

NIH HEAL Initiative: Advancing Health Equity in Pain Management Workshop

National Institute of Neurological Disorders and Stroke

National Institutes of Health

March 13-14, 2024

In-Person Meeting

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This meeting summary was prepared by Rose Li and Associates, Inc., under contract to the National Institute of Neurological Disorders and Stroke (NINDS). The views expressed in this document reflect both individual and collective opinions of the meeting participants and not necessarily those of NINDS. Review of earlier versions of this meeting summary by the following individuals is gratefully acknowledged: Jessica Tennis, Maya Sapiurka, Nancy Tuvevson.

Positionality Statement

The panelists and staff who contributed to this workshop come from a wide range of backgrounds that span their sociodemographic identities, lived experience of pain, and academic training in research or clinical care. Diversity and representation among these varied backgrounds was integral to generating insights and ideas across the workshop topic areas from multiple perspectives. All panelists, regardless of academic degree or formal training, had the necessary expertise to meaningfully contribute to this workshop.

Opening Remarks and Welcome

Cheryse Sankar, PhD, NINDS; Janelle Letzen, PhD, NINDS; Walter Koroshetz, MD, PhD, NINDS

On March 13-14, 2024, the National Institute of Neurological Disorders and Stroke (NINDS) held a 2-day workshop that convened leading experts to discuss interventions and research for groups experiencing pain disparities. The workshop's goals were to (1) identify ways to meaningfully engage communities that experience pain disparities as research partners, (2) brainstorm meaningful and feasible multilevel interventions that target social determinants of pain, and (3) develop core competencies to build the health equity in pain management research workforce.

Pain is a personal and invisible experience that is unique to each person. It is influenced by the interaction of biological (e.g., brain function, immune system function), psychological (e.g., mood, learning), and social (e.g., social support, provider biases) factors. The latter plays an important role in pain disparities – the systematic differences in pain prevalence, clinical care, and outcomes between groups. Pain disparities have been shown for minoritized racial/ethnic groups, minoritized sexual and gender groups, individuals with disabilities, individuals living in rural communities, and individuals from lower-resourced socioeconomic backgrounds. More efforts are needed to address the upstream, social factors that contribute to persisting pain disparities.

The National Institutes of Health (NIH) Helping to End Addiction Long-term® (HEAL) Initiative was created by Congress in response to the opioid crisis and aims to develop non-opioid treatments for chronic pain and help patients sustainably manage pain. Through the HEAL Initiative and within NINDS, a program of research projects was funded to create interventions to reduce pain disparities. The present workshop was held to aid in the development of future HEAL efforts to eliminate pain disparities.

Do Social Determinants of Health Promote Pain Inequities?

Burel Goodin, PhD, Washington University in St. Louis

Dr. Goodin reported research from his team showing that sociodemographic, environmental, and interpersonal factors all contribute to epigenetic changes that affect a community's health outcomes. In the socioeconomic domain, Black adults, particularly those who experience

economic insecurity, report the greatest pain in behavioral tests. In the built environment domain, Dr. Goodin’s team found that people with lower back pain tend to live in the least advantaged areas. In the domain of interpersonal inequities, stigma in the HIV and insomnia communities and discrimination in the transgender community correlate to negative health outcomes, such as worsened sleep and increased experience of pain.

Dr. Goodin also shared three strategies that his team uses to engage communities in research: (1) compensating participants and community members for their time; (2) providing services to the community, such as the clinical psychology mental health service that Dr. Goodin offered to HIV study participants; and (3) engaging and support existing community resources.

Health Equity Tourism

Elle Lett, PhD, MA, MBioStat

Dr. Lett presented current challenges and opportunities in the field of health equity research. One concern is representation in the research workforce. Diversity refers to the range of identities within a group, but representation refers to having proportions of racial and ethnic minorities that mirror those in the general population. Thus, diversity may be achieved while representation is still lacking. For example, although the number of Latine doctors in the United States increased by 2 percent from 1990 to 2020, the Latine population of the United States increased by 12 percent during the same period.

Dr. Lett discussed health equity tourism, a practice whereby investigators enter the health equity field in response to timely and often temporary increases in public interest and resources. Engaging in health equity tourism may unintentionally compromise the validity of scientific data and divert resources from the efforts of health equity scholars dedicated to advancing health justice initiatives. Structural, institutional, interpersonal, and individual factors contribute to health equity tourism. Health equity is an interdisciplinary science that requires focused training, but scholars in related fields often wrongly assume expertise.

