

The Communication of Scientific Information to Scientists, Clinicians, and the Public

Recommendations for Achieving Health Equity

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Abstract

Optimizing health care decisions relies critically on the availability of health-related information appropriate to the specific needs and circumstances of the individual. Abundant research has demonstrated that information relevant to health care decision-making reflects disparities along multiple axes of sex, race, socioeconomic status, geography, sexual orientation, and other factors. Compounding the problem is that mechanisms of access to information themselves, increasingly recognized as part of the social determinants of health, can perpetuate and even exacerbate these disparities. Critical to achieving neurologic health equity is the application of evidence-based strategies to inform the effective and efficient communication of information that can influence patients' behaviors, enhance community trust in the scientific enterprise, and shape health systems and policies. In 2020, as part of a strategic planning initiative, the National Institute of Neurological Disorders and Stroke (NINDS) charged its Advisory Council to form a working group of experts to provide recommendations for reducing health disparities. Here, we report our subgroup's findings, which focused on the role of communication in addressing neurologic disparities and inequities to achieve health equity. We find a need for incentivizing and supporting the application of communication science across the spectrum of neurologic health research. We present recommendations for NINDS and individual investigators to support communication activities that advance neurologic health equity.

Introduction

Disparities in neurologic services, care, and outcomes have been clearly documented.¹ As part of its mission to “decrease the burden of neurological disease for ‘All’ through research,” the National Institute of Neurological Disorders and Stroke (NINDS) is dedicated to the elimination of neurologic disparities (Health Disparities Research, 2022). In 2020, the NINDS launched its second strategic planning process to prioritize research and related efforts that have the potential to reduce health disparities and inequities in neurologic disorders. The authors of this article served as members of the NINDS National Advisory Neurological Disorders and Stroke Council's Working Group for Health Disparities and Inequities in Neurological Disorders (NANDSC WG). The NANDSC advises the NINDS on policy and procedures affecting its research programs. Our subgroup was tasked with reviewing and analyzing the NINDS communications strategies related to eliminating health disparities and achieving health equity, providing evidence-based recommendations whenever available, and describing “best practices” for communicating scientific information on neurologic health disparities and NINDS funding programs to diverse communities and stakeholders.

A defining feature of the early twenty-first century is the vastness of the information environment. Thanks to both broad—*information about any topic is just a simple online search away*—and

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Glossary

NINDS = National Institute of Neurological Disorders and Stroke.

deep—from a social media posting to news articles to discussion boards to scientific studies on a single topic—access to information, humans today can access almost any type of knowledge imaginable. What we can do with that information, of course, depends on both our own skills and abilities. Moreover, the rapid expansion of communication tools and channels has occurred in parallel with a movement to empower patients as partners with their clinicians in health decision-making.^{2,3} A significant consequence of the shift to shared decision-making in medicine has been the rendering of access to and the ability to make sense of health information from nonclinical sources essential for health decision-making. Yet both access to information and the ability to make sense of such information are socially patterned in ways that mirror the social patterning of other social goods and tools, often leading to sustained or new inequities, particularly in those populations designated by the NIH to experience health disparities (e.g., racial, ethnic, rural, low socioeconomic status, sexual, and gender minoritized populations). These social determinants of health, which are reviewed and discussed in depth in elsewhere in this special issue,^{4,5} are increasingly recognized as important mechanisms for disparities in neurologic outcomes and disease.⁶ As such, the information environment both contributes to and reinforces disparities in health outcomes.⁷⁻⁹

Yet through strategic approaches to deploy well-crafted messages to specific target audiences, communication can play an important role in ameliorating disparities.¹⁰ Beyond conceptualizing patients as consumers of information, the science of communication informs the way researchers communicate about their findings with distinct audiences and the ways in which messages can be crafted to maximize their effectiveness while engendering cognitive and behavioral change that can contribute to neurologic health. Well-crafted messages that are responsive to their intended audiences' preferences in both substance and form, and which reach those audiences at opportune moments and with appropriate frequency, are likely to achieve their intended outcomes.¹¹

In this report, we present a narrative review of the science of health communication and describe the implications of such for understanding and eliminating disparities in neurologic disorders, and how communication science may apply to the neurologic science endeavor.

