Abstract

Neurologic mortality is increasing in the United States and is occurring in an inequitable manner. There is a major need for innovative research strategies to eliminate these inequities. In 2020, the National Institute of Neurological Disorders and Stroke (NINDS) embarked on a health equity strategic planning process, which culminated in a 3-day public workshop and research recommendations provided by a working group of its National Advisory Neurological Disorders and Stroke Council (NANDSC WG) to the NINDS. This Neurology® supplement is dedicated to the NINDS health equity strategic planning process. As cochairs of the NANDS WG, we developed this summary to provide an overview of the process and a guide for navigating this special issue. Detailed recommendations from the NANDS WG are distributed throughout various articles in this supplement and supported with extensive commentary on the state of the science in health equity. Consolidated high-level recommendations from this process are presented at the end of this article.

Introduction

In 2020, the National Institute of Neurological Disorders and Stroke (NINDS) Office of Global Health and Health Disparities, in collaboration with the NINDS Office of Science Policy and Planning, launched a strategic planning process to prioritize research that has the potential to reduce health disparities (HDs) and inequities in neurologic disorders. To provide oversight of the process and ensure expert input into NINDS’s strategic priorities, the NINDS Director Dr. Walter Koroshetz requested that the National Advisory Neurological Disorders and Stroke Council (NANDSC), which advises the institute on policy and procedures affecting its research programs, establish a multidisciplinary working group of external research and clinical experts. The authors of this article served as cochairs of this working group, named the NANDSC WG for Health Disparities and Inequities in Neurological Disorders (HEADWAY), which consisted of approximately 30 researchers and clinical experts (NANDSC WG Page) who formally met quarterly over a 2-year period as well as several additional times in smaller subgroups.

The NANDSC WG was also charged with developing a comprehensive set of actionable recommendations to guide NINDS efforts and research investments in HDs and health equity (HE) over the next 5–10 years. The Healthy People 2030 definitions of HD and HE were used throughout this process and will be defined in detail in several articles in this supplement.

This overview provides the rationale for this special issue and serves as a guide to navigating the interrelated articles contained herein. We briefly describe the urgent need for addressing inequities in neurologic health through research and then outline how the NINDS undertook this broad
strategic planning process for prioritizing HD/HE research. Next, we provide a summary of the inputs to this process, including the NINDS-hosted HEADWAY Workshop and then summarize how the NANDSC WG (referred to as “WG” going forward) conducted its work. An index guide to the articles in this supplement is included and provides a brief explanation of each article (Table 1). Finally, a summary of consolidated high-level recommendations from the WG, that was presented to and approved by the full NANDSC, is also provided at the end of this executive summary (Table 2).

The Growing Burden of Neurologic Disorders Across the Life Span

The relative contribution of neurologic diseases to overall mortality is increasing in the United States and in other high-income countries, in part because of progress in reducing death rates from non-neurologic diseases. However, dismissing the significance of this relative increase in the burden of neurologic disorders as a statistical artifact of our progress in other areas is a mistake. Progress in neurologic disorders prevention and treatment is understandably challenging and may take more time and effort than in some other areas of medicine and public health; the nervous system is complex, and many of the mechanisms of disease, as well as opportunities for prevention and treatment, remain undiscovered. As the US population ages, the relative contribution of dementia and other neurodegenerative processes to mortality is increasing, underscoring the importance of continued efforts toward the eventual effective treatment and prevention of neurodegenerative and neurologic disorders. Furthermore, as demonstrated by the review from Woolf and colleagues in the second article of this Neurology supplement, young and middle-aged adult mortality associated with neurologic disorders is also increasing, with substantial increases in mortality from epilepsy, cerebral palsy, and inflammatory disorders affecting the nervous system. These findings are especially worrisome.

