

July 6, 2021

Shalanda Young Office of Management and Budget Executive Office of the President 725 17th St NW Washington, DC 20503

Dear Acting Director Young:

AcademyHealth welcomes the opportunity to provide input to the Office of Management and Budget (OMB) on the methods, tools, and leading practices for advancing equity and support for underserved communities.

Our comments focus on federal agencies that support research and we provide specific recommendations in the following three areas:

- Assessing agency policies and actions
- Barrier and burden reduction
- Stakeholder and community engagement

AcademyHealth is the professional home of health services researchers, policy experts, and practitioners, including those serving the most vulnerable and disenfranchised populations. Health services research examines how people get access to health care, how much care costs, and what happens to patients as a result of this care.

As the leading organization for a field devoted to improving health outcomes for all, we are committed to directly addressing systemic racism and promoting health equity. Our <u>strategic plan</u> explicitly names diversity, equity, and inclusion (DEI) as a core value of our organization. To support this mission, we have responded to two similar requests for information (RFI) about the importance of supporting DEI and providing tools, resources, and support to researchers from marginalized and minoritized communities. First, we <u>answered</u> the call of the National Institutes of Health (NIH) on how to advance and strengthen DEI in the biomedical workforce. Second, we <u>highlighted</u> the role that nurses can play as advocates against structural racism if they are given the training and tools to do so when the National Institute of Nursing Research (NINR) asked for comments on its new strategic plan. We encourage you to consider these responses as well. More information about AcademyHealth's work establishing DEI and science innovation as strategic priorities is at the end of this response, and provide further context for our lens of equity.

## **Assessing Agency Policies and Actions**

The federal government is the largest funder of health research in the world. Research of any type is not ideologically neutral - it does not happen in a vacuum that is absent from systemic power, race, and privilege. Funders choose what to fund and at what level, and researchers often choose what to study in response to funders' priorities. And data used in research reflects the underlying disparities within the health care system if that is not addressed in the study protocol. A funded grant may be the start of a research program, but it is also the end result of a series of norms, rules, and decisions that are made without meaningful engagement of diverse and minoritized researchers and communities. A 2011 study found that applications from Black investigators were significantly less likely to receive an award than

those submitted by white investigators, even after controlling for educational background, country of origin, training, previous research awards, and employer characteristics. More recently, evidence has <a href="mailto:shown">shown</a> that the topics pursued by underrepresented investigators may be contributing to this gap. For example, Hoppe et al (2019) found that topic choice alone accounts for over 20 percent of the funding gap faced by Black researchers when controlling for other variables.

## **Recommendations:**

- Federal agencies should explicitly focus on structural racism, including critically and honestly reconsider the norms, rules, behaviors, biases, and barriers within their own agency and how the agency engages with a range of stakeholders, especially communities of color and marginalized communities, including but not limited to merit review of applications.
- Federal agencies should lead the nation in improving our collective capacity to measure and
  monitor organizational progress on equity and inclusion by supporting additional efforts to
  develop and test new measures and data collection methods and update their agency processes
  and policies accordingly over time.
- Federal agencies, especially the National Institutes of Health and the Agency for Healthcare
  Research and Quality (AHRQ), should use data from their various research grants and contracts
  databases to identify submissions and awards made to researchers with diverse racial, ethnic, and
  gender identities and use this information to develop funding priorities that can result in a more
  equitable and diverse set of research projects and a mix of investigators that are far more diverse.
- Research-supporting organizations, including those in HHS, VA, and the NSF, should regularly
  gather feedback directly from their own workforce with a focus on the sense of inclusion reported
  by racially diverse staff, any structural barriers or biases they face, and suggestions for
  improvement in efforts at eliminating structural racism and implicit biases. These responses
  should be aggregated and publicly reported.
- Achieving evidence-informed policy is essential to achieving equitable outcomes. As Agencies continue with the implementation of the Foundations for Evidence-Based Policymaking Act of 2018 ("Evidence Act"), they should use this as an opportunity to assess existing agency policies and processes through the lens of equity and systematically work to innovate and learn across the agencies of government on which policies and processes are more effective at driving toward equity.

## **Barrier and Burden Reduction**

To eliminate barriers to government health services and deliver better health outcomes, we need to be able to differentiate which health care interventions work, for whom they work – including expressly evaluating if our health systems are effective for people of color – and how to continually move them toward more equitable outcomes. We also need to ensure that we account for structural inequality reflected in the data we use to conduct this research. HSR is the process through which we develop that knowledge. For example, we know that marginalized and minoritized people and communities are disproportionately contracting COVID-19, suffering worse outcomes, having less access to diagnostics, vaccinations, treatments, and are dying at higher rates. It is unambiguous that there exist deep racial and ethnic inequities within the health care system. Robustly supporting health care services research is one of the most effective ways to create actionable and scalable interventions to address systemic inequality, support the implementation and scale of these interventions (e.g. through payment policy), and then

monitor progress towards our equity goals. The federal government already reports annually on healthcare disparities and quality through AHRQ. Over the last 20 years, these reports demonstrate how little progress has been made (e.g. the 2019 report showed that when comparing outcomes for Blacks vs whites, disparities improved for 23 measures, while they stayed the same for 95 measures and worsened for 79 measures).

However, many other dimensions of inequity are simply not visible because agencies are not collecting data by sufficiently specific categories to understand the barriers to accessing services by various communities and individuals (e.g. most national surveys do not collect information on gender identity) or because of insufficient funding for health services research as compared to biomedical research and drug development.

