

# HIV Age Positively® 2021 Progress Report

By Gilead Sciences | November 2021

# Welcome Letter

Anyone who lived through the initial outbreak of the HIV epidemic remembers the generation we lost and knows the enduring impact their lives had on our community. In the early days, an HIV diagnosis was considered a death sentence. For younger people diagnosed with HIV, growing old was not often a possibility.

Now, thanks to advances in treatment, many people living with HIV are living into their 70s, 80s and beyond. Their stories are nothing short of a modern miracle: a powerful testament to the tremendous progress we've made and a tribute to the work of community-based organizations who are leading the fight against HIV.

These advancements in HIV treatment go far beyond what many of us thought to be possible. Still, while we celebrate these important milestones, the burden of HIV/AIDS remains high. This burden is greater still among lower income populations and in geographies with an especially high HIV stigma.

Gilead believes that scientific discovery is only one way of improving public health. That's why — alongside our work discovering, developing and commercializing innovative medicines — we also support advocates and organizations working tirelessly to improve people's lives. They tackle HIV on the frontlines, from addressing the root causes of healthcare inequities to engaging on issues like stigma and mental health that can inhibit people's access to quality care and harm their overall wellbeing. In 2020 alone, Gilead provided more than \$250 million in funding to support efforts focused on ending the HIV epidemic around the world. Over the last few years, we have supported community organizations and developed major programs focused on populations and geographies most impacted by HIV, like the Gilead COMPASS Initiative®, a robust commitment addressing the HIV/AIDS epidemic in the Southern U.S.; TRANScend® Community Impact Fund, which supports Trans-led organizations working to improve safety, health and wellness of the Transgender community; and RADIAN®, which seeks to address the increasing rates of HIV in Eastern Europe and Central Asia.

In 2018, we launched HIV Age Positively®, recognizing the growing need to address challenges that people 50 and older living with HIV are uniquely facing. By awarding grants to community-based organizations that invest in care coordination, wellbeing resources and policy changes, the program is solely committed to improving the quality of life for those who are aging with HIV.

We're immensely proud of what our first cohort of grantees has accomplished, and we'll elaborate further on their incredible work in this report. By supporting the work of community-based organizations and pursuing local solutions to address HIV, together, we can make a difference.

Thank you for staying engaged in the fight to end this epidemic and continuing to support the community of people aging with HIV.



Korah Zuka
Korab Zuka

Vice President, Public Affairs, Gilead Sciences Inc.







# Introduction

Current data indicates that approximately 60% of people living with HIV in the U.S. are now over the age of 50 — a once-unthinkable milestone — with that number expected to reach 70% by 2030.1 While people living with HIV are now meeting the expected challenges of the natural aging process, they're also facing comorbidities and isolation sooner and more acutely than their peers not living with HIV. Contributing to HIV/AIDS' Burden of Disease (BoD) is the dearth of wellbeing resources and requisite persistence of loneliness and isolation among populations aging with HIV, which results in an increased number of Disability Adjusted Life Years (or DALYs). Multimorbidities between HIV and other age-related medical conditions, such as cancer or heart disease, are presenting themselves more urgently. HIV stigma, which is still widespread, exacerbates the isolation already affecting older populations. As of 2018, this population included 379,000 people, and addressing these challenges is critical.2

As leaders in HIV, our team listened to the needs and supported solutions for people 50 and older living with HIV. Gilead has long supported community-led programs for people living with and affected by HIV as part of our commitment to end the epidemic. That's why, through the HIV Age Positively program, we've awarded more than \$17.6 million in grants to support 30 organizations — from healthcare organizations to advocacy groups — working to bolster the systems of medical support and the social safety nets for those aging with HIV. Gilead's initial three-year support of HIV and aging through HIV Age Positively aimed to improve care coordination, increase well-being

resources and educate and inform policy to meet the needs of aging people living with HIV.

