

# National Institutes of Health Office of AIDS Research

HIV Partner Outreach and Engagement Report: August 2021 to December 2022





# **Table of Contents**

Executive Summary	
Introduction	2
OAR Outreach and Engagement Activities	2
Methods	3
Partnering With Host Organizations	3
Discussion Guide Preparation	3
Listening Session Structure	3
Analysis of Listening Session Outcomes	3
Key Findings	4
Overview	4
Key Themes	6
Recurring Themes	6
Unique Topics	11
Topics Outside the NIH Research Scope	11
Action Steps	12
Advance the HIV and Aging Research Agenda	12
Expand the HIV and Women Research Agenda	12
Advance Technologies to Improve HIV Diagnosis and Care Research	12
Support Early Career Investigators	12
Ensure Broad Dissemination of Information in a Timely Manner	13
Conclusion	13
Appendix A: Listening Sessions Coordinated by NIH OAR, 2019–2022	14
Appendix B: Listening Sessions Discussion Guide	15
Appendix C: Acronyms and Abbreviations	16

# **Executive Summary**

The National Institutes of Health (NIH) Office of AIDS Research (OAR) coordinates the scientific, budgetary, legislative, and policy components of the NIH HIV research program. In support of its mission and to gather information to advance the NIH research agenda, OAR conducts outreach and engagement activities such as listening sessions; site visits; and meetings with academic institutions, community-based organizations, and other interested parties.

OAR expanded these efforts through a series of listening sessions initiated in 2018 that serve as platforms to gather diversified input (<u>Appendix A</u>). To date, OAR has conducted 52 listening sessions. Listening sessions were held in person until the beginning of the COVID-19 pandemic, when they shifted to a virtual format. Findings from the first of these events, summarized in <u>Report 1 (June 2018 to February 2020)</u> and <u>Report 2 (September 2020 to July 2021)</u>, informed the development of the <u>FY 2021–2025 NIH Strategic Plan for HIV and HIV-Related Research</u>.

The current report summarizes the findings of seven listening sessions held between August 2021 and December 2022 involving participants from academia, public health agencies, community-based organizations, and advocacy groups, including people with lived experience. The sessions were held in a variety of formats—in-person, virtual, and hybrid—and took place in Washington, D.C.; Houston, Texas; and San Juan, Puerto Rico. Key findings and action steps from these sessions are displayed below.

Key Findings: Listening Session Topics	Priority NIH Action Steps
• Improve health outcomes and quality-of-life for the population of people aging with HIV.	Advance the NIH HIV and Aging research agenda.
• Improve the health and well-being of women with HIV.	Advance the NIH HIV and Women research agenda.
• Support HIV research, including workforce, infrastructure, and resources.	<ul> <li>Expand resources to support early career HIV investigators from diverse scientific disciplines and institutions, particularly among underrepresented groups.</li> </ul>
• Expand inclusion and cultural competence in research.	<ul> <li>Increase communication, review policies, and advance strategies to improve inclusion and cultural competence in NIH HIV research.</li> </ul>
Research the social and structural factors that influence HIV prevention and comprehensive care.	• Expand initiatives to address the social and structural factors that impact the uptake of HIV services; accelerate the development of technology approaches to enable early diagnosis, linkage to care, and viral load monitoring.
Improve information dissemination to the broad HIV community.	<ul> <li>Disseminate findings from the listening sessions and expand additional engagement activities, with particular attention to groups and settings not yet represented.</li> </ul>

There has been unprecedented progress in HIV research over the past 40 years that has propelled scientific discoveries and enabled rapid responses to emerging communicable diseases, such as COVID-19 and mpox. People engaged in the HIV response span all ages, genders, races, ethnicities, and geographies. Continuation and expansion of listening sessions and engagement activities across diverse partners, settings, and populations will ensure that groups and locations most affected by HIV are included and represented in the NIH HIV research agenda.

# Introduction

The National Institutes of Health (NIH) Office of AIDS Research (OAR) is authorized by Congress to establish NIH HIV research priorities; develop an annual strategic plan for HIV and HIV-related research; ensure that HIV research funds are invested in the areas of highest scientific priority; address emerging HIV research needs; and coordinate HIV research across NIH Institutes, Centers, and Offices (ICOs). In support of its mission, OAR expanded its outreach efforts in 2018 to increase engagement with the broader HIV community, defined in this report as individuals, organizations, and institutions affected by HIV and/or involved in the HIV response. The HIV community includes academic, scientific, advocacy, government, private, and industry partners. OAR outreach aims to ensure that the NIH HIV research program is responsive to the needs of the HIV community while focusing on scientific discoveries needed to prevent, treat, and cure HIV.

