

National Institute of Diabetes and Digestive and Kidney
Diseases

Pathways to Health for All

Report to the NIDDK Advisory Council from the
Working Group on Health Disparities and Health
Equity Research

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Executive Summary

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Report to the Advisory Council from the Working Group on Health Disparities and Health Equity Research presents recommendations for high-impact opportunities and equity-focused principles to advance the Institute's mission. These recommendations complement the NIDDK [Strategic Plan for Research](#) to *pursue pathways to health for all*.

NIDDK conducts and supports research to improve health and quality of life for people with diabetes and other endocrine and metabolic disorders; liver, intestinal, and other digestive diseases; obesity; nutritional disorders; and kidney, urologic, and hematologic diseases. Many of these diseases and conditions disproportionately affect racial and ethnic minority populations and others who are medically underserved or marginalized. Health equity means that people of all backgrounds and ages have fair and just opportunities to live long, healthy, productive lives. The social and structural drivers of health disparities operate in multiple sectors and at levels beyond NIDDK's traditional scope, but research can make a valuable contribution toward advancing health equity.

Development of the Report: In 2021, the [NIDDK Advisory Council](#) established a Health Disparities and Health Equity Working Group to develop an Implementation Plan to advance the NIDDK health disparities and health equity research portfolio. The Working Group was charged with identifying a range of research needs and opportunities that represent the full spectrum of NIDDK science. It included community members, patients and caregivers, NIDDK staff and external researchers from across the country with multidisciplinary research expertise related to health disparities and health equity. The Institute may use the report to coordinate and prioritize health disparities and health equity activities within its mission; establish practical timelines, milestones, and metrics to track progress; embed equity-focused principles and tips in research activities; and promote multilevel and life course approaches to target root causes of disparities.

Research Recommendations: The five overarching recommendations, each with corresponding research and other related opportunities, can serve as NIDDK's roadmap for health disparities and health equity research programs. Recommendations 1, 2, and 3 focus on research topics and equity-focused processes; Recommendations 4 and 5 focus on research infrastructure and implementation needs. Social determinants of health (SDOH), structural racism, and other root causes of health inequities are acknowledged as key research areas. Authentic community engagement is also emphasized as essential for identifying the health research needs of affected populations and effective, acceptable solutions.

Special Features: Community members including patients, caregivers, and others living with or at risk for diseases within NIDDK's mission were involved throughout the report development process as Working Group members who shared their lived experiences, perspectives, values, and priorities. These insights are featured in call-out boxes throughout the report. Community members also provided feedback on the discussion outcomes and proposed recommendations.

Seven guiding principles for embedding equity into research and a list of practical tips for investigators planning health disparities and health equity research are also included.

The following page provides an overview of the report's research recommendations and opportunities that NIDDK could undertake in pursuit of pathways to health for all.

Research Recommendations and Opportunities

The Working Group's five overarching research recommendations elaborate high-impact NIDDK research and practice opportunities. Each recommendation includes corresponding opportunities that are described in the report.

Recommendation 1: Strengthen community engagement through partnership, power sharing, and capacity building to improve research

- 1-1:** Encourage, build, and sustain trusted collaborations with community members
- 1-2:** Partner and engage with trusted community entities in research
- 1-3:** Build capacity and infrastructure for community members and community-based organizations (CBOs) to engage in research
- 1-4:** Identify new models for collaboration between investigators and groups that can provide care and foster healing from trauma and injustice as needs arise

Recommendation 2: Advance research on the mechanisms by which biological, behavioral, environmental, and structural factors interact to affect health, disease, and resilience

- 2-1:** Explore how structural racism, discrimination, stigma, and other experiences of psychosocial trauma affect biological and behavioral processes and result in or worsen NIDDK diseases and conditions
- 2-2:** Determine the relationships among structural factors, SDOH, and (epi) genetics and the effects of each on health disparities and disease heterogeneity
- 2-3:** Determine promoters and mechanisms of resilience that prevent or lessen disease severity
- 2-4:** Explore whether biopsychosocial precision medicine approaches to diseases and conditions in the NIDDK mission could identify unique sociobiological phenotypes

Recommendation 3: Advance research on interventions and studies to address racism, health-related social needs, and SDOH

- 3-1:** Identify and test optimal practices in health care and community settings for integrating community-focused and regional-level social and medical care interventions
- 3-2:** Test interventions to identify and eliminate implicit bias, structural racism, and discrimination in health care delivery
- 3-3:** Expand equity-centered dissemination and implementation science research to accelerate creation, adoption, communication, and sustainability of equitable and effective interventions for diverse health care and community settings
- 3-4:** Expand flexible research opportunities to evaluate the health outcomes of community policy changes

Recommendation 4: Promote new methods, measures, tools, and technologies to accelerate achievement of health equity research goals

4-1: Develop, validate, and apply standardized methods and measures for quantifying SDOH and upstream structural exposures

4-2: Broaden and optimize use of technologies that lessen participant burden in research participation and data collection

4-3: Leverage data science approaches and tools to explore and link to “big data” from health and social services sectors

4-4: Address bias in novel predictive algorithms and any lack of diversity in their source data sets

Recommendation 5: Enhance NIDDK collaboration, structures, and programs to support robust research in health equity

5-1: Create a new, integrative guiding framework or conceptual model to support health equity research in NIDDK’s mission

5-2: Provide training for the NIDDK scientific community to enhance knowledge and skills in health equity concepts and community-engaged research

5-3: Promote cross-disciplinary efforts by sharing resources and seeking opportunities to collaborate across NIH and federal agencies

5-4: Monitor and evaluate research activities regularly to eliminate health disparities and advance health equity

Introduction

NIDDK Mission and Statutory Authority

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) was established in 1950 as part of the National Institutes of Health (NIH), and acquired its current name in 1986. As authorized by Sections 426-434A of the Public Health Service Act [42 U.S.C. 285c – 285c-9], the mission of the NIDDK is to conduct and support medical research and research training and to disseminate science-based information on the following topics (which are referred to in this plan as “NIDDK diseases and conditions”): diabetes and other endocrine and metabolic diseases; digestive diseases, nutritional disorders, and obesity; and kidney, urologic, and hematologic diseases, to improve people’s health and quality of life.

Health equity means that everyone has opportunities to live long, healthy, productive lives—no matter who they are, how they identify, or where they live.¹ NIDDK is committed to advancing health equity by supporting research to enable all communities affected by NIDDK diseases and conditions to thrive. Biomedical research can foster scientific breakthroughs and provide the evidence base needed for equitable and effective clinical practice and to inform public health programs and policies.

This report outlines research recommendations of the NIDDK Working Group of Council on Health Disparities and Health Equity, which included community members, researchers, and NIDDK staff. The recommendations complement the NIDDK Strategic Plan for Research with high-impact opportunities and equity-focused principles to advance the Institute’s mission and to *pursue pathways to health for all*.

Framing of this report

Striking health disparities have persisted despite the contributions of biomedical research to scientific advances in the etiology, prevention, and treatment of NIDDK diseases and outcomes. A key limitation is that most health disparities research has focused on individual-level drivers of disparities, such as differences in biology, genetics, or health behaviors, rather than on systemic and structural factors.² Advancing health equity and reducing health disparities will require extending beyond traditional research paradigms focused on individual-level differences to research focused on broader social, environmental, structural, and systemic drivers of population health and health disparities.

Health disparities result from the complex interplay of factors that operate at multiple levels (e.g., biological, behavioral, environmental, social, economic, organizational, policy). Addressing health disparities requires research that accounts for this multi-level complexity. Intersections with social risk factors such as exposures to adverse conditions that can trigger negative changes in health status should also be considered in research designs. Multi-level, culturally tailored approaches across the life course are therefore necessary: 1) to identify the causal pathways and mechanisms through which biomedical and social determinants contribute to poorer health and outcomes and 2) to address the social determinants of health and the upstream structural factors (e.g., policies, systems, etc.) that create, influence, and perpetuate health inequities.

Evidence is robust that social determinants of health (SDOH)—conditions in which people are born, grow, work, live, and age—are critical determinants of health and are primary contributors to health disparities and inequities. People from racial and ethnic minority groups are disproportionately affected by many of the diseases within NIDDK’s mission. Structural racism and discrimination are recognized as root causes of health disparities and health inequities for many minoritized populations. Structural racism and discrimination influence access to resources that help protect and promote health, including high-quality education, jobs, housing, health care, affordable healthy foods, and the ability to maintain healthy living conditions. Research has typically studied race as a correlate of disparities and identified attributes of the individual as the problem (e.g., non-adherent patient) rather than exploring the role of broader factors (e.g., structural and interpersonal racism) in driving health inequities.

Advancing health equity calls for changes in the makeup of people involved in research processes. Authentic engagement of patients, communities, and other interested parties is vital in identifying the needs and priorities of the affected communities and developing effective and sustainable solutions. Also important are diverse, cross-disciplinary research teams that include people affected by NIDDK diseases, as well as multi-sector and community-based partnerships (e.g., health care, public health, social services, community developers, legal system) to develop interventions that can address the upstream drivers of health inequities.

Considering non-traditional methods that are appropriate for the question under investigation is also pivotal in advancing health equity research. Traditional methods—which prioritize statistical significance, quantitative methods, and randomized controlled trials—often are not suitable for health disparities and health equity research. Many of the most important health equity research questions reflect the complexity of the multi-level and intersectional drivers of health inequities, and thus mixed method research approaches (e.g., quantitative and qualitative methods) will frequently be needed. These alternative scientific approaches have often been undervalued as valid, rigorous ways of advancing scientific knowledge by some in the research and academic communities. To meet the realities of advancing health equity research, the whole research enterprise—including study sections, research funding agencies, journal editors, and university promotions committees—will need to update criteria defining the most rigorous research. Research that addresses the underlying ethics questions for health equity issues, as well as implementation science research, which is crucial for translating evidence into practical action, is also needed.

This report addresses some of the most difficult scientific challenges NIDDK could pursue to improve health equity. Given that many NIDDK diseases and conditions are common health disparities conditions, the Working Group believes this report will be useful to NIDDK staff, researchers, and other research agencies and partners.

Key concepts and definitions

Definitions of key terms and concepts used in this report are in Table 1. Additional terms related to health disparities and health equity, as well as expanded definitions of terms presented in Table 1, are in Appendix B.

TABLE 1 Key Terms and Concepts Used in This Report

Key Term	Definition or Description
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Cross-disciplinary science (multi-, inter-, or trans-disciplinary)	Cross-disciplinarity, a global term comprising multi-, inter-, and trans-disciplinarity, is how team science draws on knowledge from different disciplines to resolve real-world, complex health problems. ^{3 4} Multidisciplinary teams work in parallel or sequentially on a discipline-specific basis. ⁵ Interdisciplinary teams work jointly to analyze, synthesize, and harmonize links among disciplines. Transdisciplinary teams integrate different disciplines to transcend traditional boundaries. ³
Health determinants	Broad interconnected factors that can influence health, including genetics, behavior, environmental and built/physical influences, medical care, and social factors. ⁶
Health disparities	A health difference that adversely affects socially disadvantaged populations groups. Examples include higher disease risk, incidence and prevalence of disease, and mortality. ⁷
Health equity	Everyone has fair and just opportunities to be as healthy as possible; ¹ no one is disadvantaged from obtaining one’s best health because of social position or other socially determined circumstances. ⁸
Health-related social needs (or unmet social needs)	Needs that are rooted in material deprivation, such as lack of resources and money to support the costs of living in modern society (e.g., food, rent, utilities, transportation, childcare, safety). The deprivation that leads to social needs being unmet is often related to SDOH, but social needs are not the same as SDOH. ⁹
Interested parties or stakeholders^a	Individuals, families, communities, or organizations who are affected by or have a direct interest in the research design, process, or outcomes (e.g., patients, research participants, caregivers, health care providers, people representing health and social care systems, advocacy groups, and scientific professional organizations).
Multi-level approaches	Multi-level approaches address at least two levels of influence (individual, interpersonal, organizational, community, educational, occupational, environmental, and policy) to target the causes of health disparities. ¹⁰
Populations with health disparities	Per NIH: Racial and ethnic minority populations, ^b less-privileged socioeconomic status populations, underserved rural populations, and sexual and gender minorities. The Working Group also included individuals with multiple chronic conditions, disabilities, and other populations in this definition. (See sidebar)
Root causes	The underlying problems or fundamental reason(s) for an adverse event, without which the adverse (health) event would not have occurred ¹¹ (e.g., economic, social, and public policies that create and perpetuate inequitable distribution of and control of health-promoting resources).

^a The Working Group acknowledges that the term “stakeholder” has negative connotations for some groups, that alternative words should be used when recommended, and that the word should be carefully defined within research teams to ensure agreement on what is meant by its use (https://www.cdc.gov/healthcommunication/Preferred_Terms.html). This Report to the NIDDK Advisory Council was written in accordance with these principles. It should be noted that the Working Group does not mean to imply that equity or equitable partnerships have been achieved where either the terms “stakeholder” or “interested parties” have been used.

^b As defined by the U.S. Office of Management and Budget and described in www.nimhd.nih.gov/about/strategic-plan/nih-strategic-plan-definitions-and-parameters.html. Self-identification is the preferred means of obtaining race and ethnic identity.

Social determinants of health (SDOH)	Conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. ¹² SDOH may include health care access and quality, education access and quality, social and community context, economic stability, and neighborhood and built environment. ¹³ SDOH affect everyone and can influence health in a positive or negative way.
Strengths perspective (or asset-based perspective)	A perspective where individuals and communities are viewed as inherently resourceful and capable of prioritizing problems and developing promising, acceptable solutions. This perspective emphasizes both individual and environmental factors to understand how they may promote or constrain health. ^{14 15}
Structural racism and discrimination	Per NIMHD : Macro-level conditions (e.g., residential segregation and institutional policies) that limit opportunities, resources, power, and well-being of individuals and populations based on race, ethnicity and other statuses (gender, sexual orientation, gender identity, disability status, social class or socioeconomic status, etc.).
Systemic conditions	Pervasive, deeply embedded conditions in systems, laws, written or unwritten policies, practices, and beliefs. In the case of structural and systemic racism, these conditions produce, condone, and perpetuate widespread unfair treatment and oppression of individuals and populations based on race and ethnicity. ¹⁶
Upstream and downstream factors or interventions	Factors that affect health or interventions to improve health. Upstream factors often occur at the macro policy level (e.g., national or state); thus, upstream interventions seek to reform fundamental social and economic structures that distribute wealth, power, opportunities, and decision-making. Downstream factors often occur at the individual and family levels, and downstream interventions seek to increase equitable access to health and social services at those levels. ¹⁷

***SIDEBAR:

Populations with health disparities

As defined by NIH:

- Minority racial and ethnic groups:^c American Indian or Alaska Native, Asian, Black or African American, Latino or Hispanic, and Native Hawaiian or other Pacific Islander
- People with lower socioeconomic status
- Underserved rural communities
- Sexual and gender minority groups

Additional populations discussed by the Working Group:

- Individuals with disabilities
- Individuals with multiple chronic conditions
- Individuals with stigmatized health conditions (obesity, HIV, mental health conditions)

^c NIH uses the racial and ethnic group classifications determined by OMB in the Revisions to Directive 15, titled [Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity](#).

- Justice-involved populations
- People with lower educational attainment
- Populations for whom English is a second language or with limited literacy skills
- Refugee populations and recent immigrants, or people with undocumented status
- Individuals with two or more of the identities in these lists

Individuals and groups may have multiple co-occurring identities from these lists. Intersectionality refers to the interconnected nature of such identities and social categorizations, which are regarded as creating exposure to overlapping systems of (dis)advantage or discrimination. The cumulative effect of the various forms of discrimination that could stem from multiple social identities is believed to exceed the sum of the parts.

