

**National Institute of Diabetes and Digestive and Kidney Diseases
National Institutes of Health**

**Designing Interventions That Address Structural Racism to Reduce
Kidney Health Disparities**

**Virtual
February 24–25, 2022**

FINAL SUMMARY REPORT

THURSDAY, FEBRUARY 24, 2022

WELCOME AND OVERVIEW

Workshop Introduction and Overview

Raquel Greer, M.D., M.H.S., Division of Kidney, Urologic, and Hematologic Diseases (KUH), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

Dr. Raquel Greer welcomed participants to the workshop and acknowledged and thanked the organizing committee, including the co-chairs, Drs. Keith Norris and Deidra Crews, for their support. She noted the logistics and emphasized the three “Cs” of workshop participation: (1) contribution of all the stakeholders to the future research directions; (2) candor to tell the frank truth of what it takes to move this area of research forward; and (3) courtesy in keeping comments brief and providing others the opportunity to share.

Welcome and Opening Remarks

Larissa Avilés-Santa, M.D., M.P.H., Director, Clinical and Health Services Research, National Institute on Minority Health and Health Disparities (NIMHD)

Gregory Germino, M.D., Deputy Director, NIDDK

Robert Star, M.D., Director, KUH, NIDDK

NIMHD

Dr. Larissa Avilés-Santa noted that the NIMHD is dedicated to research in minority health and health disparities and has a strong commitment to fostering high-quality science that helps enhance our understanding of minority health. This also enables the NIMHD to move beyond describing disparities to finding solutions to these issues through interventions. This workshop aligns with the NIMHD’s mission.

Dr. Avilés-Santa reviewed some notable findings of health disparities in the literature. A 2017 publication indicated that the interventions in attaining optimal diabetes health care in American Indian and Alaska Native (AI/AN) populations led to a significant decrease in the incidence of end-stage renal disease (ESRD) in these populations. Although that decrease was significant, the incidence was considerably higher than in the non-Hispanic white population, as well as in the composite U.S. populace that did not have such an intervention. The question remains as to whether any structural racism underpinnings explain these differences, and more research is needed to identify the role of structural racism and propose potential solutions. Furthermore, a 2021 report revealed that improvements in the incidence of ESRD have not been observed in populations that experienced low income or high levels of poverty. It is

unclear whether this represents another manifestation of structural racism and discrimination or it is an interaction of well-known problems, such as access to health care and timely health care and prevention.

In addition, a 2021 study reported in *JAMA Surgery* highlighted the inverse association between receiving a living donor kidney transplant and community-level vulnerability. High community vulnerability is inversely associated with receiving a kidney transplant. Independent of community-level vulnerability, Black individuals have a 37 percent lower likelihood of receiving a living kidney donor transplant, and individuals from other racial minority populations have a 24 percent lower likelihood than white individuals, independent of the environment. Regarding other factors the field could consider in terms of health care policy, access, coverage, and quality of care, a 2016 study reported in the *JAMA Internal Medicine* compared a disparity in the quality of care for Medicare enrollees in the U.S. mainland with enrollees in the U.S. territories. The study concluded that Puerto Ricans in the Commonwealth had 15 of 17 worse performance indicators.

The NIMHD encourages its investigators to explore multilevel factors and propose multilevel research to provide solutions and interventions. Many investigators have proposed interventions to address health disparities that focus on the individual or patient level. The Institute recognized that other factors beyond the patient or their immediate surroundings influence the success of intervention or treatments. In 2018, the NIMHD established an [NIMHD Research Framework](#) that delineates the potential levels of influence (individual, interpersonal, community, or society) and their domains of influence (biological, behavioral, physical, social, cultural, and health care system). The Institute encourages research that examines and addresses these factors in a transversal, multidimensional, multilevel way. It also encourages investigators to use the [PhenX Toolkit](#) (consensus measures for Phenotypes and eXposures), which NIMHD launched in March 2020 and includes a collection of measures of social determinants of health (SDoH). Natural and human-caused disasters also can unsettle all SDoH levels. Health care and other policies affect the health of people living on the mainland, especially in the U.S. territories. In fact, Puerto Rico and the U.S. Virgin Islands were affected significantly during the 2017 hurricane season in terms of the availability of hemodialysis. These multilevel factors need to be considered in proposing and designing interventions to increase equity and address the factors that could be improved, to provide the best care, and to maintain continuity of care, regardless of the situation.

Dr. Avilés-Santa highlighted current NIMHD funding opportunity announcements relevant to the topic of the workshop, including research that investigates the [long-term effects of disasters on health care systems](#), [health services research](#), [comprehensive care for adults with type 2 diabetes \(T2D\)](#), the [etiology of and interventions on health disparities in immigrant populations](#), [the effectiveness of school-based centers](#), the [patient-clinician relationship](#), and [health care models for persons with multiple chronic conditions](#).

NIDDK

Dr. Gregory Germino, on behalf of Dr. Griffin Rodgers, Director, NIDDK, welcomed participants and thanked the planning committee for organizing the workshop. He noted that the NIDDK mission is to conduct and support medical research and research training and to improve people's health and quality of life through dissemination of science-based information on diabetes and other endocrine and metabolic diseases; digestive diseases, nutritional disorders, and obesity; and kidney, urologic, and hematologic diseases. These chronic diseases represent some of the most common debilitating and costly conditions affecting Americans today and are diseases with the starkest health disparities.

Kidney disease, a condition within the mission of the NIDDK and the focus of the workshop, is a significant public health problem with marked racial and ethnic disparities in health care and health outcomes. For example, Black individuals are disproportionately affected by risk factors for kidney

disease and are three times more likely to develop kidney failure than white individuals. Black individuals with kidney disease are also less likely to receive nephrology care before starting dialysis. This group is less likely to have received home-based dialysis modalities and less likely to be referred to and be placed on the waiting list to receive a kidney transplant. Structural racism is recognized widely as a fundamental cause of these inequities.

Structural racism is the product of a collection of reinforcing inequitable systems related to housing, education, health care, employment, wealth, and many other spheres that limit access to health-promoting resources and opportunities among marginalized communities. This leads to greater exposure to adverse SDoH, including housing insecurity, food insecurity, inadequate health care, and other adverse social and living conditions that negatively affect health. To eliminate health disparities (i.e., the avoidable differences in the burden of kidney disease experienced by racial and ethnic minorities) and achieve health equity (i.e., every person has the opportunity to attain his or her full potential), the field must confront structural racism. The need is urgent for research to develop, implement, and evaluate interventions that address SDoH and the upstream unjust systems, policies, and laws that generate and perpetuate health inequities.

The NIDDK is committed to achieving health equity and is supporting research (1) focused on understanding the underlying causes of health inequities and (2) of interventions that address SDoH that contribute to the long-standing inequities in the care and outcomes of people living with kidney disease. In December 2021, the NIDDK released its [Strategic Plan for Research](#). The overarching themes are to empower a multidisciplinary research community, engage diverse stakeholders, and leverage discoveries of connections between diseases across NIDDK's mission to improve prevention, treatment, and health equity—pursuing pathways to health for all.

Four major scientific goals comprise the strategic plan:

- Scientific Goal 1: Advance understanding of biological pathways and environmental contributors to health and disease.
- Scientific Goal 2: Advance pivotal clinical studies and trials for prevention, treatment, and cures in diverse populations.
- Scientific Goal 3: Advance research to disseminate and implement evidence-based prevention strategies and treatments in clinics and community settings to improve the health of all people, more rapidly and more effectively.
- Scientific Goal 4: Advance stakeholder engagement, including patients and other participants as true partners in research.

Crosscutting themes of the strategic plan are (1) improving women's health, (2) stewardship, (3) strengthening workforce diversity and training, and (4) increasing health equity and improving minority health. Critical to the mission of the NIDDK is achieving health equity by eliminating health disparities among racial and ethnic minority populations and others who are underserved.

The NIDDK wants to hear from patients and community partners and encouraged sharing of opinions and recommendations during the workshop. Committed to reducing and eliminating health disparities and advancing health equity, the NIDDK has established an Advisory Council Health Disparity/Health Equity Research Work Group to develop a Health Disparity and Health Equity Research Plan. The work group is composed of experts, patients, and community experts. A kickoff meeting was held in December 2021, and the group will report to the NIDDK Advisory Council during the January 25–26, 2023, meeting.

As a key funder for kidney research, the NIDDK recognizes its responsibility to address structural racism and support interventional research that aims to dismantle or mitigate the effects of this upstream driver of

health inequities. Dr. Germino, who is a nephrologist, has witnessed the profound effects and social consequences of structural racism personally and remarked that the field must do more and do better.

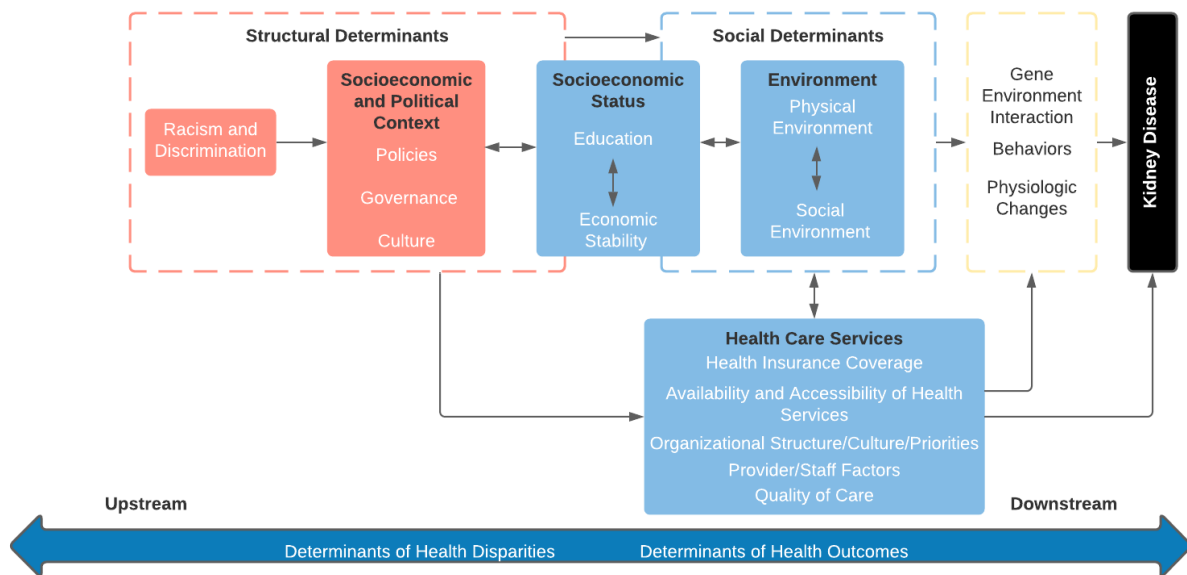
KUH, NIDDK

Dr. Robert Star also welcomed participants, noting that this 2-day workshop will consist of a series of brief and focused presentations and in-depth breakout group discussions. He pointed out that the workshop objectives are to—

- Describe the mechanisms through which structural racism contributes to health care disparities for people along the continuum of kidney diseases.
- Identify **actionable** research recommendations for interventional research focused on dismantling or mitigating the effects of structural racism.

The NIDDK aims to move beyond epidemiology associations toward causation and, critically, to interventions to stop or mitigate the harmful health effects of structural racism. Dr. Star called attention to an illustration (Figure 1) adapted from the Asthma and Allergy Foundation of America (AAFA) conceptual [Framework for Root Causes of Asthma Disparities](#) (2020 report) and the World Health Organization (WHO) [Conceptual Framework for Action on the Social Determinants of Health](#) (2010 report) of how structural racism contributes to stark and long-standing inequities in health and health care, including among people with kidney disease.

Figure 1. Conceptual framework for root causes of disparities in kidney health



This framework highlights the root cause of health disparities encompassing (1) upstream structural determinants, including inequitable societal and health care policies; (2) midstream social determinants (e.g., housing, neighborhood environment, food insecurity, access); and (3) downstream effectors of the social determinants on the lives of individuals at risk of and living with kidney disease. Achieving health equity for people with kidney disease necessitates interventions that target all levels, particularly upstream approaches that aim to dismantle structural racism, as well as effective, sustainable, and scalable interventions to mitigate the adverse SDoH that result from structural racism.

