April 9, 2021

Dr. Francis S. Collins, M.D., Ph.D
National Institutes of Health – Office of the Director
9000 Rockville Pike,
Bethesda, MD 20892

RE: Notice Number NOT-OD-21-066 Request for Information (RFI): Inviting Comments and Suggestions to Advance and Strengthen Racial Equity, Diversity, and Inclusion in the Biomedical Research Workforce and Advance Health Disparities and Health Equity Research

Dear Dr. Collins,

On behalf of the Federal AIDS Policy Partnership’s Research Working Group, we thank the National Institutes of Health (NIH) Office of the Director for the opportunity to respond to the Request for Information (RFI): Inviting Comments and Suggestions to Advance and Strengthen Racial Equity, Diversity, and Inclusion in the Biomedical Research Workforce and Advance Health Disparities and Health Equity Research. We are pleased to see the NIH taking steps to correct a longstanding disparity and beginning to push forward an agenda to uphold the vision as stipulated in President Biden’s January 2021 Executive Order (EO 13985) on Advancing Racial Equity and Support for Underserved Communities through the Federal Government.\(^1\) Without a doubt, racial equity, diversity, and inclusion in all aspects of the field of biomedical research – in particular HIV research – remains a significant challenge for our nation to achieve the ambitious vision of Ending the HIV Epidemic (ETE) across the United States.

The Research Work Group (RWG) of the Federal AIDS Policy Partnership (FAPP) is a coalition of more than 60 national and local HIV/AIDS research advocates, patients, clinicians and scientists from across the country. Our goal is to advance and support U.S. leadership to accelerate progress in the field of HIV/AIDS research.

**The disproportionate impact of HIV on BIPOC and Latinx communities**

Racial equity, diversity, and inclusion in the biomedical research workforce has particularly critical importance and value in HIV research because of the disproportionate impact of HIV on BIPOC (Black, Indigenous, People of Color) and Latinx communities. In the U.S., Black/African American people account for a higher proportion of new HIV diagnoses\(^2\) and people with living with HIV (PLHIV), compared to other races and ethnicities. In 2018, Black/African American people accounted for 13% of the U.S. population but 42% new HIV diagnoses in the

---


U.S. and dependent areas, and Black/African American gay and bisexual men accounted for 26% of new HIV diagnoses and 37% of new diagnoses among all gay and bisexual men. Similarly, in 2018, adult and adolescent Hispanics/Latinx made up 27% of new HIV diagnoses in the United States (US) and dependent areas.

Significant disparities in HIV are also seen when factoring gender with race. Data from 2018 finds that heterosexual Black women account for 61% of all new infections among women. Black and Latinx transgender women continue to see alarming rates of HIV. Great strides have been made in HIV research that have led to groundbreaking treatment and prevention interventions, but there is unquestionably more that needs to be done to centralize BIPOC and Latinx communities in our nation’s scientific response to ensure that these communities receive the maximum benefit of publicly-funded science at NIH.

Promoting practices of diversity and inclusion in HIV research must begin with transforming the very pipeline that brings young researchers to apply for coveted NIH grant funding, to overhauling policies and procedures in how research is conducted among BIPOC and Latinx communities. Measures to diversify NIH work force serve not only the urgent goals of equity and inclusion, but will have a significant effect of boosting the depth and quality of HIV research. Effective and impactful HIV research flourishes not through scientific advances alone, but also through research that reaches and benefits all those needing HIV treatment and care or who are at risk of HIV infection. Building a deep bench of BIPOC and Latinx researchers and removing historical barriers to access funding opportunities at NIH will narrow the gap in reaching populations by having research funded, led and guided by those who represent key populations. But the NIH must invest directly in the nurture and development of BIPOC and Latinx researchers.

Clear Congressional direction also underscores the value and urgency this work. Congress has found that historically underrepresented populations are the largest “untapped STEM talent pools in the United States” so that “given the shifting demographic landscape, the United States should encourage full participation of individuals from underrepresented populations in STEM fields.” A 2013 U.S Census report finds that only 6% of STEM workers were Black, up only 2% from 1970. The same report finds that Latinx community only comprises of 7% of the STEM workforce. Additionally, men (31%) are employed in a STEM occupation at twice the rate of women (15%). These disparities were recognized in the passage of the 21st Century Cures Act of 2016 which requires the NIH Director to “[d]evelop, modify, or prioritize policies, as needed to … increase opportunities for new researchers to receive funding, enhance training and mentorship programs for researchers, and enhance workforce diversity.” Without interventions in the form of policies and funding, we fear that these trends will continue and make it increasingly difficult to fill the pipeline with young, promising researchers of color.