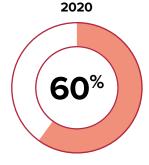
Our phase one grantees worked to meet the needs of this community, people living with HIV who are 50 and older, with an eye towards our three guiding pillars.

- 1. Improving Care Coordination. Not all providers are equipped to meet the unique needs of people aging with HIV. Our grantees work to make sure people aging with HIV receive the care they need by training and educating healthcare professionals with additional literacy around HIV and comorbidities, co-locating geriatric, primary and specialty medical services and implementing innovative models of care that prioritize holistic care.
- 2. Increasing Resources for Better Well-Being.

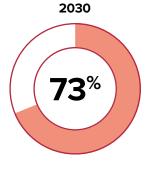
  Aging with HIV poses challenges beyond those that the healthcare system can meet. Our grantees work to provide resources such as mental health services and community support.
- 3. Educate and Inform Policy. Advocating for systemic change is at the core of creating sustainable solutions for our community. Our grantees invest in research and advocacy solutions to improve care for people aging with HIV.

By supporting community-driven solutions, HIV Age Positively helps to enhance the quality of life and care for people aging with HIV — and we're already seeing results.

Over 60% of people living with HIV in 2020 were over the age of 50.



By 2030, at least 73% of people living with HIV will be over the age of 50.







# **Program Successes**

In just three years since launch, our grantee organizations are making huge strides to meet our program's goals by expanding social support networks, building care navigation services and continuing to identify the evolving needs of our community. With support from HIV Age Positively, our grantees have been able to pilot impactful initiatives — in many cases moving digitally to do so — and maintain a consistent quality of care despite the challenges and disruptions brought by the COVID-19 pandemic.

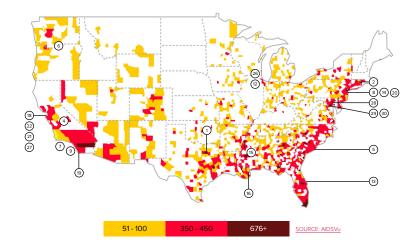
One of the greatest successes in HIV Age Positively's first phase was the focus on digital accessibility; an improvement which touches upon all of the program's three pillars. Meeting the need for more accessible digital resources, HIV Age Positively grants provided organizations with much needed support to adapt during the COVID-19 pandemic and the requisite shift from in-person services. In many cases, the advances in digital accessibility which were created as temporary solutions in 2020 will far outlast the pandemic, becoming regular parts of grantee programs.

The necessary shift to digital programming and telehealth yielded more robust virtual and hybrid models for care, **Improving Care Coordination** for people aging with HIV. These models are important pilots to refine, replicate and iterate in the future as long-term solutions to continuity of care coordination.

The transition to digital programming similarly allowed grantees to work towards Increasing Wellbeing Resources, by meeting the challenges of loneliness and isolation with more accessible wellbeing resources. For a population which was disproportionately affected by COVID-19, with Americans aged 50 and older accounting for 95% of deaths, the aging HIV community was burdened by the compounding factor of being immunocompromised, which exacerbated isolation and disrupted the continuity of care.3 In addition to these successes in patient care and community support, HIV Age Positively grantees were also successful in empowering their communities to better understand the implications of state and federal policy on their everyday lives, contributing to the program's stated goal of Educating and Informing Policy. By approaching capacity-building through the lens of advocacy and policy, grantees equipped community members with the resources needed to connect with legislators and advocate for their needs.

Below are a few tangible results of phase one, highlighted through several grantees and community leaders with a track record of success.

