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Needs Assessment of People Living with HIV/AIDS

Indiana Department of Health

Prepared by:
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Acknowledgments

The study was led by the Indiana Department of Health (IDOH) Division of HIV/STD/Viral Hepatitis, with technical support from a research team at Community Solutions, Inc. The Institutional Review Board of Indiana University School of Medicine provided study oversight and Matthew Holley, Ph.D., Assistant Professor of Family Medicine at the Indiana University School of Medicine, served as the principal investigator. Input and guidance were generously provided by the Statewide Advisory Council of the IDOH HIV/STD/Viral Hepatitis Division and a team of advocates and leaders who served on an ad hoc Needs Assessment Advisors Group.

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Their wisdom made this effort possible and their dedication to ensuring that all people living with HIV are supported by their communities is an inspiration.

Executive Summary

In 2021, just over 13,000 PLWH/A were living in Indiana, 519 of whom were newly diagnosed. The share of people who were newly diagnosed with HIV in 2021 who were connected to care within 30 days was higher than that of previous years (3,100 of whom were people not actively engaged in care (84% compared with 56% of all PLWH/A in Indiana). Just over two-thirds of PLHIV in Indiana in 2021 have suppressed viral load and 3,100 PLWH/A were not engaged in care – which indicates that 24% of PLWH/A have unmet needs.[1]

The purpose of the 2022 Indiana Department of Health (IDOH) HIV/STD/Viral Hepatitis Division - Consumer Needs Assessment of people living with HIV/AIDS (PLWH/A) was to learn from PLWH/A in Indiana about the care system barriers they face and the priorities they have for their own health and wellness. This information will be used by the IDOH to inform their strategy for funding and deploying supports and services aimed at the following: the prevention of HIV infection in Indiana, increasing the share of PLWH/A in Indiana who achieve and maintain viral load suppression, and serving people in Indiana living with the co-infection of hepatitis C (HCV). In addition, IDOH hopes to increase understanding of how the stigma still surrounding HIV impacts the availability of services and resources, how the COVID-19 pandemic has impacted people and services, and how PLWH/A can be supported to receive the care they need and want.

The study centered on the overall question, “What would it take for all PLWH/A to get the care they need to achieve and maintain viral load suppression?” It was designed to collect information from PLWH/A in Indiana about barriers to resources and service needs through in-person focus groups, virtual focus groups, and one-on-one interviews. Participants were asked to share perspectives on the stigma surrounding HIV, how it can be eliminated, how the COVID-19 pandemic impacted their ability to access resources and services, and what can be done to empower PLWH/A to live their best lives.

The study was led by the IDOH Division of HIV/STD/Viral Hepatitis, with technical support from a research team at Community Solutions, Inc. The Institutional Review Board (IRB) of the Indiana University School of Medicine provided oversight, and Matthew Holley, Ph.D., Assistant Professor of Clinical and Family Medicine, served as the principal investigator. An Advisors Group comprised of PLWH/A, HIV service and care professionals, and community advocates from across the state provided input and guidance throughout the study.

Focus group participants were recruited by the ten regional ZIP Coalitions, AIDS serving organizations (ASOs), and other organizations represented in the ZIP Coalitions. A total of 82 PLWH/A participated in the study. Data were collected using a semi-structured protocol at virtual focus groups, in-person focus groups, and one-on-one interviews. Sessions were no more than two hours in length. For virtual sessions, the facilitators

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[1] Indiana Department of Health. (2022). Integrated HIV Prevention and Care Plan for the State of Indiana.

provided the use of a web-enabled tablet to those without another option. When necessary, focus groups included professional translation services. All sessions were recorded using digital voice recorders. Due to the low participation rate, among other factors, there are limitations to how well the data represents all PLWH/A in Indiana. However, the information collected is still valuable for program and service planning, and decision-making.

