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OAR Stakeholder Outreach and Engagement Listening Sessions

September 2020–July 2021 Summary Report

Introduction

The Office of AIDS Research (OAR) of the National Institutes of Health (NIH) is charged by Congress with coordinating the scientific, budgetary, and policy elements of NIH’s comprehensive HIV research program across the Institutes, Centers, and Offices (ICOs) of the NIH. OAR regularly obtains input from multiple stakeholder communities to ensure that the overall NIH HIV research program and priorities are responsive to emerging scientific advances, changes in the epidemic, and the diverse needs of communities.

In 2018, the NIH OAR initiated activities to expand its stakeholder outreach and engagement. As part of the effort, OAR implemented a series of listening sessions in 2019 that were held in different geographic locations primarily in the United States. These events provided an open and transparent forum for stakeholders to communicate to OAR and the NIH their views on current and future research opportunities and their needs from a local and regional point of view. From early 2019 to early 2020, the sessions were held in person at universities and offices of community-based organizations (CBOs) and at times in conjunction with major meetings and conferences. The listening sessions were hosted and moderated by science and community leaders in each locale; and participants included individuals from academia and other research institutions, public health agencies, and community and advocacy organizations, including those representing people with HIV. A summary of the listening sessions and related activities between September 2018 and February 2020 is available [on the OAR website](#).

In March 2020, the emergence of the SARS-Cov-2 virus and the COVID-19 pandemic caused a pause in NIH OAR stakeholder engagement activities. As in-person meetings continued to be infeasible, OAR pivoted to convening listening sessions virtually, while retaining a geographic focus. Locations in which sessions had already been planned when in-person meetings were halted—Boston, MA; the state of West Virginia; and Nashville, TN—were prioritized. Additional virtual sessions were held with stakeholders in the state of Nebraska; San Diego, CA; and the parishes comprising New Orleans, Baton Rouge, and Lafayette, LA. This report provides a summary of these virtual meetings.

Listening Sessions

Table 1 provides information about the locations, stakeholder participants, and hosts of the events held between September 2020 and July 2021. During this period, fifteen sessions occurred across six geographic locales. The format of the sessions was similar to the in-person meetings held before the COVID-19 pandemic—a facilitated discussion organized around a few core questions. On some occasions, when participants were less familiar with the NIH and OAR, the OAR Director provided a brief overview of the mission, mandate, and activities of the Office. Discussions were moderated by local hosts from academic institutions or CBOs, and the OAR director and staff, as were other attendees from NIH ICOs, were chiefly in listening mode. The number of non-NIH participants at each session ranged from 10 to 30. Each session lasted between 45 and 60 minutes; all were held using virtual platforms.

Table 1: Schedule of OAR Listening Sessions, September 2020–July 2021

Date(s)	Stakeholders	Hosts and Moderators
9/16/2020 Boston, MA	Area researchers, students, service providers, public health officials, and community members	Harvard Center for AIDS Research Fenway Community Health and Massachusetts Department of Public Health
9/26/2020 West Virginia	Area researchers, students, service providers, public health officials, and community members	West Virginia University Community Education Group
11/18/2020 Nashville, TN	Area researchers, service providers, public health officials, faith leaders, and community members	Tennessee Center for AIDS Research Meharry Medical College Metropolitan Interdenominational Church
4/21/2021 Nebraska	Area researchers, service providers, and community members	University of Nebraska Medical Center
5/27/2021 San Diego, CA	Area researchers, service providers, public health officials, and community members	San Diego Center for AIDS Research San Diego County Getting to Zero EHE Initiative
6/30/2021 7/7/2021 New Orleans, LA	Health care and other service providers, public health officials, people with HIV, and researchers	Southern AIDS Coalition Louisiana Public Health Institute

