

Remarks to the National Institutes for Health (NIH) and White House Office on Science and Technology (OSTP) listening session on allergies, infectious diseases, and global health for the Advanced Research Projects Agency for Health (ARPA-H)

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Thank you Dr. Collins and NIH leadership for the opportunity to speak today. My name is Suraj Madoori with Treatment Action Group, representing the 60 organizations of the Federal AIDS Policy Partnership's Research Work Group, which I co-chair with Kevin Fisher of AVAC . We thank NIH leadership foremost for the incredible work in the current pandemic to save lives and moving us in the direction of an hopeful end.

We applaud the NIH and the administration for its vocal pursuit of ARPA-H, an agency that could catalyze biomedical research on the heels of unprecedented success in the rapid development and deployment of COVID-19 vaccines. Today, I will seek to reflect the guidance and priorities for ARPA-H from the HIV community, which has a long and deep history of engagement with our government's publicly funded research institutions.

First, we implore NIH leadership and the administration to include HIV and comorbidities such as tuberculosis, STIs, and viral hepatitis as priorities in the portfolio of ARPA-H. These infectious diseases take millions of lives every year and require an accelerated research agenda to end these epidemics - particularly amongst communities of color and marginalized populations.. The HIV research sector can be a partner in ARPA-H's portfolio that can be leveraged to advance more rapid breakthroughs. The history of HIV research at the NIH has shown that health interventions need to incorporate community perspectives and patient-centered design to be acceptable and, ultimately, to be effective. One area in which the DARPA model could learn from HIV research is how to integrate community and be informed by community input. Community input into trial protocols, trial enrollment strategies, and even scientific priorities at the NIAID clinical trial networks has translated into research successes both in the HIV arena as well as other diseases.

Investments in HIV research capacity have been critical to advancing the platforms necessary to enable the rapid study of and Emergency Use Approval of current COVID-19 vaccines. HIV research fueled our nation's biomedical response to COVID-19 possible, and your decades of research investments in HIV can ensure the success of ARPA-H.

As public health professionals and researchers, you understand the crosscutting nature of health outcomes and research investments. In health research, there is a tendency to work in silos instead of fostering a collaborative environment that can leverage the expertise and knowledge across multiple internal and external partners. Collaboration with unique partners will address the systemic gaps that exist in the discovery, development, and delivery continuum.

Here again, HIV research with its decades of coordination and collaboration across institutes provides an important precedent and example for ARPA-H.

The FAPP RWG strongly supports efforts to address structural racism across the NIH and increase the leadership of early-stage investigators from disproportionately impacted communities by leveraging existing partnerships and fostering new collaborations. AARPA-H provides an opportunity to design funding programs to increase recruitment and funding for BIPOC and Latinx researchers. This will bring unique perspectives to research questions and strategies concerning access, delivery, and effectiveness of care in BIPOC and Latinx communities. It is also important that the ARPA-H research portfolio reflects diversity and prioritizes the engagement of populations into research that affects morbidity and mortality in their communities.

ARPA-H must consider strategies that address commercialization, implementation, affordability and accessibility of publicly-funded research. For example, ARPA-H should require full disclosure of the cost of product development and raw materials within the agreements made between the US government and industry. ARPA-H should carefully consider industry incentives, which have historically resulted in access restrictions to the patients that most need promising new therapies. Greater transparency is needed on the part of the government and industry to foster community trust. We have seen the failure of COVID-19 vaccines reaching those who need it most across the globe, particularly low and middle income countries, due to the lack of transparency and accessibility to these publicly funded, lifesaving products. These are the same countries

Finally, NIH Institutes and Centers as well as all affected communities and their advocates must be at the center of any plans for the development, implementation, and dissemination of new technologies. Without the lived experience and expertise of those with research subject matter expertise and the community who are the ultimate consumers, research and development as well as the final use of new interventions will be unsuccessful. We have seen that the result of the failure to engage communities most hard hit by COVID-19 has resulted in vaccine hesitancy. We strongly encourage ARPA-H to lead with a robust structure for community engagement.