---

3 Id.
4 Id.
Current state of representation in R01 grants and impact on HIV research

As you know, R01 funding through the NIH is the gateway to a career in science in the U.S. Compared with applications from white counterparts, applications from Black researchers have a lower probability of being awarded R01 Type 1 funding, regardless of the investigator's degree. However, funding probability is increased for applications with MD investigators so that applications from Black MDs at medical schools have the smallest difference in funding probability compared with those from whites. This data suggests that it is possible to address this problem, and there are lessons and best practices to be learned from the experience of applications from Black MDs at medical schools.

Moreover, a worrisome trend in declining R01 applications for HIV research is particularly concerning and was first brought to the attention of the RWG as early as 2018. Dr. Carl Dieffenbach, Director of the Division for AIDS Research (DAIDS) at NIAID, at the January 2018 Advisory Council for AIDS Research (ARAC) noted this trend by pointing out to the fact that the total Research Project Grant (RPG) applications received by NIH were peaking at the time. However, in comparison HIV/AIDS RPGs received by NIAID fell after a peak in 2014 to its lowest level since 2005. This trend was seen across R01s applications for HIV as well, with low success rates in actually being funded (see Figure 1). Dr. Dieffenbach attributed this R01 drop to fewer individuals being interested in HIV/AIDS research. This trend was further magnified in a recent meeting on February 17, 2021 between the RWG and members of DAIDS leadership, where we learned that the drop of R01s continued through the mostly recently reported fiscal year and BIPOC and Latinx applicants only representing 10% of the total R01s received by the institution.

---

Deep structural inequities, systemic racism, and barriers within multiple institutions and may be driving the troublesome trends in R01s coming from BIPOC and Latinx researchers. A 2018 paper published in *PLoS One* studied the effects of racial differences in NIH awards by examining the association of between NIH R01 applicant’s race and ethnicity, and the probability of receiving an R01 award. To no surprise, Black applicants had fewer published papers and citations that factor heavily in R01 awards. The study notes that often Black researchers lack career advice, mentorship and training opportunities in comparison to white counterparts, as well as having smaller professional networks that limit their prospects for promotion of their research and further citations.\(^9\) Black applicants were also found to be subject to pressure within their respective institutions to mentor students in order to meet cultural diversity initiatives, in what is described to be a “cultural taxation” placed upon Black researchers.\(^10\) Lastly, similar research published in the *Journal of the Association of American Medical Colleges* studied R01 awards with the inclusion of gender and race. This study found that Black women (PhDs and MDs) were less likely to receive R01 award, but their white women counterparts were as likely as white men to receive funding.\(^11\) In all, Black researchers in particular have the “cards stacked” against them, having limited support and ability to navigate a deeply entrenched, institutionalized and competitive system to have their research funded.

**Under-representation of BIPOC and Latinx researchers in successful R01 applications, especially within HIV research, is perhaps the most urgent and critical issue that the NIH needs to focus on.** It is urgent because of the recent decline in HIV research among early-stage investigators and because the decisions the NIH makes today will affect HIV research for many years. Even if the NIH is able to correct the historical imbalance of R01 awards in the future, there may be lasting damage to HIV research. The Administration’s vision for ETE hinges on energizing and investing in the future workforce to reach the ambitious goals of treating and preventing new infections. Should these worrisome trends in inequities in research continue, it will be difficult to deploy a diverse HIV workforce with a depth of cultural competency and sensitivity that our response desperately needs to promote trust within diverse populations, making future outreach and research engagement with key populations even more challenging.

**Impact on science and client-based approaches from that lost knowledge of communities.**

“[L]ack of diversity among biomedical research professionals is not merely an issue of demographic equity; it undermines the realization of our national research goals.”\(^12\) If BIPOC and Latinx researchers are unable to effectively compete with R01 and other grants, the HIV field loses not only the benefit and learning about their lived experience but also their ideas and

---


10. Id.


innovation. There is a rich diversity within the U.S. that must be leveraged. Biomedical research neglects this diversity to our detriment.