Dr. Star reminded participants that this is a working meeting, of which substantial time will be spent in the breakout groups and in discussion to identify future directions for kidney disease research to inform

NIDDK-funded initiatives. He echoed Dr. Germino on seeking to hear from meeting participants, who are kidney disease and health disparities research experts, patients, members of the kidney community, and other key stakeholders. The NIDDK wants to learn from its colleagues in other fields who have done groundbreaking studies—including research on people with asthma, obesity, hypertension, and diabetes—recognizing that kidney disease will be more challenging. The voices of patients, families, and caregivers are critical in ensuring that the research and recommendations that emerge from this meeting are meaningful to the people being served.

SESSION 1: Racism and Health

*Moderators: Keith Norris, M.D., Ph.D., University of California, Los Angeles (UCLA)
Milda Saunders, M.D., M.P.H., The University of Chicago*

Structural Racism and Health: Where Have We Been and Where Are We Going?

Kimberly Jacob Arriola, Ph.D., M.P.H., Emory University

Dr. Kimberly Jacob Arriola explained that by definition, structural racism is a fundamental cause that sets in motion causal pathways, leading to health effects through downstream factors that are more readily apparent. Racism is defined as an organized system premised on the categorization and ranking of social groups into races, and devalues, disempowers and differentially allocates desirable societal opportunities and resources to racial groups regarded as inferior. Broadly, structural racism is a form of discrimination that is embedded pervasively and deeply in and throughout systems, laws, written and unwritten policies, entrenched practices, and established beliefs and attitudes that produce, condone, and perpetuate widespread unfair treatment of people of color. Gee and Ford in 2011 and others have reported findings indicating that structural racism is not what is visible (i.e., covert racism) and is not the experience of racial discrimination that is witnessed, but encompasses the values, practices, norms (i.e., standards), policies, and structures that are foundational to these experiences of racial discrimination. Although policies and interventions have changed overt racism acts (e.g., cross burnings) that are seen easily and individually mediated, they do little to change the less obvious or unseen racism, resulting in structural inequalities that remain intact.

Many of the examples of structural racism—social segregation, political disempowerment, financial practices, environmental injustice, and inequities in the criminal justice system—come together to produce and reinforce economic inequalities. Economic evidence of structural racism is observed in the racial wealth gap that continues to grow and is currently three times higher than the racial income gap. In fact, by 2013, the average wealth of white families was more than \$500,000 higher than that of Black and Hispanic families. In addition, Black workers are twice as likely to be unemployed as their white counterparts. Home ownership rates vary by race. Collectively, these factors are clearly designed and are calculated and coordinated as operating through the constructs of structural racism.

Dr. Arriola highlighted context linking structural racism and health. In 2001, Byrd and Clayton provided a historical overview of Black versus white health disparities. The authors contended that these disparities are rooted in (1) 246 years of chattel slavery, including the slave health deficit; (2) 100 years of legal segregation and discrimination and a Negro medical ghetto; and (3) contemporary social, political, and economic isolation; oppression; exploitation; and a dual and unequal health system. Since our country's beginning, poor, Black, Native American, and immigrant populations have suffered the worst health status, outcomes, and health care. Modern U.S. health care has evolved but continues to face challenges shedding its problematic past. For example, in 1876, the discrimination against African Americans to enter medical school and teaching hospitals in Tennessee was so extreme that Black physicians opened one of the nation's first African American medical schools, Meharry Medical College; the first of its kind in the South to serve the Black community.

Structural racism is a fundamental cause of health. This statement is based on Fundamental Cause Theory. In 1995, Link and Phelan argued that social factors—such as socioeconomic status (SES), social networks, and social support—are fundamental causes of disease, because they determine access to vital resources. They affect multiple disease outcomes through multiple mechanisms and, consequently, they maintain an association with disease even when those intervening mechanisms change. In 2015, Link and Phelan reported racism as a fundamental cause of racial inequities in health and concluded that it meets the same conditions as SES and social support in this context. The authors put forth two pathways: racism and health via SES and racism and health independent of SES. Structural racism explains why SES and race are linked so closely in the United States. SES shapes people’s experiences of racism but does not fully explain racial disparities and health.

Regarding racism and health, the literature suggests that racial disparities and poor health research began in the late 1800s. Early explanations for these disparities focused on biological inferiority and behavioral negligence. The 1985 landmark Report of the Secretary’s Task Force on Black & Minority Health highlighted higher death rates for Blacks and other minorities than for whites, noting there were 60,000 more deaths for Blacks annually. Increasingly, in the 1990s, studies began focusing on individual experiences of racial discrimination and clinician bias during medical encounters. A classic study published by Krieger and Sydney in 1996 examined self-recorded experiences of racial discrimination and its relationship to outcomes. Work continued to proliferate into the late 1990s and into the 2000s, and the Institute of Medicine released a major report that examined health care provider bias and its relationship to diagnostic and treatment decisions.

In the 2000s, evidence linking racial discrimination and poor health across a range of different dimensions—including hypertension, obesity, breast cancer, and cardiovascular disease—began to flourish. Research attention then began to focus on understanding structural racism. In 2012, Dr. Arriola collaborated with colleagues at Emory University on a clinical study that found a correlation of increased segregation with higher likelihood of breast cancer mortality in Black women that did not exist for white women. In 2020, Krieger *et al* published research investigating redlining—a federally sponsored policy of the 1930s that discouraged lending in areas with residents of color—that showed significant associations between redlining and the modern-day risk of preterm birth, based on infants born from 2013 to 2017. Research on racism and health is based on well-documented health outcome disparities based on race, with increasing emphasis on the social determinants of racial disparities and attention on racism as a root cause. Interventions have been conducted largely at the individual level, and more studies of interventions at multiple levels are needed. However, this work poses several challenges, including challenges with measurement at the structural level and limited use of an intersectional lens. Data from the Research Portfolio Online Reporting Tools (RePORT) shows that National Institutes of Health (NIH)–funded research on racism and health has grown significantly since fiscal year (FY) 1985 to the current year, with the highest increases from FY 2020 to the current year. Dr. Arriola highlighted that from FY 2004 and beyond, the NIDDK-funded research on this topic has moved increasingly beyond biological explanations for disparities.

Dr. Arriola next described ways to combat structural racism, noting that it requires applying an antiracism lens. In his book *How to Be an Antiracist*, Ibram X. Kendi argues that all policies and practices are either racist or antiracist. With this understanding, Dr. Arriola described what individual actors can do, including acknowledging privilege; advocating examination of antiracist policies, practices, and processes; emphasizing structures; examining their own processes and practices and the ways in which they support structural racism; and being willing to make mistakes. Clinicians and scholars can learn about, understand, and accept that structural racism is woven into U.S. history. This group also can advocate for attention to policy systems and practices that uphold structural racism; conduct research on the structural drivers of health disparities; and lead in the development of measures. Last, funders can call out structural racism as a determinant of health disparities; fund scientifically rigorous research that

examines mechanisms and interventions; build diverse review committees; encourage the creation of diverse research teams that rely on community voice; and focus research on policy, systems, and environmental change.

Interventions to Address Structural Racism: Challenges and Opportunities

Arleen Brown, M.D., Ph.D., UCLA

Dr. Arleen Brown explained that racial and ethnic minority populations face multiple levels of mutually reinforcing structural disadvantages that are linked to racism and discrimination. During the past 3 decades, the field has seen dramatic expansions of the evidence base for identifying, tracking, and understanding contributors to health disparities, including frameworks for chronic kidney disease (CKD). Many recent interventions have focused on developing and testing strategies to mitigate disparities. Most have focused primarily on behavior change at the individual and interpersonal levels, while few address the multiple drivers of health disparities and strategies to achieve sustained improvement in health or reduction in disparities.

A WHO framework on improving global health outlines strategies to improve the conditions of daily life by addressing structural drivers, specifically the inequitable distribution of money, power, and resources. This WHO framework also considers gender, race, jobs, school education, and housing, among many other factors, and is applicable to the United States. The Kaiser Family Foundation published a framework that incorporates similar elements. It focused on social and economic factors that drive health outcomes, such as economic stability, neighborhood and the physical environment, education, food and food insecurity, community and social context, and the health care system. This framework emphasizes how these factors are undergirded by racism and discrimination, resulting in a disproportionate impact on health outcomes (e.g., morbidity and mortality, life expectancy, health care expenditures, health status) in minority communities.

Structural interventions attempt to change the social, physical, economic, or political environments that may shape or constrain health behaviors or outcomes. Dr. Brown described four important features of structural interventions to improve health equity. The first is context, which influences the individual- and community-level risk and identifies points of intervention and mechanisms by which risk and protective factors interact. These influences, for example, are observed in multilevel, multi-setting interventions to address childhood obesity. These include individual and family-based education, social networks, environmental settings (e.g., access to fruits and vegetables), collective efficacy, and macro-level policies. The second is authentic community and stakeholder engagement, which is critical to the development, implementation, and sustainability of interventions. The Community Partners of Practice, a multi-stakeholder coalition to address mental health disparities in Los Angeles County, California, is one such project. This coalition collaborated to broaden the definition of mental health “treatment” to include structural factors, such as homelessness, unemployment, safety, school dropout rates, and incarceration. The third feature of structural interventions is that they are disease-agnostic and focus on the common risk factors that contribute to multiple health disparities. Two such strategies are the New York City-based [ParentCorps](#) and the Earned Income Tax Credit Policy. The fourth involves the timing and location of the intervention, which may be more effective at certain points during the life course or within specific geographic regions. One project is the U.S. Department of Housing and Urban Development (HUD)–sponsored Moving to Opportunity Study, a randomized housing experiment that demonstrated that children from low-income and minority families who relocated from very high-poverty to low-poverty areas had better long-term outcomes if the move occurred before age 13.

Dr. Brown pointed out challenges to the development, deployment, and evaluation of structural interventions. These include measurement and methodologic challenges; the lack of common frameworks; funding that is often siloed within sectors or allocated in restricted ways that limit innovation

and collaboration; and the length of time it takes to observe the impact of structural interventions. In addition, lack of data on the sustainability, scalability, and replicability of successful interventions and on how best to adapt these interventions in different geopolitical contexts and resource environments leads to gaps in understanding of dissemination and implementation. She discussed the need for rigorous study designs to evaluate structural interventions, pointing out that randomized clinical trials (RCTs) may not be feasible or desirable and the role of other approaches, such as quasi-experimental studies and implementation science approaches.

Furthermore, the authentic community and stakeholder engagement needed to make programs successful takes time, resources, and patience. Dr. Brown highlighted opportunities and recommendations to develop, implement, and test structural interventions to reduce health disparities, the themes of which include improved qualitative and quantitative data collection on structural factors at multiple levels; robust methods for design, implementation, and evaluation of structural interventions; community and stakeholder engagement and partnership to build trust and capacity; funding that is not siloed and supports collaborations, including flexible, accessible funding for community-organization; new care models for providing and financing primary and specialty care and adapting models that have worked in other settings (e.g., community health workers, navigators, etc.); and creating more opportunities for training an interdisciplinary workforce, involving more people in multisectoral work, enhancing diversity in the investigator pool, and including community members as staff or participants in the research. In conclusion, Dr. Brown noted that structural interventions can change individual and community-level trajectories of health and social well-being.

Structural Racism, Housing, and Health Equity

Danya Keene, Ph.D., Yale School of Public Health

Dr. Danya Keene remarked that the United States has a severe affordable rental housing crisis that has been further exacerbated by the COVID-19 pandemic. Housing is expensive and unaffordable, even for full-time wage earners. In 2021, an average minimum-wage worker would have to labor 97 hours per week to afford the rent for a two-bedroom apartment. Lack of housing options contributes to multiple forms of housing insecurity, including cost burdens, evictions, crowded or unsafe conditions, and homelessness, all of which affect health. Dr. Keene noted that this housing crisis has not been experienced equally. In fact, an ongoing history of racially discriminatory housing policy is responsible for substantial inequalities in housing vulnerability. Communities of color, particularly Black Americans, have experienced systematic exclusion from housing opportunities (e.g., redlining), serial displacement and housing loss from such efforts as urban renewal, and residential racial segregation, which is considered a fundamental SDoH and serves as a visible and omnipresent reminder of the nation's failure to address an ongoing history of racism. In addition, other forms of structural racism (e.g., discriminatory legal system and mass incarceration) compound housing barriers. Housing is a determinant not only of individual health but also of population health equity. Improving housing access can help address vast and persistent racial inequalities in health and is, thus, a platform for achieving health equity.