During the COVID-19 pandemic, OAR continued to conduct listening sessions, site visits, and partner meetings virtually to diversify the sources of community and scientific contributions. The COVID-19 pandemic illuminated long-existing health inequities and scientific distrust, and highlighted the need for revised emergency regulatory processes, improvements in health communications, and transparency of research activities and practices. In this context, OAR sought to engage community partner input in 2021–2022 regarding adaptations and responses of the NIH HIV research agenda to address the impact of COVID-19, the needs of people with HIV, and strategies to ensure a sustainable HIV research response with the next generation of investigators. These outreach and engagement activities (see sidebar) provide a critical forum for the community to communicate views on current and future research opportunities to NIH.

Engagement events provide OAR with valuable input as the office advances the NIH HIV research agenda to respond to the diverse needs of communities affected by HIV. Key themes emerging from these engagements were incorporated into the *National HIV/AIDS Strategy*, the *National HIV/AIDS Strategy Federal Implementation Plan*, and the *Fiscal Year 2021–2025 NIH Strategic Plan for HIV and HIV-Related Research*, as well as into activities of the NIH COVID-19 and HIV Taskforce and NIH activities related to the *Ending the HIV Epidemic in the U.S.* (EHE) initiative. The NIH HIV research program has continued to expand community research partnerships through various avenues, such as its support of more than 200 EHE projects since fiscal year 2019 (FY19) that require community partner collaborations.

The current report summarizes the findings of seven listening sessions held between August 2021 and December 2022.

# OAR Outreach and Engagement Activities

Listening sessions are small group discussions for gathering input from partners—including individuals, organizations, institutions, and other interested parties—to inform OAR programs and activities related to the NIH HIV research agenda. OAR provides guiding questions, and a moderator facilitates each session. OAR staff attend in a listening capacity.

Sites visits enhance the understanding of a location in its context of unique circumstances, needs, and opportunities of existing programs and infrastructure. They include time to engage directly with scientific and programmatic staff on site.

Partner meetings are intended to establish, develop, or further enhance relationships between OAR and academic or community constituents in a focused and direct manner.

# Methods

Planning for each listening session consisted of conducting outreach to partners that expressed interest in hosting a session, preparing discussion questions, determining the session structure, and analyzing outcomes.

## **Partnering With Host Organizations**

OAR partners with academic and community leaders to engage individuals across backgrounds, career stages, locations, lived experiences, populations, and organizations. Selection of listening session sites is an iterative process. As part of the selection process, OAR communicates with established HIV/AIDS research programs—such as the NIH-supported Centers for AIDS Research (CFARs), AIDS Research Centers (ARCs), and Research Centers in Minority Institutions (RCMIs)—as well as research and community leaders in areas with underserved and underrepresented populations. In addition, proposals for listening sessions result from OAR Advisory Council (OARAC) meetings and by request from interested partners.

# **Discussion Guide Preparation**

A discussion guide (Appendix B) serves as the framework for listening session questions and was developed by OAR in consultation with the NIH HIV/AIDS Executive Committee (NAEC) and external partners to ensure cultural competency and appropriateness. For community and scientific engagements, questions focus on serving the needs of the host community. A local moderator facilitates each session, and OAR staff attend primarily in a listening capacity. The facilitated questions prompt participants to share their collective concerns, needs, and experiences; identify perceived gaps in research and opportunities to improve the translation of research findings to programs and services; and suggest approaches to address concerns. To remain current, the discussion guide is dynamic, and the questions are reframed as priorities evolve.

# **Listening Session Structure**

The listening sessions summarized in the current report included a brief introduction by the OAR Director about OAR's mission, congressional mandate, current scientific priorities, funding levels for the NIH HIV research program, and specific data about NIH HIV research and training activities in the host jurisdiction. Participants responded to facilitated questions and discussed HIV-related issues most important to their communities and settings. During the 2022 sessions in Puerto Rico, Spanish-speaking OAR staff attended and co-facilitated the sessions by translating the discussions to enable an exchange of ideas in the language(s) most comfortable for participants. The structure and attendance for listening sessions varied depending on whether the format was in person, virtual, or hybrid. In-person events were conducted in a variety of settings, including in conjunction with conferences and meetings. Virtual and hybrid sessions were held over an invitation-only Zoom platform and moderated by an individual designated by the host.