#### **Recommendations:**

- HHS should significantly increase funding for health services research so that we can better document and identify health inequity, and identify and amplify health services that deliver equitable care. This data can then support policies and practice interventions that improve health care access and quality across underrepresented and minoritized groups. Specifically, the federal government should increase HSR funding levels for research opportunities that prioritize innovation, data, and methods that address the systemic racial, ethnic, and socio-economic disparities that create and propagate health and health care inequities. This also includes support targeted on identifying and addressing gaps and weaknesses in the health care system that disproportionately affect minoritized individuals and groups.
- The Equitable Data Working Group established in The Executive Order on Advancing Racial Equity and Support for Underserved Communities through the Federal Government, Section 9, should engage diverse stakeholders and communities as the group updates, expands, and standardizes categories of racial and ethnic data across federal agencies. As the categories are revised, the Data Working Group should engage state and local governments and communities as well as Tribal Nations to ensure that the categories are inclusive, useful for assessing impact, and allow for better flow and sharing of data for community planning and decision-making.

# Stakeholder and Community Engagement

As noted above, researchers from a range of marginalized communities (e.g. race, ethnicity, disability, LGBTQI+) know what kinds of barriers to health care access their communities face, but their perspective is not always included in federal research grants and contracts. It is critical to expand research support for topics that disproportionately impact such groups with the above discussed community-engagement strategies that have been shown to provide more sustainable solutions to promoting health equity. The federal government needs to not only do a better job of funding community-engaged research that looks at health care services, but also in building up a workforce and policymaking apparatus that better represents and includes these marginalized and minoritized communities.

# **Recommendations:**

Research funding opportunities should require that investigators meaningfully engage members
of under-resourced and under-represented communities as partners in determining research
priorities and questions, study design, implementation, analysis, reporting, and translation into
practice and policy. A key component here is "meaningfully". This means that funding
applications should describe how these communities were engaged in the process of prioritysetting to develop the research questions and the study design proposed, their agency in effecting

change, how researchers will continue to engage community members throughout the research cycle, and how the communities will benefit because of the collaboration and the new knowledge that the researcher returns to them through a 360 engagement.

- Every grant review panel should incorporate members from diverse communities, and efforts needed to accomplish this representation should be bolstered.
- Federal health services research funding should prioritize engaging with academic institutions from Historically Black Colleges and Universities (HBCUs), Minority Serving Institutions (MSIs), and Hispanic Serving Institutions (HSIs) by directing research support to include them as partners and helping to invest in building their institutional capacity.
- Federal recruitment should better prioritize engaging with HBCUs, MSIs, and HSIs to ensure a diverse federal workforce.
- HHS should eliminate barriers preventing access to opportunities like mentoring or
  apprenticeships, and directly address the role of implicit and explicit bias as barriers within
  decision making processes. These opportunities are a key component of developing emerging
  leaders who are more representative of the diversity and intersectionality of the U.S. population.

# **AcademyHealth Operates Through a Lens of Equity**

AcademyHealth is undertaking a broad initiative that was announced in late 2020 that addresses Diversity, Equity and Inclusion in three areas: (1) how we model inclusion and equity through self-assessments, staff training, and hiring policies; (2) providing leadership in collaboration with our members and partners to develop best practices in anti-racism research methods and representation of a wider variety of perspectives and expertise in our leadership forums; and (3) to facilitate changes in the field through education, training, and publications. We have been engaged with an advisory group of experts on DEI in health services research (HSR) and related fields whose recommendations will be released in summer 2021. We anticipate their recommendations will address several areas from this framework, including mentoring, networking, and career pathways; improved research methods that increase representation and reduce data bias; accountability for funders in promoting a more inclusive and equitable research agenda; strategies for organizations to address and begin to eliminate their own structural racism and biases; and building support among those organizations to promote change in their own communities. This work may provide key lessons for the federal government, especially the Department of Health and Human Services (HHS) and its operating divisions such as AHRQ, CMS, NIH, CDC, and FDA, as our country undertakes a long overdue reckoning with structural racism.

Structural racism is embedded racial bias across institutions and society. It is based on the cumulative and compounding effects of an array of historical and current events that systematically privilege and center white people and disadvantage people of color. Structural racism exists in every sector of our society, from the federal biomedical grantmaking - both in who gets funding and what projects are prioritized – to who has health care access and the quality of care they receive. As a primary funder for health care, medical research, and health services research, the federal government is a critical actor for closing the gap between our ideal of making universal and equitable high-value health care a reality for all and the status quo.

AcademyHealth's <u>Paradigm Project</u>, a multi-year initiative to develop, test, and spread bold innovations to enhance the relevance of health services research for policy and practice, has underscored the need for our field and health care broadly to address structural racism in all its institutions. Our use of human-

centered design in the Paradigm Project has demonstrated that DEI can and should be a part of any systemic reforms of the scientific enterprise. For example, one innovation we are developing to help health systems to access and apply published research in the care they provide has also evolved through stakeholder input to become a tool for addressing disparities in care and empowering community-based organizations as agents of change.

Thank you for the opportunity to discuss the perspectives of the health services research community. For further comment, clarification, or inquiry, please email Josh Caplan at <a href="mailto:Josh.Caplan@AcademyHealth.org">Josh.Caplan@AcademyHealth.org</a>.