Methods

The Communications subgroup of the NANDSC WG engaged in 3 activities to generate findings and recommendations. First, we conducted a literature review to identify key themes and general principles in health communication, including specifically best practices for communicating scientific information.

We then developed a set of key questions (eAppendix 1, links. lww.com/WNL/C926) to help guide the development of equitable and inclusive communication strategies. These questions guided our discussions with members of some of the other Health Disparities subgroups to better understand the specific communication needs related to diversifying the biomedical workforce and communicating about the social determinants of neurologic disorders. In September 2021, we presented our preliminary findings and draft recommendations drawing on these findings at the NINDS Health Disparities and Inequities in Neurological Disorders (HEADWAY) Workshop. Following HEADWAY, we revised and refined the recommendations based on the feedback from participants, who represented several different research stakeholders, including researchers, clinicians, patients, and members of the general public. In the sections that follow, we describe our final findings and recommendations. We begin by providing some context by describing a few specific theories and evidence for public communications about health. Then, integrating evidence from the subcommittee focus groups and the HEADWAY workshop, we describe how each may be relevant for advancing the strategic plan for reducing disparities in neurologic disorders. We conclude with a set of recommendations to guide both NINDS and individual investigators in integrating communication to achieve equity in neurologic health.

Results

Conceptual and Theoretical Foundations of Communication Science

The science of communication is distinct from, but informs and is informed by, the practice of communications. As a discipline, communication evolved from sociological and social psychological traditions focused on understanding processes of communication and their effects on individuals' attitudes, beliefs, and behaviors. The essential components of communication include understanding the message, the source (message sender), the intended outcome, and factors that may interfere in the pathways to message receipt or its effects. Several theoretical traditions advance understanding of each of these factors. For example, theories of mass media effects help to explain the ways in which information from the media shapes public attitudes, behaviors, and ultimately, health outcomes. Theories of message design inform strategies to craft messages for specific populations to achieve specific outcomes.

When applied in health contexts, communication scholarship relies on additional theories relevant to understanding behavior change. For example, theories from public health help to elaborate the potential outcomes of communication, whether intentional (e.g., healthier behaviors) or unintentional (e.g.,

information overload and decision paralysis), as well as to elucidate the ways in which communication may act as a social determinant of health.¹² Health communication scholarship also informs the strategies for communicating about science to distinct audiences.¹³ Among the most prolific users of health communication science is the Centers for Disease Control and Prevention, whose Gateway to Health Communication, a “one-stop shop” for health communications, delivers the latest scientific advances in effective communication and provides a repository for evidence-based communication materials.

Identifying Audiences and Communication Goals

The first stage of effective communication design involves the parallel processes of specifying the intended outcomes or goals of the communications and the identification of appropriate audiences. Intended outcomes could include a range of individual-level outcomes, from the cognitive (e.g., raising awareness of stroke risk factors) to the behavioral (e.g., reducing sodium consumption). Specifying the intended outcome of the communication can help to clarify the target audience, and vice versa. For example, if the goal is to raise awareness of a specific risk factor, the target audience could be (1) primary care providers, who might, as a result of the message, begin to screen their patients, (2) the population that experiences increased risk, who might, as a result of the message, seek medical care or support to modify their risk, or (3) a funding agency or philanthropy to support research funding to learn more about the risk factor. One could also start with the target audience. For example, in our conversations with the diversity training subgroup, we learned that efforts to diversify the neurology workforce need to start as early as elementary school. The target audience, then, is children, and the overarching communication goal is to expose them to careers in neuroscience.

The development of communication approaches depends on the nature of the communication goal(s) and the target audience(s). Two distinct paths are elaborated below: first, we describe strategies for communicating with scientists, policy makers, and communities. What these have in common is the underlying communication goal, which is to raise awareness and generate interest in the underlying issue (e.g., health disparities and outcomes of scientific research). The second path is interventional: the target audience(s) is ultimately individuals, and the communication goal is to raise awareness (i.e., educate) or influence a specific behavior.