# **Analysis of Listening Session Outcomes**

All in-person and virtual sessions were recorded with participant consent. Digital "chat" comments and conversations over Zoom and handwritten notes from OAR staff were collected. All session data were transcribed professionally for qualitative analysis. At least two OAR analysts independently reviewed all transcripts to identify recurring themes and unique input. A third adjudicator reviewed discordant results from each analyst and resolved discrepancies. Concepts and patterns identified across sessions, as well as those unique to sessions, were compiled both by location and topic. Following analysis of each session, transcripts from prior listening sessions were compared to assess distinguishable themes across time periods and regions. Themes were manually categorized and summarized in the current report, as displayed in the Key Findings section.

# **Key Findings**

# Overview

Locations of domestic OAR listening sessions to date are reflected in Figure 1. The seven sessions presented in the current report occurred virtually and in three locations: Washington, D.C.; Houston, Texas; and San Juan, Puerto Rico. Information regarding previous locations and sessions is listed in Appendix B.

Figure 1. Listening Sessions Coordinated by the Office of AIDS Research, 2019–2022





Listening session locations, conducted January 2018–July 2021\*



Listening session locations, conducted August 2021–December 2022 (current report)

<sup>\*</sup>International sessions not displayed.

Table 1. Summary of Listening Sessions: August 2021–December 2022

Date(s) Format Location (Number of Sessions)	Host (Participants)	Highlighted Themes
December 3, 2021  Virtual  Washington, D.C.  (1)	U.S. Conference on HIV/AIDS (USCHA) (Conference attendees)	<ul> <li>Stigma among individuals aging with HIV</li> <li>Cultural competence of communities participating in research</li> <li>HIV health communication, research translation, implementation</li> </ul>
May 2–3, 2022  Virtual  Houston, TX  (2)	Texas D-CFAR (Developmental Center for AIDS Research)  (Faculty, investigators, community members)	<ul> <li>Cultural competence regarding research with "minoritized populations"</li> <li>HIV health communication and dissemination</li> <li>Research to address side effects of antiretroviral therapies, such as weight gain</li> <li>Research to address syndemics of HIV and drug use</li> </ul>
May 24, 2022  Virtual  Washington, D.C.  (1)	National Council of Urban Indian Health Annual Conference (Conference attendees)	<ul> <li>Inclusion of community in research development</li> <li>Role of family among American Indian/Alaska Native (AI/AN) communities</li> <li>Connecting with urban centers to reach AI/AN communities</li> </ul>
October 6, 2022  In person  San Juan, Puerto Rico (2)	Puerto Rico Science, Technology & Research Trust  (Faculty, investigators, community members)	<ul> <li>Diversification and support of the HIV workforce</li> <li>Importance of community health promoters to assist in HIV research</li> <li>Impact of the trauma of living through natural disasters among people with HIV</li> <li>Development of strategies to transition basic cure research to mouse or nonhuman primate model testing</li> <li>Technology transfer from basic science research to products that leverage state-of-the-art facilities and training opportunities to the next generation of investigators</li> </ul>
October 9, 2022  In person San Juan, Puerto Rico (1)	USCHA (Conference attendees)	<ul> <li>Importance of inclusion of women in HIV and aging research</li> <li>The need for more research on non-binary and transgender people with HIV</li> <li>Improvement of information dissemination to the communities participating in HIV research</li> </ul>

# **Key Themes**

Findings from the seven listening sessions that took place from August 2021 to December 2022 are summarized below in three sections:

- Recurring themes emerged repeatedly across different participants and locations. These are
  categorized below by topical area, with accompanying representative quotes from listening session
  participants.
- Unique topics either were reflected in only a single session or reflected the local context of the HIV epidemic.
- **Topics outside the NIH research scope** merit emphasis and attention due to their significant impact on the HIV community but are outside the scope of NIH as a health research agency.

### Recurring Themes

#### **HIV Across the Life Span**

#### Individuals older than age 50 with HIV

- Support basic research on molecular pathways affected by HIV that may influence the onset of comorbidities, such as obesity and metabolic disease, in people aging with HIV.
- Design basic research to better define the metabolic consequences of HIV treatment (e.g., weight gain, renal disease, bone disease).
- Increase the number of individuals ages 60 and older in HIV research cohorts and clinical trials.
- Investigate strategies and multidisciplinary approaches to better assess the service and care needs of people with HIV in support of healthy aging.