This challenge will only become more urgent in the future. Recent modelling presented at the 2021 virtual Conference on Retroviruses and Opportunistic Infections found that over one third of those living with HIV in U.S. will suffer multimorbidity by 2030, forecasting a “silver tsunami” in multimorbidity, polypharmacy, and healthcare costs in US residents with HIV. HIV research that is impactful results when researchers, early in the development process, ensure interventions meet needs of impacted communities, and take care to anticipate unique challenges associated with a particular product that will need to be resolved for rollout to be successful. Existing data dissemination structures primarily rely on top-down approaches. Unless research is designed and informed with engaged communities in mind, our ability to implement scientific innovations that result from decades of public investment in HIV research and achieve clinical improvements to HIV prevention and care will be impaired.

We have seen evidence of what happens when the NIH invests in strong community involvement and engagement that focuses on racial equity and diversity in all aspects of NIH-funded research. The HIV Prevention Trials Network (HPTN) 083 study has been a noted success in reaching very ambitious recruitment and retention targets for highly marginalized communities of color. A May 2020 webinar by the HPTN 083 protocol team attributes engagement with community in problem-solving solutions, and partnership-building with marginalized groups as critical keys to success of the study. Such community-driven approaches, best practices and solutions in research must be leveraged and translated for all future research with these communities.

Lack of equity also fuels distrust of science by under-represented communities. Much has been made of the effect of the Tuskegee syphilis experiments on the attitudes of Black/African American communities. The distrust that exists is not solely rooted in Tuskegee, but is fueled by issues such as the continuing and contributing lack of diversity. This remains a very relevant problem.

Recommendations for NIH

i. *Develop new and nurture existing partnerships or collaborations that NIH could leverage to enhance the NIH-funded biomedical research enterprise*

The FAPP RWG strongly support efforts by the NIH to increase and amplify the leadership of early-stage investigators from these disproportionately impacted communities by leveraging existing influence and partnerships in addition to fostering new collaborations.\(^1^9\) An increase in funded BIPOC and Latinx researchers will bring unique perspectives to research questions and strategies concerning access, delivery, and effectiveness of care in BIPOC and Latinx communities. The following are the RWG recommendations to NIH on increasing funded BIPOC and Latinx researchers in the field of HIV/AIDS:

1. We believe that to realize our shared goal of increasing the number of HIV grants to PIs from underrepresented groups we need to increase early involvement by Black, Indigenous and people of color (BIPOC) and Latinx communities in STEM as a way to develop a cadre of researchers that are representative of the HIV epidemic in the United States. The STEM Education Strategic plan, developed in December 2018, set out a federal strategy that includes increasing resources to BIPOC and Latinx communities that are traditionally underrepresented in STEM fields.\(^2^0\) NIH cannot do this alone, so the Research Work Group supports the convening of a federal interagency taskforce/learning collaborative to review current efforts and share best practices to increase diversity (i.e., racial/ethnic and gender). Federal agencies that could participate include the Department of Education, National Institute of Health, National Science Foundation, US Department of State, Department of Defense, and other agencies.

2. We recommend fostering new and productive collaborations between the NIH and Historically Black Colleges and Universities (HBCUs), Hispanic-Serving Institutions (HSIs), and Tribal Colleges and Universities (TCUs). This collaborative relationship is important in recruiting, mentoring and nurturing BIPOC researchers and future providers as well as providing federal resources to universities serving BIPOC and Latinx communities that have previously been shut out. During the height of the COVID-19 pandemic, NIH provided Meharry Medical College, an HBCU based in Tennessee, with vital research and technical support to advance development of COVID-19 medications.\(^2^1\) Such investments can break down barriers to accessing the complex NIH funding mechanism for research institutions like Meharry Medical College to develop innovative technologies that benefit an underrepresented community.

---

\(^{1^9}\) See e.g. Research Justice Institute (RJI) and Coalition of Communities of color. [https://www.coalitioncommunitiescolor.org/ccc-researchdatajustice](https://www.coalitioncommunitiescolor.org/ccc-researchdatajustice)


3. While federal resources have been used to nurture relationship-building between HBCUs/HSIs/TCUs and NIH, there is very little understanding of the impact on the pipeline to new researchers from these groups and their success in being awarded with funding. We strongly recommend that NIH conduct a systemic evaluation of these programs to discern the impact, investigate root causes of the low level of NIH funded BIPOC and Latinx researchers, and detail the additional policy and/or fiscal measures needed to address these issues.