Communicating With Policy Makers and Communities

Policy makers represent a distinct audience to engage in efforts to achieve neurologic health equity because the objective of communicating with them is typically to help them understand the nature and significance of a problem and to suggest potential policy solutions, which can include, but is not limited to, research funding. Communicating effectively with policymakers requires scientists to focus on the effect of

their research findings for society in general or for specific subgroups.¹⁰ Generally, politicians are not scientists and do not have the skills or time to parse through dense scientific details; as such, effectively communicating with policymakers requires streamlining research and focusing on the “so what.”

Communication is also an important component of community-engaged research approaches. As described elsewhere in this special issue,¹⁴ authentic community engagement must include working with communities to ensure that the research questions and approach are formulated appropriately and reflect the priorities and needs of the communities.¹⁵ Earning and maintaining the trust of communities with not only historical, but also present-day, experiences of discrimination and racism in interactions with health care systems and scientific enterprises is a long-term project that requires effective interpersonal and organizational communication.¹⁶ Communication strategies that can support the ongoing maintenance of this trust can include regular and frequent sharing of the research process, including results of research in which the community participated. Moreover, community-engaged research can be used to identify target audiences and also to design effective messages for these audiences.

Designing Communication Campaigns

Health communication campaigns are interventions that aim to reach mass audiences with specific messages to achieve specific goals. Most commonly, campaigns aim to raise awareness of issues, increase knowledge about an issue, change opinions, or motivate people to act in a particular way. Factors that influence the campaign’s effectiveness are defined in the classic input-output matrix,¹⁷ wherein inputs are those components of the campaign messages that are manipulated to achieve some desired outcome with a particular audience and outputs are the increasingly complex information-processing outcomes through which the audience must pass to achieve the intended outcome of the communication.

The 4 primary categories of inputs are source, message, channel, and receiver. The *source* can refer to the institutional/organizational owner of the message (e.g., NINDS), the speaker or narrator of a message, or both. When designing messages, careful attention must be paid to the credibility of the source, which is a function of the expertise and trustworthiness of the source(s), as perceived by the target audiences.¹⁸ A pressing challenge for contemporary health communicators is understanding just who are trusted messengers (sources) for distinct communities in the context of the highly politicized information environment.¹⁹ This challenge is made even more difficult when considering the low levels of trust accorded to institutions by populations who experience disparities.²⁰

The *message* includes both substance (i.e., the topic, such as signs of dementia) and specific creative features involved in design. The selection of the topic typically aligns with the intended outcome or goal of the campaign. For example, a high-priority cross-cutting theme that emerged during the HEADWAY workshop was the critical need for NINDS to

focus on prevention of neurologic disease as a core component of a health equity approach. A prevention campaign would target a presently healthy population who is at risk of developing a neurologic disease, with the hierarchical goals of informing about risk factors and then encouraging behavior change to prevent the onset of neurologic disease. A recent example is the NINDS Mind Your Risks campaign, which targets healthy Black men aged 28–45 years who are at the greatest risk for uncontrolled high blood pressure and are consequently at risk of developing stroke and dementia. Campaign messaging includes educational information about risk factors and behavior change communication that aims to persuade audiences to incorporate specific simple and effective lifestyle changes (e.g., regularly checking one's blood pressure and talking to providers about blood pressure control and smoking cessation) to reduce their chances of stroke, heart disease, and dementia later in life.