#### Children, adolescents, and young adults with HIV

- Support implementation research strategies to improve tools for HIV prevention and treatment among adolescents, particularly young men of color who have sex with men (MSM).
- Develop implementation research strategies to assist with a successful transition from pediatric to adult care to improve retention in treatment and care.
- Support research on the impact of stigma on transgender youth, their health, and their access to care.
- Support multidisciplinary investigations of the impact of social determinants of health, such as housing insecurity, on the health of children, adolescents, and young adults.

"... working with transgender youth and other youth and youth experiencing homelessness, the political situation and the stigma and the just vitriol around health communications for those very vulnerable youth populations ...

...more funding to look at effective ways [to help] in these highly stigmatized, politicized, polarized environments, I think, would be helpful as well. That's something that we haven't seen before."

- Participant, Listening Session at Texas D-CFAR, Houston, Texas, May 2022

#### **Enhance Support for Women in HIV Research**

- Support the increased inclusion of women (particularly those older than age 60) and pregnant people in clinical trials.
- Expand HIV prevention and treatment research among women of color, especially Black women of all nationalities.
- Develop dual protection methods for contraception and HIV prevention.
- Address the effects of menopause on women with HIV.

"... we need to protect [women], especially women of color. Is there [an] option for effective contraceptive and HIV prevention?"

- Participant, Listening Session at USCHA, Washington, D.C., December 2021

#### Social and Structural Factors That Influence HIV Prevention and Care

- Prioritize research to investigate HIV stigma within health care, community, and faith-based organizations and to develop responsive interventions.
- Address the effects of structural racism, transphobia, divisive political rhetoric, and HIV-related stigma on people with HIV.
- Develop technology approaches that mitigate stigma (e.g., technologies that improve confidential and self-administered approaches).
- Address the effects of social determinants of health, including housing insecurity, associated with uptake and adherence to HIV treatment and prevention (e.g., long-acting therapies).
- Remove barriers that limit HIV research participation for young Black and Hispanic or Latino people born outside the United States.

"...home tests are essential, not just a great tool for people. But people are afraid to go get their drugs or admit their status and disclose that status to a partner."

- Participant, Listening Session at USCHA, San Juan, Puerto Rico, October 2022

#### **Comprehensive Care**

#### Care of the individual as a whole person

- Research quality-of-life issues for people newly diagnosed with HIV.
- Study the safety, mental well-being, and personal fulfillment of people with HIV.

"Quality of life is being looked at in some of the NIH studies. It is not just the results of the research ... it is also how these interventions or treatments will affect the quality of life of the participants. How will it impact their overall life?"

- Participant, Listening Session at USCHA, Washington, D.C., December 2021

#### Integrated care of people with HIV

- Research the effects of trauma and post-traumatic stress disorder (PTSD), particularly trauma related to natural disasters, on people with HIV.
- Support research on the development and implementation of technologies to provide health care services in a way that mitigates stigma, such as anonymous online prescreening and "smart" systems for clinic entry/exit.
- Research approaches to improve interdisciplinary integration of care for HIV, mental health, and substance use.
- Support multidisciplinary approaches and collaborations (e.g., dentists, therapists) to broaden the reach of HIV testing, prevention, and education.
- Address issues associated with nonadherence to treatment among people with HIV.
- Address substance use among people with HIV, including methamphetamines.

"Integrating substance-use treatment with HIV care, ... We have a real problem with methamphetamine use ... the bane of my clinical existence is trying to help people manage methamphetamine use and really not having great interventions for that, and that really results in bad HIV outcomes."

- Participant, Listening Session at Texas D-CFAR, Houston, Texas, May 2022

#### Community Partnership and Cultural Competence in Research

- Broaden the reach of the research enterprise with differentiated access options (e.g., remote informed consent and virtual/hybrid research participation to expand inclusion opportunities); include updated approaches to standardized data collection processes across all federal agencies.
- Involve community organizers and community leaders in the research process and pipeline.
- Engage the community to provide feedback on their needs at all stages, including research, regulation, drug approval, and health care delivery.
- Incentivize research participation through fair compensation to participants.
- Diversify clinical trials to include Hispanic or Latino populations; pregnant people; people of color, particularly women; individuals with disabilities; non-binary individuals; and transgender individuals.
- Recognize that Hispanic or Latino communities are heterogenous, with diverse cultures, experiences, and needs.
- Ensure representation of Indigenous communities in research implementation, communication, and strategy by involving Urban Indian Organizations in research strategy development and data collection.
- Develop culturally grounded programs that integrate spiritual life.

