

**White House Office of Science and Technology Policy
U.S. Department of Health and Human Services National Institutes of Health
ARPA-H Listening Sessions**

**Listening Session 4: Advocates for Research on Minority Health and
Health Disparities and Nursing
July 30, 2021**

The fourth of 10 listening sessions to gather feedback on the proposed Advanced Research Projects Agency for Health (ARPA-H) program was held virtually on July 30, 2021. Advocates for research on minority health and health disparities and nursing shared their opinions. The National Institutes of Health (NIH) is working closely with the White House Office of Science and Technology Policy (OSTP) to establish ARPA-H to focus on ambitious and innovative projects that will shape the future of health and medicine for all Americans.

Participants

White House Office of Science and Technology Policy (OSTP)

Tara A. Schwetz, Ph.D., Assistant Director for Biomedical Science Initiatives

National Institutes of Health (NIH)

Francis S. Collins, M.D., Ph.D., Director

Lawrence A. Tabak, D.D.S., Ph.D., Principal Deputy Director

Eliseo Pérez-Stable, M.D., Director, National Institute on Minority Health and Health Disparities (NIMHD)

Shannon N. Zenk, Ph.D., M.P.H., RN, FAAN, Director, National Institute of Nursing Research (NINR)

Stakeholders

Eric B. Bass, M.D., M.P.H., FACP, Chief Executive Officer, Society of General Internal Medicine (SGIM), Alexandria, VA; Director, Johns Hopkins Evidence-based Practice Center; Professor of Medicine, Johns Hopkins School of Medicine, Baltimore, MD

Adolph P. Falcón, M.P.P., Executive Vice President, National Alliance for Hispanic Health (NAHH), Washington, DC; Director, Healthy Americas Institute, Keck School of Medicine, University of Southern California, Los Angeles, CA

Annesa Flentje, Ph.D., PRIDEnet, Palo Alto, CA; Associate Professor, Community Health Systems, School of Nursing, University of California, San Francisco

Kathleen Mullan Harris, Ph.D., President of the Board, Interdisciplinary Association for Population Health (IAPHS), Eagle, ID; James E. Haar Distinguished Professor of Sociology, Adjunct Professor of Public Policy, and Faculty Fellow, Carolina Population Center, University of North Carolina at Chapel Hill

Shawn M. Kneipp, Ph.D., RN, ANP, APHN-BC, Section Chair, Public Health Nursing Section, American Public Health Association (APHA), Washington, DC; Sarah Frances Russell Distinguished Term Professor, School of Nursing, University of North Carolina at Chapel Hill

Gary Puckrein, Ph.D., President and Chief Executive Officer, National Minority Quality Forum (NMQF), Washington, DC

Nancy S. Redeker, Ph.D., RN, FAHA, FAAN, National Advisory Council Chair, Council for the Advancement of Nursing Science (CANS), Washington, DC; Beatrice Renfield Term Professor of Nursing, Yale School of Nursing, Yale University, New Haven, CT

Lisa Simpson, M.B., B.Ch., M.P.H., FAAP, President and CEO, AcademyHealth, Washington, DC

Deborah Trautman, Ph.D., RN, FAAN, President and CEO, American Association of Colleges of Nursing (AACN), Washington, DC

Meeting Summary

Welcome and Opening Remarks

Lawrence A. Tabak, D.D.S., Ph.D., Principal Deputy Director, National Institutes of Health (NIH)

Francis S. Collins, M.D., Ph.D., Director, NIH

Tara A. Schwetz, Ph.D., Assistant Director for Biomedical Science Initiatives, White House Office of Science and Technology Policy (OSTP)

Eliseo Pérez-Stable, M.D., Director, National Institute on Minority Health and Health Disparities (NIMHD)

Shannon Zenk, Ph.D., M.P.H., RN, FAAN, Director, National Institute of Nursing Research (NINR)

Dr. Tabak welcomed attendees and provided logistical information for the Q&A session that will occur at the end of the session. If approved, the Advanced Research Projects Agency for Health (ARPA-H) will be a new division within NIH, with a radically different culture and organization. The new agency will be designed to foster bold ideas that are largely use-driven and to conduct research that solves practical problems. The resulting platforms, capabilities, and resources will apply across many diseases and conditions. ARPA-H will also have a distinct focus on equity to ensure diversity in funding recipients and in the patient populations that will benefit from its breakthroughs.