Context and Content

Two key environmental changes that emerged in early 2020 affected the content of the listening sessions: (1) the COVID-19 pandemic and the social, economic, and disease burden of COVID19 on racial and ethnic minority populations; and (2) the resurgent racial justice movement following the deaths of George Floyd and other Blacks/ African Americans at the hands of police. The NIH OAR saw that these developments were relevant to the NIH HIV/ AIDS research program and had implications for the kinds of research questions to be pursued and prioritized, the structure and logistics of the research enterprise, and the character of the HIV research workforce. As a result, OAR sought to obtain input on the following core questions:

1. Within the overarching HIV research priority areas—prevent new HIV infections, develop novel therapies, research toward a cure, address comorbidities, and mitigate health disparities—what are emerging trends in the HIV epidemic that the NIH should highlight and/or increase support for?
2. What are the implications of current research strategies on the Ending the HIV Epidemic in the U.S. (EHE) initiative, cure, and other research efforts, and how can the NIH best maximize our investments to meet the goals of each initiative and those outlined in the NIH HIV Strategic Plan?
3. How can we continue to conduct high-priority HIV science in the context of COVID-19 and the racial justice movement?
 - How have the content and operations of HIV research been affected by COVID19?
 - What opportunities do both the COVID-19 pandemic and the racial justice movement provide for conducting doing HIV research in novel ways?
4. What types of training, infrastructure, capacity building, community engagement, and educational outreach efforts will be required to address current HIV priority areas?
 - What concrete steps can be taken to meaningfully diversify the HIV research workforce by race, ethnicity, sex, gender, age, geographic location, institutional affiliation, etc.?
 - Are there examples of effective approaches and initiatives?
 - How can we optimize community engagement in HIV-related research and ensure that our science is in service to all of society?

Key Findings

Across sites and groups, common themes emerged from the listening sessions. Key among these are: enhance support for priority HIV research topics; address the impact of COVID-19 on HIV work; redress inequalities in the HIV research enterprise and diversify the HIV research workforce, with attention to circumstances facing under-resourced (including minority-serving and rural) research institutions; enhance relationships between academic and community partners; and address challenges affecting early-career investigators (ECIs). In some sessions, more context-specific issues were raised, reflecting local, regional, population, and stakeholder group perspectives. Following is a summary of comments, concerns, and ideas articulated by stakeholders related to these themes.

Enhance Support for Priority Areas of Research

Participants identified priorities and specific topics in HIV research that require enhanced support in three key areas: (1) basic, clinical, behavioral, social, and implementation science; (2) populations in need of greater attention; and (3) methodological innovations. Salient themes across the areas included increased understanding of the virus life cycle to improve HIV treatment and inform HIV cure strategies; enhancing diversity in research participants and researchers to better reflect communities most affected by HIV; addressing comorbidities and co-occurring conditions—physical, behavioral, and social—that influence HIV prevention and treatment outcomes for different people with HIV; identifying the particular HIV knowledge, prevention, and treatment needs of rural and young populations; incorporating new technological and methodological advances to streamline HIV research; and engaging communities to inform what research questions are asked and to contribute lived experience as data.

The full range of research areas and foci articulated by stakeholders is shown in [Appendix 1](#) at the end of this report.

Address the Impact of COVID-19 on HIV Research Activities

The emergence and rapid spread of SARS-CoV-2/COVID-19 across the United States and the world has had a significant impact on HIV-related research activities supported by the NIH—from sustaining laboratory activities to recruiting research participants to conducting HIV prevention and treatment intervention studies. Participants across listening session sites and stakeholder groups articulated many issues related to the impact of the pandemic on their work and identified a few areas for OAR and the NIH to consider as part of the research recovery efforts.

First were the direct impacts of the emerging COVID-19 pandemic on HIV research efforts. One area of concern was the increasingly limited supply of nonhuman primates (NHP) for HIV cure and vaccine research. Participants noted that NHP resources already were strained and COVID-19 needs further exacerbated their shortage, which was a problem particularly for HIV studies that had been put on hold because of the pandemic and were just beginning to restart.