To achieve health equity, Dr. Lett encouraged researchers to consider every step of a research project as an opportunity to pursue justice. She provided two guiding questions that researchers should ask themselves: Who is represented in this study? and How might this study cause harm? Researchers pursuing health equity should include both experiential and academic expertise on their study team, collaborate with representatives of the communities of interest, and utilize strength-based approaches and knowledge sharing to ensure that proposed interventions meet community needs.

Growing Pains: What I Learned from Growing Up with Chronic Pain

Cameron Young, U.S. Pain Foundation

Mr. Young described the difficulty that individuals with intersectional identities experience in finding medical care that meets their needs, highlighting his own experience as a transgender man with childhood chronic pain caused by Ehler-Danlos Syndrome (EDS). He shared his and his

parents' difficulties in finding doctors with enough expertise to diagnose his chronic pain as a child. After diagnosis, Mr. Young and his parents had to find providers who could treat EDS and meet his other needs. Unable to find a clinician who could provide holistic expert care, Mr. Young was faced with choosing between specialists in EDS who were unfamiliar with pediatrics and specialists in gender care who did not know how to treat chronic pain. Mr. Young explained that he, like many children with chronic pain, was often uncertain whether his symptoms were serious enough to merit care. Children with chronic pain and transgender individuals often do not receive treatment because health care providers minimize their experiences, and therefore live with significant uncertainty about their health and health care.

Mr. Young emphasized the importance of community groups to people living with chronic pain and their supporters. In addition to offering emotional support, these groups provide a forum for members to share medical care knowledge and direct others to the best health care providers. In this way, Mr. Young explained, "connection creates understanding, and understanding creates solutions."

Community Engagement Panel Report Out

Panel Co-Leads: Staja Booker, PhD, RN; Roni Evans, DC, MS, PhD; Lauren Kornegay

Panel Members: Eden Buell, BS; Laquinda McCoy, AS; Charis Hill, BA; Andrea Newman, PhD; Mitchell Lunn, MD, MAS; Christine Ritchie, MD, MSPH; Eric Kaiser, MD, PhD; Andrew Subica, PhD

NIH Staff: Marlene Peters-Lawrence, MAS, BSN, RN; Naomi Booker, MPH

Ms. Kornegay and Dr. Evans explained that consistent, transparent, bidirectional communication can facilitate alignment between researcher and community values. Dr. Evans encouraged written agreements that clarify these shared values and researchers' commitment to them. These written agreements may also benefit efforts to bolster support by demonstrating the strength of the research team's preparation, community engagement, and overall productivity.

Ms. Kornegay cautioned that it is not sufficient to have a single community representative involved in a study; researchers must themselves spend time in the community. She emphasized that community members are experts on their own needs, which should guide the generation of research questions, and that researchers should engage community members throughout the research process.

Dr. Booker explained that community engagement can build on existing institutional partnerships or aim to change those existing relationships, with consideration of knowing the history of communities and their relationships with local academic and medical institutions. To be accessible, researcher-community interactions may need to be conducted online and use terminology preferred by the community, or adhere to other community needs. Dr. Booker described the ways in which marginalized populations may experience disparities, inequities, and injustices. For example, health care providers may be less likely to believe that patients

from marginalized communities have chronic pain or may not provide patients with effective treatments that they believe will not be covered by insurance.

Discussion

Community Interactions

Attendees explained that at least one researcher must embed themselves into the community to best identify the appropriate research topics in order to fully begin community-engaged research. A researcher suggested that embedded research offers opportunities for new graduate students who will spend several years in the community.

Upon completing a community-engaged research project, researchers should disseminate their findings in a manner that helps build long-term trust and benefits the community, separate from the research team itself. Participants and community members must be able to opt in or out of research communications. One researcher suggested asking study participants and community members for their best practices in managing a health problem and sharing those best practices with the broader community.

Establishing Trust

To establish trust within a community, researchers can volunteer with community organizations and make themselves available as a reliable resource to individual community members. Because community engagement is part of the research process, researchers may need to be compensated by their institutions or funding agencies for their time in the community to ensure that sufficient time is spent there. Researchers should learn community history to determine which forms of interaction are appropriate and should be willing to share their personal histories and motivations to establish trust with communities.