In terms of health outcomes and health care costs, housing affects health through multiple pathways, including through the stability, quality, and affordability of housing and neighborhoods where housing is located. Qualitative (i.e., interview-based) research by Dr. Keene and her team evaluating how housing affects the management of chronic health conditions—such as T2D—revealed many challenges for the study cohort composed of adults from low-income households. Study participants living in unaffordable housing reported having to choose between their medication, food, or rent. Others indicated being unable to find healthy foods or safe places to exercise. Some participants were homeless and could not properly store medication or take medication as needed while staying at a shelter. Many spoke on how housing challenges consume their time, energy, and emotional well-being, making it difficult to prioritize their health needs. After receiving affordable and suitable housing, participants reported improved diabetes

control. These qualitative findings are supported by epidemiological studies. A recent study by Berkowitz et al. in 2018 found that unstable housing was associated with a fivefold increase in the odds of diabetes-related emergency room use and hospitalization. Additionally, current NIDDK-funded research by Dr. Keene and colleagues suggests that being on a rental assistance waitlist associated with higher risk of uncontrolled diabetes relative to current recipients of rental assistance.

Dr. Keene reviewed studies investigating the relationship between residential segregation, diabetes, and kidney disease. In the Moving to Opportunity Study, public housing residents who received vouchers to relocate to low-poverty areas were 4 percent less likely to have an elevated hemoglobin A1C than those in a control group. A 2016 study reported that higher Black residential segregation was associated with greater diabetes mortality. In 2007, researchers found that residential segregation was associated with time-to-transplant for patients with ESRD and that dialysis facilities located in predominantly Black communities were less likely to meet Centers for Medicare & Medicaid Services (CMS) performance targets.

There are several strategies to improving health equity through housing interventions, including (1) clinic-based programs (e.g., patient navigation or medical–legal partnerships) to address barriers to housing; (2) institutional reforms, including medical respite programs and hospital system’s investments in affordable housing in surrounding communities; and (3) housing policy reform to address systemic inequalities in housing access. Examples of policy reform include efforts to address ending exclusionary zoning, implementing fair share zoning, maintaining and enforcing fair housing laws, and expanding federal rental assistance. Dr. Keene highlighted that federal investments in rental subsidies are substantially lower than the subsidies provided to higher-income homeowners through mortgage interest deduction programs and explained that a shift in these funding priorities could improve housing access. She also noted new policies to prevent housing loss—such as Right to Counsel—adopted in 2021 by Connecticut, Washington, and Maryland are likely to have significant benefits for health and well-being. Dr. Keene emphasized that it is important that housing policy interventions consider the potential for disparate impacts, unintended consequences, and unequal benefits. Dr. Keene noted that housing policies and interventions need to explicitly acknowledge the legacy of structural racism and work to undo past harms.

Advancing Health Equity Through Payment and Delivery System Reform: An Anti-racist Lens

Marshall Chin, M.D., M.P.H., The University of Chicago

Dr. Marshall Chin presented a general conceptual framework for payment and delivery system reform, described issues related to advancing health equity with payment and care transformation, and remarked on the perspective of such a reform from an antiracist lens. Dr. Chin began with key take-home messages of payment and delivery system reform:

- Be intentional about advancing health equity and addressing structural racism.
- Integrate care delivery, payment, and cultural interventions.
- Involve patients and frontline staff early.
- Use a roadmap to advance health equity that incorporates a culture of equity and systematic processes for care transformation and payment.
- Be flexible for opportunities.

In 2020, Dr. Chin published a framework for advancing health equity and outlined payment reform that supports and incentivizes care transformation that can address the patient’s medical and social needs and advance health equity. The process for ensuring the right care transformation includes implementing a roadmap to reduce disparities that involves identifying inequities within a system being evaluated, conducting a root-cause analysis to identify the drivers of disparities in your particular setting, and designing and implementing care interventions to address those specific root causes in your particular

setting. In addition to the technical aspects, the framework requires creating a culture of equity across an organization, including understanding personal biases and identifying system structures that may be biased against and oppress marginalized populations. Dr. Chin also described the need for cross-sectoral partnerships to address medical and social drivers of health, including individual drivers and structural drivers. Commitment to the mission of advancing health equity is critical to care transformation and upstream change.

The literature indicates effective interventions enable close relationships with patients, holistically address medical and social needs, and allow close follow-up and monitoring of patients. The general themes of effective interventions include multifactorial interventions that address multiple drivers of disparities, culturally tailored approaches, and team-based care models that employ community health workers and patient navigators and involve families and communities.

Dr. Chin called attention to the Robert Wood Johnson Foundation program Advancing Health Equity Leading Care, Payment, and Systems Transformation, which has the goal of aligning payment and care transformation for state Medicaid agencies, Medicaid managed care organizations, and health care organizations to achieve health equity. Payment reform that supports and incentivizes care transformation that advances health equity considers payment in terms of three general levers: rewarding reduction of disparities; providing upfront funding (e.g., capitation, per member per month, bundled payment) for infrastructure (e.g., team-based care, community health workers, data systems to refer patients to social service agencies); and risk-adjusting payment for safety net providers and hospitals that serve populations with high social risk. Payment functionality questions to consider are related to what is being incentivized or is at financial risk (e.g., outpatient care, inpatient care, total cost of care), what is the magnitude of the incentive or financial risk, what patients and populations are being served, what are the data analytic capabilities and arrangements, what is the relationship between cost savings and quality metrics, and what are the appropriate payment targets to advance equity?

Dr. Chin next described six proposed elements of antiracist payment reform.

- Increase and sustain access to quality insurance.
- Improve the scope of insurance coverage to meet medical and social needs.
- Reform payment to support and incentivize equity-focused care transformations.
- Institute managed-care contracts standards for racial equity.
- Support the safety net institutions and the racially minoritized populations they serve.
- Bolster an antiracist culture of equity.

In closing, Dr. Chin called attention to two resources that address this topic: CMS' [Advancing Health Equity through APMs Technical Guide](#) and the Center for Health Care Strategies' [Leveraging Value-Based Payment Approaches to Promote Health Equity: Key Strategies for Health Care Payers](#).

SESSION 2: Racism and Kidney Disease

Moderators and Introduction: Janice Lea, M.D., M.Sc., Emory University

Dinushika Mohottige, M.D., M.P.H. Duke University

Racism and Risk Factors for Chronic Kidney Disease

Nwamaka Eneanya, M.D., M.P.H., University of Pennsylvania

Dr. Nwamaka Eneanya reported that according to the United States Renal Data System (USRDS) 2021 Annual Data Report, the prevalence of CKD shows an overall increase across all cohorts that USRDS reports on, including National Health and Nutrition Examination Survey (NHANES) data. The prevalence of CKD by stage and race in Medicare fee-for-service beneficiaries over age 66 shows significant

disparities; in particular, these disparities were more profound in Black individuals with advanced stages of CKD. As an explanation of these disparities, Dr. Eneanya noted that diabetes, the number one cause of CKD in the United States, is highest among Black individuals compared to other racial groups. Hypertension, the number two cause of CKD in the United States, is more prevalent in Black than white individuals and hypertension control is less common among Black and non-Hispanic individuals than white individuals. In addition, Black individuals are less likely to receive nephrology care before starting dialysis compared with other racial groups, and they have a higher risk of developing kidney failure that requires dialysis or kidney transplantation.

Dr. Eneanya and a team of national and international kidney disease experts collaborated to investigate racism as a cause for the racial and ethnic disparities in CKD and the potential effects of racism and racial discrimination on kidney pathophysiology. Prior talks have discussed the SDoH. Structural racism results in inequitable distribution of power and resources that closely tracks along racial lines. Less access to appropriate housing, greater food insecurity, and less access to health care can lead to poorer control of comorbidities, such as hypertension and diabetes. Structural racism and racial discrimination can also have a general biological impact. For example, national studies have shown higher allostatic load, a measure of chronic stress, in Black individuals than their white counterparts. Structural racism and racial discrimination also lead to altered gene expression, increased sympathetic nervous system activity, and altered metabolism of insulin and other hormones, all leading to altered kidney pathophysiology. These include hyperfiltration, kidney function decline, and activation of the renin–angiotensin–aldosterone system activation and inflammation.

Dr. Eneanya discussed the impact of using race in estimated glomerular filtration rate (eGFR) equations. She noted that the National Kidney Foundation (NKF)–American Society of Nephrology (ASN) Task Force reviewed and reassessed the use of race in eGFR equations. The eGFR is a statistical equation that is used to diagnose and manage kidney disease and includes age, sex, serum creatinine, and Black race in the computation. Using the recommended CKD-Epidemiology Collaboration (EPI) 2009 equation, a Black person would have a higher eGFR reflective of better kidney function compared to a non-Black person of the same age, sex, and serum creatinine level. Race as a modifier in eGFR equations dates back to a similar 1999 eGFR equation study suggesting racial differences between serum creatinine and measured GFR, the gold standard of assessing kidney function. The study authors attributed these differences to Black individuals having more muscle mass. Multiple studies have since shown that Blacks and non-Blacks are not inherently different biologically. In fact, more genetic similarity has been shown between than within racial groups. The impact of using race as a modifier in eGFR equations leads to explicit bias such that clinicians determine which eGFR calculation to use based on a patient’s physical characteristics. Regarding implicit bias, it is unclear how false beliefs of biological differences between Black and non-Black individuals (e.g., racial differences in muscle mass) influence clinical care. Using race in eGFR equations can delay nephrology referral, kidney transplantation evaluation, and kidney failure care and lead to improper dosing of pharmacologic treatments. Race-based equations do not accommodate patients of mixed race and ethnicity and lacks transparency with patients during shared decision-making.

Dr. Eneanya shared future approaches to ameliorate the impact of racism on kidney health. She announced that the new CKD-EPI 2021 eGFR equation does not use race, was recommended by the NKF–ASN Taskforce, and is now being implemented nationally. Potential research approaches include developing policies and processes to improve access to CKD preventive care, developing interventions that combat the effects of structural racism and discrimination on kidney health, using eGFR equations or other measures of kidney function that do not use race, and tracking the longitudinal effects of race-free approaches on racial disparities in CKD outcomes.

Racism and Dialysis Care and Outcomes

Rudolph Rodriguez, M.D., University of Washington

Dr. Rudolph Rodriguez described residential segregation as the manifestation of structural racism, highlighted associations between segregation and health outcomes and SDoH, and updated workshop participants on racism and dialysis care and outcomes. His presentation referenced the University of Virginia Race Dot Maps based on 2010 data from the U.S. Census Bureau. From a policy standpoint, Dr. Rodriguez called attention to the Fair Housing Act of 1968, which addressed housing discrimination, and the 2015 Affirmatively Furthering Fair Housing Rule that recently has been reinstated. The redlining maps of Chicago, Illinois, from the 1930s show segregation in predominately African American communities in the South Side of Chicago that persists today, based on the 2010 census data. A 2020 report on race and economic opportunity in the United States described the changes in income from 1978 to 1983 across generations stratified by race based on household income. The data indicate that African American children who grew up poor remained in this status 40 years later. In addition, data following the lives of Black boys and white boys in America showed a similar pattern: Black boys are more likely to remain poor than white boys. Conversely, Black boys who grew up rich were more likely to become poor. Furthermore, the Brown University Diversity and Disparity Report on Black–white segregation that examined 50 metropolitan areas with the largest Black populations in 2020, using the 2020 census data and measured by the dissimilarity index, showed high segregation from 1980 to 2020, with little change over 10-year periods. Collectively, these data demonstrate that segregation persists today.