"...community members are telling us that what is putting them at risk is the lack of cultural competency... it starts with ground-level work to find out what your community needs and how it will respond to them. Look at the culturally grounded programs... increase cultural practices into interventions for treating HIV."

- Participant, Listening Session with the National Council of Urban Indian Health, Washington, D.C., May 2022

#### Information Dissemination to the Community

#### Disseminating research findings

- Engage communities in information dissemination strategies and approaches.
- Disseminate and communicate research findings directly to affected communities.
- Address barriers of language, communication, translation, and interpretation and their impact on patient information, education, and access to health care.
- Use culturally competent messaging tailored to communities.
- Present scientific research information in a manner designed for lay audiences.

"Communicate research findings and translate them to the community. We have to partner with the ones who have boots on the ground."

- Participant, Listening Session at USCHA, Washington, D.C., December 2021

#### Disseminating health information and educational materials

- Engage clinicians across disciplines to broaden the reach of messaging.
- Expand community education materials and approaches for pre-exposure prophylaxis (PrEP).
- Develop materials in non-English languages, rather than translating English-language materials; when translation is necessary, ensure appropriate adaptation and review.
- Leverage community health workers and promoters to provide HIV education and health care services.

"We have an entire new generation who needs a lot of information on HIV prevention. **There's a new generation who do not understand why HIV is so important.** 

The information about HIV is lost, totally lost for everyone. We don't see any other information right now about HIV like we saw in several past years. Since COVID appeared, [there is] no more HIV in the world. The people forgot it [HIV], the people forgot the test, the people forgot the treatment."

 Participant, Listening Session at Puerto Rico Science, Technology & Research Trust, San Juan, Puerto Rico, October 2022

#### COVID-19 Pandemic Impact on the HIV Response

- Leverage experience with COVID-19 to advance HIV research, treatment, prevention, and communication strategies.
- Build on the public health experience of at-home testing during the COVID-19 pandemic to expand self-testing and point-of-care technologies for HIV.
- Study the effects of long COVID on people with HIV.
- Increase awareness of HIV among younger individuals, including leveraging information-sharing advances from the recent COVID-19 pandemic.

"... your HIV providers became COVID experts and therefore you had better providers because they were working on both fields. So I think that infrastructure allowed us to have a quick response."

 Participant, Listening Session at Puerto Rico Science, Technology & Research Trust, San Juan, Puerto Rico, October 2022

#### **HIV Research Workforce**

- Increase support and opportunities for developing the HIV research workforce, including postdoctoral and early career investigators (ECIs).
- Provide a framework for developing a research training pipeline that prioritizes students during their high school and undergraduate years.
- Support programs to diversify the HIV research field by addressing barriers for investigators of color to obtain NIH funding.
- Address the lack of diversity in the NIH Center for Scientific Review peer-review panels to better reflect the diverse applicant pool.
- Expand opportunities to reach underserved and underrepresented populations, such as the RCMI programs and ADELANTE.

"How can we improve the ability of NIH to have more diverse review panels for basic science and review processes?

... the panels reviewing our proposals, very few people look like us. So we need to work on that."

 Participant, Listening Session at Puerto Rico Science, Technology & Research Trust, San Juan, Puerto Rico, October 2022

#### HIV Research Infrastructure and Resources

- Support research strategies that facilitate implementation of preclinical models for HIV cure, including mouse and nonhuman primate models.
- Standardize the processes and leverage the resources to use animal models and clinical networks among multiple institutions to expand investigator access to resources.
- Expand the research infrastructure, bolster talent retention, and strengthen the investigator pipeline through postdoctoral opportunities; build CFAR-like networks to support investigators and increase the competitiveness of their applications for funding.

"For HIV, it is a little bit unique ... I feel like if NIH ... could have a coordinated effort to have an animal model available for different [principal investigators], then [these principal investigators could test approaches] in more coordinated and standardized animal models, instead of developing [a new animal model] individually in the lab, which is much more costly and premature."