Findings and Recommendations

The needs assessment yielded a great deal of information about the service needs and barriers to resources PLWH/A face in Indiana. The data collected were used to identify key findings and develop recommendations for the IDOH and partners to consider for planning and decision-making for HIV programs and services in Indiana. This information is organized into three categories:

- Healthcare Access
- Social Determinates of Health
- HIV Prevention and Care Workforce

Healthcare Access

Respondents identified a number of barriers to accessing the care they need to support their physical and mental health, such as cost-related burdens, difficulty navigating complex systems, and limited access to mental health supports. Participant feedback regarding access to healthcare is summarized in the following:

- Insurance coverage issues were frequently cited as a barrier. Insurance coverage is often complex and confusing, a major financial strain, and not comprehensive enough to cover all health-related needs.
- Mental health services are a critical need. In addition to a general shortage of available providers, participants noted high turnover rates among mental health providers as a challenge.
- Support groups meet multiple needs/interests. Support groups help PLWH/A deal with stigma, connect with people with similar experiences, and navigate the system of care.
- COVID-19 heavily and negatively impacted support groups.
- Medication is often unaffordable for PLWH/A – among people with insurance coverage as well as those without insurance.
- Many respondents favor medication delivery services and large supplies of medicine (more than 30 days of medicine).
- PLWH/A need providers within a comprehensive health system that can meet their needs and coordinate their care.
- PLWH/A need care within a centralized location to reduce barriers to access.

Based on the findings related to healthcare access, funding and programming decisions should be made to:

- Create clear and easy-to-understand information about what resources, supports, and services are available to PLWH/A from insurance providers and Managed Care Entities (MCEs) and ensure this information is shared with clients at ASOs.
- Encourage ASOs to partner with existing health insurance navigation programs to help PLWH/A better navigate their health insurance.
- Encourage and incentivize partnerships and programs that provide more mental health services to PLWH/A.
- Increase the number and type of support groups available for PLWH/A and ensure PLWH/A know about and are accessing these groups.
- Help PLWH/A pay for medication.
- Allow medication needed by PLWH/A to be filled for 90-day periods by working with providers, pharmacies, and insurance companies.
- Implement or expand home delivery of medications for PLWH/A by working with pharmacies and healthcare providers.
- Improve linkages to care when people are first diagnosed with HIV.
- Create locations of “one-stop-shops" for comprehensive care and services for PLWH/A in all parts of Indiana.
- Reduce costs for people who are un/underinsured by working with health insurance navigation and enrollment in programs.

Social Determinates of Health

People experiencing poverty and others facing difficulty in meeting the basic needs of daily living face enormous barriers to care. Concerns over limited or inadequate access to transportation, nutritious food, safe and affordable housing, employment, and supportive services were cited by many focus group participants. Participant feedback regarding unmet foundational needs that create barriers to prevention and care is summarized in the following:

- Transportation
    - Participants struggled with acquiring transportation for medical, employment, support groups, and basic needs.
    - Participants appreciate transportation services provided by ASOs but also shared the need for more flexibility in when those services are available.
- Food Access
    - Food access is a commonly-cited concern, as food banks don’t always have appropriate food – particularly for people who have complex dietary or medical needs.
    - SNAP enrollment is complex, and renewal is difficult.
    - Many participants were unaware of nutrition support resources that may be available to them through services and ASOs.
- Housing
    - Housing is often in unsafe areas and not safe or welcoming for queer and/or older people.
    - Public housing resources are generally limited, difficult to navigate, and slow to materialize.

- Employment
    - PLWH/A experience stigma in the workplace.
    - Some participants shared that they want to work but have difficulty finding jobs or employers who are supportive and flexible enough to meet their unique needs.
- Group-Specific Challenges
    - There is a need for resources for people who do not speak English, particularly Spanish speakers.
    - PLWH/A in mixed rural/urban[2] counties often have to travel to other more populated areas to receive services for fear of stigma and to have better access to services.
    - Housing and medical services have also been reported to be limited within mixed rural/urban counties.
    - Participants living in urban counties reported positive experiences regarding the number of services available and that access to these services is easier in urban counties.