Racial and Ethnic Disparities Exacerbate the Growing Burden of Neurologic Disorders

Within the context of increasing mortality rates among Americans from neurologic disorders, Woolf and colleagues demonstrate that non-Hispanic (NH) Black Americans consistently experience higher mortality rates from neurologic disorders than do NH White Americans. The Black-White gap in neurologic disease-associated mortality has been widening since 2011. During the past decade (2010–2019), 29,986 deaths would have been averted had the NH Black American population experienced the same neurologic mortality rates as the NH White American population. The annual number of avertable deaths in the NH Black American population ranged from 2,389 deaths in 2011 to 3,587 deaths in 2019, when the largest number of avertable deaths of the decade occurred. If the NH Black American population had experienced the mortality rates of the Hispanic American population, 88,407 deaths would have been averted, and 117,519 deaths would have been averted if the NH Asian American mortality rate (the lowest of all groups) was applied.

Measuring HDs with the crude blunt instrument of mortality rates is clearly insufficient. Although robust detailed data are lacking, there are many indicators that neurologic disorder-related morbidity is also growing and that racial and ethnic disparities in neurologic disease-associated morbidity are a major problem. Barriers to education, income and wealth-building, jobs and job training, livable and equitable wages, affordable housing and transportation, and access to health care are all challenges in racial and ethnic minoritized communities, especially in the NH Black American community and likely contribute to the web of neurologic disorder causality. The harsh reality is that without a focused and sustained increase in research addressing racial and ethnic disparities associated with neurologic disorders and without a commitment as a society to implement the interventions arising from research, we will likely continue to see a worsening of the racial and ethnic disparity gap associated with neurologic disorders and with it a continuing rise in neurologic disorder-associated mortality in the United States.

NINDS Health Equity Strategic Planning Process

The NINDS is deeply committed to the elimination of all HDs and inequities in neurologic conditions and care through the funding of high-level research, from basic science through outcomes research aimed at identifying, monitoring, and targeting biologic, environmental, social, and health care system factors that confer neurologic disease and its treatment disproportionately and adversely. As mentioned in the introduction, in 2020, the NINDS Office of Global Health and Health Disparities, in collaboration with the NINDS Office of Science Policy and Planning, launched a strategic planning process to identify research priorities that have the potential to...
reduce HDs and inequities in neurologic disorders. This 2-year planning process involved a multiple pronged approach which included advice and oversight from a multidisciplinary external WG of the NANDSC Council, public input on perceived neurologic health inequities and suggested research priorities through a publicly available request for information (RFI), a HE portfolio analysis (PA) performed by an internal trans-NINDS HE workgroup, and input from a 3 half-day public virtual HEADWAY Workshop.

An overarching goal of the external WG was to ensure that the strategic planning process was data-driven, standardized, systematic, transparent, and reflected a wide range of perspectives and stakeholders. A major output was the development of an actionable list of recommendations from the WG to the full NANDSC and NINDS Director. In developing their recommendations, WG members conducted their own research, shared and developed opinions informed by their expertise, and considered data presented internally by NINDS staff. The results from all these inputs to this process and final recommendations are detailed in this special Neurology issue. These recommendations will be used to inform NINDS strategic research investments and HE planning for the institute over the next 5–10 years.

### Table 1 NINDS Health Equity Strategic Planning Process and Recommendations (Neurology Supplement Index)

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Abbreviations: NINDS = National Institute of Neurological Disorders and Stroke; SDOH = social determinants of health.
Table 2 High-Level Executive Summary of NINDS Health Equity Recommendations

1. Increase health equity research funding across all neurologic disease areas to identify/validate approaches to eliminate disparities; identify/define how SDOH, structural racism, and provider bias drive inequity; and increase minority participation in clinical trials.

2. Develop priority areas to address specific SDOH-related questions across the life span, with the goal of developing multidisciplinary targeted interventions, cocreated with patients, families, and community stakeholders, to address adverse childhood experiences and other SDOH that are uncovered in the clinical setting.

3. Prioritize the assessment, screening, measurement, and interventions on SDOH and developing guidelines for researchers and clinicians to conduct needs assessment on the burden of SDOH in their clinical setting and their capacity to screen for and address the SDOH in research using accepted screening tools and common data elements.