NIDDK commitment

NIDDK is committed to fostering equity in its research activities. This commitment is critical because NIDDK conducts and supports research on many of the most common, chronic, consequential, and costly conditions in the United States. Its mission in research, research training, and information sharing has a key role to play in promoting health and health equity and in eliminating health disparities.

Many NIDDK diseases and conditions disproportionately affect certain populations. For example:

- **Obesity** disproportionately affects non-Hispanic Black and Hispanic populations compared to White populations.¹⁸
- **Development of type 2 diabetes** is about three times more likely among Hispanic and Asian and Pacific Islander youth, about six times more likely among Black or African American youth, and almost 12 times more likely among American Indian youth than among non-Hispanic White youth.¹⁹
- **Prevalence of end-stage kidney disease** in Black individuals is 78.6 percent higher than in the next-highest group, Native Americans, and more than 400 percent higher than in White individuals.²⁰
- **Non-Alcoholic Fatty Liver Disease (NAFLD)** is more common among Hispanic individuals, followed by non-Hispanic whites and Asian Americans, including those of East Asian and South Asian descent.²¹ On average, Asian Americans develop NAFLD at a lower body mass index (a measure of body fat based on height and weight) than non-Hispanic whites with NAFLD.²²

Many medically underserved populations also experience a higher burden of complications, such as lower leg amputations, related to NIDDK diseases.²³

NIDDK is committed to partnering with and building on the expertise, strengths, and assets of diverse stakeholders—especially communities affected by NIDDK diseases and conditions and the people and organizations involved in their health care—to promote the scientific innovation needed to advance health equity within its mission.

NIDDK 2021 Strategic Plan for Research

A cross-cutting theme in NIDDK's [2021 Strategic Plan for Research](#) is "Achieving health equity by eliminating health disparities among racial and ethnic minority populations and others who are underserved." The Strategic Plan elaborates on specific research needs and opportunities that NIDDK could pursue to accelerate research into the causes, treatment, and prevention of diseases and conditions under the Institute's mission. Along with other strategic planning efforts, it also guides the

Institute's approaches to build on scientific discoveries, pursue promising research avenues, and maximize the public investment in research. This NIDDK Health Disparities and Health Equity Research Implementation Plan complements and builds on opportunities outlined in the NIDDK Strategic Plan for Research.

Guiding principles for embedding equity into research

NIDDK is also committed to ensuring that its funded research adopts a perspective that considers how values, assumptions, processes, and actions at each decision point may affect the conduct of research, the research workforce, and the overall health of diverse populations NIDDK serves. The Working Group developed the following principles to help guide NIDDK's efforts in pursuit of health equity. (See Appendix G for the full version.) These principles align with and build on the NIDDK Director's [overarching principles](#).

- **Maintain a Robust Health Equity Research Portfolio.** NIDDK research across the spectrum of biomedical and behavioral sciences will consider, examine, and address individual and structural factors that differentially lead to poor as well as good health outcomes across population groups.
- **Partner with Diverse Communities.** NIDDK will support research and engagement activities that build and sustain equitable, effective processes and partnerships with diverse patients, caregivers, and other community members affected by NIDDK diseases and conditions.
- **Include Diverse Populations in Research.** NIDDK will work to ensure that studies of people or of their samples in both clinical studies and laboratory-based studies maintain appropriate inclusion of individuals/samples from diverse racial and ethnic backgrounds, and other groups who are underrepresented in research.
- **Promote Diverse Perspectives in Research.** NIDDK will support multidisciplinary research teams that include investigators with diverse backgrounds and scientific expertise, community experts with lived experience, and leaders and frontline workers from organizations in various types of health care and non-health care sectors, including CBOs.
- **Nurture a Diverse, World-class Research Workforce.** NIDDK will seek to enrich its internal and external workforce to reflect the country's diversity in biomedical scientific expertise and in demographic, geographic, and social backgrounds, such as gender identity, sexual orientation, and disability status.
- **Support Appropriate Consideration of Race, Ethnicity, and Gender in Research.** Race and ethnicity were created for social and political reasons; and gender also is a social construct that is distinct from biological sex. None of these social identities have a biological basis.^d NIDDK will support research that uses these social categories appropriately.
- **Promote Transparency and Accountability.** NIDDK will effectively communicate research opportunities and discoveries to scientific and non-scientific audiences and communities, with a particular focus on lay-friendly language and those impacted by the Institute's diseases and conditions, their families and caregivers, and the professionals involved in their health care.

^d The mapping of the human genome demonstrated that the human population is 99.99% similar. Of the 0.01% of variation in the human genome, 87% occurs within, rather than between, population groups. Hunley (2016) Am J Physical Anthropology.

Selected examples of health equity-related programs at NIDDK

To enhance NIDDK's health disparities and health equity efforts, the Working Group recommends building on important discoveries from NIDDK's history of supporting research to reduce health disparities in diseases and conditions within its mission. Examples include:

- The NIDDK Intramural Research Program's Phoenix Epidemiology and Clinical Research Branch has worked with Tribal Communities in Phoenix—which have among the world's highest prevalence of type 2 diabetes mellitus (T2D)—for more than 57 years to understand, manage, and treat diabetes and its complications. Findings from these studies informed the development of two effective prevention programs.
 - The Indian Health Service's Chronic Care Program achieved a 54 percent decrease (from 1996 to 2013) in the incidence of kidney failure among American Indian and Alaska Native people with diabetes.^{24 25}
 - The nationally recognized Diabetes Prevention Program showed that modest lifestyle changes or metformin use could delay or even prevent progression to T2D in people at high risk for the disease, regardless of race or ethnicity.^{26 27}
- Investigators found that rates of both type 1 diabetes (T1D) and T2D are rising more rapidly in children and adolescents of minority populations than in Whites,^{28 29} and that youth who have diabetes and are from minority populations have higher rates of diabetes-related co-morbidities and complications.³⁰ In addition, adolescent-onset T2D appears to be more resistant to treatment and more aggressive than adult-onset disease.^{31 32 33 34}
- The African American Study of Kidney Disease and Hypertension (AASK) demonstrated that a class of drugs that inhibits a hormone involved in blood pressure control (an angiotensin-converting enzyme inhibitor) was more effective than two other commonly used anti-hypertensive drugs (a beta blocker and a calcium channel blocker) in slowing the rate of decline in kidney function.³⁵
- Investigators identified genetic variants in the *ApoL1* gene as a major risk factor for kidney disease in Americans of West African ancestry.³⁶
- NIDDK recently expanded the [Centers for Diabetes Translation Research](#) program with explicit health equity requirements; established funding opportunities for two national Stakeholder Engagement Innovation Centers ([RFA-DK-22-001](#), [RFA-DK-22-019](#)) to advance equity in diabetes research; and issued an initiative focused on community engagement to develop and test meaningful interventions that aim to dismantle or mitigate the effects of structural racism to reduce kidney health disparities ([RFA-DK-22-014](#), [RFA-DK-23-003](#)).
- NIDDK leads a time-sensitive policy and program evaluation opportunity ([PAR-21-305](#)) where applicants can seek support to evaluate new community-based programs or public policies that may influence obesity related behaviors (e.g., dietary intake, physical activity, sedentary behavior, sleep), weight, and other health outcomes. Funded projects have assessed a range of policies and programs, such as the effect of a new food hub (grocery store, farmers market, and social space) on dietary intake; the redevelopment of a public housing program (sponsored by the U.S. Department of Housing and Urban Development [HUD]) on health outcomes; and the role of increasing minimum wages on dietary intake and stress.
- NIDDK participates in NIH-wide efforts to advance health equity, such as [Community Partnerships to Advance Science for Society](#) (ComPASS), [NIH UNITE](#), [Rapid Acceleration of Diagnostics—Underserved Populations](#) (RADx-UP), and [Transformative Research to Address Health Disparities and Advance Health Equity](#).
- NIDDK also supports efforts to enhance the diversity of the scientific workforce by providing unique research experiences and tailored career development support for talented individuals from diverse backgrounds, such as participating in the [Diversity Program Consortium](#).

Development of This Report

Working Group charge and scope

In 2021, the [NIDDK Advisory Council](#) established a Health Disparities and Health Equity Working Group to develop an implementation plan to advance NIDDK’s health disparities and health equity research portfolio. To help ensure that future research efforts address the full spectrum of factors contributing to health disparities, the Working Group was charged with identifying a range of opportunities to address NIDDK research needs. This Plan is intended to guide the Institute in enhancing its health disparities and health equity research portfolio; in engaging diverse communities and community organizations as partners in research; in developing metrics to track progress; and in embedding equity-focused principles and best practices in research activities.

The Implementation Plan is intended to be broad and nimble in order to allow flexibility in this rapidly evolving field of science. While enhancing diversity in the biomedical and behavior research workforce is essential in carrying out the plan’s recommendations, the Working Group was not charged with identifying opportunities for those efforts. Ongoing workforce efforts at NIDDK and NIH will enable the Institute to pursue this plan’s recommendations.

Working Group framework and composition

The Working Group included community members with diverse perspectives and lived experiences with NIDDK diseases and conditions, external researchers from across the country with expertise in multiple research disciplines and fields related to health disparities and health equity, and NIDDK staff. The Working Group was divided into five thematic subgroups (Figure 1). Subgroup 1 focused on engaging communities and building sustainable partnerships; Subgroup 2 explored strategies for increasing understanding of SDOH effects on the biology of health and disease; Subgroup 3 identified various types of interventions that could be tested to address SDOH effects, eliminate disparities, and improve health; Subgroup 4 discussed research opportunities to address upstream causes of SDOH and health disparities from an NIDDK perspective; and Subgroup 5 uplifted the perspectives of people living with or at risk of NIDDK diseases and conditions.



FIGURE 1 Illustration of the framework and five thematic subgroups of the NIDDK Working Group on Health Disparities and Health Equity Research.

NOTE: SDOH = social determinants of health; SG = subgroup

Community engagement was central to the Working Group's efforts. Most of the subgroups included community members along with researchers, and the subgroup focused on community perspectives comprised exclusively of patients, caregivers, and community members living with or at risk for diseases within NIDDK's mission who provided key perspectives, values, and priorities. Subgroup 5 also provided feedback on the discussion outcomes and the proposed recommendations from other subgroups.

The Working Group was supported by an executive leadership team of NIDDK staff and guided by a Steering Committee that coordinated and facilitated its activities and the Plan's development. More information about the Working Group members and the process to develop this Plan is provided in Appendices D and E.

Research Recommendations and Opportunities

The Working Group's five overarching recommendations elaborate NIDDK research and practice opportunities and can serve as a roadmap for health disparities and health equity initiatives. The plan recognizes the need for

- integrative approaches that address the multi-level factors (and their interactions) that cause or contribute to disparities across the life course, such as differences in SDOH effects, structural conditions, and other upstream factors and root causes, as well as biological and behavioral factors
- research to test interventions and their implementation to reduce or prevent effects of adverse SDOH
- collaborative research teams with cross-disciplinary expertise that leverage the social and behavioral sciences and population health and community expertise
- community-engaged and community-led approaches that consider priorities and needs of communities affected by NIDDK diseases and conditions

Recommendations 1, 2, and 3 focus on research topics and equity-focused processes; Recommendations 4 and 5 focus on research infrastructure and implementation needs. Each requires collaboration of NIDDK and its research community with affected communities, patients, and other entities (e.g., government, not-for-profit, and CBOs). When implemented, the research activities should generate additional scientific evidence to support meaningful, sustained reductions in health disparities and yield more effective and equitable health care programs, practices, and policies.

Recommendation 1: Strengthen community engagement through partnership, power sharing, and capacity building to improve research

Conventional research has often been designed and implemented without the involvement of the communities being studied (i.e., "community-placed" not "community-based").^{37 38} Authentically engaging diverse communities in research to the level of co-ownership is a foundational requirement for research aimed at advancing health equity. Community member participation can help research teams better understand the impact of SDOH, as well as identify and address bottlenecks in real-world

processes, communications, and systems that may cause research projects to fail. It may also improve dissemination and sustainability of interventions in the communities the research is intended to benefit.

Relevant community partners and other interested parties include individuals with or at risk for NIDDK diseases and conditions; their families and caregivers; and professionals and organizations involved in health and well-being. These organizations include patient-advocacy and support organizations; professional health organizations; faith-based organizations; and other community-based or nonprofit organizations. An exemplar approach is community-based participatory research (CBPR), a partnership model that engages community members, researchers and others as equal partners in all steps of the research.^{39 40} At its core, CBPR reflects questioning about the power dynamics of conventional research and knowledge production, acknowledges the legitimacy of experiential knowledge or ways of knowing, and focuses on research aimed at improving situations and practices.^{37 39} This approach is recognized for being particularly useful when tackling health problems affecting minoritized and medically underserved populations.

➤ **Opportunity 1-1: Encourage, build, and sustain trusted collaborations with community members**

Building trust and sustaining meaningful, trusting partnerships between researchers and diverse communities are essential objectives for equity-focused research. By partnering *with*—versus conducting research *on*—communities a study is intended to benefit, researchers can learn the communities’ research priorities, values, preferences, and views of what research strategies are acceptable and feasible. By incorporating these perspectives into each stage and critical decisions in the research process, the research can be more meaningful to the community and may facilitate the community’s confidence in results and adoption of successful approaches.

Effective community engagement requires consistent and deliberate effort by researchers and a phased, iterative engagement plan with clear milestones and objectives. Values that can help build and sustain trusted collaborations with communities include mutual respect, reciprocity, transparency, openness, loyalty, and cultural humility. Researchers can cultivate these values by seeking to understand a community’s history, including injustices or oppression that community members have experienced, and by seeking to understand and use the community’s intrinsic strengths and cultural values to enhance its own health and well-being.

Researchers undertaking community-engaged work should adopt a strengths-based perspective. Rather than primarily focusing on needs, problems, or deficits, a strengths-based approach focuses on assets, resources, skills, and capacities. This perspective acknowledges that individuals, families, and communities are inherently resourceful and capable of prioritizing their health problems and generating promising, acceptable solutions. This approach fosters an inclusive focus and promotes understanding of opportunities and barriers, participation of diverse groups, and scientific innovation.

Community Member Insights: Involvement in Research Process

Subgroup 5 members liked the concept of being involved in all stages of the research and continuing to stay engaged beyond the study period. One member observed that participants are often approached about enrolling in a study only after researchers have determined the study details. Community members expressed interest in being part of the research design and question

development phase, which they thought would increase community members' sense of ownership in the research.

1-1-1: Authentically engage community perspectives/voices in the research process

Sustained, meaningful engagement with communities requires that investigators incorporate communities' input in important stages of the research process. Health equity-focused research should outline how investigators plan to meaningfully engage community partners during each stage and how the study's anticipated results will be important and beneficial to community. (See Tips in Figure 2 and Appendix H.) Researcher-Community collaborations should begin by developing a shared understanding of the characteristics of the relationship, including a governance structure that emphasizes co-control and co-ownership. Co-creating strategies to build the capacity of the community throughout the research process may be included. Potential opportunities include providing input on or co-developing:

- a) Priorities and goals for research questions, design of research studies, and recruitment and enrollment strategies, including development of understandable, relevant consent forms-- particularly for populations that are harder to reach and might be underrepresented in health care settings.
- b) Training and mentoring of researchers in how to engage community partners in meaningful and trustworthy ways.
- c) Implementation of and collaboration with data collection efforts and intervention delivery in health care or real-world settings.
- d) Review of grant applications. For example, assessing the quality and feasibility of an application's proposed plan for stakeholder engagement.
- e) Manuscripts and other reports that describe the study design or results.
- f) Dissemination plans for research findings, and activities where results are shared with the community or other researchers (e.g., conferences, workshops, traditional media outlets, social media, and community venues).
- g) Strategies for leveraging community resources, existing infrastructure, and people to sustain intervention delivery and relationships with researchers.

