provides direct access to a user-friendly, single source for national, state, and local health indicators, and the County Health Rankings

(<http://www.countyhealthrankings.org/>) provides data visualizations that can be used by community groups.

But even with the wealth of existing resources and the number of indicators from which to choose, there are a number of serious limitations in measures that can address health disparities. For example, the National Quality Forum has included a focus on health and health care disparities and population health, but a significant need exists to develop more granular population health measures and to identify measures of health disparities that are actionable at the delivery system level. This is an important gap. New indicators are needed for measuring the performance of health systems’ response to the health and health care needs of disparity populations.

Measures and data related to sexual orientation, gender identity, and disability are both limited and poorly understood, and would be valuable to both the disparities research and delivery system communities. Another important limitation of our existing measures is that the most granular measures available are at the county level, only rarely at the zip code level, and almost never at the level of a neighborhood or community. They do not measure the quality of life and access to resources within an immediate environment – e.g., proximity of fresh, affordable vegetables or exposure to air pollution – nor do they address issues of social cohesiveness, social isolation, or community resiliency.

Similarly, electronic health records provide a wealth of personal health information but these data lack context about where the person lives, works, plays, prays, and socializes. Thus, it is very difficult to translate all this new data into tailored, effective prevention strategies or early interventions. In addition, there are many, nontraditional sources of data, including those from social media, personal health information from mobile devices, and consumer purchasing behavior which provide a ‘digital footprint’ that could be utilized to create better, customized health care based on individuals’ behaviors and lifestyles.

We suggest that NIMHD consider ways to strengthen available data that would support more detailed analysis of the interactions between neighborhoods, people’s needs, health care, and health. In this regard, we are encouraged by work being done in the emerging field of geomedicine, where new data tools, such as GIS (geographic information system) software can identify neighborhoods with higher proportions of asthmatics or COPD patients and target mobile vans and other outreach methods to those areas.

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There is a need to place high value on the use of a variety of research designs beyond the classical hypothesis testing R01. For example, there are many strengths associated with mixed-methods research designs, and particularly those in which research questions are carefully conceptualized so that both quantitative and qualitative methods are appropriate and executed in a way that each cross-illuminates the other.

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Community based participatory research and other qualitative methods should be included to obtain patient-centered input and input from all relevant stakeholders.

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Broadening the analysis of data among groups, particularly in the Hispanic classification. Data usually groups all Hispanics together when there are extremely different genetic and environmental backgrounds that have an impact on the results. Hispanics are not the same, is not “one size fits all”. That is an artificially created group. Even, for example, when considering Puerto Ricans, there is a difference between the persons that classify themselves as so, but live in USA and those who actually lived in Puerto Rico.

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There is a wealth of quantitative information that illustrates broad trends in disparities, but qualitative data are essential for understanding the etiology of these disparities.

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Need to incorporate newer (e.g., epigenetic or metabolomic profiles) individual health metrics when determining the population that benefits and the health status change.

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We would like to express our support for multi-level approaches to health disparities research. Understanding and advancing the science of health disparities will require understanding and intervening at the individual, family, social, organizational, community and policy levels. Furthermore, we believe that models for best integrating these levels to reduce disparities need to be developed and researched. There is little research that has been conducted on how to integrate interventions into multiple levels. We recommend that such research be a funding interest of NIMHD.

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Data on sexual and gender minority populations, including samples large enough to permit disaggregated analyses (e.g., by gender or race/ethnicity). The 2011 Institute of Medicine report on the health of lesbian, gay, bisexual, and transgender Americans (181) constituted the first comprehensive effort by a federal body to assess the science regarding sexual and gender minority populations. Among its key findings, the committee noted that research on alcohol use has been uneven among sexual minority sub-groups and that transgender individuals have received less attention than lesbian, gay, or bisexual persons. Of particular concern is the dearth of high-quality data. Thus, the committee recommended that “data on sexual orientation and gender identity should be collected in federally funded surveys administered by the Department of Health and Human Services and in other relevant federally funded surveys.” (p. 299). We strongly concur, as there are indications of alcohol-related disparities among sexual and gender minority populations (36, 39, 182, 183) yet insufficient evidence to fully describe the problems and mount effective prevention interventions. We urge NIH to include sexual and gender minorities as priority populations in its portfolio of disparities research. Further, given the availability of standardized measures (34, 184), we call on NIH to implement routine collection of sexual orientation and gender identity information in all of its human subjects research.

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Intergenerational studies are beginning to illuminate the perpetuation of disadvantages and alcohol-related problems (i.e., family history of alcoholism) across subsequent generations of racial/ethnic minorities (177-180). In order to study the unfolding of health disparities over the lifecourse (and across generations), and specifically the health-related consequences of social disadvantage and adversity, longitudinal data are needed on individual and environmental risk (and protective) exposures, health status and health-related behaviors, and biomarkers tapping biological mechanisms. Importantly, study samples must include large numbers of racial/ethnic minorities in order to advance understanding of existing racial/ethnic health disparities that include, but are not limited, alcohol problems.

D. What methods should be used to evaluate the success of a health disparity intervention (at the level of policy, practice, or community) given the challenges often faced?

At the community level, evaluate capacity building in community of interest, and participating community partners.

The success of the intervention should be determined by the degree to which it was community-led and generated community-owned data.

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Support the implementation of RCTs on specific interventions with large and representative samples, including representation of subgroups, e.g. Puerto Ricans and Mexican Americans not just umbrella groups such as Latinos.

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Multi-community studies are essential. Cochran reviewers lament that public health researchers often attribute successes to programs without accounting for community context. Unfortunately, the same intervention might have different results in seemingly similar racial/ethnic communities living in different places. To overcome this problem, communities might be pre-defined in terms of disparities trajectories (e.g., Rust G, Zhang S, Malhotra K, Reese L, McRoy L, Baltrus P, Caplan L, Levine RS. Paths to health equity: Local area variation in progress toward eliminating breast cancer mortality disparities, 1990-2009. *Cancer*. 2015 Apr 23. doi: 10.1002/cncr.29405). Using Bayesian methods, it might then be possible to systematically select communities on different trajectories when interventions are tested, so that the effects of community context may be better understood.

Community perception is a universally important indicator, and should focus on both process and outcomes at various stages of the intervention.

E. How can resilience be captured in studying determinants of health and health disparities?

By interviewing adults who have survived adverse impacts of social determinants of health, e.g. survivors of family violence, drug addiction, incarceration, structural racism, etc.

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We are excited that the NIMHD has included a question regarding the construct of resilience and its use in research. Just as we have begun to move from deficit to asset models in research, health disparities investigators need to better understand how people positively adapt despite the adverse socio-environmental factors shaping their lives. Research in the area of resilience is complex, nuanced, and requires sustained support to further investigate these intricacies. Please see the article below for a review of the issues facing this work.

