



## 2025 SUMMIT

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Paving the way for the Stigma Index using the Greater Involvement of People Living with HIV and AIDS (GIPA) Principle in the Austin Transitional Grant Area, 2024

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# What is stigma?

- Negative attitude or idea about a mental, physical, or social feature of a person or group of people that implies social disapproval
- Stigma → *attitudes and perceptions*
- Discrimination → *actions and behaviors*
- HIV stigma is negative attitudes and beliefs about people with HIV
  - Can lead to discrimination, treating people with HIV differently than those without HIV
  - Affects people's health and wellbeing, and discourages people from engaging in HIV testing, prevention, and care
- **Violates the human rights of people living with HIV**



# Case Study: PLHIV Stigma Index in Central Texas

- In-person, interview-based assessment to gather evidence on how stigma and discrimination impacts the lives of people living with HIV
- Standardized tool
- [100+ countries](#) have completed the study
- 100,000+ PLHIV have been interviewed
- Created by global networks of PLHIV with backing from UNAIDS and Johns Hopkins University
- Interviewers **and** participants (interviewees) are PLHIV
- Interview takes approximately 60-90 minutes
- Participants will receive incentives of \$100
- Research partner selected – [Cardea Services](#)



# Methods: Phase 1

Number of PLHIV to be interviewed	
Bastrop	10
Caldwell	10
Hays	10
Travis	60
Williamson	12
<b>Phase 1 Total</b>	<b>102</b>

- Total sample size: 336\* divided into two phases
- Venue-based & referral-based sampling
- Priority populations: gay men and other MSM; sex workers; transgender persons; people who use drugs; people experiencing homelessness
  - All gender identities and sexual orientations may participate
- Main inclusion criteria: aware of HIV+ diagnosis for 12 months or longer & 18 years of age or older
- Recruitment via social media campaign, strategic alliances with local ASOs, community partnerships, tabling events

\*336 for statistical significance



# Selected Survey Topics

<b>Participant characteristics</b> <ul style="list-style-type: none"> <li>• Sex &amp; gender</li> <li>• Length of time since HIV diagnosis</li> <li>• Educational attainment</li> </ul>	<ul style="list-style-type: none"> <li>• Ability to meet basic needs in the last 12 months</li> <li>• Minority group membership</li> <li>• HIV support group membership</li> </ul>
<b>Disclosure</b> <ul style="list-style-type: none"> <li>• People/groups of people who know about participant's HIV status</li> </ul>	<ul style="list-style-type: none"> <li>• Experiences disclosing status (e.g., reaction and supportiveness from people told)</li> </ul>
<b>Experiences of stigma and discrimination</b> <ul style="list-style-type: none"> <li>• Exclusion from gatherings or activities (e.g., social, religious, family)</li> <li>• Verbal harassment</li> </ul>	<ul style="list-style-type: none"> <li>• Refused employment or lost income</li> <li>• Spouse/partner, children of participant have experienced discrimination</li> </ul>
<b>Internalized stigma</b> <ul style="list-style-type: none"> <li>• Effects of HIV status on self-confidence/self-respect, respect for others, stress-coping</li> <li>• Effects of HIV status on relationships (ability to have secure relationships)</li> </ul>	<ul style="list-style-type: none"> <li>• Effects of HIV on personal/professional goals, community, and religion/faith</li> <li>• Avoidance of social gatherings, healthcare, family/friends, jobs, due to status</li> </ul>
<b>Interactions with healthcare services</b> <ul style="list-style-type: none"> <li>• Delaying/avoiding HIV test due to stigma</li> <li>• HIV treatment status</li> <li>• Delaying/avoiding treatment due to stigma/discrimination</li> </ul>	<ul style="list-style-type: none"> <li>• Interruptions/skipping/missing doses due to stigma, discrimination or other</li> <li>• Other diagnoses (e.g., TB, mental health, substance use) and offered treatment</li> <li>• Experiences of stigma/discrimination from healthcare providers (HIV and general)</li> </ul>
<b>Human rights and affecting change</b> <ul style="list-style-type: none"> <li>• Abuses of rights (e.g., arrested, detained/quarantined, denied entry to another country, public disclosure, denied access to shelter)</li> </ul>	<ul style="list-style-type: none"> <li>• Advocacy by participant (e.g., educated people who discriminate, provide support to PLHIV, participated in organization or campaign, lobbied public figures, media awareness)</li> </ul>
<b>Stigma/discrimination experienced for reasons other than HIV status</b> <ul style="list-style-type: none"> <li>• Stigma due to sexual orientation - LGBTQ; questions disaggregated by each group</li> </ul>	<ul style="list-style-type: none"> <li>• Stigma for identifying as a sex worker</li> <li>• Belonging to support group for LGBT people, sex workers, and people who use drugs</li> </ul>