Dr. Collins welcomed participants and attendees to the fourth of 10 listening sessions to gather feedback on the proposed ARPA-H. NIH is working closely with OSTP on ARPA-H, which is a high priority for the Biden administration. ARPA-H is designed to catalyze ambitious ideas and approaches that will shape the future of health and medicine for all Americans. It will follow the Defense Advanced Research Projects Agency (DARPA) model and will focus on high-risk, high-reward projects, and it will be guided by visionary project managers. ARPA-H will recruit researchers who might otherwise not apply to NIH for support, and its projects will be driven by clearly defined milestones. OSTP and NIH want to gather opinions from stakeholders, who will play a critical role in the establishment and success of ARPA-H. The 10 listening sessions will focus on specific research areas and will involve NIH Institute and Center (IC) directors who represent those areas.

Dr. Schwetz said that ARPA-H will strive to be transformative for biomedical research. The United States has a strong biomedical research ecosystem that is supported by NIH-funded research. Results from these research studies have informed the pharmaceutical industry in its development of treatments for a range of conditions. However, the current system has some gaps between traditional fundamental research and industry. ARPA-H will help provide a new lens and a mechanism through which to support exciting biomedical research that can improve human health. Such ambitious and cutting-edge research requires a novel funding approach, and such approaches have been used in other areas of science. In ARPA-H, OSTP and NIH aim to create a distinct entity whose leadership will have the autonomy and resources to tackle some of the biggest challenges facing human health.

Dr. Pérez-Stable said that the creation of ARPA-H could create complementary, transformative, defined, and accelerated processes to help NIH and NIMHD reach their goals to eliminate the stark health disparities that currently exist in the United States. Specifically, ARPA-H could support NIMHD's current mission to develop specific interventions to reduce health disparities by using the creativity of diverse scientists working together with individuals, families, and communities in the built environment and within health care settings. With support from all Institutes and Centers (ICs), NIMHD seeks to develop interventions to understand and reduce structural racism and discrimination and fund community-engaged research, with an emphasis on community-level interventions led by underrepresented scientists and diverse, early-stage investigators. Similarly, ARPA-H projects could provide unique opportunities to discover small structural changes that result in large-scale impact, use community-engaged infrastructures to help address mistrust in science and reduce the spread of misinformation among disadvantaged communities, and employ geographic information systems to understand individual factors and social interactions that contribute to disparities in defined neighborhoods. ARPA-H could sponsor community science partnerships to implement and evaluate interventions that remove the structural barriers creating the lack of diversity in health care.

Dr. Zenk said that NINR supports the creation of ARPA-H to enhance nursing and nursing science. Seeking breakthroughs that range from molecular to societal and providing transformative solutions for patients and entire populations complements the goals of nursing science to use a holistic perspective to advance the prevention and management of acute and chronic conditions across the disease spectrum and across the life course. ARPA-H projects could develop new clinical research platforms and systems that could directly disseminate nursing science discoveries to diverse groups of providers, patients, families, and communities where they live, work, and play. Nursing science can address the health inequities that are determined by differences in social, environmental, and economic circumstances, and ARPA-H could empower this research agenda. Nurses and nurse scientists are positioned to make discoveries in all settings and across many sectors. Helping nurses reach the patients who are experiencing an excessive burden of morbidity and mortality is another goal that ARPA-H could help accomplish.

Comments from Invited Stakeholders

Lisa Simpson, M.B., B.Ch., M.P.H., FAAP, President and CEO, AcademyHealth, Washington, DC

Eric B. Bass, M.D., M.P.H., FACP, Chief Executive Officer, Society of General Internal Medicine (SGIM), Alexandria, VA; Director, Johns Hopkins Evidence-based Practice Center, and Professor of Medicine, Johns Hopkins School of Medicine, Baltimore, MD

Shawn M. Kneipp, Ph.D., RN, A.N.P., APHN-BC, Section Chair, Public Health Nursing Section, American Public Health Association (APHA), Washington, DC; Sarah Frances Russell Distinguished Term Professor, School of Nursing, University of North Carolina at Chapel Hill