Beyond the substantive content to communicate, the message component includes considerations about the format and structure. Messages may be, for example, purely didactic (e.g., informational brochures that define and list early signs of dementia), or they may convey essential information in story form (e.g., a short video of a man experiencing dementia who is eventually helped by his family²¹). Stories, or narratives, embed facts about the topic alongside the story; these are learned and have greater persuasive effects than information-only messages because narratives induce a process of transportation—audiences are transported into the storyline.²² Narrative vs didactic format is just one design decision; other essential message design features include the presentation of numeric information; the type of appeal, including the use of emotions; the use of images; and other considerations beyond the scope of the present article.^{19,23}

The *channel* refers to the myriad of potential vehicles to disseminate the message to its intended audiences. At the broadest level, channels can be differentiated by context: mediated, organizational, or interpersonal. The selected channel(s) need to be considered in tandem with the target audience. Good formative research will aim to understand not just the message strategies that could work with a specific intended audience but also the types of channels that are used and trusted for health information by members of that target audience.^{18,24}

Essential to a campaign's effectiveness is ensuring sufficient reach: that is, were the campaign messages seen by members of the target audience enough times to make an effect (e.g., to move through the output levels)? Lack of sufficient exposure is the primary reason that most campaigns fail to achieve their goals.^{11,17} Thus, planning for maximal reach and exposure is arguably the most important component of campaign planning. An important component of formative research, then, is understanding the target audience's preferred communication channels and communication modalities.

Continuing the example from the training subcommittee, communicating with young people from underrepresented

groups about careers in neuroscience, we might imagine that children in elementary school can be relatively easily reached through educational modules in the classroom or as after-school club activities and delivered, for example, by a volunteer corps of college students majoring in neuroscience. In turn, high school and college students not already aware of neuroscience careers could be reached through current social media channels with which they currently engage. The content of these social media posts must be selected by scientific/clinical professionals, but their style must be crafted by communications specialists familiar with successful messaging strategies for this demographic.

However, ensuring sufficient exposure is only the first stage of effectiveness. Once the target audience sees the message, they must pay attention to it if it is to have any effects on attitudinal, cognitive, or behavioral outcomes. Whether the audience pays attention to the message is a function of the message features, how these are put together, and how relevant they are perceived by the audience. Again, adequate formative research with members of the target audience is essential to understand the factors that will influence the message design for that particular intended outcome and that specific audience.

Further continuing the example from the training subcommittee, to increase the diversity of the neuroscience workforce, one could envision a campaign targeting Black youth between the ages of 12–15 years. Formative research efforts with this population would aim first to elucidate the extent to which they are interested in and can envision themselves pursuing a future neuroscience career, the reasons for such, the obstacles they foresee incurring and factors that would influence their decision for or against pursuing this future career choice. Campaign planners would also want to learn about the specific channels that this target population frequents and who the most trusted and influential source(s) of messages would be.

Caution! Misinformation, Information Overload, and Iatrogenic Effects of Communicating About Disparities

As described at the start of this article, the science of communication informs more than the design of specific messages for health equity; other lessons from that scholarship that are relevant to neurologic health equity pertain to the potential negative consequences of misinformation, information overload, and specific messaging strategies. The rapid spread of misinformation, the unintentional sharing of inaccurate or untrue information, and its nefarious sibling, disinformation, and the deliberate spread of false information, have been facilitated by the rise of social media.²⁵ Exposure to misinformation has been positively associated with vaccine hesitancy and individual-level health behaviors during the COVID-19 pandemic; for example, in one study, nearly three-quarters of individuals who did not see any misinformation were vaccinated, compared with just half of those who reported having seen at least six forms of misinformation.²⁶ However, misinformation and disinformation

serve not only to confuse audiences about the correct healthy course of action, but the prevalence of such also has negatively impacted trust in government and health organizations more broadly.²⁷

Beyond misinformation and disinformation, the sheer volume of information available about certain topics can be overwhelming and result in negative outcomes. For example, in the context of cancer and nutrition, a substantial literature has found that the enormous amount of information, encompassing conflicting (whether real or perceived) statements, can contribute to feelings of information overload, leading to decision paralysis or inaction.²⁸

Moreover, even as we encourage more research to better understand the mechanisms linking social conditions and health outcomes, revealing the causes of health disparities, and more widespread dissemination of such scientific findings, we urge caution regarding communicating about disparities. Research has documented iatrogenic effects of emphasizing disparities among both the population groups who experience disparities and among majority (e.g., White) populations. Specifically, exposure to repeated messages about health disparities in the news serves to discourage individuals from those groups from engaging in preventive behaviors.^{29,30} News framing of health risks as particularly pertaining to ethnic and racial minority groups has also been shown to decrease support for preventive behaviors among White Americans³¹ and for public health policies.³² As such, well-intentioned efforts to use communication to achieve health equity need to reconsider how—indeed, *whether*—to present health disparities.