4. Prioritize evaluation of the most relevant and impactful interventions for addressing the drivers of economic instability (poverty, housing, food insecurity, and employment) and the impact on neurologic health.

5. Develop and validate SDOH-informed instruments to promote detection and assessment of neurologic disorder HDs specific to diverse populations vulnerable to HD.

6. Involve the community early; Specify early community engagement in funding announcements and include in reviewers’ evaluations.

7. Encourage reporting of community engagement strategies in all NIH-funded research submitted to peer-reviewed journals. Specify importance of engaging with underrepresented communities in funding announcements and in reviews of applications.

8. NINDS should fund a range of research efforts aimed at increasing understanding of, identifying, and implementing effective strategies to address community distrust in science and scientists.

9. NINDS should fund qualitative research targeting at-risk populations to better understand how they make health decisions (before the inception of a disease), how they prefer to receive health information, and what motivates them to make healthy behavioral changes that may prevent the future onset of neurologic disease.

10. Build and disseminate curricula that address challenges in community-based participatory research.

11. Include best practices in partnering with community organizations as part of health inequity research training. These activities may include mentoring from experienced community health workers and others who can help ensure that research activities have optimal potential to benefit the communities of interest.

12. Allocate funding to support a network of partnerships between research intensive institutions and historically minority colleges and universities to allow exchange of health equity research ideas, cultural sensitivity awareness, and access to minority investigators and communities.

13. Support career development for minority junior investigators through multiple mechanisms (e.g., Diversity supplements, K-awards)

14. Require Certificate of Completion after completion of key training activities, embed health disparities training in all career development and training grant applications, develop culturally aware mentoring programs, or incorporate cultural sensitivity training into planned or existing programs.

15. Create a new NINDS funding mechanism to promote health equity research aimed at, not only URM investigators interested in this line of work, but also at non-URM scientists, who are solely interested in conducting health equity research, but also in developing opportunities to train both URM and non-URM junior investigators who are developing academic careers in health equity research.

16. Provide funding and logistical support for grant writing workshops for trainees from underrepresented backgrounds. Proactively track and invite trainees with diverse backgrounds who have not yet secured competitive research funding.

17. Emphasize interventional research as a major component of training programs for scientists (of all backgrounds) focused on health inequities research.

18. Prioritize developing SDOH-informed instruments, national HD neurologic disorder disease surveillance, and a centralized neurologic disorder HE database. Build infrastructure to generate and validate harmonized national surveillance of neurologic disease progression among HD vulnerable populations across the life span. This will support the development of early detection and prevention strategies, appropriate assessment instruments, and prompt evidence-based care.

Abbreviations: HD = health disparity; NINDS = National Institute of Neurological Disorders and Stroke; SDOH = social determinants of health; URM = underrepresented in medicine.

Inputs to the Strategic Planning Process

NINDS Research Grant Portfolio Analysis and Public Stakeholder Input Analysis

NINDS staff performed a PA of all HE-related projects funded during a 5-year period from 2016 to 2020. The results were presented to the WG for consideration in drafting their recommendations. The PA is detailed in this supplement [Article 9]. In addition to the PA, to solicit public input on known or perceived areas of inequities in neurologic disease and priorities for HE research, NINDS published a RFI, which was open for public comment from March 31 to July 15, 2021. The analysis of RFI responses was also presented to the WG, and the results are included in this Neurology supplement [Article 10]. Key topics presented and discussed at the HEADWAY Workshop also informed the WG final recommendations.

HEADWAY Workshop Summary

The NINDS hosted the Health Disparities and Inequities in Neurological Disorders (HEADWAY) Workshop from September 22–24, 2021. The Workshop objective was to identify feasible and widely scalable evidence-based interventions to reduce the disproportionate burden of disparities and
inequities in neurologic disorders and neurologic care borne by underserved groups of society. Knowledge and insight gained from the Workshop was incorporated into the WG recommendations to NINDS leadership and future planning for HDs research on neurologic disorders. Highlights from the Workshop are discussed below. The full Workshop report and videos of speaker presentations are available on the NINDS website.5