Deborah Trautman, Ph.D., RN, FAAN, President and CEO, American Association of Colleges of Nursing (AACN), Washington, DC

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Speaking on behalf of AcademyHealth members, Dr. Simpson said that health services research focuses on systems-based outcomes and making health care safer, higher quality, more accessible, more equitable, and a higher value for patients, communities, and practitioners. This type of research is conducted in partnership with communities, health systems, industry, and other stakeholders to improve the design and delivery of care. AcademyHealth is interested in discovering who does not get care and why and what the best way to implement big breakthroughs in discovery science so that every patient and all communities receive the benefit of these breakthroughs regardless of income, gender, race, ethnicity, or geography might be. ARPA-H could be a critical opportunity to supercharge the development of large high-risk, high-reward research projects. Equity must be a goal to avoid worsening long-standing and pervasive health and health care disparities, which the pandemic has made so tragically evident. ARPA-H projects should be timely, nimble, and equitable and should reward innovation. Although innovations in care delivery have multiplied in response to technology and the pandemic, little is known about which innovations will prove effective and for whom. Health systems, public health departments, and private innovators cannot wait for a 3-year study to learn the effectiveness of an innovation. ARPA-H could be used to develop and test new models of research funding allocation and increase the timeliness of research and the diversity of the investigators. A substantial commitment to health services research, implementation research, and disparities research studies should be included in the ARPA-H appropriation.

Dr. Bass said that SGIM supports the development of ARPA-H, especially for funding projects that implement research into practice, engage high-risk communities, and use community engagement, organizational behavior, and social and behavioral studies to determine the most effective ways to foster adoption and use breakthroughs. SGIM also encourages the use of transdisciplinary approaches across the social sciences, at both the

individual and community levels, to address multiple chronic conditions with shared risk factors. Inter-sectoral approaches can also address social determinants of health, which can impede the adoption and use of breakthroughs. Regarding systemic gaps in the R&D enterprise, SGIM recommends addressing how policymakers influence the translation of evidence into practice and the adoption of breakthroughs. ARPA-H projects should explicitly address incentives and allow time to effectively engage stakeholders across groups. Program managers and project leaders will need to consider how implementation can be impeded by regulatory bureaucracy at multiple levels, because many barriers exist that are beyond the reach of NIH (e.g., liability issues). A good example of a collaboration strategy that should be incorporated into the ARPA-H design is the [Community Engagement Alliance Against COVID-19 Disparities](#). Conversely, many lessons were learned from the development of the [Centers for Population Health and Health Disparities](#) and the [Centers of Excellence on Minority Health and Health Disparities](#), which might have benefited from greater investment in the infrastructure needed to sustain them. SGIM recommends listening to community voices for setting priorities, promoting diversity and inclusion when selecting program managers and project leaders, and establishing a committee of external experts and stakeholders to review the ARPA-H portfolios every 6 to 12 months.

Representing APHA, Dr. Kneipp said that the transformative language in the ARPA-H proposal and its mission to change how health is promoted and disease is prevented hold great promise. Ongoing public health initiatives, such as the [Public Health 3.0](#) movement, have sought to build novel cross-sector models for providing population-level care by including programs for housing, employment, and education, among others, because these are the sectors that essentially regulate the social determinants of health. Studies have demonstrated that these factors predict health outcomes and contribute to chronic disease. Interventions are needed to reduce health inequities by modifying these factors, but supporting cross-sector, multilevel intervention science has been difficult to negotiate within the context of the current NIH structure. Cross-sector research requires authentic partnerships with other sectors (e.g., to answer questions such as, “Which factors lead to permanent job placement for people moving into work through social services programs?”). Attempts to include both sets of outcomes in funding applications have led reviewers to indicate that the outcomes relevant to the other sector are irrelevant to NIH, even when the primary study outcomes are health-focused. When the outcomes relevant to non-health sector partners are more acceptable in an NIH study section, the resources to pursue them are often insufficient within the funding parameters of an R01 award. When cross-sector research to examine outcomes relevant to the partnering sector is partially funded by NIH, investigators are left to seek funding from other equally siloed sources, such as the Department of Labor or the Department of Education. Scientists must secure multiple sources of funding from different agencies to piece together a holistic solution to problems that extend beyond the health system. ARPA-H should fund robust, joint, cross-sector research, where funding sources and outcomes relevant to health and to the partners engaged from other sectors can be combined. This model would facilitate intervention studies that could make substantial advances toward achieving health equity.