See reference:

Luthar SS, Cicchetti D, Becker B. The construct of resilience: A critical evaluation and guidelines for future work. *Child development* 2000; 71(3):543.

Notwithstanding, this work is critically important to both future research and interventions in health disparities and health equity research with underrepresented populations.

The THRIVE (toolkit for health and resilience in vulnerable environments) approach has been used as a community assessment tool that measures community resilience. See reference:

Davis R, Cook D, Cohen L. A community resilience approach to reducing ethnic and racial disparities in health. American journal of public health 2005; 95(12):2168.

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Resilience should be captured through qualitative and quantitative methods with the goal of appropriating asset based models for assessing the social determinants of resilience, including religiosity, spirituality and forgiveness.² The practice of comparing the population with the highest disease prevalence to populations to the lowest prevalence of disease and mortality falls short of the goal of health equity.

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Qualitative data are very helpful for understanding resilience. Life history interviews, for example, can give insight into how people have coped over time with challenging circumstances in their lives.

F. How can we leverage Big Data (i.e., a plethora of data already collected by other institutions) to determine the causes of health disparities and the pathways and mechanisms through which they operate?

The use of computational tools needs to be adapted if we are going to analyze big data. This has implications for research training.

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By looking through a historical lens at population health data, not just over the last 3-5 years or even 10, but over the last two centuries.

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NIMHD should consider establishing an internal resource for big data, whereby researchers could propose questions for analysis without having to establish big data banks of their own. The emphasis should be on big data sets with individual information. For example, medical billing claims data from Medicare and Medicaid can be very useful. Currently, however, it is not only expensive to obtain such data, but also setting up the infrastructure to manage and analyze the data can be daunting as well. This essentially shuts out many talented minority scientists (for example, those who work at Historically Black Colleges and Universities and other minority-serving institutions), but it may be precisely those researchers – by virtue of unique perspectives on vulnerable populations – who might come up with the best questions. If NIMHD took care of the data acquisition and management, set up a funding system based on the quality of questions proposed, and also funded cross-institutional

mentorship, it might not only advance science but also speed the development of minority faculty. Such big data approaches should also form alliances with institutions having access to and experience with super-computers.

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Creating a national database or a repository of shared data containing health disparities measures would potentially result in standards that could be applied broadly, allowing for comparability across domains and allowing for systematic quality improvement efforts for identified populations. For example, compiling information through a data warehouse on health disparity research and efforts undertaken by multiple organizations can facilitate usage of data by multiple enterprises and help to close gaps in the current knowledge. Trend data can be used to develop projection models, allowing more precise planning around community resource allocation.

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Big data can be leveraged by mandating implementation of the CLAS; this alone will yield invaluable data related to culture, language/English proficiency, as well as outcomes based on ethnicity, race, preferred language, geographical location, sexual orientation, disability, age, etc. In some instance, information collected by other national organization including CMS, FNS.\, CDC, etc. should also be accessed.

To facilitate the use of Big Data NIMHD should promote a national standard for coding race/ethnicity

Working with Federally Qualified Health Centers (FQHCs) and Community Health Centers (CHCs) represents a key opportunity, especially given the “meaningful use” provisions for electronic health records outlined in the Affordable Care Act and the upcoming additions of social, behavioral, and psychological domains in the electronic health record. It will be important, however, to take special consideration of community engagement and cultural awareness about the acceptance of assessing these measures and how they should be addressed.

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As the field of data analytics (and related concentrations) continues to grow, and these analytics are applied to population based databases, there is a need to invest in the development, testing and refinement of analytic and reporting tools that will inform user groups (health professionals, health care/system administrators, and policy professionals) of findings relevant to racial and ethnic minority populations (as well as for the population as a whole). A focused approach at this stage will facilitate identification of minimum data sets that would guide linkages, as well inform interdisciplinary data integration. Given the user audience, this initiative will require academic, government, private sector and community stakeholder participation.

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Consideration should be given to creating an online, publically available, integrated environmental and health data set that any investigator can use for health disparities

research. The data set should be structured to include multiple years of data, multiple spatial and temporal units, and on-line tools to effectively use it (interactive mapping and calculation of rates, crosswalks to convert data across spatial and temporal units, etc.)

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Longitudinal community and population datasets that capture multilevel phenomena relevant to health across the life course, with large samples of racial/ethnic minorities, including understudied groups such as Asian Americans, Native Hawaiian/Pacific Islanders, and American Indian/Alaskan Natives.

G. How can we apply a population health systems approach to facilitate an understanding of the etiology of health disparities?

No responses

3. What practice and policy interventions show the greatest promise to reduce and ultimately eliminate health disparities? What new knowledge is needed to inform effective interventions to address health disparities?

A. What scientific research areas are most crucial to study in order to inform pressing practice and policy questions addressing health disparities?

There currently exist many potential interventions that might reduce disparities. However, there are few data from comparative effectiveness research comparing interventions in different settings, varied populations, or alternative providers such as patient navigators and community health workers. Testing interventions in subpopulations with different genetic backgrounds may prove to have a positive effect on reducing disparities.

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Translational and outcomes-focused research in real-world settings

- Continued research on the benefits of community health workers and advisors
- Pediatrics and transitions of care, especially for chronic diseases
- Evaluation and comparison of training models, including new models identified through responses to NOT-MD-15-014

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We need to understand the pathophysiology of disparities, particularly as this applies to differences between internally defined measures affecting capacity and functioning. For example, nurse visitation during and after pregnancy seems to succeed in producing long-term in some but not all cases. Understanding the reasons for variable success will likely require a better knowledge at the physiological level.

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Finally, in my opinion, much existing intervention research is premature insofar as basic data on the etiology of health disparities (and on the generalizability of standard interventions to

poor and rural populations) are lacking. Interventions have been strongly encouraged or demanded (and grants are available for conducting them) based on the popular view that we know what there is to know about the nature and etiology of health disparities -- and so it's time to do something -- when, in fact, we by and large lack such knowledge. We are ill-equipped to be the 'fourth-generation' of health disparities research, i.e., to focus on interventions.

On the other hand however, interventions to reduce certain types of health disparities, e.g., oral health disparities, are largely lacking even though such interventions are simple and always successful, and even though oral health disparities are well-established and contribute significantly to chronic disease. Likewise, although it is clear that low-education, low-income, and unemployment contribute to health disparities, there are no mechanisms to fund interventions to provide education and employment to disparities populations. Interventions have tended to focus on improving people's behaviors instead of on improving their socioeconomic status. A new fourth-generation is needed, one that focuses on improving the socioeconomic status of disparities populations, and by so doing, addresses the heart of the matter.