4. The Legacy Project at the Office of HIV/AIDS Network Coordination (HANC) coordinates the New Investigators Working Group, which aims to promote equity and representation in HIV research across the NIH HIV/AIDS Trials Networks, with an emphasis on engaging underrepresented BIPOC and Latinx researchers in the US through increased training opportunities. We recommend a robust investment in HANC and the Legacy Project to continue work to cultivate and scale-up collaboration among the NIH HIV/AIDS Trials Networks with academic and research institutions, governmental agencies and community-based organizations.

   ii. Review and amend existing NIH policies, procedures, or practices that may perpetuate racial disparities/bias in application preparations/submissions, peer review, and funding.

An NIH-commissioned analysis of grant data made clear that existing NIH policies, procedures and practices perpetuate racial disparities/biases in the grantmaking process. Based on this analysis, a black researcher’s chance of winning NIH funding was 10 percentage points lower than that of a white researcher. This gap in NIH awards results from bias favoring existing relationships and white scientists from older established and predominately white institutions. The policies and practices of traditional grant-making at the NIH need to be addressed/amended to promote and embrace diversity, equity, and inclusion (DEI). There are many actions that can be taken by NIH to address these biases and ensure biomedical research can be more impactful and inclusive. The FAPP RWG recommend these methods to more deeply embed DEI into grantmaking practice at the NIH:

   • Conduct outreach to attract a wide range of potential applicants (i.e., HBCUs, public universities, BIPOC professional associations, etc.).
   • Clarify and demystify the grant-making selection, process and timeline by providing webinars and trainings as well as guidance on publishing that promotes equity
   • Utilize a blind “Peer-review grant making” process.
   • Increase the diversity of reviewers of grant applications (i.e., race/ethnicity, age, geographic region, gender, etc.).

• Utilize scoring rubric as a tool for discussion but not as a decision-making tool.
• During the decision-making process, consider what your overall portfolio looks like and where there might be “gaps” in terms of diversity.
• NIH grant applications are notoriously difficult to complete so that most successful applicants have dedicated staff members at their institutions whose entire job focuses solely on such applications. For researchers who are not be employed by institutions that can fund these grant departments, this can be a significant hurdle and disadvantage that greatly inhibits diversity among awardees. More BIPOC and Latinx researchers, and researchers from other underrepresented communities, can be recruited through application assistance such as streamlined guidance and referrals to institutions with experience in successfully applying.

It is clear that NIH needs to take steps to make the grant-making process more accessible for BIPOC and Latinx researchers. The NIH-commissioned analysis of grant data was a good start but a deeper root cause investigation must be conducted to gain knowledge of why the gaps exist and what policies, procedures and practices are perpetuating racial disparities/biases.

iii. Enhance existing programs developed to diversify the researcher base that have failed.

In the years since the ACD Working Group on Diversity in the Biomedical Research Workforce made its recommendations, there has been modest progress in many areas.25 Yet many of the recommendations are echoed in this submission, and we believe will be in the submissions of others to the RFI. The ACD Working Group recommended among other steps that the NIH:

• Offer financial support for undergraduates.
• Review and evaluate all diversity programs.
• Assess reasons for disparity in grant awards.
• Develop interest in STEM in K-12 and beyond.
• Establish a system of mentorship “networks”.
• Mandate implicit bias/diversity awareness training for scientific review and program officers.
• Make bold, multi-year awards to enhance diversity at under-resourced institutions.

The steps the NIH needs to take remain clear. Some modest improvements have occurred which have increased the number of R01 and K grants, fellowships, and PhDs since 2012.26 These increases have not led to parity by underrepresented groups, but these modest successes do point the way by providing evidence that the NIH acting by itself can effect change. They also suggest that in order to achieve parity, these efforts will have to be doubled or tripled in scale and scope.

In the end, the NIH needs a broader policy that “combin[es] institutional policies that promote a research culture and climate for diversity with quality, evidence-based programs and networks of

26 Id.
support,” so that “we can go beyond an individual skill-based approach to generate a sustainable research workforce that will inform policy.”

iv. Increase support for researchers and research institutions based in Africa

Sub-Saharan Africa is the epicenter of the HIV Epidemic; more than two-thirds of the global population of people living with HIV live in sub-Saharan Africa. Given the scale of the HIV/AIDS epidemic in Africa, it is critical to improve research capacity that address loco-regional questions and strategies that will improve HIV prevention and care in Africa. NIH has funded groundbreaking HIV prevention and care research based in Africa and such funding should be prioritized and increased.

v. Diversify HIV Clinical Trial Participants

The NIH is mandated to ensure the inclusion of significant numbers of women and minority populations in all NIH-funded clinical research to the extent that it is appropriate to the scientific study. As mentioned above, the HIV epidemic has a disproportionate impact on BIPOC and Latinx communities and therefore those communities should be appropriately included in all HIV clinical trials, especially Phase III and IV. There are many action steps that the NIH can pursue to ensure that HIV clinical trials are truly inclusive and address barriers to recruiting diverse participants.