#### Rates of Persons, Aged 55+, Living with HIV, 20184



| 1. | Abounding | Prosperity |
|----|-----------|------------|
|----|-----------|------------|

2. Aids Project New Haven Inc. (APNH)

3. American Indian Community House Inc.

4. APLA Health & Wellness

5. Borrego Community Health Foundation

6. Cascade Aids Project

7. Center for Health Justice Inc.

8. Community Healthcare Network Inc. (CHN)

9. Family Health Centers of San Diego Inc

10. Gay Men's Health Crisis Inc.

11. <u>HealthHIV</u>

12. Hektoen Institute for Medical Research

13. Legal Aid Service of Broward County Inc. -

14. Montefiore Medical Center

15. My Brother's Keeper

16. New Orleans Advocates for GLBT Elders (NOAGE)

17. Professional Association of Social Workers in HIV & Aids

18. Project Open Hand

19. Regents of the University of California at San Diego

20. <u>SAGE</u>

21. San Francisco AIDS Foundation

22. Shanti Project Inc

23. The Aids Institute Inc.

24. The Association of Nurses in AIDs Care

25. Thrive SS Inc.

26. Tpan Network Incorporated

27. University of California San Francisco

 $28.\ \underline{University\ of\ Maryland\ Baltimore\ Foundation\ Inc.}$ 

29. Us Helping Us-People into Living Inc.

30. Washington Hospital Center Corporation

Dallas Texas

New Haven, Connecticut

National

California

Southern California

Oregon & Southwest Washington

Los Angeles, California

New York

Southern California

National National

Chicago, Illinois

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Greater New York City Area

Mississipp

New Orleans, Louisiana

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San Francisco, California

San Diego, California

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Chicago, Illinois

San Francisco, California

Baltimore, Maryland

Greater Washington DC Area

Greater Washington DC Area





# Improving Care Coordination

#### **PARTNER SPOTLIGHT:**

# AMERICAN INDIAN COMMUNITY HOUSE

#### **Grant Overview**

American Indian Community House received an HIV Age Positively grant for their Health Elders Network program aimed at identifying social determinants of health for Native American Elders living with HIV and developing strategies for increasing awareness of culturally specific HIV care needs. Through surveys and focus groups, the Healthy Elders Network identified the top five issues negatively impacting HIV treatment efforts focused on Two-Spirit and LGBTQ+ elders living with HIV:

- 1. Adherence to ARVs due to not-disclosed HIV status
- 2. Isolation and loneliness
- 3. Mental health challenges
- 4. Tribal clinic providers having out of date HIV information
- Lack of culturally appropriate HIV messaging on reservations

#### **Impact**

These learnings informed policy decisions and outreach to Native American communities and tribal leaders to provide training and supportive services that were welcomed by a number of Nations.

During Native American Heritage Month in 2020, American Indian Community House Director Sheldon Raymore expressed gratitude for community Elders who were publicly living with HIV for helping reduce the stigma in Native American, First Nations and Indigenous communities. He also recognized the progress that's been made possible with Gilead and HIV Age Positively grantees' support stating, "Those ancestors who signed treaties with healthcare rights are honored each time someone utilizes IHS for HIV treatment services. This moment in time doesn't exist in a vacuum, and indeed we owe many thanks and much honor to those Indigenous providers, advocates and frontline workers in the public health and communitybased organization sectors who work to make PEP and antiretroviral treatment more accessible for all."

By initiating conversations around HIV/AIDS care and treatment, American Indian Community House is helping to provide culturally appropriate messaging and up to date HIV information on Native American reservations. By highlighting and paying tribute to the struggle of Elders living with HIV, issues connected to HIV stigma — such as isolation, mental health challenges and ARV uptake — are also positively impacted.

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— Sheldon Raymore, Director of American Indian Community House





# Improving Care Coordination

#### **LEADER SPOTLIGHT:**

# JUNE GIPSON, MY BROTHER'S KEEPER



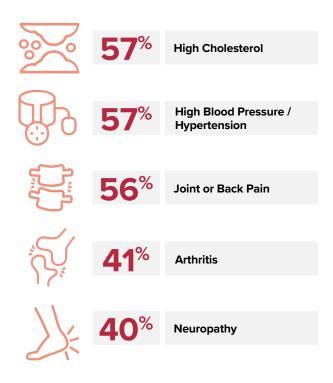
Photo provided by June Gipson.