In terms of segregation and health outcomes, residential segregation is strongly associated with the white–Black survival gap. This relationship is not fully explained by socioeconomic inequality. Residential segregation is associated with changes in blood pressure, incident cardiovascular disease, pollution exposure, climate change, and, recently, COVID-19 outcomes. Dr. Rodriguez led a study in 2007 that examined the relationships among urban residential segregation, dialysis facilities, and patient outcomes. The dialysis centers evaluated were located in areas made up of 75 percent Black residents. The study found that centers in these areas were less likely to offer home-based therapies or a late shift for services and had worse than expected mortality rates. Transplant rates were lower among both Black and white patients in segregated neighborhoods with a higher percentage of black residents. In 2013, NIDDK investigator Dr. Paul Kimmel and colleagues used the dissimilarity index to evaluate segregation, income disparities, and survival in patients treated with hemodialysis. The results revealed that Black patients in highly segregated areas had higher mortality rates, but no association with survival and income was observed.

Dr. Rodriguez detailed some recent data. Using geomapping, information from CMS Hospital Compare, and a map of all the dialysis units in Chicago, the standard mortality ratio was better than expected in areas of Chicago where white residents reside, which also had a higher number of CMS Five-Star Quality Rating System dialysis facilities. Arteriovenous fistula rate of less than 60 percent were observed in dialysis facilities in the South Side of Chicago in predominantly Black neighborhoods. Studies have shown that Puerto Rican dialysis patients have a higher mortality rate than other Latinos. Of the 50 dialysis units located in Puerto Rico, 37 have worse than expected mortality compared with the more than 7,000 units in the United States. Other examples of racism and dialysis care and outcomes include dialysis care and outcomes of undocumented immigrants, disparities in kidney transplantation, and disparities in end-of-life care.

Housing segregation is related to several factors, including racism, food insecurity, gun violence, environmental justice, among others—all of which affect dialysis patients that live in these areas. Interventions to end residential segregation include city plans (e.g., Chicago Roadmap), Yes In My Backyard (commonly called YIMBY) laws, the Affirmatively Furthering Fair Housing rule, reversal of gentrification, and school investment. Dialysis care and outcomes interventions include health system and

insurance approaches to fight segregation and poor health outcomes. In addition, Medicare Dialysis Facility Compare tools are being used to examine poor outcomes or limited services in segregated or other underserved neighborhoods.

Achieving Health Equity in Renal Disease: Transplantation as a Model

Winfred Williams, Jr., M.D., Massachusetts General Hospital

Dr. Winfred Williams described multilevel factors influencing disparities in kidney transplantation using a figure developed by Dr. Tanjala Purnell at Johns Hopkins School of Public Health and colleagues. These factors include population and community health–level influences, such as chronic disease burden, social networks, and geographic constraints; health systems–level barriers, including insurance coverage; health care provider–level influences, including communication skills; and donor–recipient level influences, which include medical mistrust, family and occupational structure, economic costs, and health literacy. In 2000, Epstein *et al.* reported race/ethnic disparities in kidney transplantation. Specifically, their results showed an 8 percent difference in African Americans being referred for nephrology evaluation, a 15 percent difference in those placed on a waitlist for a kidney transplant, and 35 percent difference in those receiving a transplant compared to white Americans. Dr. Rachel Patzer and colleagues at Emory University found an association of race and insurance type with delayed assessment for kidney transplantation in the United States among patients initiating dialysis. Young Black patients in the 18 to 35 years of age category were less likely to be presented the option for transplantation around the time of starting dialysis.

Transplant professionals from across the country conducted a review of kidney allocation in the United States from 2003 to 2013. Data revealed a mismatch in graft and patient survival, high discard rates, and biological and ethnic inequities. This review prompted the current system of allocation, which was implemented in 2014, to achieve several primary objectives, two of which include minimizing the loss of potential graft function through better longevity matching and reducing differences in access for ethnic minorities and sensitized candidates.

Dr. Williams detailed the changes of the reengineered kidney allocation system (KAS). The waiting time calculation incorporated a preregistration dialysis time. The kidney donor classification, standard criteria donor and expanded criteria donor, was replaced with the more granular kidney donor profile index (KDPI). The candidate classification incorporated an estimated post-transplant survival score (EPTS). The KDPI is based on 10 variables—including height, weight, ethnicity, and history of hypertension and/or diabetes,—and is graded from 0 to 100 percent, with lower scores, 0 to 20 percent, indicating higher caliber donor organs. Dr. Williams highlighted that KDPI values are now displayed with all organ offers in DonorNet®. The EPTS scores range from 0 to 100 percent and are based on the candidate’s age, time of diagnosis, current diagnosis of diabetes, and any prior solid organ transplant. In the new KAS, donor organs with KDPI of 0 to 20 percent are matched with candidates with a EPTS of 0 to 20 percent are combined to increase the opportunity for longevity matching. He also described other key allocation component changes of KAS.

Regarding the impact of the new KAS, after providing credit for pre-listing dialysis time, the percentage of transplants for recipients with 10 or more years of dialysis significantly increased. The USRDS 2018 Annual Data Report showed a more equitable distribution of deceased donor kidney transplant rates between Black and white patients. This narrowing of the disparities has not been observed in the living donor kidney transplant rates. Dr. Williams pointed out a new challenge and an example of one unintended consequence of the new KAS that involves the KDPI. The inclusion of a race coefficient in the KDPI was based on the observation that organs from Black donors were associated with a 20 percent higher graft failure rate. These organs from Black donors would have a higher KDPI and were more likely to have higher discard rates than organs from other ethnic or racial groups. Unless reassessed, this could

disadvantage Black waitlist candidates who may have rare antibodies against common HLAs in the predominantly white donor pool in the US. He proposed a solution to replace Black race as a factor in KDPI with genetic variation at Apolipoprotein L1 (*APOLI*), which is a genetic variants that has been identified as a major genetic risk factor of ESRD in African Americans. This approach would maintain risk discrimination for graft outcomes, but remove the race inflation factor and potentially lowering KDPI in some cases.

SESSION 3: Interventions—What Has Worked and What Hasn't Worked? What's Possible?

*Moderators: Neil Powe, M.D., M.P.H., M.B.A., University of California, San Francisco
Ebele Umeukeje, M.D., M.P.H., Vanderbilt University*

The Special Diabetes Program for Indians: Interventions to Improve Diabetes and Kidney Health Disparities

Carmen Hardin, M.S.N., ANP-BC, Indian Health Service

Ms. Carmen Hardin, who is Acting Director, Indian Health Service (IHS) Division of Diabetes Treatment and Prevention, provided an overview of the Special Diabetes Program for Indians (SDPI) and described interventions to improve diabetes and kidney health disparities. She explained that the AI/AN people are disproportionately affected by kidney failure from diabetes compared to all other races. The SDPI was established by Congress in 1997 as a grant program to provide funding for diabetes prevention and treatment services in AI/AN communities. This comprehensive diabetes program developed by the IHS uses evidence-based best practice approaches, is designed to address local community priorities, and has increased access to many types of health care services. The SDPI, a \$150 million per year grant program, supports 301 federal, Tribal, and urban health care programs across 35 states. Fiscal year 2022 began the 25th year of the SDPI. Grantees address local priorities and are required to implement a minimum of one SDPI Diabetes Best Practice with corresponding evaluation measures and participate in the Annual IHS Diabetes Care and Outcomes Audit. To date, 19 SDPI Diabetes Best Practices have been developed, including a Chronic Kidney Disease Screening and Monitoring Best Practice that can be accessed from the IHS website. The Diabetes Care and Outcomes Audit is the data collection tool used by the IHS to assess care and health outcomes for AI/AN people with diabetes across the nation. Data on diabetes and diabetes-related conditions, including CKD and associated treatments, are captured in this audit.

Ms. Hardin detailed the outcomes of implementing the SDPI. After increasing significantly from 2006 to 2013, diabetes prevalence for AI/AN adults overall decreased significantly from 2013 to 2017. This decline followed diabetes treatment and prevention interventions implemented by the SDPI grant programs in AI/AN communities. The end-stage kidney disease incidence rate among AI/AN adults overall declined by 53 percent from 2000 to 2016, more than for other race and ethnicity groups and similar to a previous report for this population. This is the largest decrease in incidence of any racial group. Other key diabetes outcomes in AI/AN adults for SDPI include a 37 percent decrease in diabetes-related mortality from 1999 to 2017; an 84 percent decrease in hospitalizations for uncontrolled diabetes from 2000 to 2015; and a 50 percent reduction in diabetic eye disease compared to reports from the 1980s and 1990s. In addition, diabetes prevention and treatment services (e.g., nutrition and weight management services) for the AI/AN communities significantly increased at many SDPI sites. Lastly, the SDPI has increased access to care, diabetes education, community outreach, and allows for tracking progress. The IHS Division of Diabetes Prevention and Treatment has developed clinical tools, including standards of care and treatment algorithms, to support the SDPI grantees, as well as clinicians, educators, and community representatives.

Health Care System Interventions/Implementation Science to Address Inequities in Transplant Care and Outcomes

Rachel Patzer, Ph.D., M.P.H., Emory University

Dr. Rachel Patzer explained that racism operates at multiple levels to contribute to inequities and that kidney transplant access and outcomes are rooted in SDoH. To address this multilevel problem, the field needs multilevel solutions. She described that health care system–level barriers and facilitators play an important role in kidney transplant access and outcomes. A recent review by Harding *et al*, published in 2021, evaluated nonmedical barriers to early steps in kidney transplantation among underrepresented groups in the United States and found that systematic racism is evident at all levels, including individual, interpersonal, and institutional levels; multipronged, multicomponent, multilevel approaches through interventions and policies at all these levels are needed to reduce disparities.

Dr. Patzer summarized interventions in kidney transplantation that have and have not worked. Multiple education interventions—such as improving knowledge about transplant as a treatment option—have shown promise in the early stages of gaining access to transplant. Multiple studies have targeted racial/ethnic minority populations or low-income groups, but few have specifically examined racial disparity reduction as an endpoint. Interventions focused on informational decision support for patients, educational resources, trained social worker navigators, and living donor financial assistance programs to help individual patients have shown mixed results and mixed success. Overarching themes across successful interventions include authentic community engagement, multicomponent/multilevel interventions, targeting social networks and the environment beyond the individual patient, and interactive and culturally competent education at multiple levels beyond the patient. Health system barriers and other structural factors have not been targeted as often. Increased emphasis is needed for dissemination and implementation science and real-world implementation of evidence into practice for successful interventions to realize the long-lasting impact. Methods that have worked to reduce racial disparities outside of transplant and kidney disease have included community and stakeholder engagement, multidisciplinary teams of providers, education using interactive approaches, and multifactorial interventions that target multiple leverage points along a patient’s pathway of care. She highlighted Robert Wood Johnson’s [Roadmap and Best Practices for Organizations to Reduce Racial and Ethnic Disparities in Health Care](#) as a helpful resource for designing interventions to address racist practices within institutions and at the structural level.

Dr. Patzer is the principal investigator of an NIMHD-funded health system intervention—Reducing Disparities in Access to kidney Transplantation (RaDIANT)—a community study being conducted in partnership with the Southeastern Kidney Transplant (SKTx) Coalition. The SKTx was formed in 2010 at the request of ESRD Network 6—which is composed of Georgia, North Carolina, and South Carolina—in response to the observation that the Southeast has the highest burden of CKD and ESRD in the nation but the lowest rate of kidney transplantation. This coalition of health systems—which consists of large and small dialysis organizations, organ procurement and transplant centers, kidney patient advocacy groups, patients and families, and researchers—aims to improve transplant rates in this region and eliminate health disparities in access. Dr. Patzer described the process of developing the intervention, which included conducting a needs assessment at multiple levels, including focus groups and surveys with the goal of addressing racial disparities. The multicomponent intervention included activities at the facility (e.g., audit and feedback on transplant metrics), staff, and patient levels. In this study, they observed that after a year there was a 7 percent mean difference in referral between control and intervention participants and there was racial disparity reduction in referral rates. In their process evaluation, they observed that only about half of intervention facilities adhered to all the activities. Dr. Patzer emphasized the need to use information about effectiveness, as well as sustainability, and to implement metrics to determine long-term sustainability.