A keynote address described the science of structural racism, and 4 thematically aligned sessions of presentations focused on addressing HDs through (1) economic, epidemiologic, and interventional analyses; (2) collaborative research teams within NIH; (3) collaborative research teams through public-private partnerships; and (4) targeted interventions. The Workshop concluded with 5 concurrent group discussions, focused on topics and draft recommendations from the subgroups of the NANDSC WG: (1) strategies for interventions to address neurologic health inequities and community engagement; (2) cross-cutting themes and social determinants of health (SDOH); (3) pediatrics and adverse childhood events; (4) communication of scientific information to the lay public, researchers, and health professionals; and (5) HDs research and training. These discussions generated additional ideas from Workshop participants regarding key challenges and gaps as well as opportunities and actionable recommendations for NINDS disparities research to further inform the strategic planning process.

NIH and NINDS Efforts to Address HDs and Inequities

Workshop participants learned about recent NIH efforts to address HDs and improve HE. Led by the National Institute on Minority Health and Health Disparities (NIMHD), NIH is increasing its commitment to addressing minority HDs, improving patient outcomes, and eliminating inequities across all institutes and centers. NIH has identified several population groups, defined by shared social disadvantage perpetuated by discrimination or racism and being underserved in health care, as experiencing HDs: all racial and ethnic minorities as defined by the Census Bureau, all people with less privileged socioeconomic status, underserved rural residents, and sexual and gender minorities. This effort to promote and advance HE research is coordinated through a range of initiatives and programs aimed at increasing opportunities for trainees from underrepresented minority groups in the biomedical research and health care fields and addressing the impact of structural racism and discrimination on minority health and HDs. The NIMHD Minority Health and Health Disparities Research Framework7 conceptualizes the factors that affect minority HDs and outcomes through multiple domains (i.e., biological, behavioral, physical/built environment, sociocultural, and health care system) and levels (e.g., individual, social, interpersonal, community, and societal) of influence and serves as a vehicle for encouraging research to understand and address the complex and multifaceted nature of minority health and HDs.

NINDS has established several programs and funding opportunities in support of its longstanding commitment to reducing disparities and increasing equity in research on neurologic health, disease, and care in underserved groups. A major goal of the Workshop was to identify feasible and widely scalable evidence-based interventions to reduce neurologic disparities, which will involve training a talented and diverse research workforce, developing tools and resources to enable discoveries, building infrastructure to support long-term and sustainable HE research in communities, and communicating and collaborating with all stakeholders. NINDS Director, Dr. Walter Koroshetz, emphasized that NINDS prioritizes solution-oriented research that aims to understand the drivers of HDs and barriers to neurologic HE (e.g., genetic and environmental effects, biopsychosocial factors, SES, patient-provider interactions, and poor access to health care), prevent neurologic diseases and health inequities, develop interventions to decrease disparities and gaps in neurologic health among disadvantaged groups, and effectively translate interventions into practice. The Workshop also aimed to increase community engagement and establish partnerships with patients and communities, which are essential for achieving NINDS’s goal to reduce disparities in the burden of neurologic disease for all.

Neurologic Disparities in Stroke and Beyond

Presentations were given describing what is known about HDs in neurologic conditions. To date, most of NINDS’s disparities research has focused on stroke, for which disparities are particularly severe. Although overall stroke incidence and mortality have declined dramatically over the past 20 years, Black Americans remain substantially more likely to have and to die from stroke than other racial/ethnic groups and that gap is not closing. Traditional stroke risk factors (e.g., hypertension, diabetes, and poor health behaviors) and socioeconomic status explain only about half of the disparity in stroke mortality; the other half remains unexplained but is potentially driven by differential impacts of nontraditional risk factors such as SDOH. The extensive body of research on disparities in stroke risk factors, incidence, mortality, prevention, and care across disadvantaged groups illustrates the many challenges that must be overcome to reduce neurologic HDs as well as the many opportunities for advancing understanding and intervention to improve neurologic HE.