• NIH should address the lack of information about available studies by utilizing social media and partnering with media to advertise.
• NIH needs to institute and enforce policies and practices that pause trials until diverse populations are recruited if there is not the appropriate proportion of BIPOC, Latinx, women, and other demographics relevant to the study.
• NIH must ensure there is an investment in community engagement efforts that begin early in the process, aligned with the Good Participatory Practice Guidelines, and require specific diversity promoting outreach activities as part of study protocols. It is also necessary to hire diverse outreach workers at clinical trial sites that reflect communities of color in order to enroll and retain participants.

Incentivize BIPOC and Latinx individuals to become Infectious Disease physicians

Over a decade ago, The Department of Health and Human Services pledged, as part of the Healthy People 2020 agenda, to achieve “health equity, eliminate disparities, and improve the health of all groups”. This has not happened. A diverse public health and healthcare workforce is crucial to increasing access to and quality of care for many vulnerable populations.\textsuperscript{30} We must invest in STEM and diversity programs to get BIPOC and Latinx students interested in medicine from an early age and address financial and structural barriers that may deter BIPOC and Latinx students from entering the field of medicine. There are some examples across the federal government that incentivize and support BIPOC and Latinx individuals to become ID doctors.

- Rep. Lisa Blunt Rochester (D-DE) recently reintroduced The HIV Epidemic Loan-Repayment Program (HELP) Act, which would address shortages by providing up to $250,000 in loan repayment to physicians and nurse practitioners who provide HIV care services for a minimum of 5 years. The exorbitantly high costs of postsecondary education often keep people from oppressed communities, including BIPOC and Latinx students, from pursuing careers which require expensive academic training. Loan repayment programs, such as those within the HELP Act, would incentivize young students of color to consider such careers in the HIV care landscape. A parallel program for HIV research could make a substantial difference in BIPOC and Latinx representation in HIV research.
- The Office of Minority Health and Health Equity at the CDC has partnered with research institutions, colleges and universities, and national organizations to develop training and internship programs to enhance recruitment of students from underrepresented communities to achieve a diverse workforce.

In summary, the RWG strongly encourages implementation of the preceding recommendations and policy strategies to effectively begin addressing racial inequities and correcting disparities experienced by BIPOC and Latinx researchers, and rooting out systemic racism from our world-renowned research institutions. The NIH remains a vital, important, and venerable institution that is needed now more than ever to inform our public health responses to HIV/AIDS, tuberculosis, viral hepatitis, and COVID-19 epidemics with a depth of science. By implementing these recommendations and breaking barriers for diversity in research, the NIH and the country as a whole stand to gain a significant advantage in achieving an end to the HIV and COVID-19 epidemics that will be made possible through cutting-edge, culturally-competent, publicly-funded science led by our nation’s best and brightest.

We welcome the opportunity to further discuss these recommendations with you and leadership at NIH. If you have any questions in regards to this comment, please do not hesitate to contact the co-chairs of the FAPP RWG: Kevin Fisher at Kevin@avac.org and Suraj Madoori at suraj.madoori@treatmentactiongroup.org.

We look forward to hearing from you and for further action from the NIH on these urgent issues of racial and gender equity in science.

Sincerely,

AIDS Action Baltimore
AIDS Alabama
AIDS Alliance for Women, Infants, Children, Youth & Families
AIDS Foundation Chicago
AIDS United
Amida Care
Association of Nurses in AIDS Care
AVAC
BELIEVE Martin Delaney Collaboratory CAB
Black AIDS Institute
CAEAR Coalition
DARE Martin Delaney Collaboratory CAB
defeatHIV Martin Delaney Collaboratory CAB
Elizabeth Glaser Pediatric AIDS Foundation
GLMA: Health Professionals Advancing LGBTQ Equality
Guiding Right, Inc
Health Gap
HIV Medicine Association (HIVMA)
HIV+Hepatitis Policy Institute
HIV+Aging Research Project
Human Rights Campaign
International Association of Providers of AIDS Care
NASTAD
NMAC
North Carolina AIDS Action Network
Positive Women's Network-USA
Prevention Access Campaign
San Francisco AIDS Foundation
The AIDS Institute
The Well Project
Treatment Action Group (TAG)