Based on the findings related to social determinants of health, funding and programming decisions should be made to:

- Increase overall support for transportation services and expand the availability of transportation services to accommodate the needs of PLWH/A.
- Promote awareness and education about food benefits, particularly SNAP benefits, and access to food banks/food vouchers.
- Ensure that PLWH/A know about and are accessing all resources available, not just services and supports funded by HIV funding.
- Streamline enrollment and reauthorization for PLWH/A who are accessing all resources available, not just services and supports funded by HIV funding.
- Increase resources that support housing for PLWH/A including financial support for mortgage/rent and utilities.
- Expand the availability of safe and welcoming housing for PLWH/A with particular attention paid to the needs of LGBTQIA people and older adults.
- Support PLWH/A who want to work or are currently working but face challenges related to their diagnosis (e.g., side effects of medication) and stigma from employers.
- Increase the accessibility of all HIV services and supports in languages other than English with special attention paid to Spanish language services and supports.

HIV Prevention and Care Workforce

Focus group participants shared a full range of experiences engaging with the system of care. A core component of those experiences is often the direct interaction with frontline staff, as well as the impact of the culture, policies, and practices of their

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[2] The research team used the Purdue University system of county classification to distinguish rural, mixed (rural/urban), and urban Indiana counties. For more information about this classification please see: https://www.extension.purdue.edu/extmedia/EC/EC-766-W.pdf

employers. Participant feedback that may be reflective of workforce development and training needs and opportunities for the HIV prevention and care workforce is summarized in the following:

- Many participants reported negative experiences with healthcare providers because of poor bedside manners, lack of support from providers, and a general sense of dismissiveness at the time of diagnosis.
- People who shared their positive experiences with providers at the time of initial diagnosis also reported a transition into HIV care with fewer challenges.
- PLWH/A have experienced providers that use offensive or stigmatizing language during care appointments.
- The language used in communications from healthcare providers and ASOs to describe resources and services can be stigmatizing and/or deter people from seeking care and services.
- Staff retention and consistency leads to positive experiences with HIV care and services.
- PLWH/A are not aware of all the resources that they are eligible for that support their health and wellbeing.
- There is a disconnect between what is available and how hard people need to work/self-advocate to get them. Many participants shared that they often feel forced to self-advocate with their ASOs or healthcare providers to survive.

Based on the findings related to participants' difficulties in navigating the system of care, funding and programming decisions should be made to:

- Increase the expertise of medical providers, especially those in private practice, at hospitals, or in community health clinics, around treating PLWH/A to reduce stigma and improve their discussion of sensitive topics, such as substance use, mental health, and sexual health.
- Create comprehensive guides about the types of HIV and social support services available to PLHW/A in Indiana. Work with ASOs to ensure they are used and accessed by PLWH/A.
- Support efforts that help retain mental health providers in Indiana.
- Create avenues for PLWH/A to better advocate for changes to care and services from their providers.
- Recruit and hire people with lived experience (HIV positive, experience utilizing the system) to serve as case managers and navigators within ASOs.
- Provide support services and warm handoffs between agencies and providers through navigation, case management, and care coordination.

Recommendations for Future Assessment

The 2022 Needs Assessment for PLWH/A in Indiana was an important step in centering the voices of PLWH/A to understand the needs, experiences, and barriers to service faced by PLWH/A in Indiana, but it was not designed to be the sole instrument for future assessment. Fortunately, there are many ways in which those with responsibility for stewardship of the available resources and supports to listen and learn from those living with HIV.