Community-Engaged and Advocacy Approaches to Mitigate Social Challenges for Patients Receiving Dialysis

Lilia Cervantes, M.D., University of Colorado Anschutz

Dr. Lilia Cervantes described social challenges faced by immigrants. The Latino community represents approximately 19 percent of the U.S. population, and many are immigrants or live in mixed immigration status families. Approximately a third report limited English proficiency and face discrimination and mistrust. Thirteen percent of immigrants (8 million people) are undocumented and do not have access to public health benefits. Dr. Cervantes emphasized that access to health care for undocumented people is a structural racism issue. Kidney replacement therapy is provided widely to U.S. citizens because of the 1972 Medicare ESRD Entitlement Program. Undocumented immigrants, as well as green card holders, are excluded from Medicare, most Medicaid programs, and the provisions of the Affordable Care Act. In many states, undocumented immigrants rely on emergency-only dialysis, which requires a 1-week wait time before treatment is provided, a process that can leave them critically ill or near death. The Emergency Medical Treatment and Active Labor Act is a federal law that states that care is reimbursed only when treatment is for a medical condition that places a patient's health in serious jeopardy. Some states adopt this exact language when creating their Emergency Medicaid programs, but CMS defers to states to define the qualifying conditions and services under Emergency Medicaid programs. Washington state and Colorado have modified their qualifying conditions such that Emergency Medicaid provides reimbursement for standard-of-care dialysis.

Dr. Cervantes described a community-engagement and advocacy approach to eliminate structural racism faced by undocumented immigrants. In partnership with undocumented patients in the Colorado health system, Dr. Cervantes and her team conducted qualitative studies and other studies that focused on patients, caregivers, and clinicians. The first study consisted of qualitative interviews of patients with ESRD being treated in a Colorado safety-net hospital who reported death anxiety and significant physical and psychosocial distress as a result of the 1-week wait time requirement for dialysis. Clinicians who provided emergency-only hemodialysis to these patients described experiencing drivers of burnout, including emotional exhaustion from witnessing needless suffering and high mortality. Clinicians also indicated detaching from their patients to reduce strong feelings of empathy. Dr. Cervantes conducted quantitative studies and described a retrospective cohort study that evaluated mortality differences and health care utilization in this population. The results showed that when comparing emergency-only versus standard dialysis patients, undocumented immigrants have a fourteenfold greater mortality 5 years after initiating dialysis and tenfold greater health care utilization. A research group in Dallas conducted a similar study and found that mortality was fivefold worse 1 year after initiating dialysis for those who rely on emergency-only dialysis.

Dr. Cervantes summarized that this process—a community engagement and advocacy approach with the Latino/a/x community—to eliminate the structural racism consists of partnering with patients and other partner stakeholders to create the necessary knowledge base to dismantle structural racism. They conducted studies, cost analyses, policy analyses, and strategic advocacy. As a result, the Colorado state Medicaid agency expanded access to standard dialysis for undocumented immigrants beginning in February 2019. In 2022, Colorado further expanded access to home-based dialysis modalities. Although Colorado's efforts in implementing these policy changes have had a domino effect throughout the country, more than half the states that serve undocumented immigrants continue to rely on emergency-only dialysis. Dr. Cervantes and her team have taken steps to change this, including (1) publishing a narrative outlining steps one can take to change access to care for undocumented immigrants in their state, (2) conducting a study that interviewed patients before and after they transitioned from emergency to standard dialysis and found improvement in all five quality-of-life subscales and symptom burden, and (3) composing a letter to state Medicaid directors, led by the National Kidney Foundation and signed by many other large physician organizations advocating for policy changes to expand access to standard dialysis care for undocumented immigrants.

Dr. Cervantes detailed a community-engaged intervention to mitigate social challenges and eliminate structural racism experienced by documented Latino dialysis patients in Denver, Colorado. Her efforts initially focused on creating a palliative care intervention; through this work, she recognized that what the patients most need is support with social challenges, and these challenges were compounded by health literacy, difficulty with communication, and frustration with dietary restriction. Dr. Cervantes and her team established a community advisory panel composed of patients, caregivers, and interdisciplinary clinicians to translate her mixed-method research findings and create a navigator (i.e., community health worker) intervention to address these needs. The first study was a prospective study of a navigator intervention in which a navigator provided support with care coordination, diet, and mental health. Forty patients were enrolled, met with a Spanish-speaking navigator, completed the study, and reported improvements in quality of life and emotional support. Many reported feeling engaged in medical decision-making.

To further shape this intervention, they conducted a qualitative study to understand the perspectives of interdisciplinary dialysis center clinicians. Thirty clinicians were interviewed and described how the social challenges of their patients affected kidney care. Clinicians reported missed and shortened dialysis sessions because of transportation issues and competing social challenges, communication issues (e.g., difficulty communicating over the telephone), and lack of Spanish and culturally responsive materials to support the work of dietitians and social workers. This qualitative study informed a multisite RCT of a peer-navigator intervention, focusing on support for social challenges, communication, and use of motivational interviewing and patient activation to help them with adherence goals. To date, 140 patients have enrolled from five inner-city dialysis centers, and 138 patients have completed the study. Dr. Cervantes emphasized that peer navigators are individuals with lived experience who recruit and obtain patient consent for the trial. Baseline assessments of social challenges showed that 50 percent of patients use public transportation, which prevents them from getting to dialysis and one-third expressed concern of losing their homes and faced food insecurity. Interviews with patients for their feedback on the intervention is in progress. Dr. Cervantes noted that to continue to build the knowledge base for eliminating structural racism with research, plans have been made to perform a cost-effectiveness analysis and to partner with state health policy stakeholders to learn from other states' approaches to sustainable approaches for navigator programs. The goal is to establish an educational and training program, as well as a certificate program, for navigators interested in working in kidney disease and make it sustainable.

Community Level Interventions Addressing Food Apartheid and Its Impact on Kidney Disease Risk

Deidra Crews, M.D., Sc.M., Johns Hopkins University

Dr. Crews reminded workshop participants of the U.S. Department of Agriculture (USDA) definition of food desert (geographical-based areas with poor access to healthy foods), noting that food apartheid is a reframing of the concept of a food desert. Food desert implies that a lack of affordable and fresh food is just a geographic problem, and not one shaped by sociopolitical forces for which we are all responsible. Food apartheid, as defined by numerous scholars, is the systematic destruction of Black self-determination to control their food, hyper-saturation with destructive foods and predatory marketing, and blatantly discriminatory corporate-controlled food systems that result in communities of color being afflicted with some of the highest rates of heart disease and diabetes in history.

Data have shown that in predominantly Black communities, access to healthy foods is limited in terms of the types of stores that exist in those communities. Dr. Crews led a qualitative study among low-income African Americans with a family history of kidney failure on their perceived barriers and facilitators or CKD prevention strategies. Some of the perspectives on food access were that healthy foods were expensive and unavailable in certain neighborhoods, unhealthy foods were more convenient to prepare or access, and unhealthy dietary practices have been a lifelong habit that would be difficult to break.

Dr. Crews also described a recent qualitative research study led by Dr. Anika Hines at the Virginia Commonwealth University School of Medicine that used PhotoVoice. The study enrolled African Americans living in Baltimore City, Maryland, who had hypertension. Study participants documented their food environment using photography and participated in discussions. For example, a participant took a picture of a vacant building, and discussed how it could be remodeled into a grocery store that would be useful to the Black community. However, they felt that discriminatory practices against the Black community prevented them from making these improvements. Dr. Crews remarked on how these study results depicted structural racism related to the options in the food environment. Models of resiliency in addressing barriers to food security—such as maintaining a home garden for food—were also reported.

Food insecurity is defined as the lack of consistent access to enough food for an active, healthy life. In the United States, non-Hispanic Black and Hispanic individuals have a greater burden of food insecurity, which has spiked in the recent setting of the COVID-19 pandemic. Data from 2021 estimated that 2 million people living in Maryland experienced food insecurity. A 2017 study by Banerjee *et al.* that evaluated food insecurity and subsequent risk of kidney failure among U.S. adults with early CKD found that those experiencing food insecurity were more likely to progress to kidney failure. Studies examining dietary patterns and CKD show lower risks of developing kidney disease for people with diets rich in fruits and vegetables, as well as those who follow Dietary Approaches to Stop Hypertension (DASH) accordant diet. Clinical trials also document that these types of dietary patterns are beneficial for the kidneys.

Dr. Crews described community-level interventions that address food apartheid. She noted that communities of color, including Black individuals, face significant barriers to healthy eating and many are experiencing food apartheid. Findings on food choices, food environment, and food insecurity and the increased risk of kidney disease suggest an opportunity to mitigate this risk. Dr. Crews and colleagues launched the Five Plus Nuts and Beans for Kidneys Trial, which leverages the results of an 8-week pilot intervention study. This trial, a 12-month, community-based dietary intervention study, has enrolled 150 African American participants, most from low-income households, who had hypertension and albuminuria. The intervention is testing whether delivery of nutritional advice to adopt the DASH diet and \$30 per week worth of potassium-rich foods—tailored to personal choices and supplied by a local grocer—will reduce urinary albumin excretion and blood pressure. Participants were randomized to one of two study arms: self-directed diet group (S-DASH) that received a \$30 gift card to the same grocer (but no guidance or coaching) or the dietician-directed and coaching group (C-DASH) that received coaching and the \$30 per week of potassium-rich foods. Several stakeholders, including community organizations, are collaborating on this NIH-funded study. In addition, a community-academic partnership between Johns Hopkins University investigators and Plantation Park Heights Urban Farm was established recently to better understand participant experiences with an urban farm program aimed at reducing health disparities. Dr. Crews summarized that community-based interventions aimed at mitigating the impacts of food apartheid on kidney disease risk are feasible and acceptable.

PATIENT/CAREGIVER PANEL

*Moderators: Richard Knight, M.B.A., American Association of Kidney Patients (AAKP)
Tanjala Purnell, Ph.D., M.P.H., Johns Hopkins University*

*Panelists: Claudia Camacho, Denver Health Medical Center
Dawn Edwards, The Rogosin Institute, NxStage Medical Company
Patrick Gee, Ph.D., iAdvocate, Inc.
Katina Lang-Lindsey, Ph.D., L.M.S.W., Alabama A&M University*

Mr. Richard Knight invited the panelists, who attended as patient consultants at this workshop, to tell the stories of their personal kidney health experiences.

Ms. Dawn Edwards has been a kidney patient for 30 years after having been diagnosed at 23 years old. She experienced several forms of renal replacement therapy (RRT), including a kidney transplant. After 6 years, she restarted dialysis because of transplant rejection and is currently a home-based hemodialysis patient. Ms. Edwards has been a patient advocate for more than 25 years and frequently visits dialysis centers and does peer mentoring with patients. When diagnosed, she was told by her nephrologist that peritoneal dialysis had a high potential for infection and death and thus was left with in-center hemodialysis. She reflected that having been told this with no choice of a modality was not the best advice for a provider to give to a young patient who was working with a 2-year-old child at home. As she progressed through her journey with kidney disease, Ms. Edwards experienced many challenges. She was not considered a good candidate for home-based therapies because of noncompliance issues due to work. When she did venture into peritoneal dialysis, she thrived and was able to be engaged in her health care. She became a patient advocate and was placed on the transplant waitlist. Although her kidney transplant lasted for only 6 years, she was able to reinvent herself, return to work and she is continuing to work. Once she began home hemodialysis, Ms. Edwards further blossomed and became involved with many other organizations, including the NIH and the NIDDK, to share her experiences with and learn from other kidney patients. As an advocate, she promotes home-based dialysis treatments and kidney transplantations, which, along with mentoring, has been a rewarding experience. She helps with educating patients to become active partners in their health care and in treatment decision-making.

Dr. Patrick Gee, Sr. started by sharing his experience during a routine visit with his endocrinologist in April 2013, who had been treating him for his type 2 diabetes for 10 years. During this visit, he was informed that he had stage 3B CKD, with 30 to 35 percent kidney function, and was referred to a nephrologist. Dr. Gee noted not being aware of this condition until this stage or that diabetes was a leading cause of kidney disease. In December 2013, he began peritoneal dialysis, and he was placed on the kidney transplant waitlist in February 2016. Two donor organs made available in May 2016, but prior to surgery were found to not function well and it was canceled. He received a kidney transplant in April 2017, but experienced several complications after the procedure. He was told his kidney was still sleeping and that he would need to do a 24-hour a day dialysis regimen every 2 days until the transplanted kidney began functioning. Other complications occurred that led to three additional surgeries. After 33 days in the hospital, he was transferred to a rehabilitation facility for 6 days for occupational and physical therapy. Forty-seven days after the transplant, his donor kidney began to function, and it has continued to function.