Community Advisory Boards

Some attendees recommended establishing community advisory boards to facilitate early, consistent interactions between research teams and community members. Researchers raised the concern that such boards engage only a small portion of community members and can lead to researchers' being less engaged with the community at large. Researchers can look beyond repeat board members to ensure that new and diverse voices can generate novel ideas.

One researcher suggested a dialogue model of engagement as an alternative to community advisory boards. With this model, researchers maintain a flexible roster of community members and ask these members which aspects of the project they would like to be involved in and to recommend new members. The dialogue model facilitates the continual addition of new perspectives to the research team and reduces burden on individual community members.

Barriers to Community Engagement

Health care providers' biases and logistical problems with insurance are two major barriers to community engagement in clinical research. Health care providers should strive to provide pain-affirming care and build trust through relationships with individuals and the community.

Securing sufficient resources to sustain thoughtful community-engaged research is another major barrier to community engagement. The panelists raised the issue that funding is needed to enable researchers to incorporate community perspectives during all phases of the research process and to compensate community members for participating on the research team. If appropriate financial compensation is not possible, researchers should offer community experts alternative benefits, such as access to higher education.

Multilevel Interventions Panel Report-Out

Panel Co-Leads: Adam Hirsh, PhD; Ashley Lincoln, MSW, LMSW; Elizabeth Merwin, PhD, RN, FAAN

Panel Members: Quána Madison, MA; Christine Von Raesfeld; Cameron Young; Vani Dawson Mathur, PhD; Jamie Rhudy, PhD; Monika Goyal, MD, MSCE

NIH Staff: Karen Kehl, PhD, RN; Andrew Wright, PhD

Dr. Hirsch outlined priorities for multilevel interventions for pain disparities, including addressing of social determinants of health (SDOH) that contribute to pain disparities, infrastructure to support multilevel interventions, and outcomes and metrics to measure the impact of multilevel interventions for pain disparities.

Poverty, the built environment, loneliness, and time constraints are key SDOH that affect whether individuals can obtain health care. These factors are highly nuanced, unevenly distributed across populations, and sometimes in tension with each other. For example, the measures that people living with pain take to represent themselves as worthy of consideration by health care providers may lead those providers to discount their pain.

Dr. Hirsch emphasized that communities are significant sources of social support and care that can create real-time social networks and generate their own health equity initiatives. Researchers and clinicians should seek to participate in existing community discussions about effective care strategies. Panelists praised the integration of patient navigators, translation services, and peer support services into health care visits.

Panelists with lived experience of pain criticized the traditional 0-10 pain scale, and researchers called for the integration of other pain assessments into electronic health records. Panelists highlighted the need to focus on a community's preferred outcomes, and for researchers to leverage scientific and clinical expertise to determine how to measure these outcomes. Grant requirements should ensure that researchers use outcomes and metrics that are tailored to the intervention being studied. The fact that certain intervention outcomes are more readily quantifiable than others does not necessarily correlate with their respective levels of significance. Finally, research results should be made available for use by people with lived experience of pain and clinics.

Discussion

Social Determinants of Health

Panelists shared examples of how addressing SDOH inequities may benefit pain care, such as housing and food insecurity projects that improve health outcomes and the addition of sidewalks that increase access to care and improve community fitness.

Networks of Support

Panelists discussed integrated group medicine visits, whereby small groups of people with lived experience of pain interact with both a physician and complementary health provider (e.g., mindfulness). This is also similar to social prescribing, which is a prescription for social activities and group therapies. Group medicine visits provide the opportunity for community members to learn from each other and for physicians to learn from the community. However, it was noted that some individuals hesitate to participate in such groups. Reducing stigma about seeking treatment for certain conditions might alleviate this hesitation.

Panelists suggested that discussions of pain inequities include a wider range of stakeholders (e.g., insurers, administrators, health software developers) to facilitate multilevel interventions, such as integrating alternative pain measurements into electronic health records.

Systems Approaches

Panelists explained that an effective, equitable health care system should reward high-quality care and improve care access. Researchers explained that although they cannot always measure independent effects of interventions, these interventions all confer benefits. Therefore, health care providers should use a variety of interventions at multiple levels and multiple sectors, which can be tailored to the individual person.

Panelists recommended using current NIH predoctoral, postdoctoral, early career scientist, and administrative grants to integrate community voices into all stages of research. However, panelists also noted that individual interventions are easier to study and implement than multilevel interventions, and new funding mechanisms should be created specifically for broader interventions.