B. What are promising interventions for addressing health disparities affecting populations of different ages?

Community engagement is key to evaluation science, and working with local populations at every stage – from crafting the intervention, to determining important clinical and community outcomes, to creating data collection strategies – is essential. Policy and program interventions are more likely to be oriented toward success when developed with communities who stand to benefit the most.

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Those that promote intergenerational relationship building; those that promote the health of elders.

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We stress that translational and outcomes-focused research should be a central theme of the vision. Interventions should be tailored to specific populations, and studies need to be conducted in, and designed for application in real-world settings such as outpatient clinics, prisons, and schools. Outcomes-focused research on training programs that incorporate cultural competency training, or implement technology and telemedicine training, could also identify cost-effective training modules that could be broadly disseminated. We are therefore encouraged that NIMHD has issued an additional RFI on interdisciplinary training in health disparities science.

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Anything targeting fundamental social and environmental causes of health, i.e. “upstream” determinants. General social justice and education initiatives targeting a variety of outcomes.

C. What are the periods in the life cycle, timeframes or entry points along developmental trajectories that appear most promising as targets for interventions addressing health disparities across the life course?

In utero (public health interventions aimed at pregnant families.)

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The Science Vision should also highlight how health disparities persist from pediatrics through the transition to adult care. Many young patients in the United States medical system are undocumented, have inconsistent access to healthcare, and face disparities as a result. For chronic diseases such as diabetes, the transition to adult care is particularly challenging, and taking ethnicity into account adds complexity.

Children's exposure to worsening socioeconomic and social conditions from fetal life through adolescence could alter the trajectory of their health, making them more likely to be vulnerable to health disparities later in life. Cumulative burden of multiple risk factors early in life may limit the effectiveness of later interventions and treatments, thereby making it unlikely to completely reverse the neurobiological and health consequences of growing up in stressful circumstances.

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Personally I am most convinced by work to support pregnant women and their families (and networks) to provide a secure and enriching environment to enable the child to thrive during gestational development and early years. I think so much of the latter health and human potential is easily created or destroyed in those early years, to merit a particular focus. So exploring the policy options to support and enable families to offer as nurturing an environment as possible in early years would strike me as being the best possible investment for research and policy.

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The consequences of inequality for the health and well-being of individuals has been long established and should remain a prominent focus for health disparities research by the NIH. The life-span developmental (LSD) perspective is a particular framework that describes the relationship between social status and health. This perspective emphasizes the need to better understand the role of inequalities in health and disease across the entire life span (e.g., gestation, childhood, adolescence, young adulthood, midlife, and elder age), including life-course factors linked to social status and health (Kuh et al, 2003; Link & Phelan, 1995). Additionally, accepting the premise that the sequence and dynamics of events, transitions, and trajectories (e.g., such as entering and leaving school, acquiring a full-time job, or marrying for the first time) that take place within specific phases of life have consequences on health is an important principle of the LSD perspective (Alwin and Wray, 2005). As a result, we submit that the lives and experiences of youth (13-17 years) and young adults (18-25 years) must become priority populations for health disparities investigators and are key periods within the life-span for intervention. Moreover, the inclusion of young people assists to diversify study populations within the NIH research enterprise. See references:

Alwin DF, Wray LA. A life-span developmental perspective on social status and health. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 2005; 60(Special Issue 2):S7-S14.

Kuh D, Ben-Shlomo Y, Lynch J, Hallqvist J, Power C. Life course epidemiology. *Journal of epidemiology and community health* 2003; 57(10):778.

Link BG, Phelan J. Social conditions as fundamental causes of disease. *Journal of health and social behavior* 1995; 35:80-94.

The prenatal period is also crucial for women's mental health and health of the infant. Many women do not seek prenatal care because they are depressed. Additionally, the period after childbirth is a crucial period in the life course for mothers' mental health as the prevalence of mental health disorders is high (e.g. 15% for postpartum depression) and psychiatric hospitalization is much higher than other periods in a woman's lifecycle. Moreover, mothers' mental health disorders in the period after childbirth have negative effects on their children's emotional and cognitive development and may sometimes lead to infanticide. Research has found racial/ethnic disparities in mental health disorders among postpartum mothers but scarce research has examined the factors that explain these disparities.

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First, start with preschoolers, teach age appropriate health management and understanding of the impact of where they live, learn, work, and play, on their health. Secondly, target pregnant women, adults, aged, and end of life decisions and care.

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Early childhood education, and continuity of both education and access to care across the life course! Good nutrition provided in schools and access to healthy foods in homes/communities.

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As NIMHD develops its own funding strategies and portfolio, we would like to emphasize the extensive body of research documenting that many adult health disparities begin in utero and throughout the pediatric period (0-21 year olds). We therefore recommend that the NIMHD prioritize strategies that support research that seeks to better understand:

- a. The timing and effectiveness of interventions to reduce disparities across life stages ranging from preconception, to childhood and including adolescence.
- b. How pediatric health or healthcare outcomes can be more proximally measured (e.g., milestone achievement, biomarkers of future health potential) or treated (e.g., adverse experiences) across disparate racial/ethnic and socioeconomic groups.
- c. How to prevent or reduce risks that contribute to disparities, or to eliminate disparities when they emerge during childhood or adolescence.

D. How can community-based studies maximize rigor without losing community acceptance? How can communities and other relevant stakeholders be involved in the design of interventions to ensure acceptability and eventual implementation of successful interventions?

Community-placed researchers & investment in their relationship-building with community partners (over years) so that they may truly listen to community needs and the community may build trust in their understanding; community-based researcher training that promotes self-knowledge & cultural 'safety' as well as academic skill-building.

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Building a strong continuum of care within the community is consistent with a recent paradigm shift in the field that recognizes the limits of a treatment model involving repeated episodes of acute care and the need for a chronic care model focused on long-term recovery management (188, 189). Socially disadvantaged and stigmatized groups are as a whole especially likely to benefit from neighborhood-based delivery of services and community-based recovery support systems (190), since these groups can be reluctant to seek services in traditional venues and since their problems can be especially persistent. Broadly, involving community members and stakeholders in research and prevention and intervention programs will be critical to ensuring that studies and programs are well-designed to meet the needs of all populations in the U.S., including disadvantaged groups at greatest risk for health problems.

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First, find communities that are succeeding. Some of these may not even know how good they are. Engage the members of successful communities and establish mechanisms for peer-to-peer communication between those folks and members of failing communities. Find failing communities and leaders who are willing and able to listen to their successful peers. Assure scientific evaluation of interventions developed from such peer-to-peer interactions.