Dr. Katina Lang-Lindsey was diagnosed with immunoglobulin A nephropathy, a rare genetic disorder that affects the kidneys, in 2000 while she was working on a graduate degree. She was placed immediately on the kidney transplant waitlist, but did not need dialysis at that time. In 2003, she began hemodialysis and noted that she did not believe home-based therapy was discussed. It may have been mentioned, but she admits given the trauma of the diagnosis, she may not have grasped that this was an option. In April 2007, she received a transplant that coincided with her earning her master's degree in social work. She did not fully realize the consequences of moving from being a patient on dialysis to a transplant recipient. After 15 years with minimal difficulty, she has recently been diagnosed with diabetes, which is presenting other challenges for her.

Ms. Claudia Camacho shared her experience as a caregiver for her father who had kidney disease. She relocated from Mexico when she was 17. Ms. Camacho worked as a language interpreter at the Denver Health Medical Center for over 5 years. She had the responsibility of explaining to patients with end-stage kidney disease that they were not sick enough to qualify for dialysis treatment. Her father was diagnosed with ESRD, and they had to go through all of the medical visits and fistula placement. They did not have a clear understanding of what the next steps were, such as filing for medical benefits. Her father was reluctant to begin dialysis, but she recognized that he was eligible as a U.S. citizen and was

able to receive dialysis three times a week, unlike the other people (undocumented immigrants) who were not as fortunate as him. Ms. Camacho's father succumbed to his illness in 2016, and she felt that they did not receive the education and information that they needed. In 2013, she was hired as a patient navigator to work with Dr. Cervantes and learned everything necessary to advise patients on their care. She remarked that had her family known about the available resources, her father may have lived longer. She is grateful to be able to work with doctors, particularly Dr. Cervantes, to interview patients to help reduce the burden of social issues and managing medical benefits and insurance.

Synopsis

Dr. Tanjala Purnell remarked on the value of having patients and caregivers share their lived experiences with kidney disease and expressed appreciation to the panel for their advocacy efforts. She summarized that the prior workshop presenters described multiple ways that racism might impact health care and health outcomes for people living with kidney disease. A major goal of this panel is to better understand the most important areas that need to be addressed and identify topics that should be a priority based on lived experiences. Panelists highlighted not being able to participate and share in treatment decision-making and how the assumptions made related to noncompliance affected treatment modality options. Medical professionals should spend more time learning about their patients and understanding patients' social context (e.g., neighborhood environment, household structure, accessibility to healthy food), rather than making assumptions or blaming patients. Other areas that were identified included the need for intervention to improve patient education and engagement in shared decision making regarding kidney replacement treatment options and the need to improve patient-provider communication and delivery of culturally competent, language-appropriate, and literacy-appropriate services that address patients' social challenges (e.g., limited access to healthy foods, transportation). Mr. Knight and Dr. Purnell thanked the panelists for sharing their stories and noted that the health care providers present would take their perspectives into consideration moving forward.

BREAKOUT DISCUSSIONS: Identify Areas for Intervention and Measurable Outcomes

Group 1: Health Care System Interventions

*Group Facilitators: Claudia Camacho, Denver Health Medical Center
Elisa Gordon, Ph.D., M.D., Northwestern University
Tom Greene, Ph.D., The University of Utah Health Sciences Center
Keith Norris, M.D., Ph.D., UCLA
Winfred Williams, Jr., M.D., Massachusetts General Hospital*

Group 2: Health Care System Interventions

*Group Facilitators: J. Richard Landis, Ph.D., University of Pennsylvania
Katina Lang-Lindsey, Ph.D., L.M.S.W., Alabama A&M University
Marva Moxey-Mims, M.D., Children's National Hospital
Rachel Patzer, Ph.D., M.P.H., Emory University
Neil Powe, M.D., M.P.H., University of California, San Francisco
Delphine Tuot, M.D.C.M., M.A.S., University of California, San Francisco*

Group 3: Community and Public Health Interventions

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Dawn Edwards, The Rogosin Institute, NxStage Medical Company
Jennifer Gassman, Ph.D., Cleveland Clinic
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Charles McCulloch, Ph.D., University of California, San Francisco
Rudolph Rodriguez, M.D., University of Washington*

Donald Wesson, M.D., M.B.A., Donald E. Wesson Consulting, LLC

Group 4: Structural Interventions Addressing Upstream Causes

Group Facilitators: Ann Bullock, M.D., retired IHS

Deidra Crews, M.D., Sc.M., Johns Hopkins University

Patrick Gee, Ph.D., iAdvocate, Inc

Dinushika Mohottige, M.D., M.P.H. Duke University

Tanjala Purnell, Ph.D., M.P.H., Johns Hopkins University

Guofen Yan, Ph.D., University of Virginia

Dr. Greer briefly reviewed the process for the breakout group sessions that were designed to help identify actionable recommendations for interventional research addressing structural racism to reduce kidney health disparities. Participants could join one of four breakout groups: two groups focused on health care system interventions, one group focused on community and public health interventions, and one group focused on structural interventions addressing upstream causes of kidney health disparities. The charge to the breakout groups on Day 1 was to identify areas for intervention, discuss meaningful and feasible interventions to address these areas, and identify key measurable outcomes to assess the impact of these interventions. On Day 2, the breakout groups selected several potential interventions identified during Day 1 and discussed approaches and study designs needed to evaluate the effectiveness of the interventions. Reporting sessions occurred after each breakout group session. Guiding questions were provided to focus the discussions.

Reports from Breakout Sessions—Intervention and Measurable Outcomes

Moderator: Raquel Greer, M.D., M.H.S., KUH, NIDDK, NIH

Dr. Greer invited the breakout group leaders to report the results of their discussions, touching on the initial considerations for a clinical trial to evaluate the effectiveness of the intervention.

Breakout Group 1 – Health Care System Interventions

Dr. Norris summarized the key themes from the group's discussion. He first framed the discussion by acknowledging that structural racism and other dimensions of power act through disenfranchisement, in which the system and other key players distance themselves from patient. This disenfranchisement results in a lack of empathy. Interventions should include using testimonials to help promote a sense of shared humanity, similar to the powerful testimonials shared by the patient panel during the workshop. Additional considerations for developing interventions that address structural racism to reduce kidney health disparities included that they should be patient-centered/patient-focused; be created in partnership with patients and communities; use culturally sensitive strategies; and promote effective patient communication to facilitate true patient engagement. When implementing interventions, investigators should employ appropriate implementation science approaches and obtain a commitment from the health system to enhance the sustainability of the intervention after the study is completed. Examples of interventions included CKD navigators (peer patients, *Promotoras*, community health workers, social workers, pharmacists) with structured training, as well as technology interventions and interventions to facilitate shared decision making. Outcome measures discussed included patient-centered outcomes, such as patient satisfaction, quality of life, and sense of empowerment, as well as perceived communication with health care providers and disease awareness; clinical outcomes, such as urine albumin-to-creatinine (UACR) ratio, blood pressure, eGFR slope, and medication and lifestyle adherence; and other outcomes, such as connecting patients to resources to address SDoH.

Breakout Group 2 – Health Care System Interventions

Dr. Delphine Tuot reported that the group discussed where—and at what level (e.g., individual, health care team, system)—to intervene within a health system. Members highlighted several areas in which to intervene, including culture change among providers and health care teams; educational tools and resources for both patients and clinician teams; CKD hotspots to address geographical disparities; electronic health record (EHR) systems (coupled with education/discussions); linkages between health systems and community organizations that could provide additional support and resources for marginalized communities; and use of risk prediction to identify patients/families most in need. The group also discussed the need to hold health care delivery institutions accountable for equity (e.g., transparent data, new metrics related to equity), to shift NIH study section priorities to advance this area of research (e.g., implementation over innovation), and to develop policies that facilitate greater patient engagement in health (e.g., transportation, childcare, paid time off). Dr. Tuot listed potential meaningful and feasible interventions, some of which include applied approaches for patient education and applied risk prediction tools (including tools that include factors related to SDoH), as well as interventions to facilitate individual engagement (e.g., increasing digital/health literacy, transportation/parking availability), reduce fragmentation of care documentation, create linkages between health care systems and community-based organizations, implement new models of care delivery (e.g., social and medical care integration, telehealth, mobile clinics), reform health system and provider incentives to address SDoH or structural racism, and increase referring providers' comfort with nephrology. The group identified two themes of key outcomes: (1) moving from efficacy to effectiveness and (2) moving from process outcomes to hard outcomes (e.g., waitlisting and transplantation). Three levels of outcomes were discussed: (1) individual outcomes that matter to patients, such as quality of life; (2) population health and health systems outcomes, including equity and structural racism measures, blood pressure, UACR, eGFR decline, and reduced end-stage kidney disease or mortality in a neighborhood or region; and (3) implementation outcomes.

Breakout Group 3 – Community and Public Health Interventions

Dr. Rodriguez summarized the group's discussions. In response to the question on where to implement an intervention to address structural racism, the group discussed the need to move beyond individual and interpersonal interventions. Discussions focused on interventions to empower communities to effect change by leveraging existing community assets to meet health needs. This includes breaking down barriers between community and providers and identifying safe and trusted places within a community (e.g., churches). The group discussed patient, community, and community-based organization engagement, calling attention to patient groups—such as the HIV AIDS Coalition to Unleash Power—that have fought for policy changes. Members highlighted the need to study policy changes and for collaborations between federal agencies, such as NIH and HUD. Other strategies discussed by the group included engaging a popular opinion leader or influencer to disseminate information and education and implementing payment/incentive reform for large dialysis organizations that serve disenfranchised communities. The group also highlighted several considerations for interventions, including meeting people where they are, rather than have them come to a health care setting; creating and strengthening partnerships with community and health care settings to ensure people are connected with services after screening; intervening at the community level (e.g., zoning laws that limit the existence of food swamps/deserts/apartheid); and fostering cross-sector collaborations to impact the context in which people live. Dr. Rodriguez highlighted key outcomes that had not previously been discussed, including community outcomes (e.g., Community Well-Being Index), social outcomes (e.g., patient activation, social risks); and kidney (e.g., rates of ESRD, transplant listing or home dialysis modalities) and other health outcomes (e.g., better diabetes control). The group also emphasized the need to validate surrogate markers, because some clinical outcomes may not be seen in the typical time frame of a grant award period and intervening upstream requires longer-term projects to provide time for planning and relationship-building between researchers and communities.

Breakout Group 4 – Structural Interventions Addressing Upstream Causes

Dr. Dinushika Mohottige summarized the group's detailed deliberations, noting that an overarching comment throughout the discussions was the need for multi-stakeholder engagement that centers the voices of individuals

with kidney disease and community organizations in all aspects of the research process. The group identified several key themes in discussing meaningful structural interventions to eliminate or reduce kidney health disparities: incentivize primary care physicians to detect, refer, and treat CKD equitably (e.g., address USPSTF guidelines); rectify major financial and business incentives of dialysis organizations (e.g., mandating accountability for key outcomes and reimbursement policies); systematically address diversification of the kidney care workforce; dismantle race-based medical practices and bolster antiracist and antibiased education; increase federal support for impactful programs, such as the IHS SDPI; enhance telehealth and broadband access; expand overall health care access; address multilevel SDoH (e.g., reduce barriers to care and health-promoting resources); increase regulation of health-harming products and incentivize health-promoting products; dismantle structurally racist federal, state, and local policies that impact all dimensions; increase support of funding for upstream factors that influence health across the life course; and reform CMS policies to ensure that equity and antiracism are embedded in dialysis and transplant center practices. Dr. Mohottige summarized the group's discussions of key outcomes, with emphasis on patient-centered outcomes (e.g., patient activation, self-efficacy, quality of life, and other patient-reported outcome measures). The group highlighted the need to ensure greater data transparency and that racialized SDoH data (e.g., income, housing, policing) are stratified by race and ethnicity. The group also proposed several additional key considerations, including the need to support data linkages across sectors, the need for funding mechanisms to consider life course factors that are upstream (e.g., childhood education, food security), and the need to increase communication regarding the landscape of interventions addressing structural racism to facilitate research collaborations and avoid duplication. The group also emphasized the need to incentivize multidisciplinary, cross-sector collaboration.