While those who facilitate the system of care should be careful and dedicated listeners to the community of PLWH/A, formal studies remain a useful tool. As the population of PLWH/A in Indiana changes and their service needs, resources, and issues accessing services change, regular assessment must be done for use in program and service planning. Listed below are recommendations for future periodic needs assessment studies:

- Conduct a formal assessment of needs every 2 – 4 years, depending on the depth, quality, and comprehensiveness of consumer input collected through funded programs and partners.
- Engage grassroots groups, community advocates, and frontline service providers in study design, participant recruitment, and developing findings and recommendations.
- Utilize a mix-methods approach, specifically a convergent parallel design, through which quantitative and qualitative data are collected simultaneously and later merged to produce results to answer the research question.
- Oversample for priority populations such as Black MSM, Black Women who have Sex with Men (WSM), People Who Inject Drugs (PWID), youth, those currently or recently incarcerated, and so forth.
- Blend random sample methodology with other approaches to collect information from hard-to-reach populations, including individuals who are not stably housed, immigrants, and those with lower reading levels than the survey may accommodate. Examples include working through grassroots organizations and administering surveys at care sites serving large shares of clients in the oversample categories.
- Increase outreach efforts for priority populations and consider non-traditional means of engaging with priority populations including through organizations and events related to arts and culture.
- Review and compare information from this and other recent needs assessments to review findings, recommendations, and assessment samples for patterns, trends, and gaps. (i.e., Marion County EHE Needs Assessments, 2019 “What Matters to YOU?” Needs Assessment for People Living with HIV in Indiana)

There remain several priority areas of exploration that were touched upon in the current study and should continue to be investigated in future research, including:

- Specific barriers in access to services for non-majority populations, specifically people of color, females, and individuals who are non-MSM.
- Specific barriers and lived experiences of Latino/a/x and Black populations.
- Overall utilization of services by PLWH/A and priority populations to ensure equitable access and use of services and supports.

- The specific role and impact of race and racism within systems of HIV prevention and care.
- The role of family (birth or chosen) in PLWH/A seeking care or services for HIV

Background and Introduction

HIV in Indiana

Human Immunodeficiency Virus (HIV) is a virus that attacks the CD4 (T-cells) of the body's immune system, damaging the immune system and making it more difficult for people living with HIV (PLWH/A) to fight off infection and disease.[3] HIV has three phases: acute HIV infection, the first two-to-four weeks after transmission; clinical latency, asymptomatic HIV or dormancy; and Acquired Immunodeficiency Syndrome (AIDS), the final and most severe stage.[4] Approximately 1.2 million people in the United States are living with HIV, with 30,000-40,000 new diagnoses each year.[5] With early diagnosis and proper medical care, progression to AIDS is almost completely preventable, and the life expectancy among PLWH/A is comparable to that of the rest of the population.[6]

In 2021, just over 13,000 PLWH/A were living in Indiana, 519 of whom were newly diagnosed. The share of people who were newly diagnosed with HIV in 2021 who were connected to care within 30 days was higher than that of previous years (3,100 of whom were people not actively engaged in care (84% compared with 56% of all PLWH/A in Indiana). Just over two-thirds of PLHIV in Indiana in 2021 have suppressed viral load and 3,100 PLWH/A were not engaged in care – which indicates that 24% of PLWH/A have unmet needs.[7]