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We strongly encourage efforts to educate and engage communities in the scientific process and to educate and engage scientists about the community processes. Novel approaches are needed and funding for those approaches will be necessary. For example, helping to establish science oriented research centers in underserved and/or socially isolated areas would prompt exchanges between scientists and community members which in turn would help to educate youth and allow scientists to become engaged in the life of the communities. This network science approach can help better understand how persons interact in their communities in regard to health behaviors, receptivity to change and the implementation of community based interventions. Social network analysis tools could be developed to identify how health information is understood, disseminated and acted upon in disparities communities. Also, multimodal community-based interventions that target common risk factors (e.g. childhood obesity risk factors overlap with dental caries risk factors) need to be developed and tested.

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Use the community based participatory research approach; research does not make a difference if it is not relevant for the community. Also, identify and enlist the help of community “influencers” to ensure adherence to meaningful research standards that will enjoy community acceptance. Community involvement, community participatory research, collective impact, and greater use of health equity impact assessments. Please refer to the work of Kien S. Lee, PhD and Chau Trinh-Shevrin, PhD.

E. What approaches are needed to produce scientifically sound evidence that can be used to inform effective policy?

Seek evidence of partnership vs. paternalism. First, require “equity” in the research process. Researchers and methodologies should clearly demonstrate equitable partnership with communities of interest. How is “power/decision making” and “resources/money being shared among partners?

Walk the Talk in the application, funding and implementation processes. If the research process is not “equitable”, what confidence will communities of interest have that the methodology will be “equitable” or “effective”.

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We would like to express our support for multi-level approaches to health disparities research. Understanding and advancing the science of health disparities will require understanding and intervening at the individual, family, social, organizational, community and policy levels. Furthermore, we believe that models for best integrating these levels to reduce disparities need to be developed and researched. There is little research that has been conducted on how to integrate interventions into multiple levels. We recommend that such research be a funding interest of NIMHD.

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In short, we believe there are many areas of high priority for research funding. Attention to these areas and resources will be critical to addressing alcohol-related disparities. We would like to emphasize the need for continuing research especially on national and community samples: Monitoring and addressing disparities cannot be accomplished with (for example) animal and college student studies because disparities are so tightly linked to the broader social conditions that produce them, and because a lifespan framework is needed to fully appreciate the nature and extent of disparities (such as, for example, health disparities emerging later in life). Prevention efforts must likewise be multi-pronged and involve entire communities rather than select populations, such as college student populations and primary care populations, because (as argued above) selectively targeting traditional venues for intervention could enhance rather than reduce disparities. Similarly, involving entire communities in providing ongoing, integrated systems of care for those with alcohol problems stands to improve outcomes for all in addition to reducing disparities.

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There is already a good deal of science that ought to be informing effective policy. For example, it is established that primary seat belt laws save lives and that those most likely to be hurt by secondary seat belt laws are members of minority populations like Hispanics and

blacks/African Americans. Still, 17 states do not have primary laws. Another example relates to laws permitting exposure of migrant farm workers to conditions that would be illegal for US soldiers. Many other examples exist. Unfortunately, the so-called “anti-lobbying law places severe restraints on the ability of federally supported scientists to inform legislators. However, if federally supported researchers need to engage community members to conduct research, why is it taboo for those same researchers to support community-based efforts to pass laws and implement policies based on that research? It would seem that while nominally intended to protect the people from lobbyists, anti-lobbying law may actually protect lobbyists from the people.

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Need to insure that translatability of interventions is included.

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1) Establish new standards for interventional research to eliminate health disparities, such that each study contributes to a cumulative body of evidence that has utility beyond the community with whom the study was conducted.

a. Mechanistic research: Experts in the field have suggested that designing intervention studies to test causal mechanisms is one powerful tool to develop such a cumulative science of behavior change. The Common Fund’s Science of Behavior Change program promotes such an approach, developing the tools necessary to apply a mechanistic approach across a wide range of health behaviors and IC missions.

b. Ensuring rigor: The trans-NIH Behavior Change Consortium developed specific recommendations for the rigorous conduct of behavioral and social intervention research. Among those recommendations was the inclusion of treatment fidelity monitoring in intervention trials (see Bellg et al., 2004). Quoting from their recommendations, “Funding agencies, reviewers, and journal editors are encouraged to make treatment fidelity a standard part of the conduct and evaluation of health behavior intervention research.”

c. Study algorithms for precision interventions: A workshop convened by the NIDCR solicited recommendations for future directions in health disparities research. A multi-disciplinary group of workshop participants recommended that health disparities research expand its work testing tailored interventions for specific communities to work testing how to tailor algorithms. By understanding what works for whom under which circumstances—i.e., tailoring algorithms—research produces powerful tools to address the behavioral and social needs of a broad range of communities.

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As NIMHD advises the NIH science vision for health disparities, we urge it to prioritize health services and systems research as a crucial component in the continuum of health research. In particular, we believe that the body of work being generated by Community Engaged Research, including Community-Based Participatory Research (CBPR), as promoted by the NIH Office of Behavioral and Social Sciences Research (OBSSR) and many other NIH components, is an extremely valuable way to produce evidence that can be applied directly to improve population health and reduce disparities. This highly collaborative approach

provides a best practice for engaging partners with different expertise and areas of interest to identify shared problems that can be addressed by developing actionable solutions that all parties can agree to.

4. What are the dissemination and implementation science approaches that will lead to effective practice and sustained policy intervention to reduce and eventually eliminate health disparities?

A. *What criteria should be used to determine whether a health disparities intervention is ready for dissemination and implementation? Can we develop systematic approaches for assessing “Implementation Readiness” of biomedical knowledge and interventions?*

We need to recognize the limitations of evidence-based interventions. There has been too much attention placed on implementing evidence-based interventions with fidelity and not enough attention to adapting interventions to the unique social, cultural and environmental characteristics of the affected communities.

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Many stakeholder groups are invested in health equity research. Researchers, communities, health system administrators, public health agencies, local and state legislators, patients and others care deeply about determining which programs and policies are effective at minimizing or eradicating inequities in health and health care. However, the metrics that matter to these groups differ: while communities might care most about population health outcomes, health systems might value system efficiencies while legislators focus on neighborhood economic impacts. Assuring that health equity-focused evaluation science incorporates outcomes salient for multiple groups is a first step. Disseminating pertinent outcome information to those groups in effective ways is the second.

AAMC urges NIH and NIMHD to engage a large number of diverse stakeholder groups to determine how to communicate the results of health equity research in ways that increase the likelihood of adoption and implementation of evidence based strategies.

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Monitor the research process to ensure that it passes the test for diversity and cultural competence in design, etc.

Ensure that models used reflect the input of diverse stakeholders and “tested models” should evidence the concerns and priorities of diverse populations, especially those disproportionately impacted by health disparities.

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This is not an easy answer. However, the degree of enthusiasm from the community for particular interventions goes a long way toward informing how to proceed.

B. *How do we ensure that interventions are tailored to the needs of various health disparity populations, while maintaining adequate fidelity of the intervention to a tested model?*

Create and fund mechanisms to solicit community feedback/review/critique of interventions.