June Gipson is the President and CEO of My
Brother's Keeper, where she approaches capacity
building in Mississippi through the lens of education
and community organizing. Acknowledging that
with criminalization laws and inconsistent access to
healthcare coverage, people living with HIV must work
within a broken system in many ways just to get the
care they need. HIV resources and knowledge are
difficult to find and often hidden from communities who
are underserved and underprivileged.

"It's the not knowing that creates these inequities," June says. "The most urgent systemic change the aging HIV community needs is holistic care. It should not be so hard to find an HIV doctor. People get lost when they don't know where to go, especially living with a disease whose care ecosystem is even more limited than cancer." In her work, creating programs which prioritize education and training for healthcare providers, the shortage of doctors is one of the greatest difficulties. Because CBOs don't have all the information they need to provide their communities

with resources that are otherwise hard to come by, education is at the center of My Brother's Keeper's work. "You have to figure out how to work with the systems you have. We're making lemonade out of lemons," she says.

My Brother's Keeper aims to partner with Open Arms Healthcare Center and the University of Mississippi Medical Center using its grant to expand services available through The LifeStyle Project to include clinical processes and support services specifically designed to address the healthcare needs of the community aging with HIV. They are working to establish coordinated care and better manage HIV comorbidities in order to take a more holistic approach to patient care.



Nearly 60% of respondents to HealthHIV's "State of Aging with HIV" Survey reported having at least one comorbidity. $^5$ 





# Improving Care Coordination

#### **LEADER SPOTLIGHT:**

# VINCE CRISOSTOMO, SF AIDS FOUNDATION



Vince presents at the SF Principles press conference. Photo provided by SFAF.

Vince Crisostomo identifies as a Gay Chamorro man living with HIV for 34 years and a life-long community advocate, based in the Bay Area. He is currently serving as Director, Aging Services at the San Francisco AIDS Foundation (SFAF), was appointed to the LGBTQ+ Human Rights Commission and is one of the authors of the SF Principles, a manifesto on HIV and aging. The SFAF program has served as a model for several other sites across the US. "The most pressing need of the aging HIV community is a need to age with dignity and grace," Vince said of his wholehearted belief in community-based solutions. "Over 70% of people in San Francisco who are living with HIV are over the age of 50, yet we're still an afterthought. We're not included in the solution. We don't have a seat at the table. My philosophy is this: Nothing about us without us." SFAF approaches care coordination through this lens, providing members with the resources to "treat the whole person."

During COVID-19, this meant addressing the immediate need to bridge the digital divide in order to continue the same care without access to in-person services. With their HIV Age Positively grant, SFAF was able to provide members with internet access, devices and webinars to increase digital literacy. Because of this, they were able to continue their work rather than putting things on hold.

In reflecting on the past year, Vince said "COVID forced us to live through yet another pandemic, but this time, we used it as an opportunity to reframe the previous pandemic around community resilience. It was life affirming. Many parts of our stories don't serve us. But in a way, this grant has allowed us to rewrite our stories with happy endings."

"Over 70% of people in San Francisco who are living with HIV are over the age of 50, yet we're still an afterthought. We're not included in the solution. We don't have a seat at the table. My philosophy is this: Nothing about us without us."

 Vince Crisostomo, Director of Aging Services at the San Francisco AIDS Foundation





# Increasing Wellbeing Resources

#### **PARTNER SPOTLIGHT:**

## **SHANTI**



#### **Grant Overview**

Shanti's Finely Aged Project promotes and empowers clients to engage with their own healthcare by providing culturally competent education and support to over 300 aging people living with HIV every year. From social support to care navigation services to medical case management and peer support-building activities in Spanish and English, Shanti provides a menu of options based on an individual's needs. They received an HIV Age Positively grant to expand medical case management for people 50 and older living with HIV, increase support for volunteer matches and provide additional community activities.