An emerging priority from the Workshop is the need to expand research on disparities in neurologic health and disease to other disorders beyond stroke and cardiovascular disease, where clear disparities also exist but for which little research has yet been performed. These disorders include traumatic brain injury, Alzheimer disease and related dementias, Parkinson disease, pain, epilepsy, headache, and a range of other common and rare neurologic disorders. Neurologic disparities research must include a broader range of minority and disadvantaged population groups and communities to address the extensive heterogeneity within R/E groups and in groups based on geographic location (rural and urban), sex and gender, disability status (physical, cognitive, and sensory), mental health, age, and other demographic characteristics.
Approaches to and Priorities for Addressing Neurologic Disparities and Inequities

Workshop presentations highlighted a range of strategies and approaches to tackling disparities and inequities in neurologic research and patient care. Epidemiologic studies, which have revealed much of what is known about heart disease and stroke, are essential for identifying and characterizing the disparities in neurologic health and disease that exist across disadvantaged groups and neurologic disorders. However, an implementation gap exists between knowledge and progress toward achieving HE, and the need to build the evidence base about drivers of health inequities and effective interventions should not preclude or delay efforts to translate the existing evidence into real-world practices. To bridge the gap and ensure the effectiveness and sustainability of interventions, the field should couple transdisciplinary implementation research and broad stakeholder engagement with dissemination and translation of successful strategies into real-world practice.

Research must also expand to examine the impacts of factors beyond genetics and other biological and health variables that are known to contribute to neurologic disease risk and disease disparities; these include socioeconomic status; environmental, psychosocial, and societal factors; adverse childhood events; and other social determinants of health experienced throughout the life course. The impacts of racism and segregation, in particular, as well as discrimination based on many other attributes (e.g., gender, education, income, religion, and age) must also be addressed. These variables are risk factors for toxic stress and can have long-term consequences for physical, mental, and cognitive health and disease across the life span.

Impacts of Racism on Health and Disease

The Workshop addressed the measurable impact that racism has on health inequities. For the past 25 years, research has explored whether racism is a critical missing piece of the puzzle to fully understand the pattern of racial disparities that exists across a broad range of health outcomes. Racism is fundamentally an organized societal system, rather than individual beliefs and behaviors, that categorizes and ranks individuals, devalues and disempowers some groups, and allocates fewer opportunities and resources. Institutional, individual, and cultural racism, including residential segregation, lead to inequities in health and a broad range of other conditions. The negative effects of racism on health emerge early in life and the cumulative exposure to discrimination and psychosocial, economic, physical, and chemical stressors lead to accelerated aging and earlier onset of chronic disease. Future research must prioritize gaining a better understanding of the consequences of racism and discrimination for neurologic health and disease.

Partnerships, Collaborative Research Teams, and Community Engagement

To eliminate neurologic HDs and inequities, stakeholders must form collaborations and partnerships across individual, community, institutional, and societal levels as well as academic, private, and public sectors. Innovative public-private partnerships and NIH-led programs and initiatives provide powerful collaborative models for understanding and intervening on neurologic HDs. Community engagement and partnership are key to understand and intervene on HDs. Partnering with communities to plan, conduct, disseminate, and implement research studies builds sustainable outcomes and trust. Community should always be at the center of neurologic HDs research.

Findings and Recommendations of the Working Group and Guide to the Articles

The WG was divided into 8 subgroups based on expertise of the committee members and topics deemed to be most relevant to achieving equity in neurologic care, service, and research. Informed by the inputs listed above as well as expertise and research by the WG members, each subgroup authored a publication in this issue. See Table 1 for a list and brief description of all the articles in this supplement. An explanation and description of the subgroups’ work, results, and recommendations are briefly provided here.

The consolidated high-level recommendations presented at the end of this summary were approved by the full NANDSC as a representation of all work and recommendations from the WG (Table 2). This dedicated Neurology supplement is the NINDS 2020 Health Equity Strategic Plan. Readers should review each article in this supplement to better understand the context, evidence, and scientific reasoning for each of these recommendations.