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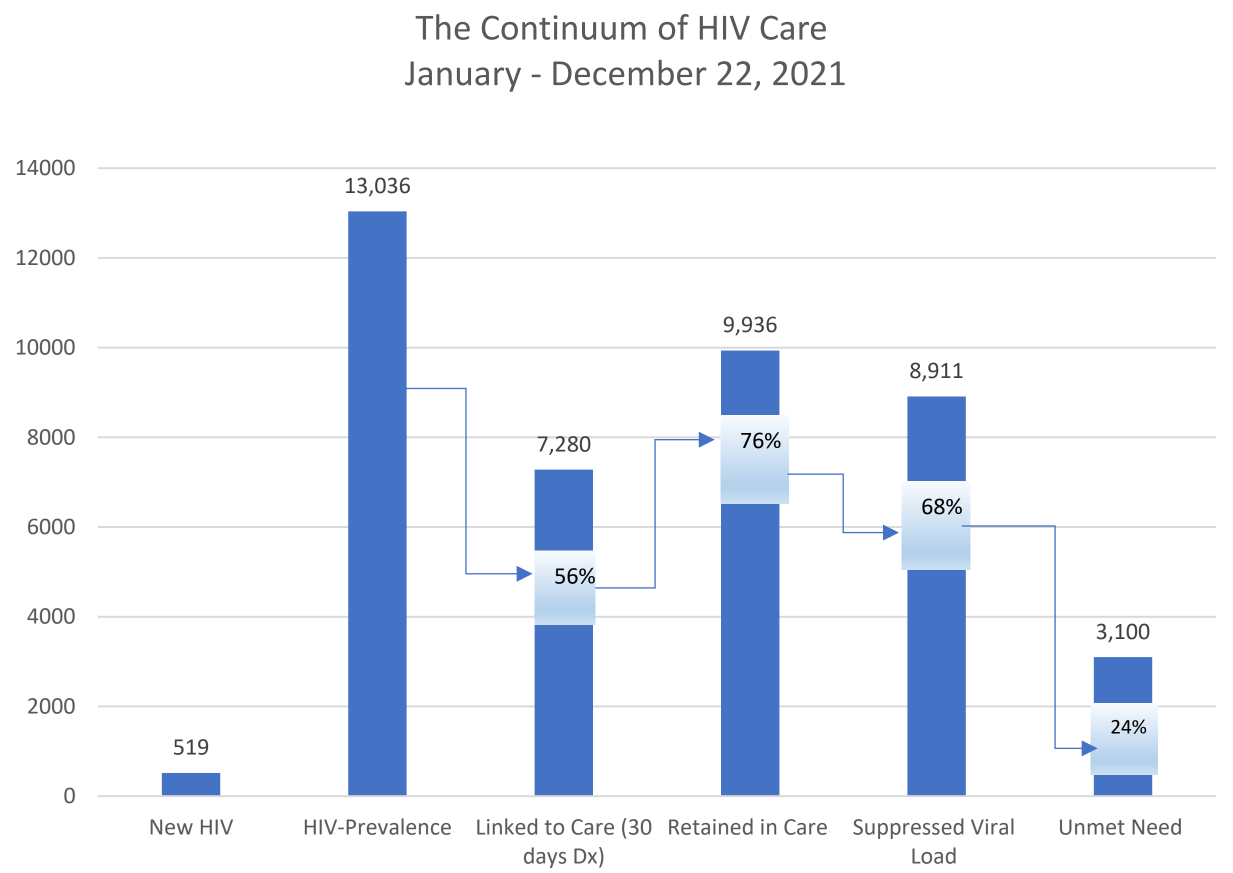
[3] Centers for Disease Control and Prevention. (2019). About HIV/AIDS. Retrieved from https://www.cdc.gov/hiv/basics/whatishiv.html

[4] Ibid.

[5] HIV.gov. (2019). U.S. Statistics. Retrieved from https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics

[6] Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *Lancet (London, England)*, *382*(9903), 1525–1533. doi:10.1016/S0140-6736(13)61809-7

[7] Indiana Department of Health. (2022). Integrated HIV Prevention and Care Plan for the State of Indiana.



Source: Indiana Department of Health Integrated Prevention and Care Plan (2022)
HIV prevalence represents those aware of their HIV status
Of the persons living with HIV/AIDS 76% vs 72% (2020) are retained in care (past 12 mo.)
Of persons living with HIV/AIDS, 68% vs 64% (2020) have suppressed VL
Of those newly diagnosed in 2021, 84% were linked to care within 30 days
CDC Prevalence of Diagnosed and Undiagnosed HIV Infection - United States, 2008 - 2012.
MWWR 2015 64:657 - 662

Figure 1: Continuum of HIV Care (2021).

The majority of PLWH/A in Indiana are male, with the greatest share of cases being males ages 40 years or older. African Americans are the most disproportionately impacted demographic group and account for almost one-half of those newly diagnosed. Almost one-half of PLWH/A in Indiana and new diagnoses live in the central region of the state, specifically Boone, Hamilton, Hancock, Hendricks, Johnson, Marion, Morgan, and Shelby counties, with the greatest share living in Marion County. More than two-in-five PLWH/A in Indiana live in Marion County.[8]

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[8] Ibid.

