



Aging with HIV:

Advisory Board Discussion and Recommendations

By Gilead Sciences | June 14-16 2018

Anyone who lived through the 1980s and 90s remembers the generation of Americans we lost to the HIV epidemic.

In its early days, AIDS was a death sentence. Since then, healthcare providers, advocates, governments, industry leaders, people living with HIV and other allies have worked together and made remarkable strides in the fight against the HIV epidemic.

Thanks to these efforts, 2019 will be the first year in American history when nearly half of people living with HIV are over the age of 50. In fact, by 2030, up to 70% of people living with HIV in the United States will be over 50.

It's worth celebrating that people living with HIV are now able to live longer, healthier lives. Their stories are an inspiring and powerful reminder of the heroic efforts of the community that have made these advancements possible.

However, people living with HIV are facing a new set of challenges as they age, as are healthcare providers and the broader community of allies who surround them. One study estimates that by 2030, more than 80% of people living with HIV will face at least one age-related medical condition, compared to just 29% in 2010 — an under-examined, underappreciated and underfunded public health issue demanding urgent attention.

In 2018, Gilead hosted an Aging with HIV Advisory Board meeting to identify potential interventions to support the needs of aging people living with HIV and inform Gilead's priorities related to giving and long-term community engagement and support.

Our meeting uncovered insights into the scope of the issue and the range of challenges we can help overcome through collaborative solutions. We're pleased to share this report on our findings and contribute to the growing body of work on the experiences of people aging and living with HIV.

We look forward to working with healthcare providers, community partners and others to help tackle new challenges and are proud to continue to support this community as they embark on a new chapter of their lives.

Korab Zuka, VP of Public Affairs

Advisory Board Participants

This meeting and report were informed by the expertise of the following attendees and advisors:

Advisors:

- Jeff Bailey, Director of HIV Access, AIDS Project LA
- Jeff Berry, Director of Publications, TPAN
- Mackey Friedman, Ph.D., Professor, University of Pittsburgh
- Allen Gifford, MD, Professor, Boston University
- Stephen Karpiak, Ph.D., Senior Director of Research, ACRIA
- Maile Karris, MD, Assistant Professor, UCSD
- Michelle Lopez, Consultant, HTW Campaign
- Aaron Tax, Director of Advocacy, SAGE
- Steven Wakefield, Director of External Relations, HVT

Framing Challenges

The Advisory Board determined the following problems represent the biggest challenges to caring for aging people living with HIV, as well as the areas where the most effective improvements can be made:

Health systems and patient/community approaches aren't integrated

- Health providers and community organizations both treat people aging and living with HIV, but their treatments are uncoordinated and leave gaps in care as primary health providers assume problems are age or HIV-related instead of a combination of the two. New programs and strategies are needed to ensure better coordination of care, patient education and empowerment and increased access to care for aging people living with HIV.

Stigma is a consistent barrier to accessing care

- Stigma plays a major role in the challenges faced by aging people who are living with HIV, and in addition many people experience guilt or trauma from losing loved ones. These issues exacerbate barriers to accessing care and can increase the isolation of individuals growing older with HIV. Beyond HIV, aspects of stigma are associated with identifying as LGBT, managing co-morbidities and aging itself. To reduce stigma, we need interventions specifically tailored for aging people living with HIV.

There is a lack of community investments and policies to coordinate care

- Programs related to the quality of life are vital in supporting aging people living with HIV, especially for those who are more active or are still consistently looking for work. Support related to substance use and mental health are also important, as substance use impacts people aging and living with HIV differently than those who are not living with HIV. Mental health challenges, especially related to depression and isolation, also necessitate investment and policies to ensure needs are met.

The Advisory Board offered the following as potential solutions to decrease the challenges faced by the community of aging people living with HIV:

Increase coordination between health systems and patient/community programs

- Enhance care coordination and improve communication between doctors/providers supporting aging people living with HIV. Michelle Lopez, an HTW Campaign consultant, commented that “[It needs to go] beyond EMR; it’s about having a multidisciplinary team to connect the dots.”
- Offer programs with Continuing Medical Education / Continuing Education to infectious disease physicians, pharmacists and allied healthcare providers, to train them to incorporate geriatric issues into their infectious disease care.

Reduce stigma and isolation through educational programs and training

- Increase the focus on depression and mental health programs for aging people living with HIV, including specific interventions to address and decrease isolation.
- Determine different approaches for long-term survivors under 50 and aging people living with HIV to understand how the two groups’ needs differ and address the types of trauma each is facing.
- Develop health systems that are more accessible and easier to navigate for aging people living with HIV; additionally, fostering “welcoming and nurturing” interactions with providers, including physicians and hospital/clinic staff, is important to help ensure their comfort and openness to coordinated treatment.
- Establish trainings on culturally appropriate language to reduce confusion and encourage people to seek additional resources. One advisor described the difference between asking a patient “Would you like to be part of an Integrative Care Model?” and “Would you

like to learn more about other help/support available?” as essential to comfort.

Invest in community programs and promote positive policy changes

- Contribute resources to support collaborations between community and clinical partners on social services that can better manage the co-morbidities that aging people living with HIV face.
- Develop effective programs to encourage social interaction and replicate them when they’re successful. These include programs in care coordination and those related to housing, social events and workforce training.
- Engage with groups such as Amida Care, the Health Disparities Working Group in New York or the Health/ care Disparities Research Program at Boston University to identify specific policy changes that could benefit aging people living with HIV.
- Coordinate community organizations and partners seeking to coordinate care to mine the current HRSA quality indicators using a social epidemiologic approach to identify clusters of already successful programs.
- Support the reauthorization of the Older Americans Act, which is important to fully address the needs of this community as it decreases barriers to comprehensive, coordinated care.

“Compassion combats stigma.”

Maile Karris, MD, Assistant Professor, UCSD

The Advisory Board believes solutions cannot be achieved without first addressing the collective challenges that exist within the healthcare system and the general community that are intrinsically merged together. Our challenge now is to help those affected by HIV continue to live the healthiest life possible as they age.

To foster this collaboration, Gilead will provide targeted grant funding to a range of organizations—from healthcare organizations to advocacy groups—to find new, innovative and coordinated solutions that will:

1. Increase care coordination between health systems and patient/community programs through training programs for doctors and nurses, co-location of medical services, innovative models of care and other strategies to make sure that people aging with HIV receive care tailored to their needs.
2. Reduce stigma and isolation through educational programs and training to ensure care providers are welcoming and culturally appropriate towards aging people living with HIV, especially in the language they use.
3. Invest in community programs related to housing, entertainment, workforce training and mental healthcare to ensure needs are met beyond medical treatment, and advocate for laws that increase care for people aging with HIV.

Thank you to the Advisory Board, without which such a thorough assessment of these challenges and potential solutions would not have been possible.

Advisor Perspectives: Key Takeaways for Success

Don't silo HIV and aging services, but integrate them into other services.

Jeff Bailey, Director of HIV Access, AIDS Project LA

Leverage Gilead's influence to assist with developing policy with science behind it.

Allen Gifford, MD, Professor, Boston University

Understand the importance of cultural competency training for providers.

Aaron Tax, Director of Advocacy, SAGE

Study quality-of-life issues and indicators, and convene organizations with peer support or other models to identify key learnings.

Steven Wakefield, Director of External Relations, HVT

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