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To ensure that interventions are tailored to the needs of various health disparity populations, we suggest the blend of the cultural adaptation and implementation science fields with the goal of understanding both the transformation of the context and strategies that aim to facilitate the uptake of the intervention while also adapting the intervention (Cabassa & Baumann, 2013)

C. *What novel business models can be used to inform health disparities intervention development, implementation (including quality improvement to achieve sustainability and reproducibility), and dissemination?*

The committed partnerships between stakeholders are the key to engage patients in their own health and health care. Public health leadership will be needed to encourage and sustain the partnerships among various stakeholders. Such leadership should be able to establish long-term relationships with community residents, assume more responsibilities for underserved populations, and commit to promote population health. Local health departments, for example, have the potential to lead the implementations to encourage patient engagement, since within their charge to perform the essential public health services they should: “inform, educate, and empower people about health issues, develop policies and plans that support individual and community health efforts, enforce laws and regulations that protect health and ensure safety, link people with needed personal health services and ensure the provision of health care otherwise unavailable.” (Handler, Issel, & Turnock, 2001).

In addition to local health departments, federally qualified health centers (FQHCs) (Centers for Medicare & Medicaid Services, 2015) also have the mission to provide comprehensive health care services for vulnerable populations. More research will be needed to further explore the roles of local health departments and FQHCs in integrated health care system.

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The community health business model/ community organization model should be employed

D. *How can we effectively disseminate scientific findings to communities, policymakers and other stakeholders?*

I believe that participatory methods such as community based participatory research (CBPR), action research and positive deviance should be encouraged more in health disparities research. Community members are often the subjects of research but after the conclusion of said research, have not learned the results nor the future steps researchers will take to address health disparities. It should be a requirement that researchers make presentations to the community at the conclusion of their projects to increase local dissemination and encourage partnerships to continue their work beyond funding. I think service-learning is another way to create community partnerships that can lead to participatory research on health disparities, and have more sustainability.

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NIH might consider including a 'Dissemination Strategy' section in their RFPs to ensure that investigators consider their audiences and the outcomes - as well as the communication channels - that matter for those audiences. NIH might also engage PCORI to understand how its AHRQ-assisted dissemination strategy has increased communication and adoption of research findings.

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If communities are involved in the process, there will be support and a buy-in prior to dissemination of the results.

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Evidence shows that dissemination strategies, including messaging, need to be targeted to their audience to be effective.

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Develop strategies to increase adoption of EBPs in health care settings that serve racial and ethnic communities.

Current science advances that are of the most or least value to the health disparities research community (including basic, biomedical, behavioral, clinical and translational science, population health, health services and science of community engagement); and any promising scientific disciplines that will be needed to support the evolving science.

(a) Reducing the Racial Achievement Gap: A Social-Psychological Intervention
Geoffrey L. Cohen, Julio Garcia, Nancy Apfel, Allison Master. SCIENCE VOL 313 1
SEPTEMBER 2006 1307

(b) Amartya Sen's concepts of capacities and functionings

LEAST VALUABLE:

I sincerely doubt that research based on developing sixth grade level educational materials will do much good. I do not think that defects in literacy and/or numeracy, for example, prevent people from knowing the difference in food value between healthy vegetables and fried chicken.

NEEDED DISCIPLINES

Psychology; Cultural Anthropology; Epigenetics/pathophysiology of poverty; Computer science (supercomputer algorithms and capacity to use them); less biostatistics and more epidemiology; more clinical training for PhD's.

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To help inform the process of development of a vision for health disparities research in the next decade, please consider the following current scientific advances in the following fields:

1) Advances of most value to the health disparities research community and promising scientific disciplines needed to support further research:

Of value in the study of health disparities amongst pediatric patients with renal disease is the utilization of collaborative, multicenter studies designed specifically to investigate the impact of social determinants of health, environmental factors, and genetic differences between populations.

Specifically, large cohort studies, using data from NAPRTCS and USRDS, have enabled us to identify the differences seen in access to dialysis and transplant between health disparate populations

The multicenter Chronic Kidney Disease in Children (CKiD) study demonstrated racial differences in hemoglobin (Atkinson et. al.) These types of studies are crucial to improve understanding of modifiable vs. non-modifiable factors that lead to disparate health outcomes among different groups. There is current NIDDK-supported research to examine how geospatial analysis can better characterize where patients live and where they receive care, but broader studies are needed to truly understand the interplay of one's social environment, healthcare setting and access to optimal care.

Recognition of the prevalence of APOL1 alleles amongst African Americans in the FSGS Clinical Trial (Kopp et al., 2015) has led to mounting evidence of their risk association with renal disease in this health disparate population. More large population studies are necessary to understand fully the implications of genetics such as this one in health disparate groups, and the inclusion of children in such samples should be prioritized.

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Health literacy as a scientific discipline is an essential complement to this research.

We submit that there should be a priority placed on research focused on intervention trials and action (3rd and 4th generation public health research). The field has already progressed past research that seeks to simply document disparities or explore reasons behind them (1st and 2nd generation research). For example, please see the following website as an example of research and response to the growing oral health care crisis:

<http://sph.umd.edu/center/che/mid-maryland-mission-mercy-mom>

Also see the following reference:

Thomas SB, Quinn SC, Butler J, Fryer CS, Garza MA. Toward a fourth generation of disparities research to achieve health equity. Annual review of public health 2011; 32:399.

Additionally, clarifying translational research to include community-engaged research; not just "bench to bedside" or drug discovery research is paramount

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The most important may be the behavioral, clinical and translational science, population health, health services and science of community engagement to really implement health disparity research and solutions. It will be necessary to engage nursing, nutrition, public health, education, counseling, and social work as they are the major community involved professionals and researchers. Of course methodologists and economists that can cross settings, conditions, and levels of intervention or translation would be important.

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With few exceptions academic partners are not good at engaging community in long term partnerships which are needed to address health disparities, mostly because the carrots and sticks in academia do not value it. The add on of a community advisory board that meets a couple of times a year to a research project is not likely to have much impact on the conceptualization, implementation, translation, or dissemination of the research. It may actually work better to fund community partners to partner with academic partners to translate, disseminate and implement health disparities research. Community partners are more likely to be committed over the long haul to promoting a reduction in health disparities, unlike academic investigators whose first priority often is to supporting their salary, regardless of the source of funds.