Researchers also lamented the reduced research productivity caused by the pandemic and cited stalled recruitment of study participants, interruption of laboratory work, supply chain shortages, inability to collect preliminary data for future grant proposals, and the overall difficulty in planning future studies, given the level of uncertainty. Researchers in Boston mentioned the impact of COVID-19 on their ability to conduct international research, including limited or no access to international collaborators and sites, not knowing when on-the-ground research and engagement would resume, severe cuts in support for international (especially African) investigators, and a sense that domestic (U.S.) research would be prioritized over international research going forward. Participants in San Diego noted the “massive disruption” to both clinic and research work in HIV with binational (U.S.–Mexico) patients. At the same time, the researchers experienced a broader reach to this population through expanded telehealth and mHealth approaches.

Second, many participants were concerned that the understandable and necessary pivot from HIV to COVID-19 work might produce a shift in focus that would come at the expense of HIV in both the near and long term. They framed the challenge for the next few years as enhancing pandemic preparedness, while assuring that the scientists conducting HIV research are retained and not lost to other fields.

Researchers in Nashville made the point that the pivot to COVID-19 work was particularly challenging to under-resourced institutions that have limited funding and, therefore, are at a disadvantage with respect to such activities as reopening laboratories that were closed and recompeting for grants.

Finally, some stakeholders feared that gains made toward reaching the goals of the Ending the HIV Epidemic in the U.S. (EHE) initiative would be lost if attention continues to be shifted to COVID-19 and if people are unable to access HIV prevention and treatment services because of COVID-19 pandemic-related needs and restrictions.

Although most stakeholders focused on the negative impact of COVID-19 on HIV work, some did identify opportunities arising from the pandemic response, such as the ability to leverage technologies in novel ways (e.g., to do research, to provide services), harness altruism to expand the pipeline of investigators and build capacity for HIV research, and reinvigorate basic immunology and virology research, particularly related to HIV vaccines and cure.

Redress Structural Racism in the HIV Research Enterprise and Diversify the HIV Research Workforce

Achieving meaningful diversity—by age, race, ethnicity, sex, gender identity, and region—among those conducting HIV research is a key priority of NIH and the OAR. Events of the past year related to racial and social justice movements have elevated and expanded discussions among stakeholders about how best to do this. Listening session participants identified concrete steps related to grant review and funding, mentoring, and capacity strengthening that OAR and the NIH could implement to address structural racism in the health research enterprise and diversify the investigator pool. The comments and recommendations underscored the need to acknowledge the unique perspectives and experiences of underrepresented groups, particularly investigators of color. Areas of improvement identified by stakeholders include:

- **Scientific Review of grant applications:** Most participants perceive review process as highly competitive and often favoring those who already are successful. A consensus recommendation included to expand diversity in review panels to reduce implicit bias that might hamper the success of underrepresented groups. Additionally, participants suggested including recognition during grant review that underrepresented minority investigators may have a scientific advantage in addressing some questions, particularly topics related to the investigators' communities.
- **Mentorship:** Stakeholders expressed the need for a more concerted effort to support underrepresented researchers as a key part of capacity building and strengthening. Specific recommendations included offering NIH sponsored mentoring workshops with a focus on working with people from heterogeneous backgrounds and those who do not fit the traditional prototype of an academic, and providing funding for mentorship of underrepresented minority investigators in a range of grant mechanisms.
- **Capacity building in relevant communities:** Participants urged the NIH to build research capacity among people “who look like” communities and who are trusted by communities—for example, by supporting historically Black colleges and universities (HBCUs) to include students via internships, specialized programs, or classes in various science disciplines in areas important to addressing issues in the Black community. Participants emphasized the importance of strategic investments across the education pipeline—undergraduate college and graduate school—and to support research networks of people of color throughout their career trajectory. Participants in San Diego noted that the University of California, San Diego, is a Hispanic-serving institution, but it has few Hispanic or Latinx scientists and physicians.

To increase the proportion of awards to underrepresented groups, stakeholders recommended that the NIH expand and more widely disseminate information about diversity supplements; include non-U.S. citizens as eligible investigators; and provide resources to support development of grant applications, particularly in under-resourced institutions, such as HBCUs.