Sufficient time and funding are critical for building reciprocal trust between researchers and the communities the research aims to benefit. Building trust involves addressing mistrust stemming from any history of unethical research practices or from ongoing inequities experienced. Community-engaged research requires one or more years for sufficient planning. Community members should be compensated appropriately and in a timely manner for contributing their time and perspectives.

Furthermore, relationships between researchers and communities can be strengthened by promoting sustained engagement after the research has been completed. Sustained engagement demonstrates a substantive, long-term commitment to improving the health of affected communities and is mutually rewarding to researchers and communities. These relationships could support development of wellness programs and policies, and enable the rapid assembly of research teams to deliver medical interventions when urgent public health emergencies arise (e.g., COVID-19). Building and sustaining—and sometimes restoring—trust are distinct processes and call for different strategies and resources.

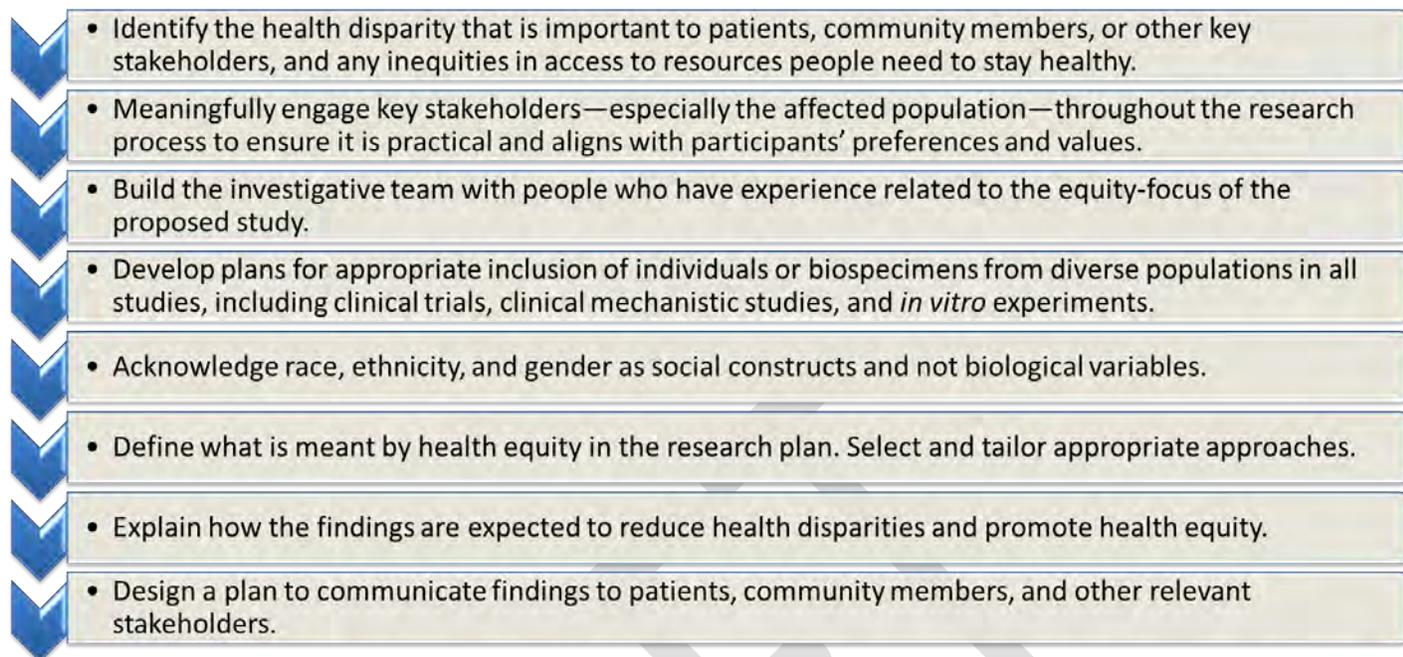
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- Identify the health disparity that is important to patients, community members, or other key stakeholders, and any inequities in access to resources people need to stay healthy.
 - Meaningfully engage key stakeholders—especially the affected population—throughout the research process to ensure it is practical and aligns with participants’ preferences and values.
 - Build the investigative team with people who have experience related to the equity-focus of the proposed study.
 - Develop plans for appropriate inclusion of individuals or biospecimens from diverse populations in all studies, including clinical trials, clinical mechanistic studies, and *in vitro* experiments.
 - Acknowledge race, ethnicity, and gender as social constructs and not biological variables.
 - Define what is meant by health equity in the research plan. Select and tailor appropriate approaches.
 - Explain how the findings are expected to reduce health disparities and promote health equity.
 - Design a plan to communicate findings to patients, community members, and other relevant stakeholders.

FIGURE 2 Tips for pursuing competent health equity research. (See appendix H for full version.)

1-1-2: Improve participation of diverse populations in research

U.S. research studies often lack adequate representation of diverse communities, despite NIH requirements.⁴¹ While reasons for this deficiency are numerous, the ongoing practice results in knowledge gaps and biased predictive algorithms that can exacerbate health disparities. Conclusions are based on genetic, pharmacogenomic, and clinical studies that are greatly enriched for European-descendent populations while lacking sufficient numbers of people from the diverse ancestries, which may not apply or may even be detrimental when applied to racial and ethnic minority groups. The potential for inapplicability occurs because the sequelae of structural racism and discrimination may affect underlying biology in ways that could influence the effectiveness of interventions across race or ethnicity, and because European-descendent populations include only a narrow slice of the genetic diversity that exists within the human species.

Achieving and maintaining sufficient participation in clinical studies is essential so that subgroup analyses can determine whether a diagnostic, intervention, or medication leads to different outcomes in different populations. This principle also applies for mechanistic clinical studies, where comprehensive analyses are performed to understand a biological or behavioral process, the pathophysiology of disease, or the mechanism of action of an intervention. Detecting whether such differences exist can also inform precision treatment models and indicate whether population-specific prevention or clinical guidelines may be warranted and what additional data needs remain.

Improving diversity of biosamples from genetically and racially and ethnically diverse populations in biobanks, and in tissues and cells used in laboratory-based research, can provide insight into mechanisms of disease in different populations and may allow identification of contributors to cross-group disparities that exist in disease risk, onset, progression, and treatment. Both genetic and racial

and ethnic diversity are critical, as substantial genetic heterogeneity exists within racial and ethnic groups.^e In addition, racism may have unique biological consequences.

Community Member Insights: Facilitators and Barriers to Research Study Enrollment/Retention

An important first step in promoting community engagement in research is to solicit and seek to understand the community's motivations for, perceived benefits and harms of, and concerns about participating in research. Subgroup 5 members shared that their motivations to participate in research include:

- hearing positive experiences of others who have participated in research
- connecting with other individuals who have the same disease or condition
- learning how to better manage their disease or condition
- having their visit summaries and test results from the study provided to their primary health care provider
- gaining awareness of new potential treatment options
- being informed of the research purpose and how participant data will be used
- having someone from the same demographic background explain the study and obtain informed consent for research
- having a consistent research team in order to foster trusting relationships
- experiencing a sense of satisfaction from contributing to the research

They shared that their concerns about and barriers to participating in research include:

- fear of the unknown or of being exploited for the researcher's career gain
- lack of researcher follow-up after data collection to share results and next steps
- inability to participate because research can be time-consuming and inconvenient, especially when the site is far from one's home and when the study is not flexible on when participants can come to the research site.

Several participants mentioned that it is helpful when research opportunities meet people where they are and sign up is easy. Participants described telehealth as a welcome method for participating as it eliminates transportation barriers, but noted that some communities do not have reliable, adequate internet access, and that some individuals are not "tech savvy."

➤ Opportunity 1-2: Partner and engage with trusted community entities in research

NIDDK partners with a variety of groups—including industry, academia, health care and patient advocacy organizations, professional societies, CBOs, and non-governmental organizations—in research activities across its mission areas. These partners bring unique expertise and strengths and may serve as trusted brokers of health information, assist with navigation to services, and deliver interventions as part of or separate from health care and research teams. The synergy that can result from such research partnerships can speed progress toward common goals to protect trust and reduce duplication of efforts.

^e For example, Black populations include people who descend from different regions of Africa and consequently may have genetic differences—e.g., presence of *APOL1* variants in people of West but not East African descent—that may stem from adaptation to regional conditions. Diversity in racial and ethnic population groups does not equal genetic diversity if, for example, all of the Black participants descended from West African populations.

Partnering with community entities within and beyond medical settings is a way to meet people where they are--in familiar spaces, engaging trustworthy people--for mutual benefit. Community partners are invaluable in helping to tailor strategies to enhance recruitment and maintain research participation of underrepresented communities. Partners could also provide input on, assist, or co-develop the general study outreach, intervention delivery and adoption, sustainability of strategies that work in diverse communities, and dissemination of study results with community members. Community partners can be key actors in sustaining relationships with researchers beyond the formal research period to maintain positive outcomes from the research.

Trusted community partners could include community health centers and workers, social service organizations, faith-based organizations, patient advocacy and support organizations, mutual aid organizations, community organizers, civic groups, minority-serving institutions, local businesses such as barbershops and beauty salons, and other frequently visited community sites that play central roles in people's lives (e.g., community centers, grocery stores, pharmacies). Virtual communities and support groups may also be important trusted partners to reach individuals who experience bias or stigma, such as LGBTQ+ individuals or people for whom English is a second language. Trusted partners can vary by community, among the different populations in a given community, and even within a specific population in a community given the inherent heterogeneity that exists in all population groups. Therefore, identifying appropriate community partners for a given population is important.

1-2-1: Evaluate and measure the effectiveness of community engagement

Researchers should evaluate the quality and effectiveness of their community engagement mechanisms and approaches, including partnerships with community entities, alongside other aspects of their research. Community members should have opportunities to provide feedback about the community impacts of research-oriented partnerships. One strategy to measure the impact of research partnerships (in the social and health service sectors) is to ask community members to share their perspectives on how and to what extent a given research partnership has influenced them, their organization or group, and their community.⁴² The Working Group encourages NIDDK to support research to develop or improve evaluation metrics for community partnerships and research engagement, so that metrics reflect relevant content and outcomes of interest to all partners.

Community Member Insights: Returning Research Results

Subgroup 5 members shared that in their experience, researchers rarely follow up with participants to share the results of the study nor explain how the results could benefit the community. Community members expressed great interest in receiving a summary of research results for the study in which they participated. They suggested that a presentation at a library or another local, accessible venue (or virtually) would fulfill their desire for follow-up about research outcomes. One Working Group member suggested that if a community site had helped recruit participants or collect data, results could be presented in the same venue, which might also increase the likelihood of using the venue for future research and encouraging people there to participate.

- **Opportunity 1-3: Build capacity and infrastructure for community members and community-based organizations (CBOs) to engage in research**

Building capacity and infrastructure for community members and CBOs to engage in research fosters meaningful involvement. Building capacity and infrastructure also helps equip community members and CBOs to drive future research and collaboration and take an active role in advocating for policies that improve the community.

1-3-1: Share and enhance knowledge about best practices and research gaps as they relate to cultivating and sustaining community engagement

The Working Group encourages NIDDK to promote and support activities to build academic research capacity for community-engaged research. Workshops, lectures, or staff training modules could include research opportunities to broaden the evidence base on engaging patients and communities, strategies for building sustainable academic-community engagement, and understanding how engagement may need to be recalibrated in the wake of COVID-19 or other public health emergencies.

Additional training and educational opportunities for community members and CBOs is a way to build community research capacity. Community members who participated in the Working Group shared that being informed about the context for new research would improve their motivation to participate. Community training and education program topics could include the relevance of community-engaged research to daily life, the purposes of research and benefits of participating, addressing misinformation about research participation, acknowledging historical injustices experienced by some populations in the context of research, providing examples of roles that community members can play in research, and explaining research concepts and methodologies.⁴³ Participants could be made aware of or connected with opportunities to enroll in research.

Educational efforts should flow in both directions. For example, community participants could be invited to share with researchers what is important and motivating to them about research; which strategies will and will not work in their neighborhoods or health care settings; and which practices will align culturally and maintain trust. Such insights will help researchers craft better research questions and improve communication of the value of the research in grant applications, during study participant recruitment efforts, and through other venues. Patient advocacy and CBOs can also offer perspectives on meaningful communication with affected individuals.

1-3-2: Explore approaches to make research data accessible to the community

Community members and CBOs may want access to data that researchers collect from their communities. Efforts must be made to share data with appropriate steps taken to obtain consent for sharing and to protect individual privacy. Community partners may need training in how to access and interpret data so that they can fully leverage the data to gain deeper insights into community conditions or to support local efforts to make health-promoting policy changes. Community partners could also use research data to drive future investigations and collaboration by proactively approaching researchers with community-generated ideas.

1-3-3: Support CBOs in applying for research funding

When CBOs seek research funding, funders should provide enhanced guidance as appropriate, such as detailed information about an initiative and how to apply.⁴⁴ Funders should also consider offering technical assistance to CBOs on completing the application (e.g., provide guidance for estimating costs involved in research participation and items to include in indirect costs and overhead expenses). Applicants who are not awarded funding would benefit from personalized feedback and advice for re-submission (if re-submission is an option).

1-3-4: Reduce practical barriers to community engagement in research

Logistical and practical challenges can be barriers to community participation and engagement in research. Examples of how researchers can improve the feasibility and appeal of community participation include minimizing up-front costs and addressing other logistical challenges, such as transportation needs, childcare arrangements, and accessibility accommodations. Additionally, using technology (e.g., web-based meetings, telehealth) may reduce scheduling, location, and transportation barriers and promote greater engagement with remote communities.

Equipping, incentivizing, and compensating CBOs are important features to building effective research partnerships. For example, CBOs may have limited capacity for data collection, tracking, and reporting, and may benefit from technical assistance or other resources to enhance these functions. Capacity could be built by providing additional training for existing staff, such as training home visitors to gather data for a research effort. Communities could support work with the research team by informing them about what data to collect, assisting with content for surveys, and interpreting data, especially qualitative findings.

➤ **Opportunity 1.4: Identify new models for collaboration between investigators and groups that can provide care and foster healing from trauma and injustice as needs arise**

Researchers must acknowledge the roles that science and biomedical research have played in fostering health inequities experienced by various populations. Researchers should know that these experiences contribute to a community's perspectives on participation in research. Historical trauma is cumulative emotional harm experienced by individuals or generations of a cultural, racial, or ethnic group due to major (usually violent) events that oppressed people (e.g., colonization, slavery, genocide, forced migration) and can result in unresolved or complicated grief.^{45 46 47 48} While some groups may experience no effects of historical trauma, others may experience disrupted family patterns and poor mental and physical health. Modern and cumulative trauma (e.g., multiple losses, community violence, medical mistreatment) can compound generational trauma. Research models that incorporate trauma-informed practices into the research process should be explored. Investigators should consider 1) identifying resources needed to connect participants to additional services, and 2) working with partners who can provide care and services to foster safety and wellness beyond the diseases or conditions under study (whether needs existed prior to the research or arose during the research process). One way researchers can provide this type of support is to bring resource guides when collecting data in the community, so they are prepared to promptly connect participants with key community resources as social needs emerge.