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Greater involvement of community members and stakeholders in research. Health disparities research requires the voices and life experiences of the research study population, whether racial/ethnic minorities or socially disadvantaged groups (including women, youth, and low socioeconomic status individuals). While research often involves these groups in a passive way (i.e., as subjects), we believe that these populations should have an active voice at the research table. We call for more participatory studies that involve “equitable engagement of all partners throughout the research process, from problem definition through data collection and analysis to the dissemination and use of findings” (186, 187). Other institutions (e.g., the Patient-Centered Outcomes Research Institute, the Office of National Control Drug Policy’s Drug-Free Communities program) already encourage participatory approaches. We recommend that NIH-funded research now emphasize “equitable engagement” and maximize the expertise of all partners, including researchers, study populations (in particular, those who have experienced or been affected by alcohol-related problems) treatment and healthcare providers, alcohol retailers and other businesses involved with alcohol access/availability, and policy makers. We also encourage NIH to continue existing community-based participatory research (CBPR) program announcements, such as PAR-05-026, as well as to include participatory research strategies in NIH-funded research. Finally, we envision the NIH taking a participatory approach when establishing research priorities, evaluating grant proposals, and making funding decisions on health disparities research, since involving community members and stakeholders will make the research most relevant to the disparities populations under study.

Current Science Advances- health and policy professionals

A broad approach that integrates patient data, with genomic and environmental data is most likely to generate research findings with implications for clinical and public health practice

and public policy. In addition, computational analysis, mathematical and statistical modeling, and GIS are tools that need to be integrated into health disparities research. Support for transdisciplinary team science also is greatly needed.

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Important to target largest groups and most at risk groups for impact and importance. We may not be able to cover all conditions or all populations at one time. Comparison research may hold good promise rather than just individual populations in studies. It would be important to consider how we deal with immigrant health (and culture) as the discussion and numbers now impact much of the safety net. May be time to decrease the traditional longitudinal studies for all conditions and try to see if we can make changes in outcomes and behavior for 2 years rather than 4 at least initially. Some of the drug trials may be of use long term, but is there a mechanism to speed these for more current application and translation?

Appendix B: Research Recommendations

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- I. What role do different cultural practices (such as particular food traditions or healthcare routines) play in cancer risk?
- II. What behavioral factors contribute to cancer risk, and are these behavioral factors different for specific populations?
- III. What are the differences in quality of care and health outcomes between Medicaid, Medicare, and private insurance patients? What are the quality of care and health outcome differences between managed care Medicaid and state-run Medicaid programs?
- IV. What does a “culture of health” look like, specific to individual cultures?
- V. What is the impact of racial discrimination as it relates to stress and cancer?
- VI. What role does literacy/health literacy play in cancer health disparities?
- VII. What role does the digital divide play in literacy/health literacy and cancer health disparities?
- VIII. What are the institutional factors and organizational practices that play a role in health disparities? For example, how does health care financing mitigate or worsen access to quality health care and, ultimately, health outcome disparities?
- IX. What is the link between lifetime levels of access to care and the risk for a cancer diagnosis?

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I might then want to explore what additional factors contribute to further disadvantage particular groups, such as race and the clustering of disadvantage in a neighborhood.

In addition I would want to explore whether there are protective factors which appear to protect particular groups, or individuals from the harm others experience from the social determinants of health across the income gradient.

Personally, and I am not mainstream in this thought yet, I would explore the implications of personal (and unmanageable) debt on health inequalities. I think ‘indebtedness’ is the forgotten additional dimension of ‘poverty’.

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There needs to be more emphasis on studying populations where socio-economic barriers have been overcome. Studying failing communities may tell researchers about the social, ecological, environmental and behavioral pathways leading to disparities, but such studies will not necessarily provide guidance about the kinds of activities needed to eliminate those disparities.

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More research is needed on risk factors but especially more on protective factors, with additional knowledge about the health protective factors that are associated with culture of origin.

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Knowledge also needs to be expanded about the social determinants of health to include cultural determinants of health, such as acculturation and acculturation stress.

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How do social determinants of health contribute to disparities in access and outcomes amongst children with chronic kidney disease, kidney transplants and on dialysis?

How do poor educational attainment, health literacy, and health numeracy affect the development of disparities amongst families of children with pediatric kidney disease?

How do biological factors and epigenetics contribute to differences in health outcomes for children with kidney disease?

What is the role of population-specific genetic patterns (e.g. over-representation of APOL1 gene expression in African Americans and Hispanics with kidney disease) in the development of health disparities?

What is the role of, and the degree to which, co-morbid chronic conditions (e.g. diabetes, hypertension, and obesity) contribute to disparities seen in pediatric chronic kidney disease?

What can be done to increase recruitment of under-represented and health disparate populations into pediatric research studies to facilitate appropriately powered studies that are able to identify patterns of genetic and epigenetic susceptibility to kidney disease?

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NIMHD should lead the NIH in revitalizing the RFA Understanding and Promoting Health Literacy

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Could epigenetic changes serve as a measure (biomarkers) of cumulative health impacts of multiple environmental and social stressors? How practical would that be?

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There is little research funding focused on disparities in infectious diseases and how existing disparities will place those populations at greater risk during a public health emergency, such as a pandemic or bioterrorist attack.

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Develop calls for research and health disparities that require an understanding of the biological and sociocultural foundational dynamics producing lowered health status in health disparity populations.

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Future research should focus on identifying the specific mechanism by which social and cultural factors contribute to health disparities.

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Understanding Subgroup Differences in Health Disparity in Asian/Chinese

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Social context as a determinant of health. We need more research is about urban versus rural settings, small towns versus mid-size towns, and migration experiences. This research is relevant for many ethnic and racial minority groups such as African Americans, American Indians, and Latinos.

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I. Has the Patient Protection and Affordable Care Act (ACA) had a measurable impact on the cancer health disparities faced by underserved and vulnerable communities? How so?

II. How does variability in Medicaid coverage and benefits by state impact access to specific health care services? How does access variability relate to disparate health outcomes?

III. For expansion states, has expanded Medicaid had a measurable impact on the cancer health disparities faced by underserved and vulnerable communities?

IV. Have the states that did not expand Medicaid seen even higher health disparities and poorer health outcomes than prior to the passage of the ACA?

V. What should bundled payments or other payment structures look like for oncology care given the move to value-based medicine? What services and factors should be incentives and requirements for provider payment?

VI. How can cross-disciplinary researchers come together to leverage systems science methodologies to reduce health disparities?

VII. By what standards should oncologists abide to ensure equitable, patient-centered care?

VIII. What standards should be required of clinical pathway programs to ensure scientific rigor and transparency? Do clinical pathway programs improve health outcomes and mitigate disparities and to what extent?

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Despite the fact that oral health disparities generate and perpetuate significant differences in the overall health status of many different groups, oral health care remains largely overlooked. Research into the underlying factors that continue to drive these disparities will allow our nation to better assess and address the complex and multifaceted nature of oral disease and conditions. By specifically including oral health in the NIMHD's scientific vision, we can fill significant gaps in current research that prevent translational efforts from realizing their full potential to contribute to the public's health

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These are diseases and conditions our Community Advisory Board identified as priorities:

- Diabetes
- Obesity
- Depression & suicide
- Drug & alcohol prevention
- Sexual health

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I. What practices help cancer clinical trials more successfully enroll minority populations?