Enhance Academic–Community Partnerships

Participants across sites and stakeholder groups offered several recommendations of how OAR and the NIH could enhance academic–community partnerships.

An overarching sentiment was the need to actively support the involvement of key stakeholders and community organizations in all phases of research. For example, develop a mechanism to fund community partners directly and include direct funding as a requirement of an award grant; require inclusion of community partners as part of research teams from their inception; and require evidence of meaningful and long-lasting inclusion of community partners.

Stakeholders suggested extended timelines for projects to develop bidirectional engagement and learning (i.e., for researchers to gain community competency—understand structural issues affecting community—and for community members to gain research and health literacy); establish community–academic trust; and embed implementation research.

Both researchers and community members want to see the NIH enhance support of community-based participatory research and expand the definition of innovation used by the NIH in assessing the merits of proposals to include community-defined innovation. Participants also pointed out that the metrics of success for funded projects should be altered from a major focus on peer-reviewed publications to include community impact. For example, instead of asking researchers to describe only the papers that will be produced as a component of the research dissemination plan, the NIH could require researchers to describe what the planned uptake of findings will be, how the findings will address inequity, and what the implications will be for affected communities.

Focus on Early-Career Investigators

Supporting and advancing the careers of ECIs—including NIH-defined [early-stage investigators \(ESIs\)](#)—is a priority for [OAR and the NIH](#). During the Boston, West Virginia, and Nashville listening sessions, concerted efforts were made to engage ECIs in the discussions to hear about their experiences, concerns, and recommendations in general and in the specific context of the COVID-19 pandemic.

With respect to COVID-specific challenges, ECIs identified three main areas of concern. The first was the competing demands on both themselves and their mentors that were leading to disruption in research timelines. Specific experiences included increased clinical work resulting in loss of protected time for research; decreased work hours and capacity due to child care responsibilities, which was seen as particularly affecting women; less access to mentors due to their competing demands; delays in job recruitment and hiring; and emotional impact, particularly among investigators of color, whose communities have been hardest hit by COVID19.

A second area of concern was the potential impact of COVID-19 on career trajectories. ECIs wondered whether there will be gaps in funding; less funding for HIV-related research going forward; extended timelines to compensate for lost productivity; COVID-related research will “count” if one’s planned trajectory is HIV-focused; one should shift their research focus completely from HIV to COVID-19; delays in research projects will affect timelines for promotion; and the COVID-19 pandemic ultimately will affect ECIs’ decisions to pursue a research career.

Finally, ECIs were worried about the loss of opportunity to collect preliminary data for future research grants, which are essential to their career trajectories.

The most salient non-COVID-specific needs identified by ECIs and senior researchers who mentor them were related to funding support—with respect to both dollars and award mechanisms. In particular, participants recommended extending and enhancing T and K award funding by extending K grants by 1 to 2 years and increasing salaries for people on T and K grants. They also recommended providing a surge of pilot grant funding [via the Center for AIDS Research (CFAR) Network of Integrated Clinical Systems (CNICS) and other networks] and expanding the Loan Repayment Program.

Other recommendations for improving the experience of ECIs and supporting their commitment to HIV research included the following:

- Create a mechanism for ECIs to serve on study sections (e.g., as “fourth reviewers”) to gain experience and to help with their own grant writing.
- Streamline the approval processes to allow nimbler reallocation of NIH funds to respond to fluid and sometimes acute research needs (e.g., costs of personal protective equipment).
- For international work, support ECIs in pairs—one at a U.S. institution and one at an international institution—to invest in investigator teams of benefit to both participants.
- Support training programs in comorbidities that can lead to new investigators who can transition to HIV from other fields.