Recommendation 2: Advance research on the mechanisms by which biological, behavioral, environmental, and structural factors interact to affect health, disease, and resilience

Diseases and conditions in the NIDDK mission affect people in different ways. Varied social influences, environmental exposures, behavioral patterns, and genetic and biochemical predispositions contribute to overall health via a complex interplay of mechanisms that are not yet fully understood. This web of factors can result in disease heterogeneity, in which people have different risks of developing a certain disease; experience different disease symptoms, progression rates, prognoses, responses to treatment;

have different degrees of biological resilience; or develop different disease phenotypes (or subtypes of a disease) that have similar symptoms but distinct underlying mechanisms. It is therefore essential that clinical studies and mechanistic studies requiring human specimens recruit diverse individuals, including those historically under-represented in research.

Additionally, race and ethnicity are social constructs that must be distinguished from ancestry and genetics. Racial and ethnic groups are genetically diverse, and genetic variation is more substantial within race groups than between them. Race, however, correlates loosely with geographic ancestry and genetic adaptations to local environments can produce regional variation in genotype; race, therefore, may at times be associated with specific genetic alleles.^f

Key research objectives are outlined in the following opportunities, and examples of relevant research topics and opportunities are in Box 2.

- **Opportunity 2-1: Explore how structural racism, discrimination, stigma, and other experiences of psychosocial trauma affect biological and behavioral processes and result in or worsen NIDDK diseases and conditions**

Experiences of psychosocial trauma could contribute to development or progression of NIDDK diseases or conditions. A variety of biological pathways could be involved, such as alterations in immune function; the cumulative burden of chronic stress and life events (i.e., allostatic load), neuro-endocrine status; communication between the brain and other organs (e.g., the gut-brain axis); the microbiome, dietary patterns; psychologic processes, developmental programming; telomere shortening; or epigenetic mechanisms. To identify such pathways in populations experiencing health disparities, measures of biological responses to psychosocial trauma, physical or psychological stressors, environmental exposures, and other SDOH are needed, such as:

- a) metabolomic effects of diet and food insecurity, including the effects on microbial metabolites of certain dietary exposures (e.g., ultra-processed foods) that are related to structural conditions – acknowledging that many other factors influence microbiome composition
- b) phage/viral changes that affect the microbiome
- c) psychological effects of stress and discrimination, and how they interact with mechanisms of disease initiation and progression, including prenatal/postnatal developmental programming (e.g., effects on nephron mass, metabolic imprinting, effects of childhood feeding patterns on brain circuitry during development)
- d) mood and cognition, including clinical information about patients' disease symptoms
- e) neuroendocrine response to stress and other social and environmental exposures, such as racism

^f For example, certain alleles of *APOL1* that increase risk of kidney disease are common in people from parts of West Africa, but are absent in people from other parts of Africa and the rest of the world. Because of this pattern, *APOL1* appears to associate with Black race in the United States. However, this association occurs only in a subset of people of Black race—a portion of those with West African ancestry. Nevertheless, prevalence of *APOL1* kidney risk alleles in people of West African ancestry contributes to higher rates of kidney disease in this population, and thus to disproportionate rates in Black Americans.

Different measures may be needed for different diseases, and for different stages of a given disease. Some measures may already exist and need to be further validated or refined. Likewise, studies that examine the physiologic response to different experimental or therapeutic interventions (behavioral, dietary, pharmacologic) should include participants with different SDOH and exposure to various experiences of psychosocial trauma and assess how these factors affect outcomes.

Studies also are needed to determine whether impacts of racism, discrimination, and stigmatization, such as social stress, can be sufficiently emulated in animal models. If so, animal models could help assess the biological consequences of social stress or social dominance (e.g., effects of allostatic load on tissues, epigenetics, or telomere length in target tissues or cell types), as well as how these responses vary due to genetic differences. Animal models also could be used to test whether various treatments could improve these biological markers or other traditional measures of health (e.g., estimated glomerular filtration rate or hemoglobin A1c).

➤ **Opportunity 2-2: Determine the relationships between structural factors, SDOH, and (epi) genetics and the effects of each on health disparities and disease heterogeneity**

Research is needed across the lifespan to help understand how genetic, social, and environmental factors interact to cause disease and its heterogeneity or to provide “biologic resilience.” For example, *APOL1* is a significant genetic risk factor for kidney disease in some people with West African ancestry but a “second hit” is required to trigger pathologic processes that result in renal injury. Social and environmental factors may be important contributors to the “second hit,” so even in this example of a genetic risk that partially correlates with race, SDOH related to racism may be important added load toward triggering disease. Unraveling the drivers of disease heterogeneity could help identify the causes of health disparities; lead to more targeted and effective disease prevention, diagnosis, and treatment; and inform data-driven environmental and policy strategies to address health disparities. Because societal and environmental factors often take years to manifest their influence on health outcomes, research of an appropriate duration is necessary to detect endpoints (e.g., change in disease biomarkers, diagnosis of an NIDDK disease), evaluate outcomes of interest, and identify appropriate surrogate markers.

Longitudinal cohort studies and natural experiments (as described in Recommendation 3) involving diverse populations and settings should be enriched with multi-level data (e.g., socioeconomic status and geospatial information) to deepen insights into such research questions. Biorepositories that include samples from diverse populations (across race and ethnicity, sex and gender identity, socioeconomic status, and stress levels) linked to these cohort studies and to other clinical studies can be used to study disease heterogeneity, provide insight into mechanisms of disease in different populations, and ensure findings are applicable across communities. NIH longitudinal studies like the [All of Us Research Program](#), its associated [Nutrition for Precision Health](#) project, and the [Environmental Influences on Child Health Outcomes](#) (ECHO) Program may be useful resources.

Studies also are needed to better understand the associations among race, racism, and biological variables that have been used to assess disease status. For example, the level of metabolites such as serum creatinine and hemoglobin A1c vary across racial populations. Whether correlations between biomarkers and race reflect associations between race and ancestry (as is the case for *APOL1*) or a biological consequence of racism is unclear. Future studies that assess health-related gene polymorphisms may help identify and distinguish genetic from acquired contributors to health

disparities in populations where disease prevalence differs in groups by race, ethnicity, or ancestry. Determining the mechanisms by which group differences in health-related gene polymorphisms result in health differences may lead to development of novel therapies targeting those pathways.

➤ **Opportunity 2-3: Determine promoters and mechanisms of resilience that prevent or lessen disease severity**

Some individuals exhibit resilience, i.e., they do not develop the disease for which they are at high risk, or they recover from disease faster than other people. Relatively little is known about the concept of resilience and the extent to which it results from biological or social factors, or a combination. In addition, little is known about whether or how a local community's intrinsic strengths or cultural values and traditions may enhance resilience. While strategies are urgently needed to address the powerful structural forces (SDOH and others) that can overwhelm an individual's personal agency and community resources, evidence-based strategies to promote resilience could be combined with broader SDOH initiatives to improve disease prevention and health promotion. The Working Group encourages research to develop robust measures and definitions for individual, family, and community resilience, as well as physiologic measures of resilience.

Studies of multi-layered, linked data sets that include information about pathophysiology, SDOH, behavior, environment, race and ethnicity, marginalized social status, and various "omics" are needed. In order to facilitate development of biological measures and definitions of resilience and its underlying mechanisms, research should also include individuals who remain healthy despite biological or social risk factors. Better understanding of resilience to disease may elucidate protective factors that could be developed into interventions. Such measures of resilience can be incorporated in intervention trials to assess 1) their predictive potential for positive response to the intervention, or 2) their utility to identify individuals who may benefit most from certain interventions.

BOX 2

Additional Research Topics and Opportunities to Understand SDOH Effects on the Biology of Health and Diseases in the NIDDK Mission

- How do social and environmental interventions affect biological measures in various populations?
- What factors drive geographic variation in health outcomes (e.g., prevalence, effectiveness of interventions)? What are the underlying mechanisms?
- What are the long-term impacts of COVID-19 on health disparities?
- How do discrimination and disease stigma interact to influence health outcomes, and via what mechanisms?
- How do unaddressed social risks negatively affect health outcomes over time?
- Which social risks or environmental exposures, individually or in combination, pose the greatest barrier to health promotion and disease prevention or control, and in what diseases? How do they operate to result in illness or increase severity?
- How does the disproportionate impact of climate change or extreme weather contribute to disparities?
- How do food, housing, or nutrition insecurity--and interventions to address them--affect development of disease or response to treatment?

- How do unprecedented events (e.g., natural disasters, pandemics) differentially affect the health of underresourced populations? (e.g., isolation, disruptions in social and health services, stress responses)
- What are the mechanisms and underlying risks for overweight or obesity in groups historically underrepresented in research? How do these mechanisms and risks contribute to development, progression, or management of other diseases?
- How well do race- and ethnicity-free prediction equations for onset or progression of disease perform across diverse groups?
- How do diagnostics (such as pulse oximeters) or interventions (such as medications) perform across demographic groups?
- What biological mechanisms (e.g., epigenetics, developmental programming) play a role in the intergenerational transfer of SDOH effects over the life course?

➤ **Opportunity 2-4: Explore whether biopsychosocial precision medicine approaches to diseases and conditions in the NIDDK mission could identify unique sociobiological phenotypes**

Precision medicine approaches have historically focused on understanding genetic and other biologic contributors to disease, placing less emphasis on how social risks may interact with genes or directly affect biology to contribute to unique disease phenotypes. This approach reflects only part of the pathway from genotype to phenotype.

Broadening the lens of precision medicine to more fully include potential social contributors to disease can provide a more complete picture of disease pathways and enable more targeted and superior treatments—especially for populations that disproportionately experience social risks. To make precision medicine work for everyone, an understanding is needed of how social and behavioral factors influence development, progression, and treatment of diseases and conditions. Mechanistic clinical studies that involve individuals from diverse backgrounds and with deep sociobiological phenotyping are needed to determine how biological, behavioral, and social risk factors interact to cause or prevent disease.

Recommendation 3: Advance research on interventions and studies to address racism, health-related social needs, and SDOH

Both incremental and transformative research are needed to address SDOH, structural racism, health-related or unmet social needs, and other fundamental (i.e., “upstream”) drivers of health disparities. For example, one intervention approach to lessen the impact of social and economic challenges is to provide support⁴⁹ such as rental assistance and transportation to medical appointments or to the pharmacy. Another approach could be regional coordination of health care system and community-based systems. These strategies mitigate acute social and economic challenges faced by some individuals, families, and patients, but only for a small segment of the population and without implementing long-term fixes.⁹ Research opportunities could go further upstream to target racism and other root causes that may perpetuate health inequities, such as by evaluating the health impact of changes in structural conditions (e.g., improved public transit, increased minimum wage). Such interventions may require

collaboration and community-engaged activity (e.g., CBPR) with research and implementation partners at the community, state, and federal levels.

Community Member Insights: Healthy Living Supports and Barriers

Subgroup 5 members shared their perspectives on healthy living and listed resources that help them live healthy lives. They also shared examples of barriers to their living healthy lives and barriers to navigating the health care system. Many of their comments touched on social determinants of health such as:

Supports for healthy living

- Access to basic needs: healthy, affordable foods such as fruits and vegetables, housing resources, transportation, green spaces, and affordable health care
- Education/health information in plain, jargon-free language on how to manage one's condition and advocate for oneself in health care settings
- Technology (social media and smartphone apps)
- Community unity and support programs
- Trusted organizations such as schools, churches, interfaith ministries, service organizations, and disease-specific foundations

Barriers to healthy living

- Unsafe communities and neighborhoods
- Under-resourced communities
- Limited accessibility of health care, particularly specialty care
- Time spent waiting between pre-qualifying for and obtaining resources (e.g., Social Security)
- Inability to qualify for certain programmatic supports (e.g., federal food assistance programs)
- Medical trauma—resulting from frequent hospital visits, medical procedures, and medications—which led to negative effects on mental health

➤ Opportunity 3-1: Identify and test optimal practices in health care and community settings for integrating community-focused and regional-level social and medical care interventions

The integration of social and medical care interventions is a promising strategy for addressing health disparities in the context of health care delivery. Health care providers may conduct screenings for unmet social needs and refer and connect patients to appropriate services and resources. Providers may also use SDOH and social needs information to personalize the care recommendations and offer medical options that reflect the patient as a “whole person” and considers potential challenges to achieve the best outcomes. Conversely, CBOs, and non-medical professionals may also conduct health screening in community or home settings, identify health risks and health care needs, and refer and connect individuals to treatment or disease prevention resources (e.g., community-based Diabetes Prevention Program sites, food voucher programs).

The Working Group identified the following questions to advance evidence on interventions that integrate social and medical care:

- What are the most effective approaches to screen patients for NIDDK diseases and conditions and health-related social needs or unmet social needs, and then navigate or connect patients or caregivers to identified services and resources? How, when, and by whom is screening most acceptable and productive? How can screening and referral practices be adapted for cultural appropriateness and preferences of specific populations experiencing health disparities?⁵⁰

- How long does it take to resolve or adequately address different unmet social needs and improve health outcomes? How does duration or severity of exposure to adverse SDOH influence the intervention effect, and what other factors matter (e.g., lifestage of the recipient; family composition; primary recipients-- children or the household?--of supplemental food services)?
- For which unmet social needs and adverse SDOH is community capacity adequate to provide needed assistance? Which interventions—including policies such as SNAP—most reliably resolve a person’s social needs?
- How can unmet social needs be addressed holistically and with individualized, precision approaches?
- How long do the benefits of social needs interventions last and what might extend the duration? For example, if an intervention addresses a need one month, how long until that need reemerges; and how can we move toward more durable benefits?
- How does identifying and addressing adverse SDOH and unmet social needs affect prevention and treatment of NIDDK diseases or conditions? Do outcomes vary when social needs interventions are long-lasting (e.g., policy change) vs. short-term (e.g., crisis relief)?
- What type of training for health care screeners—in SDOH, unmet social needs, communication strategies—is most effective in facilitating integrated social and medical care interventions? Which strategies and resources promote patients’ use of social service referrals and medical advice?
- What role might coaching, patient activation (i.e., follow-through on referrals and medical regimen), and patient advocacy efforts play in these strategies beyond linking to services?
- Which navigator or community health worker intervention models—such as providing health education materials to patients or explaining how addressing unmet social needs could improve their health—lead to the best health outcomes?
- When diseases or conditions occur in people from populations that experience health disparities, what practices to intensify treatment (social or medical care interventions) improve long-term outcomes?

Researchers could develop innovative regional partnerships that aim to achieve population-level outcomes related to NIDDK diseases and conditions. (See Opportunity 3-4 for recommendations on “natural experiments,” in which investigators are not deploying the primary intervention.) For example, cross-sector and collaborative care models could coordinate integrated health care system and community assets to systematically assess communities and patients for unmet social needs and address them via affordable resources (e.g., foodbanks, farmers markets, pharmacies) located in or near their home communities; and policies designed to intervene upon SDOH. Such large-scale projects also have the potential to embed and test innovative intervention components to advance health equity while simultaneously leveraging local businesses and trusted community entities. Multi-level and holistic approaches to engage patients, providers, health care entities, and community businesses could improve trust and increase a community’s capacity to sustain effective intervention strategies after the research ends.

The Working Group identified the following research questions featuring cross-sector partnership innovations to address integrated social and medical care:

- What large-scale or regional collaborative models are most effective for improving health care delivery, treatment outcomes, and prevention?
- What intervention components or combination of components improve process outcomes, unmet social needs, and disease outcomes—both short-term and long-term?

- How should multi-level, cross-sector projects be evaluated? What are the most important process and outcome measures? Which measures align with priorities and outcomes of each partner or sector and each intervention component?
- What are effective ways to systematically collect SDOH and social needs data to inform personalized medical and social care for multi-level, cross-sector interventions?