HIV System of Care

Living with HIV can affect many aspects of a person's life, resulting in unique service needs. These service needs may be related to housing, employment, accessing and paying for HIV care, adhering to HIV-related care and medications, side effects from HIV or medications, other health problems, mental health issues, substance use, stigma, and discrimination. For these reasons, effective primary prevention strategies are critical as they can prevent new cases of HIV infection. Available and accessible support services for PLWH/A, including HIV medical care, case management, and social support are important in the long-term quality and duration of life of PLWH/A in Indiana.

The current system of HIV care includes services that help PLWH/A meet their unique medical and support needs. This system aims to help individuals maintain continued care services by minimizing the barriers that inhibit access and supporting resources to increase access to HIV-related services. The US Health Resources and Services Administration (HRSA) provides grants to states, cities, counties, and community-based groups to help provide care, medication, and essential support services to PLWH/A through the Ryan White HIV/AIDS Program (RWHAP).

The IDOH receives funding through RWHAP Part B to fund core medical and supportive services that aim to improve HIV-related health outcomes. PLWH/A who meet eligibility requirements may enroll in the HIV Services Program (HSP) to access these services at state-funded, community-based clinics and sites.

Core Medical Services	Support Services
Early Intervention Services	Emergency Financial Assistance
Medical Nutrition Therapy	Foodbank / Home-delivered Meals
Medical Case Management	Health Education / Risk Reduction
Mental Health Services	Housing
Outpatient/Ambulatory Health Services	Linguistic Services
Substance Use Services (outpatient)	Medical Transportation
AIDS Drug Assistance Program Treatments	Referral for Health Care and Support Services
Health Insurance Premium and Cost-Sharing Assistance for Low-Income Individuals	Outreach Services
	Psychosocial Support
	Non-medical Case Management
	Other Professional Services
	Substance Use Services (residential)

Table 1: Indiana HIV Services Program Core Medical and Support Services.

There are three eligibility requirements for HSP enrollment: one must by living with HIV, be an Indiana resident, and have a household income no greater than 300% of the federal poverty level.

PLWH/A who are enrolled in an HSP and are not eligible for Medicare, Medicaid, or an employer-based health insurance program may also enroll in comprehensive health insurance coverage through Health Insurance Premiums and Cost Sharing Assistance (HIAP) during open enrollment. For those needing coverage starting outside of the open enrollment window, they may enroll in ADAP, a temporary insurance program that covers HIV-related medical care.

Any PLWH/A in Indiana, regardless of income level, may access nonmedical case management services funded through IDOH. Nonmedical case management is the delivery of a range of client-centered activities that focus on improving access and adherence to core medical and supportive services. These services include coordination, guidance, and assistance in accessing medical, social, community, legal, financial, employment, vocational, or other needed services.

Services funded through the Ryan White Part B grants managed by the IDOH are not the only services available to PLWH/A in Indiana. Regional or local institutions may provide additional services for PLWH/A in their communities with funding support from RWHAP Parts A, C, and D, as well as a multitude of other publicly funded grants, community and private foundations, and individual donors.

While HRSA provides the largest direct investment in HIV prevention and care among the U.S. Department of Health and Human Services operating divisions, several other agencies play a significant role, as well. In 2019, HHS launched the *Ending the HIV Epidemic in the U.S.* (EHE) initiative[9] to streamline federal efforts to leverage the powerful data and tools now available to reduce new HIV diagnoses in the United States by 75% by 2025 and by 90% by 2030. The 10-year EHE effort is working to accelerate progress toward this goal by directing new funds to those communities most impacted by HIV in a phased approach, starting with the geographic areas facing the highest burden. Communities are encouraged to facilitate state and local strategic partnerships and planning in four areas to achieve the ambitious goals of the EHE:

1. **Diagnose** all people with HIV as early as possible.
2. **Treat** people with HIV rapidly and effectively to reach sustained viral suppression.
3. **Prevent** new HIV transmissions by using proven interventions, including pre-exposure prophylaxis (PrEP) and syringe services programs (SSPs).
4. **Respond** quickly to potential HIV outbreaks to get needed prevention and treatment services to people who need them.