FRIDAY, FEBRUARY 25, 2022

WELCOME AND RECAP OF DAY 1

Raquel Greer, M.D., M.H.S., KUH, NIDDK, NIH

Dr. Greer welcomed participants to Day 2 of the workshop and recapped the discussions from Day 1. She noted that the overall goal was to identify actionable research opportunities for interventional research focused on dismantling or addressing the effects of structural racism to reduce disparities and improve care and outcomes for people living with kidney disease. The NIH and the NIDDK are asking how they can support and foster this work that is so critically needed to address long-standing racial inequities. The Day 1 panel sessions described how structural racism creates and perpetuates racial disparities in health, specifically for individuals with kidney disease. The experts assessed the status of interventional research to address structural racism to reduce kidney disease on this issue, detailing what has worked and what more is needed. A major highlight was the patient panel, in which invited guests shared their experiences and their perspectives on what is needed to address this issue. All sessions stimulated robust conversations. Experts in the field also identified meaningful interventions that focus on health care system factors, social and environmental factors, and upstream factors that can contribute to kidney health disparities. Dr. Greer emphasized that a common theme of the Day 1 presentations was the need for meaningful and authentic patient and community engagement throughout the research process. The Day 1 sessions set the stage for the work that will occur in the remainder of this workshop.

PLENARY SESSION

Excuse Me. Can You Tell Me How to Get to Social Justice?

Derek M. Griffith, Ph.D., Georgetown University

Dr. Derek Griffith explained that he has always heard of and sought to reach this place called Social Justice, but it and another place, Health Equity, are not described as destinations. Instead, both are described by the characteristic that they do not include: health disparities. Dr. Griffith noted that many of his ancestors have attempted to journey to these places, but it is unclear whether they reached their destinations, nor did they leave

any directions for how to get there. For his journey to Social Justice and Health Equity, as a trained health professional and public health psychologist, Dr. Griffith seeks direction getting there; details on the length of the trip; what to pack, including health professional tools to carry; how to prepare; and how to discern the right path and associated guideposts, in order to arrive confidently at the right place.

Since the 1960s, the idea of justice has been studied at an abstract level, but disagreement remains regarding the concrete details. Equality is not the same as equity and, ultimately, we are striving for justice. Equality is defined by giving everyone the same thing, regardless of need. Equity involves establishing programs, interventions, and initiatives designed to change certain structures that provide people opportunities for a period of time. At least some theories of justice, however, emphasize changing the fundamental societal structures to provide fair and equitable opportunities that will persist across generations. But it remains unclear whether social justice means achieving equity in structures and opportunities to enable people to be healthy or whether success occurs only after equal health outcomes are achieved. It is also unclear whether Health Equity is in the same direction as Social Justice or whether they are the same location. Finally, it is unclear whether Health Equity is a place, a process, or a set of values to guide our actions.

Dr. Griffith also has explored the responsibilities of the residents of Social Justice and whether everyone arriving would have already met the requirements, or if equity skills could be developed once there. He and his colleagues have identified key principles that are part of living in Social Justice:

- **Commitment to antiracism principles.** Anti-racism refers to the conscious decision to make frequent, consistent, and equitable choices that require ongoing self-awareness and self-reflection on one's personal conduct, work practices, and sociocultural expressions. Well-meaning and committed people define and practice antiracism differently. A common theme of antiracism principles is a structural analysis that helps to recognize that the world is controlled by systems, with traceable historical roots, that harm some and benefit others.
- **Emphasis on self-reflection and attention to racial equity, justice, and race and racism consciousness as foundations.** People are attentive to these goals and values and hold one another accountable.
- **Commitment to actively acknowledging their own racial, economic, and cultural biases and privilege** and to actively combatting systems of oppression across disciplines and research.
- **Understanding the history and ongoing experiences of racism in the world,** specifically where they work or conduct research.

In their most recent work, Dr. Griffith and colleagues focus on the application of antiracism to implementation science. Shelton *et al*, 2021, have proposed recommendations for addressing structural racism in implementation science that emphasize applying an equity lens to the core elements of implementation science. Their recommendations are to include structural racism in implementation science frameworks, models, and research measures; applying transdisciplinary and intersectoral, and using multilevel approaches. Recognizing that it is not possible for most people to leave their lives to travel to Social Justice, Dr. Griffith built on these lessons and suggested making our current communities more like Social Justice. From his research, this will require making critical decisions and choices about the types of changes needed and identifying which changes the field is willing to make. The challenge is that structural racism consists of multiple facets that are cultural (e.g., norms and practices), institutional (e.g., clinical care), and in different sectors (e.g., housing). Each facet brings a unique perspective and set of issues, which must be addressed collectively. In addition, research has shown that structural causes cannot be eliminated by addressing intervening mechanisms and, therefore, solving this scourge will require addressing root causes.

An overarching question is how to balance curing an illness—structural racism—with creating conditions for health and well-being in communities (i.e., social justice). The key to creating structural interventions that work

for social justice will be to leverage the existing strategies that have been effective in other health contexts, for example, HIV/AIDS. Dr. Griffith proposed creating interventions that work by (1) altering the context in which health is produced or reproduced, (2) locating the source of public health problems in factors in the social, economic, and political environments, and (3) recognizing that approaches should seek to change the root causes that affect individual risk and vulnerability. As part of an overall health strategy, structural approaches must be complemented by efforts that address individual agency to achieve maximum, long-term benefits.

Structural interventions should consider factors that influence access to information and resources (i.e., availability); social norms, values, cultural practices, and beliefs that influence health promotion (i.e., acceptability); and social, economic, and political factors that affect resources and opportunities for people to be healthy (i.e., accessibility). Dr. Griffith proposed a multilevel strategy that would focus on four areas to create social justice change. These areas are (1) **mitigate**—help individuals and communities adapt to unhealthy contexts while we work to change the environment, because many people will continue to experience harm before we achieve success; (2) **resist**—build the capacity of existing organizations and community resources that have been “standing in the gap” created by our public health and health care infrastructure; (3) **undo**—change inequitable policies and institutions that create and perpetuate inequity in opportunities and outcomes; and (4) **create**—develop new policies and institutions that develop, monitor, and sustain health and well-being.

Dr. Griffith concluded by quoting Dr. Martin Luther King, Jr.: “Human progress is neither automatic nor inevitable.... Every step toward the goal of justice requires sacrifice, suffering, and struggle; the tireless exertions and passionate concern of dedicated individuals.”

BREAKOUT DISCUSSIONS: Potential Interventions and Study Designs

Participants reconvened the breakout group discussions to finalize their clinical trial designs. The charge was to discuss approaches, strategies, and study designs needed to evaluate potential interventions.

Reports from Breakout Sessions—Final Considerations

Moderator: Raquel Greer, M.D., M.H.S., KUH, NIDDK

Dr. Greer invited the breakout group leaders to present their clinical trials.

Breakout Group 1

Drs. Norris and Williams presented the Group 1 clinical trial design. Dr. Williams explained that the group considered a number of ideas and decided to design an intervention for an NIDDK at-risk population, the pediatric CKD population.

Study: “Vulnerable Families in CKD Outcomes (VOLCANO)” (final name would be determined by patient advisors)

Aims

1. Create an innovative, patient-centered intervention to address CKD in pediatric/transition patients located in vulnerable communities.
 - a. The group proposed to include both racially/ethnically minoritized populations as well as low-income white populations because low-income white populations have experienced the “collateral damage” of post-civil rights policies
2. Test a community outreach strategy in a randomized trial of targeted communities.

3. Assess targeted outcomes, including clinical measures, patient satisfaction, establishment of trust, and cost effectiveness.

Structural Target: SDoH that impede access to care for children with CKD and their families (e.g., transportation barriers, lack of parental work leave policies, healthcare systems that are difficult to navigate)

Intervention: Pediatric transitions of care program for children with CKD and their families that:

- Provides patient navigator, social worker, and/or *promotora* outreach to vulnerable communities
- Leverages mobile technology (mHealth) to provide easier access to care
- Delivers services via a mobile van for home visits to enhance community engagement and overcome transportation and work barriers
- Includes a secondary focus on linking to community services
- Partners with local community organizations (e.g., barber shops, beauty salons, churches, community centers)
- Structured training for outreach providers

Target population: People with CKD age < 26 and their family from underrepresented minority or low-income non-Hispanic white communities

- Target lowest quartile ZIP code/census tract by income
- Potentially consider percent minority population in targeting neighborhoods
- CKD defined by Kidney Disease Improving Global Outcomes (KDIGO) criteria: elevated UACR, reduced eGFR

Design: Cluster RCT

- Cluster randomization by neighborhood
- Possible usual care control group or stepped wedge design or other delayed intervention control group
- 5-year study: 1–2 years of recruitment, 3–4 (or 5–6) years of follow-up
- 20 families per community or neighborhood
- 24 communities or neighborhoods

Outcomes: All outcomes would consider equity and include the patient and family

- Patient activation as a primary outcome to all more power and more efficient design
- Kidney biomarkers (e.g., eGFR, UACR)
- CKD risk-factor control
- Adherence
- Quality of life
- Medical trust
- Depression/anxiety
- Navigator fidelity

Discussion

- Dr. Tom Greene suggested including patient-reported outcomes that would be measured at baseline prior to the intervention.

- In response to a question on whether the major target is linkage to care or linkage to community, or both, Dr. Norris clarified that the primary level is care and the secondary target is the community.
- When asked about cost for conducting the intervention, Dr. Norris explained that this would depend on the health care setting and the insurance, noting that Medicare and Medicaid are implementing these types of models. The aims are to deliver care to this group of individuals, improve outcomes, show effectiveness and then have those data inform payment models. Dr. Williams added that this is a more patient-centered approach. Dr. Donald Wesson emphasized using the research to determine what works and then challenging the reimbursement system to support those services. He also suggested reconsidering the study name, VOLCANO, which Dr. Norris agreed.
- Dr. Norris clarified that clinical care would be supported within the capitated payment model. Dr. Greer asked what other institutional or organizational support would be needed to facilitate this intervention. Dr. Williams noted that the intent is that the study would be funded to support the initial expenses.
- Dr. Geer also asked how this intervention would demonstrate reducing disparities. Dr. Williams remarked that improving outcomes would mitigate disparities by bringing services to marginalized communities and segregated populations. Dr. Norris added that this design is about addressing a vulnerable population, but not necessarily assessing the intervention's impact on disparities because it does not include populations who are unaffected by structural barriers.
- Don Wesson noted that sustainability has been a perpetual issue in this type of work and that collaborating with community organizations may help with sustainability.

Breakout Group 2

Dr. Tuot presented the Group 2 clinical trial design. She noted the challenge in deciding between focusing on minority populations versus the broader inclusion for sustainability within a health system. Dr. Tuot also explained that the intervention will require 1 year to plan and will engage the study's community advisory board, the health system leading the intervention, and other stakeholders, which the group has identified.

Study: Tailored Virtual Team Care to Remove Structural Barriers for Individuals with CKD

Structural Target: Social needs identified by clinical screening and patient goal-setting

Intervention: Tailored, virtual team care involving:

- Navigator to identify and screen for social risks using EHR tools
- Quarterly discussions with the care team, patient, families, and caregivers about goals and needs.
- Culturally and linguistically tailored referrals to community organizations to address barriers.
- Registered nurse and pharmacist discuss medical concerns, medications, and care coordination.
- Quarterly reports in her that are available to the medical team.

Design: Three arm patient-level RCT, stratified by primary care or emergency department:

1. Usual care
2. Low touch (3 touch points over 6 months). Navigator recruits and screens for SDoH using a tool embedded in the EHR and links to primary care if needed.
3. High touch (2 years). Encompasses the low touch intervention, patient goals, virtual care team (e.g., social worker, navigator, registered nurse, pharmacist)

Target population

- *Inclusion criteria:* Individuals with unrecognized CKD or at high risk of CKD identified by clinical factors in EHR; primary care patients; individuals in the emergency department without care

Outcomes

- *Primary:* Quality of life, activation, trust in the system, engagement in goal-setting, satisfaction, general distress, caregiver burnout
- *Nephrology, primary care staff, provider:* Burnout
- *Health:* eGFR, UACR, blood pressure control
- *Equity:* Stratify by race and ethnicity, SES level
- *Implementation:* Costs and resource utilization, patient and caregiver engagement, medication changes, number of quarterly reports reviewed by providers

Barriers and facilitators

- Health care systems need to be involved and engaged for success and sustainability.
- Needs to be centered on patients and their goals.
- Staffing is expensive; clinicians may be challenging to include.
- Less physician oversight may result in less buy-in.