NIDDK has supported pragmatic trial research (e.g., [Chin et al., 2014](#)). NIDDK also supports the NIH Common Fund's [ComPASS Initiative](#), which may reveal promising intervention and partnership approaches. The Working Group encourages NIDDK to build upon these examples and support new research activities designed to improve individual- and population-level health outcomes.

➤ **Opportunity 3-2: Test interventions to identify and eliminate implicit bias and structural racism in health care delivery**

Health care providers can hold negative explicit and implicit biases against patients based on socioeconomic status, racial or ethnic background, social identity, weight, or other characteristics. In addition, institutional policies and practices may further disadvantage specific groups. For example, inclusion of race in medical algorithms and guidelines may systematically change how and when patients receive care. Certain medical technologies also may not have been adequately tested in diverse populations and can result in skewed test results. This margin of error has been documented, for example, with pulse oximeters during the COVID-19 pandemic, where overestimated levels of arterial oxygen saturation in people of color led to treatment delays.^{51 52} These biases can harm patient-clinician communication and trust, clinical decision making, institutional practices,⁵³ and treatment outcomes.

The Working Group identified the following research questions that could inform improvements in health care delivery for populations that experience health disparities:

- What are the pathways by which reducing implicit bias would achieve health improvement goals? Do effective pathways involve improving specific health care system policies or provider trainings; patient-physician trust and communication; patient satisfaction; rates that providers recommend the best available treatments; community-based or context-specific interventions?
- What are effective education, awareness, and skill-building strategies for eliminating and managing harmful provider biases? Do these strategies improve care delivery and outcomes, including patient acceptance of and follow-through on medical advice?
- What training approaches (e.g., self-advocacy, standards of care awareness, patient rights education) help patients participate robustly in the medical encounter and mitigate health care bias or discrimination?
- How do different multidisciplinary care models and teams protect against or exacerbate harmful provider biases—for example, do teams in which nurses or peer educators have greater authority and actively engage with patients reduce instances of bias?
- What health care policies and practices disadvantage vulnerable communities? Can changing these policies and practices improve outcomes for health care delivery?
- How can clinical guidelines and electronic health record (EHR) algorithms be evaluated to ensure they do not reflect or propagate biases?

Additional opportunities and research questions on interventions to address SDOH effects are in Box 3.

Subgroup 5 members confirmed that training health care providers to recognize and address racism (and other “isms”) and its effects on patients is important. They shared their views that some health care providers may not realize—or may even deny—that racism exists in their communities. Participants thought that those beliefs may be perpetuated, intentionally or unintentionally, by physicians or other health care providers in the same setting.

BOX 3

Additional Opportunities and Research Questions on Interventions to Address SDOH Effects

- How are the effects of upstream SDOH—such as housing policy or generational wealth accumulation—transmitted across generations? What interventions effectively interrupt the transfer of adverse effects?
- What strategies promote positive commercial determinants of health (e.g., marketing healthy food options) and lessen or eliminate the effects of negative commercial determinants, such as the racialized marketing of unhealthy foods and beverages to low-income children, families and communities?
- What are the most effective intervention windows across the lifespan (e.g., early childhood, transition from adolescence and adulthood, pre-pregnancy) to mitigate the negative effects of racism, discrimination, or unaddressed social needs?
- How should interventions be tailored to different settings and life stages?
- What are the most effective interventions to address negative multi-generational risks and influences (such as poverty) and supports to sustain positive strengths and influences (such as wealth, quality education, or healthcare) related to disease onset and treatment?
- What are best health care practices for sustaining effects of proven interventions? What frequency, intensity, and duration of support are necessary to help people overcome barriers to maintaining health improvements? Can EHR algorithms be leveraged proactively to identify patients with evidence of losing achieved gains or to alert providers when different forms of outreach and support may be needed?
- What are effective, sustainable models for using multidisciplinary health care teams to address behavioral and social determinants of health simultaneously? What intervention models that embed community health workers or peer supporters are most effective and under what conditions?
- What is the health impact of interventions that integrate topics such as optimal navigation of the health care system and assurance of health care rights for all populations?
- What interventions most effectively improve resilience among specific populations experiencing health disparities? At what level of delivery (e.g., individual, household, community, societal) are they most effective? At what point(s) or key risk periods in the lifespan should they be delivered (e.g., pregnancy, early childhood, transition to young adulthood, older age, during a health crisis)?
- Could targeted stress reduction interventions (e.g., physical activity, mindfulness, green space) improve disease outcomes?

➤ **Opportunity 3-3: Expand equity-centered dissemination and implementation science research to accelerate creation, adoption, communication, and sustainability of equitable and effective interventions for diverse health care and community settings**

Implementation science research offers promising frameworks and tools to accelerate improvements in population health and health equity.⁵⁴ Its methods and strategies facilitate the understanding and uptake of scientific evidence into real-world settings by examining factors such as process, acceptability, feasibility, and health outcomes. It has particular potential for achieving health equity goals by identifying effective strategies to adapt “one-size-fits-all” interventions to diverse settings and populations of adults and children. A more effective and expedient approach, however, may be to begin generating evidence for diverse populations and settings, then adapt it to non-disparity populations if needed. By incorporating a health-equity focus in new (or expanded) dissemination and implementation (D&I) research, the field may be enriched with new partners (researchers, practitioners, and implementers) who are deeply knowledgeable about the SDOH, histories, and strengths of affected communities, and health care system practices, policies, and attitudes that may allow inequities to arise.⁵⁴ Science communication is also critical to D&I health equity efforts to establish a shared understanding and use of concepts (root causes of health inequities; equity-focused principles and strategies) and to spread awareness about acceptable and effective strategies to diverse implementers and communities.

The Working Group identified research questions that could be addressed with implementation science methods, including:

- a) What strategies work best for generating evidence for diverse, medically underserved populations and settings, and tailoring and adapting the strategies for more socially privileged populations and health care settings if needed?
- b) What infrastructure and resources need to be in place for health care organizations that serve low-income and minority populations to succeed using proven approaches? Such organizations often have fewer resources with less capacity than larger systems to integrate new, innovative, effective solutions.
- c) What are the active components of interventions and implementation strategies that can be delivered efficiently and disseminated broadly at relatively low cost to diverse populations in an equitable manner?
- d) What are the implementation challenges and barriers that prevent adoption or hamper sustainability of efforts in diverse populations across interventions or programs?
- e) How can longitudinal studies be used to capture the equitable scale-up of interventions through organizations outside the traditional health care system (e.g., CBOs, public health agencies, schools) across populations experiencing health disparities?
- f) What communication strategies are effective for adopting equity-focused principles in research and spreading awareness and uptake of interventions that work?

Additionally, few studies have identified and addressed the challenges of terminating health care services and public health programs and policies that are inappropriate, inequitably delivered, ineffective, or harmful to the stewardship of limited resources. Studies of novel methods and strategies for effective de-implementation of practices, programs, and policies that worsen inequities are also needed. In this area, research is needed to:

- a) Evaluate unintended consequences of health care practices, programs, and policies on health disparities in NIDDK-mission diseases
- b) Identify low-value, overused, or inappropriate medical care for these diseases that are ineffective at reducing health disparities (e.g., screening, diagnostic services, treatments)
- c) Test de-implementation and mis-implementation strategies for terminating ineffective, low value, or harmful practices and policies

➤ **Opportunity 3-4: Expand flexible research opportunities to evaluate the health outcomes of community policy changes**

Adverse SDOH that limit human potential and health may result from underlying structural factors such as policies and systems that reinforce health inequities. Likewise, policies can also promote health equity and positive SDOH effects. For example, some policies and programs expand access to quality housing, employment, the accessibility of fruits and vegetables, or improve the safety and built environments in neighborhoods so that they are more conducive to physical activity. When health-promoting policies are implemented, it provides a “natural experiment” opportunity for researchers to evaluate the health effects of the policy change, explore whether there are any disparities in who benefits from the change, determine why a program or policy may work in some communities but not others, and identify unintended consequences.

When a program or policy is put in place with limited advance notice, it is important for studies to be initiated expeditiously as there may be limited opportunity to collect baseline data before the program or policy starts that would allow comparison of health outcomes pre- and post-intervention. To facilitate such studies, NIDDK developed a [rapid grant program](#) for research that proposes to evaluate public policies and programs designed to influence obesity-related behaviors and weight outcomes. The Working Group encourages broadening this program to include other NIDDK diseases and conditions. An expanded program could also examine events that are associated with health disparities in the community, such as public health emergencies or social injustices.

An important opportunity to advance natural experiments is incorporating community input throughout the evaluation. Individuals (e.g., patients, community members, professionals) and institutions impacted by the program or policy being evaluated could bring invaluable perspectives and feedback on supports or barriers to successful implementation. Impacted entities can help researchers understand barriers that affect implementation (e.g., administration, policies, education, awareness, outreach, and delivery), or aid in interpreting qualitative findings (e.g., interview data with providers or patients).

Recommendation 4: Promote new methods, measures, tools, and technologies to accelerate achievement of health equity research goals

Research that examines relationships between SDOH and health and disease outcomes must collect data on structural, social, environmental, behavioral, and biological factors. Many types of data might be collected within one study, or a study could pair its original data collection with an existing database that contains different types of data (although the same individuals are not necessarily represented in each data set). Standardized methods and measures for these factors increases the ability to compare results across studies and draw conclusions.

To better understand disease heterogeneity (or differences), research must make links between multi-level factors that affect health and contribute to health disparities. Therefore, tools and technologies are needed to collect, analyze, and integrate data from various sources, and to identify trends in the data by relevant subgroups (e.g., race/ethnicity, language) to reveal associations. The resulting discoveries can point to new medical advances and suggest targets for environmental and policy interventions.

➤ **Opportunity 4-1: Develop, validate, and apply standardized methods and measures for quantifying SDOH and upstream structural exposures**

Collecting accurate data about SDOH and health-related social needs must be done in a respectful, valid manner tailored to the population of interest. Determining who should collect the data and who should have access to the data is important, as well as what can be done to prevent data breaches and how any breaches should be handled. Typically, SDOH measures are collected at a single point in time and indicate only whether the exposure is present, but duration of an adverse SDOH exposure is also important. If multiple SDOH exposures are present and of interest, their cumulative effect should also be measured as it may reflect intersectionality of the individual or population under study.

Improved methods and measures, including small-area (e.g., census-tract level) measures, are needed to assess and characterize SDOH exposures, such as:

- a) Psychosocial trauma (e.g., as a result of stigma, bias, discrimination)
- b) Structural racism and other forms of oppression
- c) Access and quality of health care, including language access and health literacy considerations
- d) Bias in health care providers or workers
- e) Housing affordability and security
- f) Food environments, including food and resource security
- g) Other social and environmental stressors impacting populations that experience health disparities

The more precisely SDOH can be measured, the more accurately intervention targets can be set. For example, housing insecurity encompasses both housing stability and housing security; food insecurity can encompass availability, accessibility, affordability, as well as cultural relevance of options in those three domains. Researchers should also consider when SDOH is best assessed at the population level (e.g., geomapping social risk based on zip code or census tract) or individual level (e.g., screening during clinical encounters) and the tradeoffs between these approaches. The NIH [PhenX Toolkit on SDOH Collections of Measures](#) is a resource for high-quality, standard SDOH measures and SDOH measurement protocols. Additional data resources are available from AHRQ,⁵⁵ HUD, and CMS.

➤ **Opportunity 4-2: Broaden and optimize use of technologies that lessen participant burden in research participation and data collection**

Collecting health data in real-world settings allows researchers to meet people where they are. It also facilitates equitable research across populations that may not have access to transportation or paid time off from work to travel to a research site. Integration of accurate, user-friendly, and convenient technological tools can ease burdens on study participants and present a clearer picture of an individual's health in real-world settings. Home-based tools and technologies—such as wearable devices that track activity, behaviors, and biologic metrics including heart rate, body temperature, glucose level, or the fluctuation of hormones over time—enable study participants to capture their own data

measurements. Telehealth is another technology that allows people to attend health, medical, and potentially research appointments from their homes.

As use of these tools expands, research is also needed to optimize their utility and address the challenges with implementation across various populations to ensure acceptability, as well as equitable access and understanding. Specific research questions could include:

- a) What are the reach, uptake, barriers, and impact of various technologies (e.g., cell phone apps) or combinations of technologies on interventions tailored to diverse populations?
- b) How do different combinations of technology (e.g., virtual/e-health care models, telehealth, texting, mobile clinics) impact equity in intervention delivery and outcomes among populations experiencing health disparities?
- c) How can new technologies or approaches be adapted to address inequities such as the digital divide and lack of access to broadband internet, limited skill in internet navigation, etc.?

➤ **Opportunity 4-3: Leverage data science approaches and tools to explore and link to “big data” from health and social services sectors**

Tremendous growth in data collection along with advances in computing power and data accessibility present an opportunity for researchers to apply artificial intelligence (AI) technologies and machine learning (ML) algorithms to process and link large-scale proteomic, molecular, genomic, communication, and psychosocial data with clinical, geographic, social, environmental, and policy data. These approaches could also be used to supplement existing cohort data with social data, obviating the need to recruit additional cohorts and collect new data. Statistical techniques could be used to identify multiple potential causes and contributors to the development of diseases and conditions in the NIDDK mission, and to assess the effects of SDOH and of upstream drivers.

Unlocking the power of such “big data” often requires decoding the complex patterns and associations embedded within various streams of evidence. Computational biologists and bioinformaticians are needed to implement these technologies for health equity research, and training opportunities should be available to help both early-stage and established investigators integrate “big data” analysis techniques into research projects.

Community Member Insights: Medical Records and Hidden Data

Subgroup 5 members highlighted that the identities of populations that experience health disparities are not always accurately or completely documented in clinical data. For example, cultural preferences and sexual and gender identity questions may not be asked during clinical encounters, and race may be assumed based on appearance or not recorded at all; therefore, patients have to proactively provide these preferences and identities if they are to be reflected in clinical data. Some people may be reluctant to share information about their sexual preferences, gender identity, or disability status in health care settings, however, due to fear of discrimination or differential treatment. When these patient characteristics are not included in clinical data, the ability to generate insights (e.g., from data linkages) that could benefit these populations is hindered. Missing qualities also lessens the likelihood that health care guidance and interventions will be tailored to the full picture of the patient.

Key ethical concerns regarding AI technologies include protecting individual privacy and ensuring the results of research using big data benefit all populations equitably. There is also a need to mitigate potential bias that could result, for example, from using source data sets that are not sufficiently representative of the population to train AI technologies—as risk and other assessments generated from such analyses could disadvantage communities left out of the algorithms and perpetuate or exacerbate health inequities.

4-3-1: Enhance large health data sets, including electronic health records (EHRs), with social and social services data

Linkage of multiple “big data” sources could help detect relationships between SDOH and health outcomes, as well as the strength of those relationships and potential confounders. These discoveries will enhance understanding of the differential impact of SDOH on populations experiencing health disparities and how these contribute to development of adverse health outcomes. Such research may also identify which social risks, or combinations of risks, pose the greatest barriers to health promotion and disease prevention or control. Additionally, these data could provide insight about the specific SDOH barriers to address in order to make interventions more accessible.

The Working Group encourages NIDDK to support research to enhance existing longitudinal cohort data by the addition of EHR and social services data or small area estimates (e.g., at the census tract or zip code level) of SDOH measures, or by merging data sets, particularly those that employ geocoding.