- [Article 1] The current article describes the work of the summary writing team led by the WG cochairs. The scope of this article is described above. The cochairs reviewed the recommendations from each of the WG subgroups, consolidated recurrent themes, and created a list of 18 high-level recommendations felt to convey all concepts from the subgroups and presented this information to the full NANDSC for approval.
- [Article 2] This describes the work of the mortality calculation subgroup. In this article, the authors present a novel calculation of the societal cost of excess deaths from neurologic conditions in the United States due to race and ethnic health inequities. The cochairs highlight some of the results from this article in this overview to emphasize the immediate need for biomedical research and effective health interventions to achieve HE.
- [Article 3] This describes the work of the SDOH across the life span subgroup. In this article, the authors provide evidence-based recommendations on screening, epidemiology, and intervention-related priorities for the NINDS to pursue in supporting SDOH research, with the goal of achieving HE.
• [Article 4] This describes the work of the neurologic HE interventions subgroup. In this article, the authors argue that community-engaged research is a prerequisite to developing and conducting high-quality HD/HE research, and they provide recommendations based on a scoping review highlighting the complexities of community-engaged research in neurologic interventional studies, examined through a HDs and social justice lens.

• [Article 5] This describes the work of the HDs research training subgroup. In this article, the authors give recommendations for potential target stakeholder populations and key elements to be included in HDs research training curriculum. The HDs training and HDs diversity training subgroups started as 1 training subgroup. However, because the WG felt that HDs training is a topic that should be taught to all interested in the biomedical sciences, the topics were split into separate manuscripts. The reader should keep in mind that there will be some overlap in the topics and recommendations.

• [Article 6] This describes the work of the diversity in HDs training subgroup. In this article, the authors describe recommendations for training scientists from historically underrepresented backgrounds in domains relevant to the mission of the NINDS and topics related to diversity, equity, and inclusion. As stated above, the HDs training and HDs diversity training subgroups started as 1 training subgroup. However, because the WG felt that HDs diversity training is a topic that requires special focus, the topics were split into separate manuscripts. The reader should keep in mind that there will be some overlap in the topics and recommendations.

• [Article 7] This describes the work of the neurologic HDs communications subgroup. The authors of this article provide recommendations for evidence-based strategies and best practices for communicating scientific information on neurologic HDs and NINDS funding programs to diverse communities.

• [Article 8] This describes the work of the neurologic HE framework subgroup. These authors present a novel framework contextualizing behavioral, biological, social, and economic factors for researchers to consider when developing interventions to reduce inequities in neurologic disease. This framework can be used in combination with the NIMHD HE framework.7

• [Articles 9 and 10] These articles contain grant portfolio and public input analyses conducted by NINDS staff and are described above in “Inputs to the Strategic Planning Process.”

Findings and draft recommendations from the WG were presented on the third day of the HEADWAY workshop for public comment and discussion. After the workshop, the recommendations were further refined by the WG subgroups. Final recommendations from subgroup chairs were presented to the authors of this overview who cochaired the WG. Given the breadth, depth, and extensive nature of the recommendations from each of the subgroups, the WG cochairs summarized and combined common themes from the recommendations for presentation to the full NANDSC Council. This consolidated list of 18 high-level recommendations was presented to the full NANDSC on February 2, 2022, and accepted as formal recommendations to the NINDS as required under the Federal Advisory Committee Act (Table 2).

Conclusion
The WG was asked to ensure that this NINDS strategic planning process was comprehensive, scientific, and transparent. The contextual information and recommendations presented here are based on published research, expert opinion, and community stakeholder feedback. We hope that this Neurology supplement will lead to impactful research and greater equity in neurologic care, service, and outcomes.

Acknowledgment
The authors thank all members of the NANDSC health equity workgroup and the NINDS staff for their commitment and contributions to this work. We also offer special thanks to Dr. Richard Benson and Dr. Sara Dodson for their general assistance in supporting the committee in the work described. Finally, the authors thank Dr. Walter Koroshetz, Director NINDS, for his commitment to health equity and for tasking the NINDS advisory council to take on this work.

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Appendix Authors

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