Dr. Trautman said that AACN members would be excited about ARPA-H if its discoveries were sustainable, inclusive, and conducted through broad partnerships. AACN believes that nurse scientists are critical to improving health care and addressing societal challenges. ARPA-H could provide opportunities to support learning experiences for students and expand interdisciplinary teamwork through community-based partnerships and initiatives that integrate health care and social services. Reducing the time from discovery to societal benefit is crucial. Involving the public as much as possible is essential, not only in the dissemination of the findings from research but also when setting research priorities. Conducting nimble research is both an opportunity and a challenge, but DARPA has proven success in this area. AACN commends the administration for providing opportunities for disruptive innovation, a stronger connection between the community and the public, and the continued advancement of science and discovery. More must be done to help Americans understand science and disseminate that knowledge to others.

As the scientific voice for the American Academy of Nursing, CANS formulates and advances research, scientific training, and career development. Dr. Redeker said that ARPA-H would provide immense opportunities for nursing scientists to help achieve health and wellness for all. Innovative solutions that truly change lives and improve health are broadly needed, but they also need to be broadly accessible. For example, digital tools like biosensors, remote monitoring, and data capture are all additive, but individuals who reside in rural areas, have low incomes, have no access to broadband, or lack personal devices are increasingly left behind. There are also cultural issues related to the use of technology in health care, particularly around trust, so addressing these needs with a holistic view that considers individual preferences and capabilities is paramount to any innovative health solution. There is a need for new and different solutions to deliver health care and record and store individual health and well-being information, regardless of an individual's location, financial means, or digital literacy. Telehealth remains underused, and its effectiveness should be studied. Although it was widely used during the pandemic, telehealth needs to be studied to identify who it works for and in which situations. For example, can telehealth be used effectively to screen for hypertension, glucose levels, vision, or chronic disease management? Multiple omics approaches are needed to understand health and disease in large, diverse, longitudinal cohorts. Omics approaches need to be combined with social determinant and exposome data and included in medical records so that those records are also research-friendly. Although these types of data studies are sometimes funded by NIH, they tend to be small in scale and short in duration. Larger and higher-risk studies are needed. CANS would like to see an ARPA-H initiative to explore innovative, high-risk proposals without the limitations of the NIH review process. This will require a visionary director, changing the makeup of review panels, consideration of new scoring criteria, and a focus on commercialization potential and dissemination and implementation across the population. The model should also include patient stakeholders in the review process. Finally, ARPA-H needs multidisciplinary roles, including embracing the role of people in industry who may not have a typical NIH biosketch to further advance science into practice.

Speaking on behalf of NAHH, Mr. Falcón said that although the ARPA-H proposal represents a fundamentally different approach, it must also *demonstrate* a fundamentally different approach. American science cannot advance without recognizing that it has failed to provide inclusion. Inclusion should be a core principle of ARPA-H, and its inclusion metrics should apply to its personnel, research agenda, and funding. ARPA-H should make a clear commitment to community-based participatory research. When funding research, ARPA-H should use a relevant scoring system that measures each proposed research effort against equity and inclusion principles for diverse communities, with a focus on populations that are underrepresented in biomedical research (UBR). Approved ARPA-H research projects should be required to report findings by each UBR population, a component of the current NIH Inclusion Policy that has never been fully realized. Regarding systemic gaps, ARPA-H could provide trend data for design and forecasting, because current data do not adequately include UBR populations (even for gender). Forward progress cannot be made without examining past biases on which that progress would be predicated. ARPA-H could launch a national effort, focusing on UBR populations, to expand postmarket approval studies and initiate additional targeted studies to reverse the “one-size-fits-all” approach on which too many medical treatments are based. Prioritization of the post-approval studies would be based on the most widely used therapies for the diseases and conditions with the highest prevalence in UBR populations. Regarding R&D challenges, although some of the most promising treatment approaches use digital monitoring and wearable platform strategies, these strategies are not accessible to UBR populations in rural areas. Limits and bans on providing digital technologies by trial sponsors should be reexamined, and partnership strategies should support the decentralization of clinical trials. The [Hispanic Community Health Study](#) and the [All of Us Research Program](#) are good examples of how inclusion can be a key principle for mission, funding, UBR, and, more importantly, long-term commitment. Finally, NAHH suggests fostering specific UBR community research ecosystems to bring together multiple stakeholders in an infrastructure that could serve as a platform for ongoing research.