4-3-2: Develop and incorporate common data elements into research

Data elements, or information that describes the pieces of data to be collected in a study (such as a person’s age or blood glucose level), are important components of clinical studies. Researchers can use common data elements (CDEs)—data elements that can be used in multiple clinical studies—for systematically collecting and analyzing information, and for ensuring that collected data are high quality and comparable across multiple studies. The Working Group encourages the incorporation of CDEs in health equity research to streamline data collection and enhance the potential to investigate relationships between data from different studies, and facilitate the reuse of shared data to build upon research findings. NIH maintains a searchable [CDE repository](#) that researchers can use to find, create, and share CDEs for clinical studies, and the [PhenX Toolkit](#) provides a set of CDEs that can be leveraged to enhance SDOH studies.

➤ **Opportunity 4-4: Address bias in novel predictive algorithms and any lack of diversity in their source data sets**

Predictive algorithms are increasingly used to support decision-making in medicine. It is important to acknowledge that bias can enter these tools, either through biased data to build them, biased analyses to verify them, or biased use of the algorithms during medical care.⁵⁶ Several diagnostic algorithms and practice guidelines make adjustments for race or ethnicity and guide clinical decisions. However, race is not a reliable proxy for disease-related genetic differences. Adjusting for race in these equations ignores the substantial diversity within self-identified racial or ethnic minority study participants and downplays other factors that may more directly contribute to disease risk or progression.⁵⁷ The Working Group encourages new research to evaluate alternatives to race-based tools and algorithms to improve the

⁵⁶ AHRQ is conducting a systematic review on this topic. See <https://effectivehealthcare.ahrq.gov/products/racial-disparities-health-healthcare/protocol>.

accuracy of disease diagnosis, prognosis, and treatment and to identify those algorithms that are detrimental. As an example, a Task Force from the National Kidney Foundation and the American Society of Nephrology unanimously agreed in 2021 that race should be removed from glomerular filtration rate (GFR) estimating equation calculation and reporting.⁵⁷

Additionally, research is needed to mitigate bias and improve equity by adapting or refining existing tools so that they are based on data from a broader diversity of patients. For example, several type 2 diabetes risk prediction equations that are derived on data based on mostly White populations do not perform as well for predicting disease in Black populations. Use of such equations could systematically provide Black and possibly other understudied populations and their health care teams with less accurate information to guide health care decisions.^{58 59} Improving representation of diverse populations in the data that underlie predictive algorithms can help improve the accuracy of the algorithms for predicting risk, onset, and progression of NIDDK diseases across various populations. Large health data sets, such as electronic health record data, may be more representative of diverse populations than cohort studies or clinical trials, which often have strict exclusion criteria. However, certain populations (e.g., under-insured populations) may still not be well-represented in such data sources.

Recommendation 5: Enhance NIDDK collaboration, structures, and programs to support robust research in health equity

The Working Group recommends NIDDK optimize infrastructure, collaborations, and resources to promote health equity research, patient and community engagement, and scientific workforce development.

➤ Opportunity 5-1: Create a new, integrative guiding framework or conceptual model to support health equity research in NIDDK's mission

Research that addresses health disparities involves study designs that account for interactions among multiple levels of influence (e.g., individual, interpersonal, organizational, community, environmental, and policy) and that examine socioeconomic and environmental determinants of disparities. Therefore, a framework or a conceptual or logic model—that blends social and behavioral, clinical, and biological theory and methods, with practical application—would help promote effective health equity research study designs. A number of frameworks and models for research on health disparities and health equity are available, such as the [NIMHD Research Framework](#), which can be adapted.

Various frameworks include common concepts, such as the importance of community contexts as key health determinants and their associations with race and ethnicity, as well as socioeconomic status, gender, and geography.⁶⁰ Each framework has different utility depending on the research question, methods, and intended outcomes. Some models have limited information about the directionality and causality of relationships between SDOH exposures and outcomes, and few models specifically acknowledge structural racism and other forms of oppression and discrimination. Additionally, while multi-level designs advance research to address health disparities, the field lacks metrics for assessing how each level of influence and its corresponding intervention component may vary for a given disease.

A more integrated framework would better reflect the complexity of health disparities and health equity issues and illustrate how interventions to improve health equity could be designed and conducted. The Working Group encourages NIDDK to support the development of a new scientific research framework for health equity research across the institute's mission areas. A new framework tailored to NIDDK research should recognize the effects of social and structural determinants as key drivers of health and disease and should center patient and community member engagement as critical for eliminating health disparities and advancing health equity. The new framework could be adapted from existing frameworks, such as those in Appendix C, and should be empirically tested and refined as needed.

➤ **Opportunity 5-2: Provide training for the NIDDK scientific community to enhance knowledge and skills in health equity concepts and community-engaged research**

When investigators pivot into health equity research without developing the requisite skills, or engaging those who have the necessary expertise and relationships for high-quality, community-engaged work, community trust in research and health care can suffer and ironically, disparities and inequity can potentially worsen. Investigators must have appropriate training, experience, and scientific humility to optimize engagement and avoid unintended, adverse effects on communities. With growing demand for health equity-focused research, building a sufficient workforce in this space may require a combination of approaches. Possibilities include: expanding support for health equity experts to attract them to NIDDK research areas; educating existing NIDDK researchers who want to initiate new health equity research programs; and providing support and professional growth opportunities for students and trainees in this research area.

At least as important as recruiting new investigators into the field of health equity research is ensuring that the research and academic ecosystem embraces and nurtures their research programs. Historically, health equity grant applications that propose use of different, less-traditional methodologic approaches have fared less well in review despite using methodology necessary to address the multi-level complexities inherent in health equity research. Promotion committees also have been slow to champion this work. While the practices of academic promotion committees and academic journals are outside of the domain of NIDDK, the Working Group encourages the Institute to support health equity researchers by ensuring that the work is evaluated by reviewers competent in health equity research.

NIDDK can build the competency of the research community by promoting the scientific workforce's orientation to key concepts in health disparities and health equity research, and by providing guidance for integrating those concepts into NIDDK-funded research projects. The Working Group has developed a set of tips for investigators planning research in this research area that leverages the work and effective practices of experts in the fields of public health and community-engaged research. (See Figure 2, Appendix H)

The Working Group also encourages development and promotion of education and training opportunities through workshops, online modules, or other mechanisms to enhance knowledge, awareness, and skills in health equity and community-engaged research. Potential topics could include:

- a) **Historical injustices in biomedical research:** The history and cultural legacy of unethical research on people from racial and ethnic minority communities, how research practices have changed, and areas for continued improvement.
- b) **Benefits of and best practices for community and patient engagement:** The value that community engagement brings to research; identification and mitigation of investigators'

implicit biases; best practices when initiating, conducting, and sustaining rigorous community-engaged research, including how to develop infrastructure, trusted relationships, and partnerships that nurture individual and community capacity; concepts such as shared decision-making, asset- or strengths-focused framing, anti-racism, and structural drivers of inequities; and standardized metrics for evaluating effectiveness.

- c) **Relevant research designs and evaluation methods:** The methods, tools, and approaches to conduct rigorous health equity research, such as:
- i. Collaborative, transdisciplinary, and multi-sector team science, and the value of building teams with varied expertise (particularly health equity expertise), backgrounds, organizational experience, and lived experience;
 - ii. Community-based research, particularly leveraging the principles and science of community-based participatory research;
 - iii. Application of mixed methods (qualitative and quantitative) and diverse research designs (e.g., experimental, quasi-experimental, and observational studies, including natural experiments; adaptive interventions; SMART designs) that are tailored to context and uplift community voices, and why the traditional hierarchy of study designs and methods (e.g., randomized controlled trials) are not well-suited for studying upstream SDOH;
 - iv. Dissemination and implementation science to accelerate the reach and adoption of effective strategies in diverse communities, public health, and health care settings; or to terminate practices that are potentially harmful or unnecessary;
 - v. “Big data” analytic techniques to address health disparity topics and how to apply them; initiating collaborations with data science experts
 - vi. Integration of research findings into learning health systems to drive practice improvements; and
 - vii. Training on communicating to communities with NIDDK diseases and conditions and other interested parties using lay language and strategies appropriate to reach diverse communities.

Community Insights: Community-engaged Research

Subgroup 5 members shared that they hope communities with health disparities benefit from research by having more diversity in research represented, that researchers involve community members in the research process as much as possible and include their perspectives during the research development phase, and that more community-engaged research is initiated as a result of this report. Community members shared that they hope these research efforts will lead to greater equity in health for low income, medically underserved, and racial and ethnic communities.

➤ Opportunity 5-3: Promote cross-disciplinary efforts by sharing resources and seeking opportunities to collaborate across NIH and federal agencies

Cross-disciplinary efforts—such as multidisciplinary team science that involve representatives from academic research, medical, and non-medical institutions and sectors—are important for paving the way for groundbreaking insights and new, effective strategies to improve health equity. Collaborations across NIH or with other federal agencies provide a forum to share ideas, pool and synergize federal funds and other resources, and could facilitate expansion of existing studies to address multiple federal

priorities. For example, the National Clinical Care Commission’s report provides a roadmap for how different agencies could collaborate on diabetes prevention and treatment.⁶¹

5-3-1: Promote cross-governmental efforts to create a collaboration hub for federal SDOH-related research projects to share resources, data, and information

Researchers across federal agencies and NIH Institutes are studying various aspects of SDOH but may not be fully aware of efforts outside their home agency or division. The Working Group encourages the development of an online hub to consolidate and organize information about current or previous federal SDOH-related research, including descriptions of the study cohorts and types of data available. This crosswalking could minimize redundancies; generate ideas for new cross-agency, multidisciplinary partnerships and collaborations (e.g., data linkage opportunities); and provide a way to identify common interests. For example, in November 2022, NIDDK participated in a multi-agency workshop about housing and obesity in collaboration with six NIH Institutes and Centers, HUD, and the Centers for Disease Control and Prevention (CDC).⁶²

A collaboration hub could also offer a gateway for new investigators and trainees who want to conduct community-engaged research on SDOH but lack existing relationships or resources on which to build. Such an “on-ramp” might facilitate the matching of new and experienced investigators in the field and could provide a locus for advertising opportunities for early-career investigators to support existing community-partnered work.

5-3-2: Encourage and facilitate cross-department/agency longitudinal research that examines the effects of multiple SDOH on health and disease

The evidence base around SDOH consists predominantly of cross-sectional studies and short-term interventions that modify single determinants. Research that examines multiple determinants over longer periods of time is needed to understand how determinants interact and whether synergistic benefits may result when intervening on multiple interconnected areas. The typical five-year grant cycles used by NIH are often not long enough to yield this depth of understanding, or to mitigate or reverse the health effects resulting from longstanding systems of inequity. Therefore, the Working Group encourages NIDDK to explore, with other federal departments and agencies that focus on various SDOH, potential innovative funding mechanisms and methods to support longitudinal SDOH research with cross-sector collaboration. For example, an intervention study could explore the ripple effects of gentrification on neighborhoods with a research team that included city/urban/regional planners as potential partners.

➤ **Opportunity 5-4: Conduct ongoing monitoring and evaluation of research activities to eliminate health disparities and advance health equity**

Many organizations across sectors and disciplines are engaged in efforts to advance health equity within their mission areas and spheres of influence. As this dynamic space evolves, additional best practices and validated methods and metrics will become available to inform NIDDK’s efforts to eliminate health disparities and advance health equity. The Working Group encourages NIDDK to incorporate these advances into evaluation activities as they become available.

5-4-1: Conduct routine evaluation of NIDDK’s minority health and health disparities investments and public health impact

It is imperative to assess the impact of research investments on public health and the health of individuals, families, and communities. Evaluation efforts should include regular reporting of scientific

breakthroughs to the public using lay language and communication strategies appropriate to reach diverse communities. In addition, community input should be sought to inform improvements and ensure their relevance for the community members.

Further, the Working Group encourages NIDDK to continue to conduct quantitative and qualitative analyses of NIDDK investments in health equity research and related activities such as training and workforce diversity. For example, the baseline portfolio analysis process and approach described in Appendix H can be refined and replicated annually to track trends in NIDDK’s minority health and health disparities portfolio. These analyses could be augmented to incorporate additional [Research, Condition, and Disease Categories](#) or new tools that are developed through the [NIH UNITE](#) effort. NIDDK may also explore additional ways to characterize and qualitatively and quantitatively assess its health equity portfolio. Findings from regular portfolio analyses and other metrics collected to track implementation of recommendations in this Plan should be highlighted on NIDDK’s website, news releases, research updates, annual reports, and other venues.

5-4-2: Establish an ongoing forum to identify appropriate metrics and monitor progress in implementing this Plan

This Plan’s research recommendations and opportunities could be implemented on short- and long-term time horizons. The ultimate goals to eliminate health disparities and improve health equity in people with NIDDK diseases and conditions are naturally distal outcomes, given that many NIDDK diseases and conditions take years to develop. Identifying more proximal “surrogate” outcomes will be important to indicate progress toward this goal. The Working Group suggests that NIDDK establish an ongoing forum or committee with appropriate scientific expertise, as well as community members, to help identify metrics that can be regularly assessed and reported to monitor progress on the Recommendations presented in this Plan.

Conclusion

Health equity means that all people have fair and just opportunities to live long, healthy, productive lives. Many diseases and conditions within the NIDDK mission disproportionately affect many racial and ethnic and medically underserved populations, and the contributors to these disparities are wide ranging. This Implementation Plan elaborates on specific research needs and opportunities that NIDDK could undertake in pursuit of pathways to health for all. NIDDK research can foster scientific breakthroughs and provide the evidence base needed for equitable and effective clinical practice and inform public health programs and policies. NIDDK is poised to act—both within its traditional scope and with innovative strategies and collaborations—to implement the recommendations in this Plan to effect meaningful change within its research mission.

Community Insights: Reflections on Working Group Participation

Subgroup 5 members shared that they appreciated their opinions being valued and that they were able to advocate for their communities. Participation in the Working Group inspired some members to begin examining what may be missing in their own communities and how they can help fill the void in their respective communities. Community members hope that NIDDK-funded research will incorporate the Working Group’s perspectives, ideas, and suggestions to help communities and provide a better health outcome.

Selected quotes from Subgroup 5:

“Being a part of this working group meant that my voice was heard. I feel as though I was able to advocate for people that look like me.”

“It made me feel proud and honored that my opinion was valued, and it made me want to go out and do research in the community to see what is missing or where we can help or fill the void to respond to the community’s voice or the community’s calling.”

“I hope you [NIDDK] will take our ideas to help better serve our communities to help us live a healthier life and hopefully prevent diseases.”

“I believe participating in this group will facilitate change for us that feel we have been left behind.”

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DRAFT

Appendices

Appendix A: Acronyms

AASK	African American Study of Kidney Disease and Hypertension
AI	artificial intelligence
APOL1	apolipoprotein L1
CBO	community-based organization
CBPR	community-based participatory research
CDC	Centers for Disease Control and Prevention
CDE	common data element
ComPASS	Community Partnerships to Advance Science for Society
D&I	dissemination and implementation
EHR	electronic health record
GFR	glomerular filtration rate
ML	machine learning
NAFLD	non-alcoholic fatty liver disease
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
NIH	National Institutes of Health
NIMHD	National Institute on Minority Health and Health Disparities
RADx-UP	Rapid Acceleration of Diagnostics—Underserved Populations
SDOH	social determinants of health
T1D	type 1 diabetes
T2D	type 2 diabetes

Appendix B: Key Terms—Additional and Expanded Definitions

Biopsychosocial approach systematically considers biological, psychological, and social factors and their complex interactions in understanding health, illness, and health care delivery.¹

Cross-disciplinary science (multi-, inter-, trans-disciplinary) is a global term comprising multi-, inter-, and trans-disciplinarity, that references how team science draws on knowledge from different disciplines to resolve real-world, complex health problems.^{2,3} Multidisciplinary teams work in parallel or sequentially on a discipline-specific basis.⁴ Interdisciplinary teams work jointly to analyze, synthesize, and harmonize links among disciplines. Transdisciplinary teams integrate different disciplines to transcend traditional boundaries.