# LIVE BOLDLY, END HIV STIGMA IN CENTRAL TEXAS

Your experience can make a difference: Be a part of the Central Texas HIV Stigma Index project led by people living with HIV for people living with HIV.



## WANT TO HELP END HIV STIGMA? GET INVOLVED TODAY!

Are you:

- Living with HIV
- 18 or older
- English or Spanish speaking

You may be able to participate in a confidential 60-90 minute interview about your experiences with HIV stigma to inform policies, improve services and strengthen advocacy efforts for people living with HIV.

You will receive a \$100 incentive for your participation.

Scan QR code for more information or reach out to our secure and confidential email to get involved: [austinstigmaindex@cardeservices.org](mailto:austinstigmaindex@cardeservices.org)



[linktr.ee/ftcsdohe](https://linktr.ee/ftcsdohe)



06/26/2025

# What will we learn?

This study will guide us to have...	Which will help us to address stigma by:
<ul style="list-style-type: none"> <li>• Clearer picture of HIV-related stigma and discrimination and its impacts</li> <li>• Detailed information by county</li> <li>• Detailed information by race, sex, ethnicity, and gender*</li> </ul>	<ul style="list-style-type: none"> <li>• Informing development and implementation of FTC advocacy plan</li> <li>• Targeted interventions and programs (location, race, ethnicity, etc.)</li> <li>• Evidence to build empathy and drive advocacy, policy, programming</li> <li>• Engage PLHIV in services, networks of support</li> <li>• Advance equity across PLHIV</li> <li>• Enhance health outcomes for PLHIV</li> </ul>

\*If sample size is reached



# The Greater Involvement of People Living with HIV (GIPA) via

*Ways this project embodies the GIPA:*

<b>Policy-making</b>	Participate in the development and monitoring of HIV-related policies	<i>PLHIV help create advocacy plan to drive policy and programmatic changes, petition for funding</i>
<b>Program development and implementation</b>	Provide knowledge and skills towards participation in global organizations, and in implementation of programs and research	<i>Direct involvement in data collection &amp; analysis</i>
<b>Leadership and support, group networking and sharing</b>	Take leadership of HIV support groups or networks, encourage participation of new members or participate by sharing experiences	<i>Participation in monthly Steering Committee meetings</i>
<b>Advocacy</b>	Advocate law reform, inclusion in the research agenda and access to services; and for resource mobilization for networks of people living with HIV	<i>Increases familiarity with available resources, gaps in care, networks of support</i>
<b>Campaigns and public speaking</b>	Spokespersons or speakers at public events and in other arenas	<i>Presentations with local ASOs, support groups, annual HIV Planning Council town hall</i>
<b>Personal</b>	Actively involved in their own health and welfare	<i>Engages PLHIV in services, advocacy, opportunities for personal &amp; professional growth</i>
<b>Treatment roll-out and preparedness</b>	Support treatment roll-out through educating others on treatment options, side effects and adherence	<i>Community resource guide with input from PLHIV and ASOs Connecting interested persons to LHD for LTC options</i>

# Lessons Learned

- Local health departments can support capacity building to engage PLHIV, ensure visibility, accountability, and ownership of the project
- PLHIV must be involved in every aspect of implementation
  - Steering Committee, data collection, data analysis, and soon...advocacy plan
- Community shows up when you're consistent & build trust
- Make incentives a priority during planning phase





# Recommendations

- Remain flexible, adapt project as needed
  - Timeline, funding sources, scale back as necessary
- Connect with others – for lessons learned and/or to work together
  - Jurisdictions that have completed implementation
  - Local HIV Planning Council, Ending the HIV Epidemic team, etc.
- Use City staff to help liaise between community members and accessing City resources



# Thank you

Please reach out with questions, comments, or feedback!

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