#### **Impact**

During the pandemic, Shanti maintained individual in-person services as was allowed by public health orders and expanded online weekly programming to include Relatos Positivos (a support group for Spanish-speaking women), Older and Positive (support group for people 50 and older living with HIV), HIV and Cancer (twice monthly support groups for people living with HIV at any stage of cancer or cancer treatment) and Positivxs (twice monthly support group for Spanish speaking people living with HIV). The online support groups have been popular and well received, reaching 42 people and allowing clients who were previously unable to attend in person programming the opportunity to access these supportive services.







# Increasing Wellbeing Resources

## **LEADER SPOTLIGHT:**

# MALCOLM REID, THRIVE SS



Photo provided by THRIVE SS and taken by Kevin Kenner, Member of the Silver Lining Project.

Malcolm Reid is the Director of Programs at THRIVE Silver Skills (SS) where he works to support his peers - fellow Black men 50 and older living with HIV with social support networks and HIV education. "I've always been civically engaged in my community. When I started getting involved in LGBTQ+ advocacy for older people living with HIV, I looked around and realized I didn't see anyone else who looked like me," Malcolm reflected. Acknowledging this need, he started working with THRIVE SS. In THRIVE SS' curriculum, Malcolm and his peers foster discussion about everyday issues related to living with HIV, such as treatment and wellness, and they host webinars to educate the community on broader topics such as trauma, stigma, HIV advocacy and criminalization laws in Georgia. Above all, THRIVE SS creates a community space where older Black men can talk about what it's like to live with HIV in a society which still criminalizes and stigmatizes people like them.

Malcolm's theory of change is that healing isn't possible without meaningful involvement of people living with HIV. Systemic change is needed, especially considering 20,000 people in Georgia are living with HIV and are not in care, and many people outside Atlanta aren't in close proximity to an infectious disease doctor. Due to inaccessibility, some try to get HIV medication through the mail. Malcom has heard of incidents where the mail carrier will drop their packages down at the end of the driveway, sometimes a half a mile away from their front door, out of fear. "While we tackle these systemic challenges," he notes, "it's important to provide a safe space for people to learn and gather."

When asked why he does this work, Malcolm reflected on the evolution of a peer who started attending Oba's Roundtables before the pandemic. Oba is a West African word meaning King or Leader. "At his first Roundtable, Richard was really quiet," said Malcolm. "Then he started talking more and more. Eventually he became one of the most vocal members of the group. A few weeks later we all attended an annual event for lovers of house music. We decided to make this a group outing. Richard not only attended, but he danced the night away. With tears in his eyes, he said to me, 'Thank you. I rarely leave the house anymore. I haven't danced in years."

With support from its HIV Age Positively grant, THRIVE SS was able to make its resources available online, expanding roundtables to a national scale by broadcasting five webinars on Facebook live and reaching 60 additional people. By making resources more accessible, THRIVE SS has been reaching a larger audience and bringing in otherwise hesitant new members, such as Malcolm's peer, whose story echoes many others both in Georgia and nationwide.

\*Names have been changed to respect client anonymity.