Discussion

Our results underscore the importance of communication throughout the scientific enterprise because it pertains to achieving neurologic health equity. We provide a number of recommendations for NINDS and the NIH more broadly as well as for individual investigators to use communication to achieve health equity (Table). We characterize these under 3 broad categories: trust, substance, and audiences.

First, our work revealed that a lack of trust of the scientific enterprise and of scientists is a central truth that influences not only the perpetuation of health disparities but the challenge of reaching populations who experience disparities. Mistrust in science is not purely a communication problem nor is it a challenge for NINDS and NINDS-funded investigators to tackle alone. We thus recommend that NINDS and the NIH work together to invest in communities who, owing to historical and present-day medical racism and structural racism, have legitimate reasons to mistrust scientific endeavors. Overcoming these legacies is not a simple solution and requires long-term commitments that imply sustained funding and engagement from and with investigators in ways that do

not necessarily align with the typical 5-year research grant cycle. However, by developing funding opportunity announcements that require deep and authentic community engagement, NINDS can incentivize investigators.

Along with requiring community engagement, NINDS funding opportunities can incentivize communication by requiring plans for dissemination of scientific findings with community participants and other key stakeholders at the application stage. The process of planning for such communication from the project's inception can help to ensure that communities' perspectives about the science itself are incorporated into the projects and also lay the groundwork for effective dissemination strategies throughout the research process.

NINDS can also participate in the newly announced NIH Common Fund's Advancing Health Communication Science and Practice Program, which aims to investigate, develop, test, and share new approaches for effective and equitable health communication. The program will fund extramural grants and research support as well as inter-Institute collaboration on cross-cutting communication science, including issues of diminished trust in institutions, misinformation/disinformation, and strategies for effectively reaching historically underrepresented communities who experience disparities. Substantively, this program could also support communication to advance primary prevention of disease, neurologic and otherwise.

Relatedly, and consistent with NINDS' goal to diversify the neuroscience workforce as a strategy to achieve health equity, we encourage NINDS to develop detailed strategic communication plans to ensure that investigators from underrepresented groups are aware of funding opportunities. Given the compounding nature of disparities, it is possible that the most qualified investigators to advance health equity goals may be at institutions without a strong tradition of NINDS funding. In such cases, NINDS should consider innovative funding mechanisms to support partnerships between, for example, collaborations between Historically Black College or Universities and nearby non-minority-serving medical schools.

The second category of recommendations is topical, that is, we identified 3 specific types of information that NINDS and NINDS-funded investigators should prioritize disseminating with distinct specific audiences. The first type of information to prioritize is prevention. An important discussion that cut across workgroups during HEADWAY was the need to advance scientific and public understanding of both the behaviors that can reduce neurologic disease (and disparities) and the social determinants of neurologic health. The second type of information that should be disseminated by NINDS relates to the need to diversify the neurologic workforce as part of a comprehensive plan to achieve health equity. In addition to communicating about general neuroscientific findings, research demonstrating neurologic disparities needs to be communicated to scientists and to policymakers who can advance policies that can support health equity.

Table Institutional-Level and Investigator-Level Recommendations for Communicating About Neurologic Science to Achieve Health Equity