Ethnicity is a social-political construct used to refer to a large group of people based upon a presumption of shared cultural origin or background, language, history, religion, and set of traditions. Ethnicity categories are not scientifically based. Ethnic affiliation refers to individuals' own sense of group membership and the characteristics of the group as defined by its members.^{5,6}

Gender refers to socially constructed roles, behaviors, activities, and/or attributes that a given society associates with being a woman, man, girl, or boy, as well as relationships with each other. As a social construct, gender varies from society to society and can change over time.⁷

Health determinants are broad interconnected factors that can influence health, including genetics, behavior, environmental and built/physical influences, medical care, and social factors⁸ and should be considered in research strategies and interventions.

Health disparities is a health difference that adversely affects socially disadvantaged populations groups. Examples include higher disease risk, incidence and prevalence of disease, and mortality.⁹ Health disparities are potentially avoidable¹⁰ and could be ameliorated through scientific advances.^{9,11,12,13} as they stem from a variety of internal and external causes and contributors and include systemic differences in 1) social determinants of health, and 2) structural conditions, such as racism and other systems of oppression that drive different SDOH effects. Biological differences also contribute to health disparities—such as genetic risk factors that are more prevalent in one ancestry group than in another—and behavioral differences, which can be influenced by both biology and external factors.

Health equity means that everyone has fair and just opportunities to be as healthy as possible;¹⁴ no one is disadvantaged from obtaining one's best health because of social position or other socially determined circumstances.¹⁵ The pursuit of health equity requires addressing the social and environmental factors, which combined account for an estimated 50% to 60% of health outcomes.^{16,17} These social and environmental factors collectively are known as social determinants of health (SDOH).^{8,18,19}

Health-related social needs (or unmet social needs) are rooted in material deprivation, such as lack of resources and money to support the costs of living in modern society (e.g., food, rent, utilities, transportation, childcare, safety). The deprivation that leads to social needs being unmet is often related to SDOH, but social needs are not the same as SDOH.²⁰ Social needs can be detected by affected individuals or screenings to help connect people, including patients, to assistance interventions.

Interested parties and stakeholders are individuals, communities, or organizations who are affected by or have a direct interest in the research design, process, or outcomes. Includes patients, research participants, caregivers, health care providers, people representing health care systems and other systems, advocacy groups, and scientific professional organizations. The Working Group acknowledges that the term “stakeholder” has negative connotations for some groups, that alternative words should be used when recommended, and that the word should be carefully defined within research teams to ensure agreement on what is meant by its use (https://www.cdc.gov/healthcommunication/Preferred_Terms.html). This Report to the NIDDK Advisory Council was written in accordance with these principles. It should be noted that the Working Group does not mean to imply that equity or equitable partnerships have been achieved where either the terms “stakeholder” or “interested parties” have been used.

Internalized racism is private beliefs and biases about race and racism influenced by culture, sometimes resulting in acceptance of negative messages about one’s abilities and intrinsic worth. It may take different forms: prejudice towards others of a different race; internalized oppression; belief about the superiority or entitlement of White people.²¹

Interpersonal racism (also known as personally mediated racism) occurs when individuals from socially and politically dominant racial groups behave in ways that diminish and harm people who belong to other racial groups. Examples include demonstrating a lack of respect (poor or no service, failure to communicate options), suspicion (shopkeeper’ vigilance, everyday avoidance), devaluation (surprise at competence), and dehumanization (police brutality, hate crimes).²¹

Marginalized groups are groups and communities that experience discrimination and exclusion (social, political and economic) because of unequal power relationships across economic, political, social and cultural dimensions.²²

Minoritized groups emphasizes that one is not born into a minority status, but rather oppressed into such via systemic structures that confer power or privilege on one or more groups.²³ Social identity groups that have been minoritized include race and ethnicity, gender identity, sexual orientation, physical and learning disability, and others.

Multi-level approaches address at least two levels of influence (individual, interpersonal, organizational, community, educational, occupational, environmental, and policy) to target the causes of health disparities.²⁴

Several health equity frameworks are available and include common concepts, such as the importance of community contexts as key health determinants; the fundamental roles of race, ethnicity, socioeconomic status, gender, and geography in determining health; and an emphasis on the need to tailor conceptual frameworks according to different health domains and contextual levels. Virtually all frameworks emphasize the need for mutually reinforcing interventions at multiple levels to represent interrelationships among influences at each level—individual, community, neighborhood, institution, and policy. Each framework has different utility depending on the research question, methods, and intended outcomes. For example, some frameworks are designed to explain causes of disparities, while others are designed to show where and how solutions to disparities could and should focus.

Populations that experience health disparities include racial and ethnic minority populations (American Indians or Alaska Natives, Asian Americans, Black or African Americans, Hispanics or Latinos, and Native

Hawaiians or other Pacific Islanders),^a less privileged socioeconomic status populations, underserved rural populations, and sexual and gender minorities. The Working Group also included additional populations in their working definition. (See page 11.)

Race is a social-political construct used to group people often based on physical appearance, social factors, and cultural background; and is not anthropologically or scientifically based.^{5,6}

Root causes are the underlying problem(s) or fundamental reason(s) for an adverse event, without which the adverse event would not have occurred.²⁵ For example, certain economic, social, and public policies are root causes that create and perpetuate inequitable distribution of health-promoting resources. In a community, root causes are the conditions that determine whether people have access to the opportunities and resources they need to thrive and maintain health and well-being. For example, unequal allocation of power and resources are root causes that create unequal social, economic, and environmental conditions. Those conditions then lead to poorer health outcomes.²⁶

Sex is a biological category based on reproductive, anatomical, and genetic characteristics, generally defined as male, female, and intersex. *Sex* is used when describing anatomical, chromosomal, hormonal, cellular, and basic biological phenomena (e.g., sex development, sex hormones, sex characteristics).⁷

Sexual and gender minority (SGM) populations include, but are not limited to, individuals who identify as lesbian, gay, bisexual, asexual, transgender, Two-Spirit, queer, and/or intersex. Individuals with same-sex or -gender attractions or behaviors and those with variations in sex traits are also included. These populations also encompass those who do not self-identify with one of these terms but whose sexual orientation, gender identity or expression, or reproductive development is characterized by non-binary constructs of sexual orientation, gender, and/or sex.⁷

Social determinants of health (SDOH) are the conditions in environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.²⁷ SDOH may include health care access and quality, education access and quality, social and community context, economic stability, and neighborhood and built environment (e.g., availability and access to health-promoting resources such as healthy food and safe places to be physically active).²⁸ SDOH affect everyone and can influence health in a positive or negative way.

Sociobiology explores how human behavior is influenced by underlying biological and genetic characteristics as well as cultural factors.²⁹

Strengths-based or asset-based perspective views individuals and communities as inherently resourceful and capable of prioritizing problems and developing promising, acceptable solutions. It views individuals and communities as inherently resourceful and capable of self-determining priority problems and promising, acceptable solutions. It builds upon their strengths and avoids an outsider focus on the problem and pejorative descriptions that further perpetuate harmful biases. This perspective emphasizes that both individual and environmental factors should be identified that may promote or constrain health.^{30,31}

^a As defined by the U.S. Office of Management and Budget described in www.nimhd.nih.gov/about/strategic-plan/nih-strategic-plan-definitions-and-parameters.html. Self-identification is the preferred means of obtaining race and ethnic identity.

Structural racism and discrimination refers to macro-level conditions (e.g., residential segregation and institutional policies) that limit opportunities, resources, power, and well-being of individuals and populations based on race, ethnicity and other statuses, including: gender, sexual orientation, gender identity, disability status, social class or socioeconomic status, religion, national origin, immigration status, limited English proficiency, physical characteristics or health conditions.³²

Systemic conditions are pervasively and deeply embedded in systems, laws, written or unwritten policies, practices, and beliefs. In the case of structural and systemic racism, these conditions produce, condone, and perpetuate widespread unfair treatment and oppression of individuals and populations based on race and ethnicity.³³

Upstream and downstream factors or interventions follow a metaphor of the flow of water in a stream to describe various levels of and relationships between factors that affect health as well as various levels of interventions to improve health. What happens “upstream” affects the water “downstream.” Therefore, addressing problems that are “upstream” can prevent “downstream” problems. Upstream factors often occur at the macro policy level (e.g., national or state); thus, upstream interventions seek to reform the fundamental social and economic structures that distribute wealth, power, opportunities, and decision-making. Downstream factors often occur at the individual and family level; and downstream interventions seek to increase equitable access to health and social services.³⁴

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Appendix C: Examples of Health Equity Frameworks

Framework	Description
NIMHD Research Framework ¹	Multi-dimensional model depicting different domains and levels of influence that help promote minority health and health disparities. Includes factors ranging across the lifespan to consider in NIMHD and NIH minority health and health disparities research portfolios.
WHO Conceptual SDOH Framework ²	Action-oriented framework demonstrating how structural determinants, social determinants of health inequities, and intermediary determinants play roles in determining health outcomes.
De Beaumont Foundation Social Determinants and Social Needs Moving Beyond Midstream ³	Strategies and tactics for addressing social determinants and social needs beyond medical interventions. Discusses health as a stream metaphor with upstream factors bringing downstream effects.
BARHII: Public Health Framework for Reducing Health Inequities ⁴	General health equity framework to illustrate connections between social inequalities and health; has been used as a guide and framework for public health departments' decision-making.
The Health Equity Implementation Framework ^{5,6}	Informs an understanding of health care disparity implementation challenges and selection of implementation strategies. Can be used to modify other implementation frameworks to better assess health equity determinants.
A Framework for Understanding the Relationship Between Race and Health ⁷	Emphasizes macro social factors (racism, history, geography) that determine the social categories to which people are assigned and their exposure to risk factors and resources. Informs understanding of the relationships between race, medical/health care, and health.
Theoretical Model of Interconnected Mechanisms Underlying Associations Between SES and Health ⁸	Depicts interconnected mechanisms underlying associations between socioeconomic status and health. Racial biases may amplify associations between SES, social determinants, and health outcomes.
Conceptual Models: Racism as a Root Cause of Disparities in Diabetes ^{9,10}	Depicts discrimination and racial segregation as extensions of socioeconomic deprivation and root causes of disparities in diabetes outcomes in marginalized and minoritized populations.

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Appendix E: Working Group Process

In January 2021, the [Advisory Council of the National Institute of Diabetes and Digestive and Kidney Diseases](#) (NIDDK), established a Health Disparities and Health Equity Working Group in response to NIDDK's three-part [Council Forum on Underrepresented Investigators and Science](#). The goal of the Working Group was to identify a range of recommendations to address high-priority research gaps and opportunities NIDDK could pursue to eliminate health disparities and advance health equity within its mission.

Executive leadership for the Working Group was provided by Dr. Gregory Germino, NIDDK deputy director; and Dr. Pamela Thornton, senior advisor for NIDDK workforce diversity and health equity; and Reaya Reuss, executive secretary.

The Working Group of Council comprised community members with diverse perspectives and lived experience with NIDDK diseases and conditions, external researchers from across the country with extensive expertise in interdisciplinary research fields related to health disparities and health equity, and NIDDK staff with scientific and administrative expertise. The Working Group members served on at least one of five subgroups, each with defined goals.

- Subgroup 1. Engaging communities and building sustainable partnerships
 - Identify effective engagement strategies to enhance participation in all phases of research (from idea conception through award close) by communities that experience disproportionately worse health outcomes
 - Propose strategies to create and sustain partnerships for research
 - Identify strategies for developing community-driven research priorities
- Subgroup 2. Understanding social determinants of health (SDOH) effects on the biology of health and disease
 - Identify biological factors affected by SDOH
 - Examine how these factors contribute to disease development, severity, and long-term outcomes
 - Identify biological consequences of intergenerational stressors and their long-term impact on health and risk of disease
 - Identify promising intervention targets for prevention and treatment
- Subgroup 3. Identifying interventions to address SDOH effects, eliminate disparities, and improve health
 - Identify interventions that help people overcome adverse SDOH to improve health
 - Meet individuals “where they live, work, play, learn, and pray” to understand strengths, resources, and challenges in their environments
 - Examine health care and community-based supports that will improve equitable access to health promoting services and care
- Subgroup 4. Addressing upstream causes of SDOH and health disparities from an NIDDK perspective
 - Identify ways to understand/address systemic barriers to improve a community's social environment and advance health equity

- Identify cross-Federal or public-private-academic partnership opportunities to test natural experiments or participate in pilot demonstration projects to inform policy and health care practice
- Subgroup 5. Listening to community perspectives
 - Gather input from people living with and at risk of NIDDK mission diseases including
 - perspectives about health and health care experiences;
 - research needs, values, and priorities;
 - community strengths and living conditions that promote or hinder achieving optimal health; and
 - collaborations and partnerships needed

The Working Group’s business was conducted via virtual meetings, email, and an online collaboration space (Teams) in the era of COVID and restrictions on in-person meetings. A Kickoff meeting was held in December 2021, and each Subgroup met twice – once in March or April 2022 and again in June or July 2022 – to discuss recommendations. In addition, the Steering Committee – comprising the external co-chair and a community expert representative from each subgroup, the NIDDK staff co-chair from each subgroup, as well as NIDDK executive leadership, including the executive secretary – met in February and June 2022 to coordinate the activities of the Subgroups. The report was drafted by a science writer, and the Working Group was given an opportunity to revise and comment on the draft. Subgroup 5 (Community Perspectives) and the Steering Committee convened a third time, in November and December 2022 respectively, to review and discuss the report.

The NIDDK Advisory Council was provided regular updates on the Working Group’s activities throughout the process. The final report draft will be presented in January 2023 to the Advisory Council for acceptance.

Appendix F: Guiding Principles for Embedding Equity into Research

The Steering Committee of the Health Disparities and [Health Equity Working Group of Council](#) led discussions towards the development of these values and principles to guide NIDDK's health equity research efforts.

Creating pathways to health for all

The NIDDK [Strategic Plan for Research](#) and this report both aim to foster research that creates *pathways to health for all*. Health equity, the state in which everyone has a fair and just opportunity to attain their best health, is a fundamental goal of this work. It requires embedding equity or fairness into *all* research activities across the spectrum of NIDDK's basic, clinical, and translational biomedical sciences.

Applying an equity lens

Embedding equity into research entails adopting an equity lens or perspective that considers — at each decision point — how processes, values, assumptions, and actions may affect inclusive excellence in our research and workforce, and the overall well-being and health of diverse population groups. An equity lens considers systemic inequalities to ensure all people have access to the same opportunities and outcomes, especially communities who experience historical and contemporary forms of marginalization, discrimination, or oppression. A key strategy for addressing health inequities includes expanding individual-level approaches to also address broad levels of influence that shape population health, namely the social determinants of health (SDOH). An equity lens also views individuals and populations through an asset-based approach that recognizes their strengths and resources; and examines individuals in the context of their environment, including the obstacles they face to achieving their best health.

NIDDK should embed equity into its research efforts to promote biomedical research innovation, eliminate health disparities and advance health equity, and create pathways to health for all.