Dr. Flentje said that PRIDEnet has learned much about how to engage and partner with communities for research, including how to ask questions, garner trust, and be trustworthy. Communities will share what research is needed to improve their health and when research approaches miss the mark. A pervasive belief that researchers or institutions know more about health problems than community members is an ongoing problem that reduces the impact of research in improving health within communities. Another problem is discrediting participant-reported outcomes as invalid or unvaluable in research. The lack of integration between researchers, community members, and organizations is a barrier to affecting change. Sexual and gender minority communities are overburdened with illness and disability, but solutions to enhance and optimize their health cannot be created in a vacuum. Creating and testing solutions does not work without community input, but current NIH funding models, including funding announcements and study sections, do not prioritize community engagement or input. Like in PCORI, ARPA-H community members should have decision-making power and authority and should be compensated. Many health disparities researchers do not have access to UBR populations, and many people from UBR communities do not feel safe

participating, so a notable investment in digital infrastructure to connect participants with researchers or a platform on which research can be conducted could be helpful. Funding is needed to support the development of digital systems that connect researchers and participants. There is also a need to establish large, funded consortia with community-serving organizations, including nonprofits, for-profits, and nongovernmental organizations. Consortia membership could be based on UBR group identity, balanced with the intersection of other identities (e.g., LGBTQ+ balanced with African American and Latin American people within the LGBTQ+ community) and an investment in reaching the populations that the research was designed to serve. Funding is also needed for implementation and dissemination directly to communities. For ARPA-H to deliver solutions as quickly as possible, it should prioritize community engagement and offer solutions that will work for communities.

Representing NMQF, Dr. Puckrein said that ARPA-H is an agency that should have been created long ago. The American health care system lacks leadership in targeting specific interventions that challenge the public, so perhaps ARPA-H can fill this role. ARPA-H could be used to build a clinical trials infrastructure that would include minority populations that have been underrepresented in clinical research. A structured clinical trial enterprise would reduce cost, speed innovation, and be critically important to ARPA-H projects. ARPA-H must determine how to get new therapies to the bedside—and to all populations, despite the many barriers. ARPA-H must also find a way to bring deliberate speed to the health care system: When new therapies are not quickly generalized to the American population, reaching all populations, the result is additional disparities. Patient education is also crucial. For example, the problems that have occurred with COVID-19 vaccination are due to a failure to educate the American public. ARPA-H must take a strong position to make sure that its research is available to the American public.

Dr. Harris said that IAPHS supports the creation of ARPA-H to advance the science of population health and health equity. Social scientists should be used to help advance health equity, and economists, sociologists, criminologists, anthropologists, and public health experts should be used to address the roots of health disadvantages. These types of scientists have developed novel data and methods to understand complex social systems and have forged intellectual partnerships across the health sciences to translate findings. Because advantaged populations benefit the most and the earliest from breakthroughs in biomedical science, ARPA-H must advance health equity by ensuring that medical innovations also reach and benefit high-risk populations. This type of dissemination requires understanding life conditions, a job for teams that integrate social science with health services, research, medicine, and behavioral science. ARPA-H should also fund health research that disrupts structural disadvantages; identifies how poverty or racial injustice translates into higher risks for cardiovascular disease, substance use disorder, and other diseases; and tests interventions that counter these diseases. This work requires the integration of social, health, and biological sciences, and IAPHS members are primed for this type of research project. ARPA-H should provide interdisciplinary teams with the resources needed to harness naturally occurring data, such as cell phone movements, consumer expenditures, Twitter feeds, health care records, police records, and zoning and foreclosure data, and then integrate those data with rigorous population-level data and

analytics to better characterize the linkages between health care delivery and social systems. ARPA-H should also support machine learning to identify predictors of rare events (such as suicide) in existing large databases. ARPA-H projects should be guided by input from communities, especially the minority and low-income communities that experience inequities firsthand. Projects for medical interventions should require a community advisory component and input from people who would experience the intervention or who are in the best position to inform researchers how such an intervention would be received in their community. ARPA-H could extend ongoing grants on critical health issues (such as substance use disorder) for another year beyond their grant period to allow investigators and community members to analyze results. Developing interventions or programs that would save lives and reduce disparities requires setting expectations and designating funding for dissemination. Studies are needed for implementation science that focuses on implementation in disadvantaged populations. It would also be wise to partner with media platforms and other commercial social network platforms to communicate research-driven messaging about new medical interventions and targeted communications to vulnerable populations and to promote health equity.