Action Steps

In response to input received from stakeholders during the first year of listening sessions, NIH OAR acted on a number of fronts within our purview, including the following:

- Diversified the sites for holding the next round of listening sessions.
- Reshaped the listening session discussion questions to consider current events.
- Engaged early career and senior investigators in early career-focused listening sessions and an expert panel, respectively.
- Included input from the listening sessions in OAR's EHE and COVID-19 Task Force activities, as well as the recently released National HIV/AIDS Strategy.

Based on the input from stakeholders received during FY2021, OAR will undertake additional action steps, including the following:

1. Continue the listening sessions and related engagement activities with diverse stakeholders in fiscal year 2022.

- Convene listening sessions in various locales to obtain additional input from people in geographic regions not yet reached.
- In collaboration with relevant NIH ICOs, convene topic-specific sessions to highlight priority areas of HIV science (e.g., HIV and aging).
- Collaborate with other NIH ICOs to discuss HIV research-related topics of interest to specific stakeholder groups (e.g., the Tribal Health Research Office).

2. Apply and disseminate the findings from the listening sessions.

- Use inputs from stakeholders to inform broad NIH and U.S. Department of Health and Human Services HIV-related initiatives (e.g., ongoing activities in support of the EHE initiative and the updated National HIV/AIDS Strategy).

3. Work with NIH ICOs on initiatives related to enhancing support for ECIs in HIV—particularly those from underrepresented groups—working in diverse disciplines and academic institutions.

4. Work with NIH ICOs on COVID-19 pandemic-related research recovery strategies.

5. Work with NIH ICOs to identify and address the legal and policy impediments to crafting and supporting academic-community research partnerships with co-equal roles (e.g., as co-principal investigators, as co-funded institutions).

Conclusion

The challenges of the past two years for all engaged in HIV research have been profound. The advent and relentless, persistent spread of the SARS-Cov-2 variants continue to disrupt everyday life, including the conduct of research, as well as devastation to human lives and to health systems throughout the world. The cumulative effect of multiple instances of police violence against Black Americans forced an uncomfortable, but essential reckoning about how racism is structured and institutionalized in American society, including the health research enterprise. Together, these unprecedented occurrences provide an opportunity to approach things differently: In the midst of crisis, better ways of operating emerge out of urgency and necessity and provide an opening to examine what is possible.

OAR stakeholders across locales demonstrated their commitment to supporting a robust and sustained NIH HIV/AIDS research program that focuses on addressing the highest priority areas of science, while engaging in structural changes within and outside the NIH to ensure a more heterogeneous HIV research workforce. They discussed not only the negative impact of COVID-19, but also the positive learnings that emerged about how HIV research can be done in novel ways. They reiterated the importance of community engagement at all stages of research to ensure diversity, equity, and inclusion of all people affected by HIV and to integrate lived experience into HIV science.

Appendix 1

Stakeholder-Identified Priority HIV Research Areas and Foci

Priority Research Area	Foci
<p>Basic Science</p>	<ul style="list-style-type: none"> • Support virology, immunology, and structural biology that informs the following: <ul style="list-style-type: none"> » Vaccine development » Drug discovery, particularly novel applications (e.g., similar to long-acting compounds) • Enhance research on viral reservoirs. • Examine sex differences in preclinical cure research: <ul style="list-style-type: none"> » Biological underpinnings and maintenance of HIV latency, including the role of estrogen receptors • Facilitate greater access to nonhuman primate resources. • Early career investigators and the pipeline of career development.
<p>Clinical Science</p>	<ul style="list-style-type: none"> • Focus on attrition in HIV care. • Address comorbidities across the lifespan, including syndemics: <ul style="list-style-type: none"> » Tuberculosis » Sexually transmitted infections » Aging: <ul style="list-style-type: none"> ◦ Cognitive issues and dementia ◦ HIV and menopause ◦ People over 70 years old » Substance use and addiction: <ul style="list-style-type: none"> ◦ Methamphetamines » Mental health and illness: <ul style="list-style-type: none"> ◦ Depression ◦ Racialized trauma » Chronic health conditions: <ul style="list-style-type: none"> ◦ Inflammation, cardiovascular disease, diabetes, cancers • Better understand the neurological complications of HIV. • Monitor the spread of integrase inhibitor resistance, particularly with antiretroviral therapy (ART) rollout in resource-limited countries. • Evaluate the balance between investigator-initiated clinical trials and network-funded clinical trials. • Create a mechanism to link NIH-funded entities (e.g., CFARs, HIV/AIDS Clinical Trials Units) with rural sites for cohort studies. • Ensure the representation of women and young people in cure clinical trials. • Increase the representation of women and people of color in HIV research. • Consider the endpoints for measuring effectiveness: <ul style="list-style-type: none"> » Not just viral suppression, but also quality-of-life factors.