Recommendation	Activities	Key actors
Plan, fund, and implement efforts with a broad range of community stakeholders to transform the clinical neurologic research paradigm to one that includes planning for communications efforts to diverse populations	<ul style="list-style-type: none"> • Develop RFPs that <ul style="list-style-type: none"> ◦ Incentivize the planning and design of neurosciences research that promotes population-specific evidence-based community engagement and participation in research, including the active involvement of community members, organizational representatives, researchers, and other stakeholders in all aspects of the research life cycle ◦ Incorporate the design of culturally appropriate health interventions ◦ Include plans for tailored, targeted communications strategies 	Institution
	<ul style="list-style-type: none"> • Require NINDS-funded researchers to submit a plan for communications to diverse audiences in funding applications • Provide training and resources to aid NINDS-funded researchers to <ul style="list-style-type: none"> ◦ Develop and implement effective communications ◦ Establish partnerships at the earliest stages of the research life cycle with national-based and community-based diverse organizations that can collaborate in delivering research findings to key audiences 	Institution, investigator
Develop and implement communications strategies to disseminate neurologic research findings to diverse populations and key targeted populations	<ul style="list-style-type: none"> • Seek and obtain training in scientific communications • Collaborate with experienced communication scientists and/or practitioners to <ul style="list-style-type: none"> ◦ Conduct formative research to better understand the target audience(s) with whom research findings need to be communicated ◦ Implement established communications best practices 	Investigator
Address mistrust of scientific research and researchers among specific communities underrepresented in neurologic research and who experience disparities	<ul style="list-style-type: none"> • Fund research to <ul style="list-style-type: none"> ◦ Increase understanding of the sources of community distrust in science and scientists ◦ Identify, evaluate, and disseminate effective strategies to address the sources of distrust 	Institution, investigator
	<ul style="list-style-type: none"> • Engage with communities directly using evidence-based strategies to address the sources of distrust 	Institution
Focus on prevention by integrating the science of communication and behavior change	<ul style="list-style-type: none"> • Fund research with and for populations who experience neurologic disparities to better understand <ul style="list-style-type: none"> ◦ How they make health-related decisions ◦ Factors that may motivate or limit behavior change to prevent future onset of neurologic disease ◦ How they prefer to receive health information 	Institution
Expand the reach and effect of NINDS priorities, policies, and funding opportunities to underrepresented neurologic researchers and health care professionals	<ul style="list-style-type: none"> • Regularly solicit input from diverse stakeholder groups, including trainees and scientists from underrepresented groups • Develop tailored communications strategies to better engage high-need research communities, especially those least familiar with NIH 	Institution
Increase diverse young people's understanding of neuroscience and neuroscience careers	<ul style="list-style-type: none"> • Promote neuroscience careers, prioritizing personalized messaging to underrepresented minorities • Spotlight researchers and trainees from underrepresented backgrounds to intramural and extramural communities 	Institution

Finally, our recommendations clarify several specific audiences whose specific communication needs should be considered by NINDS and NINDS-funded investigators. NINDS staff and the policymakers responsible for allocating funding are an essential target audience for scientific information about neurologic disparities, the social determinants and of health, prevention, and community-based research. Scientists engaged in neurologic research should be considered an important audience for communications focusing on disparities, for funding requirements relating to communication and community engagement, and for training on effective communication. Community-based partners and residents of communities who have partnered with researchers, as well as individuals from groups that experience disparities, should be

considered important target audiences for messages intended to demonstrate authentic engagement and interest by the scientific enterprise in advancing health equity and for behavior change messaging to support preventive behaviors.

Along with the recommendations presented throughout this special issue, the recommendations described here were formally endorsed by the NINDS Council, and they now reflect strategic priorities for NINDS to guide its health equity efforts for the next 5–10 years.

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TAKE-HOME POINTS

- To achieve health equity in neurologic disease requires a paradigm shift in the way research is funded, planned, conducted, and disseminated. A core principle must be the authentic engagement with communities who experience health disparities.
- A lack of trust in the scientific enterprise and of scientists specifically by communities that experience health disparities influences not only the perpetuation of health disparities but also the challenge of effectively communicating with these populations. Overcoming mistrust requires sustained engagement and investment by NINDS and individual investigators; communication can play an important role in this process.
- Communication efforts to support neurologic health equity must consider multiple audiences, including NINDS staff and the policymakers responsible for allocating funding, scientists engaged in neurologic research, community-based organizational partners, and ultimately, individuals who may be at risk of neurologic disease.
- The science of communication should be incorporated into NINDS-supported research to help scientists communicate more effectively with each other and with other key audiences.

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