- Participant, Listening Session at Texas D-CFAR, Houston, Texas, May 2022

## **Unique Topics**

Topics that were not repeated in other sessions include the following:

- Translation of basic science discoveries into accessible products that are responsive to user preferences.
- Consideration of public-private "incubator" initiatives to foster learning environments (e.g., the
   <u>University of Puerto Rico Molecular Sciences and Research Center</u> has a dedicated floor that
   houses startup companies aiming to advance product portfolios with Center activities in a co located environment).
- Research to better understand the impact of trauma and PTSD on people with HIV after natural disasters.

# Topics Outside the NIH Research Scope

Topics that are beyond the scope of NIH as a biomedical and behavioral research agency include the following:

- Ensure funding for PrEP for communities experiencing increased risk of HIV acquisition.
- Address the effects of nonexpansion of Medicaid on HIV treatment and prevention.
- Train the next generation of HIV advocacy partners to benefit from core HIV research information and resources.

# **Action Steps**

Themes from listening sessions are essential to informing the overall NIH HIV research agenda, including research priorities, strategic goals, and funding opportunities. OAR will use information gathered from listening sessions to help develop the next strategic plan for HIV and HIV-related research so that it effectively responds to evolving needs. In response to specific input received from the listening sessions highlighted in this report and through other contributions, OAR is currently expanding the efforts of four existing Signature Programs that foster collaborative research. Current activities and planned actions are featured below.

# Advance the HIV and Aging Research Agenda

- Analyze the HIV and Aging research portfolio; disseminate findings through public and internal NIH meetings.
- Expand the HIV and Aging working group to facilitate collaborations across NIH.
  - o Include other federal and community partners in the working group.
  - Plan an interactive HIV and Aging listening session, followed by a workshop to share information and accelerate activities across sectors.
- Collaborate with ICOs on funding opportunities at the intersection of HIV and Aging.

## Expand the HIV and Women Research Agenda

- Analyze the HIV and Women research portfolio; disseminate findings through public and NIH internal meetings.
- Support the NIH-wide HIV and Women working group to facilitate collaborations.
- Conduct workshops centric to women's health and HIV to share information and accelerate activities across sectors.
- Ensure support for women in HIV careers to reach their full potential.
- Collaborate with ICOs on funding opportunities at the intersection of HIV and women's health.

# Advance Technologies to Improve HIV Diagnosis and Care Research

- Expand research to develop innovative products, such as affordable at-home tests for viral load monitoring, and increase access to point-of-care testing within communities.
- Convene a multidisciplinary working group to determine the scope and priorities of this program.
- Develop partnerships to accelerate transformative innovation for HIV testing and monitoring.

# **Support Early Career Investigators**

- Analyze mechanisms, trajectories, and patterns in grant awards among early and midcareer HIV investigators.
- Collaborate with ICOs through the NAEC ECI working group; prioritize enhanced funding opportunities and information sharing.
- Host an annual OAR ECI workshop.
- Solicit and incorporate feedback from partners regarding enhanced ECI support activities.
- Continue collaboration with ICOs on initiatives that support ECIs, particularly from underrepresented groups, from a diverse array of scientific disciplines and academic institutions.

# Ensure Broad Dissemination of Information in a Timely Manner

- Disseminate findings of outreach and engagement activities in the form of executive summaries, regular reports, information sheets, displays at scientific meetings, and other resources through the OAR website.
- Promote the <u>NIH OAR HIV Data Hub</u> to provide researchers and the general public with easy
  access to details regarding the HIV research portfolio.
- Solicit and incorporate feedback from partners to help inform the next NIH Strategic Plan for HIV and HIV-Related Research.

# Conclusion

There has been unprecedented progress in HIV research over the past 40 years that has propelled HIV discoveries and helped enable rapid responses to emerging communicable diseases, such as COVID-19 and mpox. The dynamic nature of the HIV pandemic is remarkable, evidenced by the variety of issues discussed since OAR listening sessions were initiated.

Data from OAR listening sessions are a fundamental contribution to the development of the next multiyear *NIH Strategic Plan for HIV and HIV-Related Research*. OAR plans to continue its listening sessions through FY24, with an emphasis



on topics and communities with emergent priorities, given the current HIV research landscape. These include aging-related HIV issues across the life span—including people with perinatally acquired HIV; unique issues for cisgender and transgender women with HIV; and underrepresented and underserved populations, such as AI/AN and immigrant communities. The listening sessions will be leveraged to inform any needed updates to NIH HIV Research Priorities as they emerge in a dynamic research landscape.