II. What value do patient navigators bring to cancer patients, healthcare providers, payers, and other stakeholders in mitigating health disparities?

III. Why do individuals who have access to certain preventive measures (such as immunizations) not utilize them? How can uptake and coverage be improved to reduce outcome disparities?

IV. In locations which offer robust options to access care, why do health disparities persist among different populations?

V. What role do interdisciplinary teams play in the reduction of health disparities?

VI. Can culturally-appropriate communications training for healthcare professionals mitigate health disparities? To what extent?

VII. In light of the Precision Medicine Initiative, how should personalized, patient-centered medicine take health disparities into consideration?

VIII. How can team science from multi-disciplinary areas, particularly basic science and clinical research, help address cancer health disparities?

IX. How can we use publically accessible large databases to address cancer health disparities?

X. How can we facilitate translational research for clinicians and basic scientists to go from bench to bedside and back to address diversity and cancer health equity?

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We need more research on the prognosis and customizing treatment because even when controlling for the stage of diagnosis African Americans have a poorer prognosis and higher mortality.

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How do effective interventions need to be adapted or tailored to meet the needs of individuals who are racial and ethnic minorities?

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We believe that additional research is needed in the area of individual and community resilience. While much research has focused on the causes of disparities, we have yet to understand how people are able to be healthy in toxic environments.

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How can the health care disparities research community be better positioned to help address gaps in knowledge of implementation and dissemination science?

What efforts can be made to partner with at-risk and health disparate populations (e.g. parent groups, adolescents, and ethnically diverse dialysis and transplant recipients) to implement effective interventions and disseminate research findings?

How can researchers partner with community leaders (i.e. church leaders, local governments) to apply effective interventions and disseminate research findings?

To what degree are poor health literacy and educational attainment obstacles to implementing and disseminating science among health disparate children and families with kidney disease?

What role can social media and mobile technology play in connecting providers with patients and families, and connecting patients and families with one another?

How can the local, state, and federal advocacy efforts of the pediatric kidney community be leveraged to disseminate findings of health disparity research to both policymakers and affected populations?

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What implementation strategies are feasible, effective, and sustainable in low-resource settings to help move evidence-based treatments from research settings to real world health delivery sites?

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What are the root causes of health disparities, including modifiable features of clinical care that can be altered through discoveries from D&I research?

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How can changes associated with the Affordable Care Act, specifically those related to integrated behavioral healthcare, be most efficiently and effectively implemented into primary health care, specifically Federally Qualified Health Centers (FQHCs)?

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Studies are needed that examine organizational capacity to integrate and deliver evidence-based practices.

Studies are needed that will yield discoveries about how to prepare the intervention and the service delivery context for the successful implementation of an intervention or policy, how to promote their large scale impact and sustainability and how to de-implement interventions or policies that are not effective. Implementation science extends the efficacy and effectiveness research by identifying, testing, and reporting effective implementation strategies.

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What methods of provider training and supervision are effective in equipping physicians, psychiatrists, social workers, nurses, and allied health personnel to delivery high quality and culturally competent care to racial and ethnic clients and low-income families and communities?

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How can under-resourced settings sustain improvements to health delivery over time? Implementation science seeks to understand the organizational, community, leadership, and financial factors associated with capacity to sustain high quality care over time. Researchers need to identify the most effective ways of conducting research in under-resourced organizations and communities to ensure continued benefit from both the research and its products.

Explicit documentation and study of the implementation process. In recent literature reviews, we have found that few published studies report the frameworks selected to guide the implementation process, few implementation outcomes are being measured and very few implementation strategies are being tested. Implementation strategies, defined as a “systematic intervention process to adopt and integrate evidence-based health innovations into usual care”, require study in terms of their impacts on implementation outcomes as details of their mechanisms of impact.

Test novel research designs including hybrid implementation-effectiveness designs.

Robust measurement of carefully conceptualized implementation process and outcomes, to reflect stakeholder adoption, sustained delivery and penetration of evidence-based care throughout delivery systems

Team science, specifically research teams that include health services, policy, and implementation science expertise. Implementation research is best conducted by teams bringing expertise in such areas as treatment development and testing, health economics, clinical epidemiologists, decision-making researchers, industrial and organizational psychologists

Leveraging and examining effective features of community-research partnerships A variety of types of partnerships are needed, to evaluate which types of service system partnerships are effective in reducing health disparities, and how are they best formed and sustained over time. These studies need to be conducted in the types of settings that reach, and therefore have potential to extend evidence-based care to low income individuals and those from racial and ethnic minorities, such as: primary care, specialty behavioral health (psychiatry and social work); social service sectors, particularly those addressing income support, housing, and child welfare; the criminal justice system; and community groups such as churches and peer run organizations.

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We would like to emphasize the need for continuing funding of work on disparities related to alcohol. Alcohol is the third leading cause of preventable death in the U.S. (1), and accounts for an estimated \$223.5 billion in economic costs to the U.S. (as of 2006), about \$1.90 per drink sold (2). Further, there are striking disparities in alcohol use, alcohol-related problems, and utilization of alcohol treatment by race/ethnicity, socioeconomic status, and sexual orientation.

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As NIH and NIMHD works to address the issues of health disparities, I recommend that attention be focused on:

- 1) The GENDER issues impacting the experience of and exacerbation of health inequities;
- 2) The needs to consider theory, intervention, and practice issues that impact on the access and use of PREVENTIVE health approaches across racial, gender, sexual orientation and able groups;
- 3) Consideration of how the recent ACA legislation in concert with existing health offerings impact the experience of health inequities; and
- 4) Identifying and addressing the contextual factors that impact on the exacerbation of health inequities across specific groups (e.g., child welfare involved families, families with experience of domestic violence and sexual assault, etc.)

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Please make sure that cultural research – work on acculturation, discrimination, other cultural stressors, ethnic identity and other cultural assets, and influences on family functioning in immigrant and minority communities – is sustained and supported. In my own work, I am finding that cultural stressors and assets contribute strongly to risk and protection

for health-related behaviors among immigrants and minority group members, and that this work has critical implications for intervention.

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More research needs to be done to identify the barriers within the research community limiting minority participation, and strategies for increasing minority participation in clinical trials. Medical advancements occur through clinical research, thus, minority health outcomes will not improve if these groups are not appropriately represented in clinical research. Additionally, we urge more support provided to institutions that have strong connections to minority communities.

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That some attention be given to qualitatively advancing and improving healthcare service and delivery within the US juvenile Justice sector.