Discussion

- Dr. Tuot clarified that the group had not identified the navigators during this workshop and noted that *promotoras* and community health workers likely will be considered.
- Dr. Patzer emphasized the importance of gaining buy-in on the health system level, proposing multi-level, multi-component interventions to address multi-level barriers, automating solutions at the health system level, tailoring interventions to the patient's perception of what their needs are, and measuring the impact of patient burden.
- Dr. Greer asked about other unintended consequences of this intervention. Dr. Tuot replied that the group discussed potential burnout among the virtual care team and remarked on the need for consistency in providing resources to patients and their caregivers.
- When asked how the community health workers and navigators would work in collaboration with the clinical care team, Dr. Tuot noted that the group discussed such engagement by these study team members participating in regular patient-clinician visits, especially if appointments are via telehealth.
- In the context of implementation, Dr. Kevin Fowler suggested engaging organizations (e.g., Evergreen Nephrology), who are changing care models and doing similar work addressed in this study, including SDoH.
- Dr. Cervantes commented that as part of her interventional study, patients who have expressed difficulty with understanding dietary restriction are accompanied by Ms. Camacho, (who spoke on the patient/caregiver panel) for their initial appointment with the registered dietician so that information is culturally tailored. Patients also are accompanied on other clinical visits by Ms. Camacho, who also is a member of the nephrology team.

Breakout Group 3

Dr. Wesson presented the Group 3 clinical trial design. He explained that the group focused on two key aspects to address: (1) health care systems have barriers that limit vulnerable populations from accessing care and (2) the persisting medical mistrust issues. Dr. Wesson described the group's strategies to engage patients and stakeholders, including transitioning from research "on" the community to research "with" the community and designing interventions based on neighborhood structure.

Structural Target: Exposure to adverse SDoH (e.g., transportation barriers, housing insecurity, food insecurity, barriers to accessing care) specific to the contexts, needs, assets and preferences of each participating community

Intervention: Train the Trainer Program to Equip Community Health Workers that will provide:

- Screening for CDK, diabetes, and hypertension.
- Culturally and language concordant, trusted care education.
- Motivational interviewing, patient activation, and patient-centered goal setting
- Telehealth visits
- Partnership with CBOs to address social risks

Design: Stepped wedge RCT with waitlist control

Target population: Minoritized populations with or at high risk for CKD

Outcomes

- Patients screened for social risks
- Connection to care as needed
- Knowledge and awareness of CKD in community participants
- Patient activation and self-efficacy
- Community Resilience

Barriers and facilitators

- Some states require clinicians to be onsite for community health workers to deliver intervention
- Ensuring sustainability
- Leveraging existing community sites
- Certification requirements for community health workers
- Ensuring education and training is paired with resources

Discussion

- Dr. Cervantes called attention to community health worker training being developed at the University of Colorado, with curriculum spanning the kidney disease spectrum.
- Dr. Greer asked what is needed to facilitate authentic community engagement across the research process. Dr. Wesson noted setting up structures to get this input from the community to enable bidirectional conversations. One approach that has worked in his research has been establishing a ministerial advisory board that meets regularly, provides input, discusses community issues, and reviews grants. Dr. Greer

also asked for advice on what the NIDDK can do to foster these types of relationships. Dr. Wesson suggested prioritizing community-based research and/or protocols that examine contributors to CKD.

Breakout Group 4

Dr. Mohottige presented the Group 4 clinical trials, noting that the group identified 2 distinct studies.

Study 1

Study question: Does holistic provision of healthy food to people at risk of ESRD and rapid CKD progression improve kidney outcomes and risk factors for kidney disease, DM, hypertension, and other risk factors of these conditions?

Structural target: Food apartheid/food deserts, predatory food marketing (e.g. by media), and barriers to nutrition education. Structural racism manifests as variable food availability across communities, with a disproportionate burden of food swamps and food deserts in minoritized communities, as well as racialized marketing of foods that are kidney harming versus kidney health promoting.

Intervention: Multi-level food and nutrition program for individuals at risk for CKD.

Health system or provider

- A provider best-practice alert within the EHR that notifies providers when a patient lives in a food swamp or desert.
- Equip providers with the option to refer a kidney dietician trained in the principles of structural competency and equity.

Community, food environment, retailer

- Provide tax credits to food suppliers and individual stores to provide affordable access to high-quality produce and other food.
- Incentivize stores and major producers to implement kidney-friendly labeling that is plain language and culturally and linguistically tailored.

Individual

- Provide patients and families education, coaching, and nutritional support.

Design: Single, 5-year longitudinal study, with multiple time points for data collection. Clustered randomized study with randomization at two levels: 1) community level: 50 percent of communities receive healthy labeled food intervention; 2) individual level: 50 percent of participants receive patient education and health care interventions.

Target population: Individuals with early CKD and poorly controlled CKD risk factors

Outcomes

- *Individual level:* CKD progression, eGFR decline, albuminuria quantification; control of progression risk factors

- *Community level/store level:* changes in consumer availability; pricing of kidney health–promoting items; availability of kidney-friendly labeled items

Barriers and facilitators

- Buy-in from business and regulator sectors in applying an antiracist lens
- Data integration

Study 2

Study question: Do SDoH-targeted interventions (e.g., increasing food access and housing, reducing poverty) during the *in utero* period reduce risk factors for CKD across the life course?

Structural target: Resource deprivation/financial resource *strain*. Structured racism manifests across wealth inequity, housing inequity, and food insecurity and has long-term impacts beginning early in the life course (i.e., *in utero*); a life course perspective that recognizes multi-generational trauma is essential to having the greatest impact on long-term outcomes that span beyond kidney health.

Intervention: Food, housing, and income support to pregnant people to address multigenerational trauma

- Unrestricted income supplements (e.g., Baby’s First Years)
- Housing vouchers (e.g., Moving to Opportunity Study)
- Ensuring provision of healthy food to mothers and families

Design: Longitudinal multi-level RCT, 1–5 years of intervention delivery; 10 to 30 years of follow-up at various time intervals.

- Randomization of families and mothers to intervention or usual care

Target population: Pregnant individuals and their children who reside in structurally disadvantaged communities

Outcomes

Short/long-term (examples)

- Birth weight, visceral adiposity, insulin sensitivity, cortisol levels, lipids, glucose, nephron number
- eGFR decline, albuminuria
- Blood pressure, A1C, obesity
- Allostatic load, experiences of discrimination, patient activation, trust in health care

Maternal health (examples)

- Maternal food health literacy
- Dietary patterns
- Trust in health care
- Quality of life, stress, activation, anxiety

Barriers and facilitators

- Need for improved data integration

- Cost of multi-tiered intervention and follow-up
- Demonstrated impact of targeting income and wealth
- Necessitates integrating antiracism training in health systems

Discussion

- Dr. Crews clarified that the idea is to incentivize food outlets to provide healthy foods in communities that currently have limited access to these items.
- In response to a question from Dr. Williams about how the communities would be randomized to goods and benefits without introducing a new disparity, Dr. Crews explained that in the Five Plus Nuts and Beans for Kidneys Trial, groups were randomized to receive either food provision from a grocer and coaching or a gift, also provided by the same grocer. The study’s Community Advisory Board was strongly in favor of both groups’ receiving a food benefit. Dr. Wesson added that studies should be designed to address the research question on dietary interventions, as well as protect the health and well-being of the participants.
- Dr. Kevin Fowler pointed out that another area for consideration would be the role of exercise, noting that exercise has been underutilized in kidney disease.
- Dr. Williams commented that the life-course health food intervention is an ambitious trial, would be expensive to conduct, and needs to consider all that shapes the outcomes; the payoff would take more than 10 years. Dr. Ann Bullock explained that the study can be done as a short-term project, with intermediate markers that can be measured on a smaller scale.
- Dr. Powe suggested potentially narrowing the scope and increasing feasibility by focusing on gestational diabetes.

CLOSING COMMENTS

Robert Star, M.D., NIDDK

Dr. Star remarked on the energy of the discussions, the insights shared, and the progress made during discussions. He thanked the organizing committee and Dr. Greer for leading this effort. He also thanked the speakers, moderators, and facilitators for the lively discussions and expressed appreciation to the patients whose emotions, energy, and insight are critical to the NIDDK. Dr. Star commented that this workshop tackled some difficult discussion and that participants considered what he refers to as “precision antiracism” approaches to dismantling structural racism. The interventions spanned the spectrum of effectors contributing to structural racism, and Dr. Star emphasized that addressing upstream factors will be challenging. He reflected that this workshop would be remembered 20 years from now. He summarized the themes and key messages of the workshop.

Patient-Centered Themes

Patient presentations and discussion highlighted the following:

- Need for respect, careful communication, thoughtful education, and a central role in informed shared decision- making
- Need for cultural competency and greater trustworthiness
- Daily struggle with structural racism, systemic biases in healthcare and insurance systems, fragmented care, and SDoH

Timing of Interventions

In terms of standard kidney endpoints, interventions in all three areas—health care systems, community and public health, and upstream causes—had a degree of similarity to address structural racism. Proposed interventions spanned adult, pediatric, and *in utero* care. Multiple interventions emphasized early detection of CKD, with interventions centered on entry into the health care system, referral, early and appropriate treatment, and slowing CKD progression (e.g., UACR, eGFR, and trajectory). Despite initial discussions, transplant and dialysis were the least considered as endpoints for an intervention.

Interventions

The following key principles emerged from proposed interventions:

- **Putting patients first.** This includes meeting people where they are (mobile clinics, telehealth, mobile devices). Several interventions suggested developing new models of care that challenge the current reimbursement systems to provide coverage for what works—including social support and insurance for all. Many interventions also emphasized housing, the food environment, and wealth/resources as critical to health.
- **Patient navigator/community health worker studies.** Several studies highlighted the need for providing support to patients and families in accessing the health system and community resources. Many used a train-the-trainer model. Certification issues may present a barrier for such programs.
- **Large, NIH-wide studies.** A few studies may require a greater investment and could span multiple NIH Institutes. These included providing healthy food choices (via vouchers, tax credits) and nutrition education to high-risk communities and addressing multigeneration trauma by providing food, housing, and income support to pregnant women and new mothers.

Endpoints

Dr. Star noted types of endpoints that should be measured:

- Fidelity of the intervention, including adherence;
- Patient-centered measures (e.g., respect, trust, shared decision-making, satisfaction, quality of life, resilience);
- Standard kidney disease/function and trajectory;
- Associated conditions (diabetes, hypertension, obesity, allostatic load).
- Regulatory requirements—what data FDA (safe and effective) and CMS (necessary and reasonable) will need

Other Ideas

Dr. Star also noted several other ideas that had emerged during the meeting: (1) community-led interventions in which a community chooses the social risks to address based on its needs; (2) microfinance grants to support people at risk for CKD to spend on what they need; (3) support for research to address dissemination and implementation of strategies known to be effective, such as a pharmacist intervention focused on getting patients with CKD on the appropriate medication; and (4) behavioral economic incentives to improve adherence and trust.

Planning and Moving Forward

Dr. Star emphasized the need to ensure that the solutions (i.e., interventions) will be used by the health care system and will be sustainable. Having discussions with payors about the evidence they need to implement new payment models will be essential. For example, CMS is interested in understanding the evidence to support coverage for patient navigators. Efforts should be focused on working across diseases and engaging NIH-wide

activities, because patients typically have multiple chronic conditions. Dr. Star explained that a meeting summary will be posted and potentially other papers will be developed. He conveyed that the NIDDK is interested in this topic and announced that a research initiative on this topic has been approved by the NIDDK Advisory Council, and a funding opportunity is forthcoming.

ADJOURNMENT

Dr. Greer thanked the organizing committee, panelists, moderators, and facilitators for their support and all participants for attending the meeting. The meeting was adjourned at 3:35 p.m. EST.

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