Workforce Panel Report-Out

Panel Co-Leads: Edwin Aroke, PhD, CRNA; Tamara Baker, PhD; Michael Falcon, OTD, MHA; Ericka Merriwether, PT, DPT, PhD

Panelists: Tom Young, Burel Goodin, PhD; Lauren W. Yowelunh McLester-Davis, PhD; Elle Lett, PhD, MA; Flavia Penteadó Kapos, DDS, MS, PhD; Brandon Ng, PhD
NIH Staff: Laura Wandner, PhD; Nora Hathan, BA

Dr. Merriwether led the discussion on reimagining or reforming training structures to develop a diverse pain disparities research and treatment workforce. Panelists emphasized that the pain disparities research community should be engaged in an ongoing commitment to ideals, rather than measuring core competencies at a single point in time. Panelists suggested that NIH could

support workforce development with grants to compensate researchers for their time spent mentoring trainees.

Panelists discussed the possibility of a funding mechanism for community-based organizations. The mechanism would start with a conversation between NIH and community representatives to determine what area or question the research will address, followed by community-based organizations bidding to work with NIH researchers throughout the project. This hypothetical funding mechanism would empower communities and encourage researchers to work with community organizations as true partners.

Discussion

Development of Personal Character Traits

Panelists noted that personal character traits, such as humility, are essential to the health equity and pain disparity workforce. Panelists preferred the term “raising” to the term “training” in reference to preparing people for the workforce. Described as rather than just training investigators, raising them to fully develop their skills & identity in the pain equity research workforce. The workforce preparation will change depending on a researcher’s career stage, but mentorship will remain critical throughout all career stages. Mentors can model personal character traits and provide strategies and resources for working within institutional structures.

Panelists suggested that professional organizations can help integrate health equity into a professional identity; for example, a medical society could incorporate equity training into clinician license renewal.

Community-Engaged Research Outcomes

Panelists highlighted the differences in outputs and impacts of community-engaged research. Because this type of research requires time to develop trust, outcomes such as new partnerships with community organizations are both more realistic and more essential in the short term than the more typical outcomes of gathering data and publishing journal articles. Panelists discussed strategies that institutions could employ to show that they value the outcomes of community-engaged research as highly as those from other types of research, such as funding the outputs from community engagement.

Panelists cautioned that structural problems cannot be solved on an individual level and encouraged funding agencies to include community engagement as a grant requirement. Panelists explained that the impact of community-engaged research should be community benefit. Conversations within and among institutions and funders will clarify that pain equity is a priority.

Diversity Supplements

Panelists recommended the tying of diversity supplements to the candidate whose identity increases the diversity of the team rather than to established principal investigators. This is one

example of how systems can be made more robust and fairly reward labor from trainees from underrepresented groups.

Closing Remarks: Workshop Summary and Wrap-Up

Katie Reichard, PhD, AAAS/NINDS

Dr. Reichard thanked the invited speakers, moderators, workshop panelists, and organizers for their creative approach and robust discussions. She highlighted the expected outputs from the workshop, including graphical summaries and a white paper that will be distributed to workshop panelists. Feedback from the workshop will eventually inform NIH's efforts. NIH will distribute contact information to facilitate collaboration, and [further comments](#) are encouraged.

Key Definitions

Health Disparities: Health differences that harm disadvantaged populations compared to advantaged populations; populations that experience health disparities are socially disadvantaged due to racism and/or other types of discrimination and are underserved in health care.

Pain Management: Ways of preventing, treating, and managing pain.

Key Concepts

Community Engagement: Strategic process to directly involve groups of people – connected by geography, identity, and/or special interest – in the process of addressing the concerns of those people.

Community-Engaged Research: Using community engagement to set research questions, design research studies, collect research data, make sense of results, and/or share research findings in a way that is best for the community's needs.

Community Partners: People who are not formally trained as researchers but work with a research study team as advisors or equal partners to plan the research project's goals, activities, and ways of sharing findings with others.

Community-Based Organizations: Organizations that are driven by and represent a community's needs.

Research Participants: People who go through a research study’s activities, like filling out surveys or receiving a new treatment, to provide their data. The research team combines data collected from research participants in a study to answer the research questions.

Social Determinants of Health: Nonmedical factors that affect health; the conditions of where people are born, grow, live, work, and age.

“Health Equity in Pain Management” Research Workforce: A diverse, inclusive, and sustainable group of people across career stages and backgrounds who engage communities experiencing pain disparities to run research that tries to advance health equity in pain management.