# Educate and Inform Policy

#### PARTNER SPOTLIGHT:

# SAGE



We refuse to be invisible

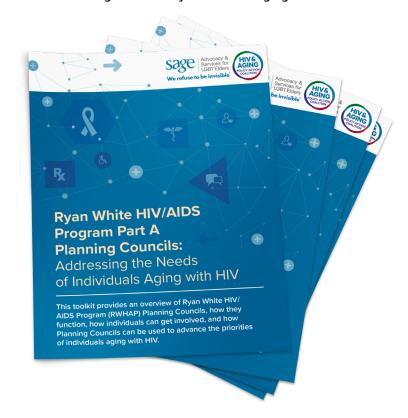
#### **Grant Overview**

SAGE'S HIV Age Positively grant is supporting the launch of an initiative called HIV & Aging Policy Action Coalition (HAPAC) which aims to build a dynamic, diverse and long-term survivor driven HIV/Aging Think & Act Tank. Their mission is to publicly acknowledge, raise awareness and meet the needs of long-term survivors and older LGBTQ+ people living with HIV. HAPAC was primarily launched to educate policymakers around the intersection between aging and HIV/AIDS with a focus on the social determinants of health. Many policymakers and healthcare providers see HIV/AIDS and aging as disparate issues, despite the overwhelming number of people 50 and older living with HIV.

#### **Impact**

SAGE's HAPAC is educating and empowering longterm survivors and their allies to drive support for the passage of Long-Term Care Bills of Rights, which would, among other things, prohibit discrimination based on HIV status in long term care facilities. Another policy priority includes legislation to designate older people living with HIV as populations of "greatest social need," under the Older Americans Act, which funds programs like Meals-on-Wheels. To meet these goals, HAPAC is educating community members not only on the issues and policy priorities themselves, but also on how to advance them. By building a toolkit for people aging with HIV to get involved with Ryan White HIV/AIDS Program Planning Councils, SAGE aims to engage more than 6,000 older people in Louisiana who are Ryan White HIV/ AIDS Program Clients community members to push for these policy changes at the local level.

An excerpt from SAGE's toolkit titled, "Ryan White HIV/AIDS Program Part A Planning Councils: Addressing the Needs of Individuals Aging with HIV."







# Educate and Inform Policy

#### **LEADER SPOTLIGHT:**

# SCOTT BERTANI, HEALTHHIV

Scott is the Director of Advocacy for HealthHIV and leads the National Coalition for LGBTQ+ Health. Having worked within the field of HIV and communicable diseases for over 20 years, Scott brings to the table perspectives as both a long-term and graying consumer of HIV services and front-line leader in the care as prevention field.

Prior to joining the staff at HealthHIV he was the Director of Policy & Community Relations for Lifelong AIDS Alliance in the state of Washington. There, he served for multiple successive terms as the state's Community Co-Chair to the HIV Planning Steering Group (HPSG); was a multi- year member of Seattle's Ryan White Planning Council; and served on the state's Health Care Authority Bree Collaborative's workgroup on minority sexual health clinical care recommendations for LGBTQ+ populations served by Medicaid. He was also the community lead in getting the STD Modernization Omnibus passed, which included the de-felonization of HIV exposure.

Throughout his own personal and professional journey, Scott's theory of change—especially for people aging with HIV—centers on the idea that "we're more than the sum total of our viral loads." He emphasizes the many ancillary needs that aren't being met at the medical level and the patient needs that are lost in translation between geriatricians, primary care providers, behavioral health professionals and HIV care providers. Though holistic, lifelong care is key to supporting people aging with HIV, there is no one common definition of coordinated care. "For some providers, that simply means getting to an undetectable viral load. For others, health is much more nuanced; it means assessing all the aspects of someone's clinical and behavioral health, their quality

of life, their social determinant circumstances, their sense of self, personal agency and so on."

On treating the whole person, Scott underscored that "In our system of publicly-funded HIV care coordination, we treat the body first, the mind second, and the spirit, or anything that shapes our quality of life, as a non-fundable service category.... we need to define universally what care coordination actually is and should be — across all aspects of our health."

As part of its HIV Age Positively grant, HealthHIV conducts an annual national survey of nearly 500 participants to report on the <u>State of Aging With HIV</u>?. The survey helps inform policymakers, providers and the public not only of the distinct challenges faced by those aging with HIV, but also the social determinants of health which are interwoven in almost all aspects of service delivery and policymaking. HealthHIV also conducts roundtables to discuss and guide care coordination for those aging with HIV, as well as medical education on clinical and behavioral health for those living with HIV for over fifteen years.