Values and principles for embedding equity into research

To advance equity in research, NIDDK should consider and adopt the following values and guiding principles:

- **Maintain a Robust Health Equity Research Portfolio.** NIDDK research across the spectrum of biomedical and behavioral sciences will consider, examine, and address individual and structural factors that differentially lead to poor and desirable health outcomes across population groups. This involves addressing contributors to population health disparities in NIDDK-related mission diseases and conditions since social factors, such as health and structural determinants, are major contributors to population health disparities.
- **Partner with Diverse Communities.** NIDDK will support research and activities that build and sustain equitable and effective processes and partnerships with a diverse group of individuals, patients, and community members impacted by NIDDK diseases and conditions. These relationships must be

rooted in trust that is developed over time; have shared leadership models, reciprocity and mutual benefit; and pursue research activities that address the priorities of communities the research is intended to support. NIDDK will prioritize building relationships with communities most impacted by the Institute's mission-related diseases and conditions, and those stakeholders involved in providing their health resources and care.

- **Include diverse populations in research.** NIDDK will work to ensure that studies of people or of their samples in both clinical studies and laboratory-based studies maintain appropriate inclusion of individuals/samples from diverse racial and ethnic backgrounds, and other groups who are underrepresented in research.
- **Promote diverse perspectives in research.** NIDDK will support multidisciplinary research teams that include investigators with diverse scientific expertise, community experts with lived experience, and leaders and front-line workers from healthcare, CBOs, and non-health care sectors. NIDDK research activities will promote inclusion of these diverse voices, recognize their unique expertise, and facilitate shared power on research teams to co-create approaches and scientific innovation that advance health equity.
- **Nurture a Diverse, World-class Workforce.** To attract and retain the talent needed at all career stages to achieve the Institute's scientific mission, NIDDK will seek to enrich its internal and external workforce to reflect the country's diversity in biomedical scientific expertise and in demographic, geographic, and social backgrounds, including gender identity, sexual orientation, and disability status.
- **Support Appropriate Consideration of Race, Ethnicity, and Gender in Research.** NIDDK will support research that appropriately recognizes that race and ethnicity were created for social and political reasons and do not have a biological basis. However, race and ethnicity can be a risk factor for racism and associated stressors. In addition, gender is distinct from biological sex and reflects social roles and behaviors that occur in a historical and cultural context and vary across societies and over time. NIDDK will consider the multiple mechanisms through which racism creates and perpetuates health disparities among racial and ethnic minority populations (e.g., biological consequences of racism), and will support research that thoughtfully considers how race, ethnicity, and gender are incorporated in the study design and interpretation of the results.
- **Promote Transparency and Accountability.** NIDDK will effectively communicate research opportunities and discoveries to scientific and non-scientific audiences and communities, with a particular focus on lay-friendly language for those impacted by the Institute's diseases and conditions, their families and caregivers, and the professionals involved in their healthcare. NIDDK will regularly assess and report on progress towards our health equity research goals and seek community input to inform improvements.

Appendix G: Tips for Pursuing Competent Health Equity Research

The Working Group Steering Committee discussed and recommended NIDDK provide a series of considerations for investigators planning research to eliminate disparities and advance health equity. The tips presented here were developed by NIDDK staff in response to those discussions. They leverage the work and effective practices of experts in the public health and community-based participatory research fields.¹

NIDDK encourages researchers to emulate competent equity research in health by considering and implementing the following *strategies*, as appropriate to the specific study aims and methodology. NIDDK will build upon this list as the field continues to grow and evolve.

1. Identify the social factors or inequities in access to the resources and opportunities needed to be healthy. The health concern should be important to key stakeholders, especially affected populations.
2. Meaningfully engage key stakeholders, especially the affected population, throughout the research projects (before, during, after) to ensure the research is practical, more fully informed and aligns with participants' preferences and values.
3. Build the investigative team with professionals and people who have prior experience and expertise related to the equity-focus of the proposed study. Appropriately cite key literature in the field of health equity and health disparities research.
4. Develop plans for appropriate inclusion of individuals and biospecimens from diverse populations in all studies, including clinical trials, clinical mechanistic studies, and *in vitro* experiments.
5. Acknowledge race, ethnicity, and gender as social constructs and not biological variables. Explain why or how they are important to health outcomes (e.g., differential exposure to stressors such as racism, environmental and other factors, etc.).
6. Define what is meant by health equity in the research plan (i.e., concept, populations affected by the health condition, intended impact of the intervention or study). Operationalize the stated definition of health equity through the research approach, framework, and activities through the following:
 - a. Describe the affected population to be studied in terms of historical and social contexts
 - b. Include the affected population(s) in the research appropriately.
 - c. Tailor the intervention approach to the practical, sociocultural, or socioeconomic realities, need, and preferences of the affected population(s).
 - d. Describe anticipated challenges in enrolling and retaining participants from the priority population(s) through primary and contingency recruitment plans

- e. Uses well-established methods and standards that aim to understand or address the complex interplay among individual, behavioral, social and structural factors and their impact on population health. (See PCORI's Standards for Studies of Complex Interventions as an example.)
7. Explain in the research plan how the findings are expected to provide evidence for reducing health disparities and advance progress toward achieving health equity.
8. Design a dissemination plan to communicate findings to relevant stakeholders, especially study participants and affected populations, and the professionals and organizations involved in providing resources needed for health.

NIDDK acknowledges Dr. Shiriki Kumanyika, Dr. Spero Manson (Subgroup 3), and the Steering Committee for their thoughtful contributions and feedback during development of these concepts.

¹ Supplement File B, for American Journal of Public Health Article "A Framework for Increasing Equity Impact in Obesity Prevention," by Shiriki Kumanyika (kumanyika@drexel.edu). DOI: 10.2105/AJPH.2019.305221

Appendix H: Portfolio Analysis

NIDDK conducted a quantitative analysis of its supported portfolio by examining the categories of Health Disparities (HD) and Minority Health (MH) under the publicly available *Estimates of Funding for Various Research, Condition, and Disease Categories* (RCDC). Reporting for these categories is manually assigned as HD, MH, or both by NIH subject matter experts based on the categories' definitions. These definitions are examined on a regular basis and the category classifications have gone through restructuring and redefinition over time. Currently, the HD and MH categories contain five HD and MH subcategories, intended to capture the full breadth of activities that can impact minority health and health disparities. These subcategories include scientific research activities, inclusion of racial and ethnic minorities in clinical studies, training and workforce diversity, capacity building, and outreach and communication.

In this analysis, NIDDK characterized the reported portfolio of FY 2018-2021 HD and MH awards. This window was selected because the subcategories were fully implemented across NIH beginning with FY 2018, and FY 2021 is the most recent year with data publicly available. Through FY 2020, NIDDK used a distributed work model for coding MH and HD data. NIDDK's Office of Research Evaluation and Operations (OREO) staff pulled QVR data (NIH's internal database) according to a set of parameters. The awards list was then distributed to approximately 60 NIDDK Program Officers (POs) for them to assign awards within their portfolio as either MH and/or HD, and related subcategories, according to provided business rules. POs returned their designations to OREO staff, who then uploaded the data into the system for official reporting. This process was laborious and inherently led to variability in interpretation of the guidance for coding.

NIDDK changed the administrative process by which the HD and MD categories and subcategories are manually assigned from a distributed model to a centralized process beginning in FY 2021. Potential awards were identified for validation using existing RCDC fingerprint methodology. Two to three OREO staff members assigned MH and HD categories and subcategories according to business rules, or marked as not MH/HD. This change in administrative process has contributed to some variations in the year-to-year data.

The portfolio analysis did not re-assess either prior categorization of awards as MH, HD, or both, nor the subcategory assignment(s). Rather, it sought to standardize methods to quantitatively evaluate, characterize, and report about the portfolio after such determination was made.

Analysis Methodology

Microsoft Excel was used to perform the analysis. The primary data included exported award listings from the Manual Categorization System (MCS) for the MH and HD categories for each fiscal year 2018 to 2021. "All other" NIDDK awards data were downloaded from [EXPORTER](#), a key component of the NIH "open government" initiatives to provide more transparency into NIH activities, and to improve the quality and usability of data collected.

To determine the total award count and awarded amount for each subcategory, the full data set of 15,834 records was isolated to individual tabs by subcategory. For example, all Scientific Research-categorized awards were moved to the "Research" tab which contained any duplicate records across the general categories of HD and MH.

To obtain total awarded dollar amount per project, the Appl IDs (application identifiers) were selected as the primary focus along with secondary columns using a remove duplicates command execution to identify all unique values. The Appl IDs were chosen for this task, as some of the individual project numbers had multiple subawards. Each award or subaward was scrutinized for duplicity by removing any duplicate records where the amount funded in the obligated funds column and if the corresponding Central Account Number (CAN) were identical.

When the duplicate values were removed, all remaining data were combined by the project number using a pivot table. This consolidated the unique Appl IDs and amounts for each specific project number. The combined amount as presented in the pivot table was then matched to the Project Number on the subcategory specific tab using a “vlookup” formula to display the total amounts by project. A random sampling was then reviewed to verify that the data presented matched the Project total. These “cleaned data” were then used for all further analysis in the data tables and graphs presented.

Results

Table H-1 provides a summary of unique MH or HD awards and associated funding amounts for all subcategories. The columns are not additive, as awards may be assigned to more than one subcategory.

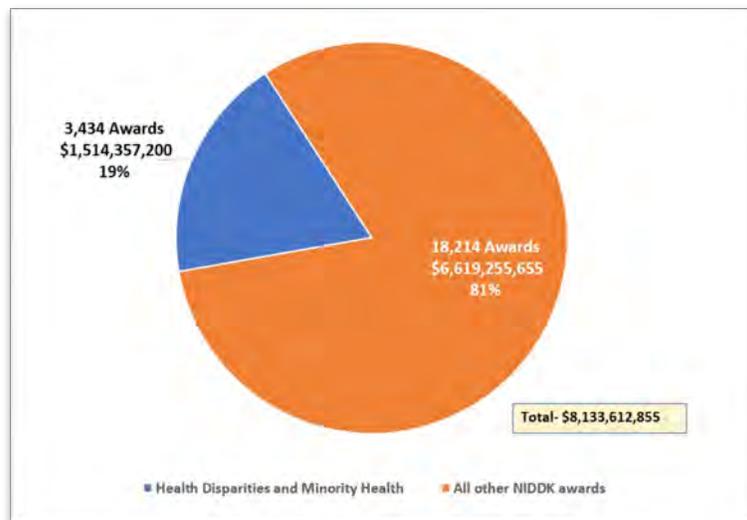


FIGURE H-1: NIDDK HD or MH awards (including research, workforce diversity, inclusion, and related subcategories) vs. all other NIDDK awards, FY 2018-2021

During FY 2018-2021, NIDDK awards categorized as HD, MH, or both numbered 3,434 and totaled \$1.514 billion, which was approximately 19 percent of the Institute’s total funding awarded during that time period (Figure 1). Nearly 37 percent of those awards were assigned to the “research” subcategory, which includes awards and projects that primarily focus on answering MH or HD research questions. The majority of MH and HD coded awards are assigned to the “inclusion” subcategory. This subcategory can be hard to interpret as clinical trials that NIDDK supports have inclusion goals for underrepresented populations to ensure results are broadly applicable; however, the research question of the trial may

not necessarily be focused on addressing a MH or HD topic. Similarly, the “biomedical workforce diversity” subcategory will be an important component to monitor as NIDDK works to realize health equity but was not the focus of this analysis.

TABLE H-1: NIDDK Awards Within HD and MH by Subcategories, FY 2018-2021

Subcategory	2018		2019		2020		2021		Grand Total	
	# of Awards	Attributed \$\$								
Biomedical Workforce Diversity	98	\$11,031,081	124	\$14,318,132	222	\$22,113,463	169	\$24,509,652	613	\$71,972,328
Capacity Building (Infrastructure)	4	\$1,911,509	9	\$10,857,191	19	\$18,769,909	58	\$21,987,780	90	\$53,526,389
Inclusion of Racial & Ethnic Minorities	543	\$297,268,678	521	\$280,835,444	541	\$261,784,496	463	\$215,846,415	2068	\$1,055,735,033
Outreach & Communication	17	\$2,567,561	17	\$2,554,992	24	\$3,109,470	40	\$8,939,014	98	\$17,171,037
Research	203	\$86,948,709	243	\$109,850,281	299	\$140,791,878	512	\$190,958,826	1257	\$528,549,694
Unique Total (not additive)	802	\$386,714,631	797	\$382,870,101	938	\$387,548,115	897	\$357,224,353	3434	\$1,514,357,200

NOTES:

- Awards are counted once within the subcategory even if coded as both MH and HD; individual awards, however, may be attributed to >1 subcategory.
- Unique Total (bottom row) is the unique number of awards and total attributed dollars to the MH or HD overall category for each fiscal year; it is not an additive value of the column.
- The Grant Total columns are additive across rows and represent the total unique count of awards and attributed amount without duplication within each subcategory.

As the Implementation Plan will focus on research activities that NIDDK can pursue, the “research” subcategory was further characterized. This subcategory includes awards and projects that primarily focus on answering MH or HD research questions. NIDDK examined the distribution of MH and HD awards among the extramural scientific divisions (Figure H-2): [Division of Diabetes, Endocrinology, & Metabolic Diseases](#) (DEM); [Division of Kidney, Urologic, & Hematologic Diseases](#) (KUH); [Division of Digestive Diseases & Nutrition](#) (DDN); and [Office of Minority Health Research Coordination](#) (OMHRC). Support was relatively evenly distributed between the three primary scientific divisions (DEM, KUH and DDN). Interestingly, OMHRC supported approximately 10 percent of the absolute number of awards, however, the total attributed funding by OMHRC was only about 3 percent of MH and HD funding. This difference in share is likely due to the relatively smaller size of grants supported through OMHRC programs. This is an important consideration as NIDDK aims to attract and support new and diverse researchers and research activities in the health equity space.

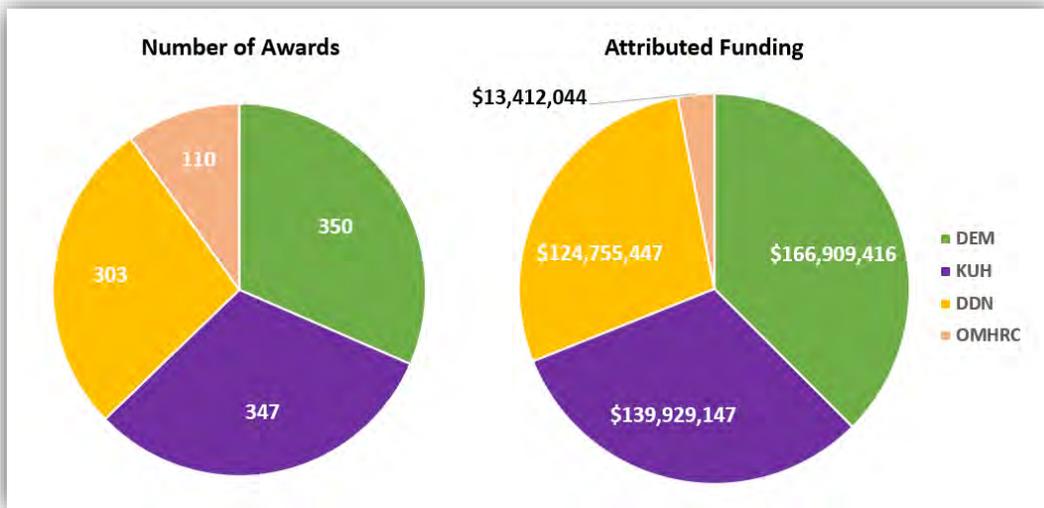


Figure H-1 - Research Subcategory MH and HD Awards by Programmatic Division, FY 2018 – 2021