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Population ethnic groups especially from South East Asia (from the Indian sub-continent including countries from India, Pakistan, Bangladesh, Sri Lanka, Nepal etc.) are rapidly growing communities in the US and are genetically predisposed to metabolic conditions and related diseases. These populations remain understudies and are grossly underrepresented in clinical trials.

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For NIMHD and NIH to remain global leaders in addressing health disparities, we propose that the NIH science vision must support research to examine two critical research questions. First, intervening on diet to improve health and minimize diet-related inequalities requires examination of the causes of food and beverage purchases and consumption, and thus requires better understanding of our food system and how it is changing. Second, and of equal importance, there is a great need to understand how the food environment and purchasing behaviors can be modified by regulatory and voluntary initiatives in order to minimize diet-related disparities, and the development of innovative approaches for evaluating these interventions are valuable to policy professionals to leverage this knowledge into effective policy.

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We believe that additional research is needed in the area of individual and community resilience. While much research has focused on the causes of disparities, we have yet to understand how people are able to be healthy in toxic environments. This concept of resilience is critical and more research is needed. Likewise, we urgently need a better understanding of how racism shapes health and interacts with other environmental and biologic factors.

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Research Need 1. Research addressing the extent of alcohol-related racial/ethnic health disparities and mechanisms that may contribute to the same, toward informing the most relevant health outcomes and points of intervention.

Research Need 2. Research describing the full spectrum of harms to others that result from alcohol consumption and how and why these may vary across racial/ethnic and socioeconomic groups.

Research Need 3. Research to identify appropriate health screening and brief intervention methods among racial/ethnic minority and uninsured populations.

Research Need 4. Research identifying factors explaining disparities in utilization of alcohol treatment and related support services.

Research Need 5. Research examining the differential efficacy of behavioral interventions and other support services for alcohol dependence among racial/ethnic minority groups.

Research Need 6. Research exploring the differential impacts of specific policies found to limit alcohol consumption in the general population (e.g., increased taxation, reduced alcohol outlet density) among specific minority subgroups.

Research Need 7. Research examining which neighborhood and community characteristics put people at risk for alcohol-related problems and how these factors contribute to disparities.

Research Need 8. Continuing research to monitor disparities in alcohol use and related problems as they evolve over time.

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As NIMHD develops its funding strategies and research portfolio, we would like to emphasize the importance of research on pediatric health disparities. Based on our collective experiences across different sectors, we propose two areas for focus. As a first priority, future research must recognize that the health of an individual child occurs within the context of a family and social networks that may influence health outcomes or be influenced by scientific interventions. We therefore recommend that the NIMHD prioritize strategies that support research that seeks to better understand.

As a second priority, the availability of data across sectors represents an extraordinary opportunity for understanding and addressing health disparities. However, use of such data requires novel research questions and analyses. Data silos across and within industries present enormous challenges. Combining clinical data with other sources such as geospatial data or community economic data requires skill and resources.

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1. How can we study and improve patient-provider communication by teaching providers to deliver culturally dexterous care, and measure its impact on elimination of surgical disparities?

2. How can engagement and community outreach – including the use of technology – optimize patient education, health literacy and shared decision-making in a culturally relevant way? How can these techniques be disseminated and evaluated in order to reduce disparities?

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Focus on our food system, related to where and what Americans buy and eat, and how natural experiments can be used to identify optimal strategies for reducing diet-related disparities in health.

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Despite the dearth of information on many health disparity issues, much of prior and current research focuses on Asian as a whole. While many know that there are subgroup differences among Asian: Indian, Chinese, Japanese, Korean and etc. This is not enough.

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Understanding broader contextual cultural specific issues within health disparity research.

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Intergenerational Issues and Studying Household Level instead of Individual Level:

Much of the health disparity research has been focused on individual and disease level. While it is important, it largely ignores the inter-connectedness of health disparity across individuals, family members and generations.

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Biological Differences in Health Disparity:

We assume that any given drug will work on white, black, Latino and Chinese equally, despite the paucity of evidence to do so. Across cultures, there are great differences in genetic predisposition, diet, environment and etc. For example, the studies of alcohol and CVD, where there is not a linear relationship. Too little or too much may not be good for one's health, but the right dosage effect is difficult to determine.

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Intervention in Specific Racial Subgroups:

While there are many interventions that have proven to be effectiveness for minority populations, it remain unclear if they can be culturally and linguistically appropriately translated and implemented into other minority groups.

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Technological change can be a transformative agent in healthcare. However, uptake and access to new technologies may introduce new disparities or worsen existing disparities. As the pace of technological change accelerates globally, new technologies such as electronic medical records will need to include ethnicity-specific templates to help physicians recommend and deliver patient-focused interventions that consider cultural differences and environmental barriers. It will be critical to conduct research to understand why new technologies are more or less effective, and what commonalities enable successful implementation and dissemination of effective technology.

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For financial reasons or time constraints, underserved populations may not have access to centers of excellence with expertise in a specific condition. It will therefore be important to support research to evaluate access by underserved populations to specialty centers, and assess infrastructure models that enable highly-trained physicians to practice in these communities. For example, NIH-funded research could identify unexplored opportunities in telemedicine or models of distributed learning and care, such as training in unconscious bias

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Repeated, national survey studies with strong measurement of alcohol consumption and the full range of alcohol-related harms. Systematic surveys of both drinkers and non-drinkers are critically needed to identify factors placing special populations and subgroups at elevated risk of alcohol-related problems

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I believe that people involved in the criminal justice system are an important focus population for health disparities research. This includes not only those who are incarcerated, but the much larger number of people who are on community supervision (probation and parole). The confluence of factors related to criminal justice involvement (poverty, racism, substance use, mental illness) reflect some of the key etiological elements of health disparities in the United States today. Importantly, there is strong potential to intervene in health disparities with this population at the individual and structural levels, through their involvement in the criminal justice system.

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Include examining the effect exposure to violence on developmental outcomes of minority communities

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Encourage comprehensive multilevel studies on how the SDOH act on multiple levels (e.g., neighborhoods, policies) to understand their contributions to disparities, as well as the effect and mechanisms of interventions designed to enhance cultural competence.

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Generation of patient-derived xenograft models of cancer using samples obtained from minority patients

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I would like to see NIMHD embrace health literacy in its portfolio. Right now health literacy lives nowhere, and it contributes to racial and ethnic health disparities. Additional content can be provided if there is interest.

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The study of the intersection of racial and ethnic disparities and disability disparities is crucial to study in order to inform pressing practice and policy questions addressing health disparities.

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Significantly enhance research focused on the prevention of male suicide.

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Tie research with access to quality healthcare to assess whether access is changing some of the health concerns of minority populations. Perhaps some of the questions can address measures for racism and discrimination in relation to stress and health outcomes across the lifespan. This is a biological as well as social concern and should expand both fields.

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Disability based health disparities