"In our system of publicly-funded HIV care coordination, we treat the body first, the mind second, and the spirit, or anything that shapes our quality of life, as a nonfundable service category.... we need to define universally what care coordination actually is and should be — across all aspects of our health."

 Scott Bertani, Director of Advocacy for HealthHIV





# What's Next

After three impactful years, \$17.6 million in support and key input from community leaders, we've learned even more about the unique needs of the aging HIV community.

Building upon the program's positive impact on the coordination of care, access to wellbeing resources and advocacy for people who are 50 and older aging with HIV, there are several key opportunities to focus grantee support in future phases of the program. Based on grantee feedback, further clarity around care coordination, prioritizing inclusivity and information sharing are several key opportunities for support in future phases of the initiative.

In a new three-year round of funding, HIV Age Positively will support 24 diverse organizations with direct funding to participate in the program. Grantees will address the challenges of people aging with HIV based on programmatic work that builds upon the work accomplished in phase one and focuses on the following areas.

## **Clarity Around Care Coordination**

Through the second round of grants, HIV Age Positively will work to clearly define care coordination and share best practices for implementations that are sustainable and scalable. Future exploration is needed to develop models of holistic care coordination for people aging with HIV and to address questions around the impact of mental health, substance use and housing on care coordination. Phase two will also expand the community in consideration by supporting solutions, not only for those living with HIV, but also for those in the broader community affected by it, including friends and family of those with HIV/AIDS diagnoses.

## **Prioritizing Equity and Inclusion**

To further serve the members of our community that are under-represented in its leadership — with a focus on those uniquely challenged by the compounding impacts of housing insecurity, mental health crises and substance use on HIV treatment — there is an opportunity for increased visibility and a full seat at the table for people with diverse lived experiences in the HIV community. This is especially true for transgender women, cisgender Black women, people who have a primary language other than English and Black or Indigenous people of color. To ensure HIV Age Positively serves the needs of all members of our community, it is also critical that we continue asking how services can be more inclusive of cis women and people of trans or non-binary experience. Though the majority of people who are 50 and older living with HIV are cisgender white men, the rate of new cases is much higher among other demographic groups.

# **Opportunities for Information Sharing**

Acknowledging the vital role that regional conveners have played in Gilead's other strategic HIV initiatives, HIV Age Positively's second phase will include a new organizing center dedicated to supporting the needs of the program. This organizing center will convene a community advisory board and facilitate collaborative discussions on emerging issues, learning opportunities, processes for feedback and dissemination of resources among community leaders. The decision to select an organizing center dedicated to HIV Age Positively came from grantees' strong desire to learn and share amongst the community. We expect the benefits of sharing best practices and iterating accordingly will be felt not only on the individual grantee level, but also on a programmatic level. In future stages of funding, models will include formal opportunities for feedback, spaces to share learnings and opportunities to iterate. In the long term, the program aims to create a central location to access resources, protocols and successful training content developed through this initiative and on the topic of HIV and aging more broadly.





# Conclusion

By improving the quality of life for those aging with HIV, from long-term survivors on the frontlines of the fight for decades to people aged 50 and older who've been newly diagnosed, we can meet the urgent and growing needs of this community. We believe that increasing the quality of care alone is not enough to fully support those aging with HIV. Instead, we're committed to supporting the whole person — taking a holistic approach to wellbeing with person-centered solutions and effectively scaling proven models of coordinated care. To realize accessible supportive services, coordinated systems of care and a healthcare system that is meeting the needs of older people living with and affected by HIV, policy at the local, state and national level must reflect this, and we're dedicated to funding advocacy solutions that will make these necessary changes possible.

We look forward to seeing what's possible in the future of our program and convening a diverse cohort of organizations who are working — actively and deliberately — to realize the HIV Age Positively commitment to bettering the lives of those aging with HIV.





# Appendix

#### Citations and Sources

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