Priority Research Area	Foci
<p style="text-align: center;">Behavioral and Social Science</p>	<ul style="list-style-type: none"> • Address inequalities and health disparities: <ul style="list-style-type: none"> » Gender and racial inequities in treatment and prevention services: <ul style="list-style-type: none"> ◦ Intersectional stigma ◦ Medical and institutional mistrust and hesitancy ◦ Misgendering of transgender people ◦ Low access to and uptake of pre-exposure prophylaxis (PrEP) among Black women » Assess poverty as a health disparity. » Enhance attention on rural populations. • Develop novel interventions that increase PrEP uptake, decrease stigma, and increase sexual pleasure. • Investigate the role of social support (e.g., housing, food security, financial training) in HIV-related health outcomes. • Investigate holistic community engagement strategies focused on the needs of people interacting with systems and institutions, such as prisons, transportation, and housing sectors. • Support research on behavioral and social issues in vaccine trial design: <ul style="list-style-type: none"> » Assess willingness to participate in clinical trials of HIV vaccine products with partial efficacy in the context of 95% effective COVID-19 vaccines. » Investigate how study participants weigh individual versus community benefits of research participation. • Assess the role of emerging, novel technology in helping to achieve balance between public health needs for brief, sustainable interventions and behavioral health needs for optimal intervention dosing. • Address the mental health and substance use barriers to uptake, adherence, and sustained use of HIV prevention and treatment technologies (i.e., ART for treatment, PrEP).
<p style="text-align: center;">Implementation Science</p>	<ul style="list-style-type: none"> • Identify creative ways to deliver health services “where people are”: <ul style="list-style-type: none"> » Prioritize rural and remote areas. » Develop and evaluate low-barrier, low-threshold programs. » Assess integrated models of care to address medical consequences of substance use disorders, including mental illness, HIV, and hepatitis B and hepatitis C. • Focus on provider education about LGBTQI+ health, sexual health, and PrEP. • Evaluate how well various treatment and prevention strategies will maximize return on investment. • Examine how to leverage HIV care mechanisms to provide health care more broadly. • Advance modeling methodologies to assess the impact of novel HIV prevention and treatment approaches. • Assess the impact of shifting the service delivery platform from in-person to technology-supported platforms (e.g., telemedicine, delivery of behavioral interventions, etc.).

Priority Research Area	Foci
<p style="text-align: center;">Populations for Additional Attention</p>	<ul style="list-style-type: none"> • Rural populations: <ul style="list-style-type: none"> » Support rapid studies on delivering HIV care. » Conduct pragmatic trials of prevention and treatment strategies. » Address provider discomfort in prescribing PrEP. • Young people: <ul style="list-style-type: none"> » Increase research focus on teenagers and young adults (ages 13–24), particularly minors (ages 13–18). » Assess how young people are accessing HIV, health, and sexuality information. » Leverage technology-based platforms to engage young people to deliver HIV and health information and services. • Justice-involved populations: <ul style="list-style-type: none"> » Develop and evaluate support services for people re-entering the community from prisons and jails. • Migrants and people living binationally.
<p style="text-align: center;">Methodology</p>	<ul style="list-style-type: none"> • Support clinical informatics and bioinformatics in HIV. • Support and promote adaptive trial designs. • Support qualitative and community-based research methods, including those that incorporate the lived experience of people with HIV.