People engaged in the HIV research response span all ages, genders, races, ethnicities, and geographies. Continuing OAR listening sessions across diverse partners, settings, and populations helps ensure that NIH research is inclusive and reflective of the communities most affected by HIV. It is essential that NIH continue to partner with the multisectoral, interdisciplinary HIV community—individuals, organizations, and institutions affected by HIV and/or involved in the HIV response—to continue to build a well-rounded and responsive research agenda.

# Appendix A: Listening Sessions Coordinated by NIH OAR, 2019–2022

Date	Locations	Number of Sessions
March 2019	Seattle, WA	3
March, April, and October 2019	Atlanta, GA	4
June 2019	New York City, NY	5
July 2019	Jackson, MS	1
August 2019	Birmingham, AL	3
September 2019	Chicago, IL	2
October 2019	Baltimore, MD	2
November 2019	San Francisco, CA	7
January 2020	Cape Town, South Africa	1
January 2020	Ekurhuleni, South Africa	1
February 2020, December 2021,* and May 2022*	Washington, D.C.	3
September 2020*	Boston, MA	3
September 2020*	Morgantown, WV	2
November 2020*	Nashville, TN	3
April 2021*	Lincoln, NE	2
May 2021*	San Diego, CA	2
June 2021*	New Orleans, LA	3
May 2022*	Houston, TX	2
October 2022	San Juan, PR	3

<sup>\*</sup>Denotes virtual meetings.

# **Appendix B: Listening Sessions Discussion Guide**

#### Discussion Guide for listening sessions with—

- U.S. Conference on HIV/AIDS (USCHA), Washington, D.C., December 2021
- Texas Developmental Center for AIDS Research (D-CFAR), Houston, Texas, May 2022
- Puerto Rico Science, Technology & Research Trust, San Juan, Puerto Rico, October 2022
- USCHA, Puerto Rico, October 2022
- 1. What key research questions need to be asked in the following areas?
  - HIV over the life course (including aging with HIV)
  - Long-acting injectable methods for HIV prevention and treatment
  - Strategies for an HIV cure
  - Health communication and dissemination
- 2. How can NIH approach these areas of research (and others) with an eye toward ensuring equity (across populations, groups, and settings) in research participation and focus?
- 3. What kinds of training, infrastructure, capacity-building, community engagement, and/or educational outreach efforts are needed to—
  - Ensure diversity of HIV researchers so all relevant populations and communities are represented?
  - Ensure that all stakeholders have access to the findings from NIH-supported research?
- 4. Beyond what is being done currently, what is needed to address the impact of the COVID-19 pandemic on HIV research (including both academic and community research), particularly in places that have been hardest hit?

# Discussion Guide for listening session with the National Council of Urban Indian Health, Washington, D.C., May 2022

- 1. What kinds of training, infrastructure, capacity-building, community engagement, and/or educational outreach efforts are needed to ensure diversity of HIV researchers so all relevant populations and communities are represented?
- 2. What kinds of training, infrastructure, capacity-building, community engagement, and/or educational outreach efforts are needed to ensure that urban AI/AN people have access to the findings from NIH-supported research?
- 3. AI/AN community's response to the COVID-19 pandemic was rapidly implemented. What are the lessons learned from the COVID-19 response that can be used to build on and enhance the HIV response?

# **Appendix C: Acronyms and Abbreviations**

**AI/AN** American Indian/Alaska Native

**ARC** AIDS Research Centers

**CFAR** Centers for AIDS Research

**COVID-19** (Novel) Coronavirus Disease, 2019

**D-CFAR** Developmental Centers for AIDS Research

**ECI** Early Career Investigator

**EHE** Ending the HIV in the Epidemic in the U.S.

**FY** Fiscal Year

ICO Institutes, Centers, and Offices of the National Institutes of Health

NAEC NIH HIV/AIDS Executive Committee

**NIH** National Institutes of Health

OAR Office of AIDS Research

OARAC Office of AIDS Research Advisory Council

**PrEP** Pre-exposure Prophylaxis

**PTSD** Post-Traumatic Stress Disorder

**RCMI** Research Centers in Minority Institutions

**USCHA** United States Conference on HIV/AIDS