Discussion

- *Where will ARPA-H live within NIH and what will it look like?* Dr. Tabak said that ARPA-H will be a division within NIH, but it would be distinct from an Institute or Center because of its unique and singular culture. To allow rapid decision making at every level, ARPA-H will have a flat, nimble structure.
- *Describe the ARPA-H leadership team. What attributes will the director and the program managers possess?* Dr. Schwetz said that the director will be someone who is a technical expert in their field and a strong leader who empowers their team's independence. The director is likely to be a well-rounded individual with a variety of experience, someone who has spent some time in industry, worked at DARPA or ARPA-E (ARPA-Energy), spent time in academia, or a combination of these. They will also serve as an ambassador for the organization. Program managers will be experts in their own right and will be given a high level of autonomy and independence. These leaders should not be limited by bureaucracy, overarching processes, or paperwork.
- *How will ARPA-H projects and priorities be chosen?* Dr. Tabak said that ARPA-H staff will be looking for the best ideas that have the greatest potential for impact while considering issues related to equity. NIH ICs will be a rich source of potential ideas, but health disparity and health equity research transcends traditional NIH and HHS borders. Receiving input and suggestions from beyond NIH is also important for ARPA-H. Dr. Schwetz added that an interagency committee, which includes many federal agencies within and beyond HHS, has been established to coordinate the development of ARPA-H. Because each agency has a unique role and the potential to add benefits through collaboration, the purpose of the committee is to facilitate robust relationships and focus on

- possible mechanisms for fostering close partnerships.
- *How will ARPA-H address structural barriers faced by community-based researchers (e.g., having an eRA Commons account, obtaining support for interdisciplinary research)? Will ARPA-H reach out to community-based investigators who might not normally think about NIH as a source of support?* Dr. Schwetz said that the answers will depend on the programs being developed. The process used by other ARPA models must be amended to be relevant and fit the medical research environment. Identifying ideas for programs will be a robust and dynamic process that includes input from multiple sources and community stakeholders, such as patients, patient groups, researchers, and others, early in the process. Ideas will also come from the ARPA-H program managers and possibly NIH program directors. After an idea is formulated, a period of extensive market research will begin, including conducting webinars and other ways of gathering feedback.
 - *How will ARPA-H deal with the many aspects of structural racism? One example, artificial intelligence's role in exacerbating health disparities.* Dr. Tabak said that NIH has already issued a research opportunity announcement (ROA) as part of its [AIM-AHEAD program](#). AIM-AHEAD is designed to tackle these issues by identifying inclusivity and diversity bias in the datasets that are used to train artificial intelligence and machine learning algorithms. ARPA-H will consider these types of issues on a much broader scale.
 - *How do we get nurse scientists, particularly those from diverse backgrounds, engaged in ARPA-H?* Dr. Zenk said that NINR is committed to training a diverse workforce of nursing scientists and has been expanding strategies in this area. A recent NIH analysis was conducted to determine which topics African American investigators tend to submit, and NINR is committed to doing better at funding these topics. Dr. Pérez-Stable added that enhancing diversity in both scientific research teams and clinical care will probably lead to a decrease in disparities. There is enough empirical evidence to show that ARPA-H should tackle this type of bold intervention. With support throughout NIH, there is a tremendous opportunity to move the needle in this area.

Closing

Lawrence A. Tabak, D.D.S., Ph.D., Principal Deputy Director, NIH

Dr. Tabak thanked participants and attendees for their interest in ARPA-H. ARPA-H is a work in progress, and OSTP and NIH will be hosting additional listening sessions to continue gathering information to help guide its establishment. Dr. Tabak invited attendees to send comments and questions to the ARPA-H comment box (ARPAHcomments@nih.gov) and to visit the [ARPA-H webpage](#).