In response to the EHE call to action, the Indiana Department of Health Division of HIV/STD/Viral Hepatitis developed the statewide Zero is Possible – Indiana (ZIP-IN) initiative, which aims to reduce HIV incidence rates by 90% by the year 2030. The work

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[9] Ending the HIV Epidemic in the U.S. (EHE). (2022, June 7th). Center for Disease Control and Prevention. Retrieved December 8th, 2022, from www.cdc.gov/endhiv

to do so is guided by the *ZIP-IN Plan* which sets a decades-long course of action to guide collective efforts to eliminate the transmission of HIV and ensure optimal quality of life for PLWH/A in Indiana.[10] One of the key strategies of the ZIP-IN plan is the creation of ZIP Coalitions. There are ten ZIP Coalitions in Indiana, each responsible for leading regional efforts to end the HIV epidemic, including the engagement of diverse partners—especially PLWH/A. ZIP Coalitions receive financial support from IDOH to offset costs associated with coalition management and engagement, as well as assistance from IDOH staff.

In addition, Marion County was selected by the Department of Health and Human Services (DHHS) as one of the priority jurisdictions to receive Ending the HIV Epidemic (EHE) investments. The Marion County Ending the HIV Epidemic (EHE) Task Force developed a 5-year plan (2021-2025) focused on the Ending the HIV Epidemic efforts for Marion County. This planning process engaged more than 50 governmental and non-governmental organizations and hundreds of people across Marion County. The resulting plan was designed to monitor and track progress on the four state and national EHE pillars of Diagnose, Prevent, Treat, and Respond. Efforts specific to the Marion County EHE Plan are ongoing.[11]

The IDOH Division of HIV/STD/Viral Hepatitis evaluates progress toward public health goals as well as the quality and accessibility of services, resources, and supports using a variety of strategies. One key strategy is to conduct a periodic assessment of needs and barriers experienced by PLWH/A in Indiana. A 2019 study utilized a two-phase, random sample survey approach that yielded responses from nearly 300 PLWH/A in Phase 1 (short-form survey) and nearly 200 responses from PLWH/A in Phase 2 (long-form survey). While the study generated useful information, there were limitations to the utility due to methodological constraints and low participation rates. Community partners, advisors, and the research team agreed that future inquiries should include qualitative research in the form of individual interviews or focus groups.

Purpose of this Study

The objective of the 2022 Needs Assessment of PLWH/A in Indiana is to inform the IDOH strategy for funding and deploying supports and services aimed at the following: the prevention of HIV infection in Indiana, increasing the share of PLWH/A in Indiana who achieve and maintain viral load suppression, and serving people in Indiana living with the co-infection of HCV. In addition, IDOH hopes to increase understanding of how the stigma still surrounding HIV impacts the availability of services and resources, how the COVID-19 pandemic has impacted people and services, and how PLWH/A can be supported to live their best lives.

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[10] Zero is Possible – Indiana's Plan to End HIV and HCV, 2021-2030. https://www.zipindiana.org/

[11] Marion County Ending the HIV Epidemic (EHE), https://thfgi.org/marion-county-ending-the-hiv-epidemic/

Study Approach

The study centered on the overall question, “What would it take for all PLWH/A to get the care they need to achieve and maintain VL suppression?” and was designed to collect information about service needs and barriers to resources from approximately 200 PLWH/A in Indiana through in-person and virtual focus groups and key informant interviews. Participants were asked to share perspectives on the stigma surrounding HIV, how it can be eliminated, how the COVID-19 pandemic has impacted people and services, and what can be done to empower PLWH/A to live their best lives.

Data were collected through focus groups and key informant interviews using a semi-structured protocol (Included in Appendix C: Focus Group Protocol). Sessions were no more than 2 hours in length. For virtual sessions, the facilitators provided the use of a web-enabled tablet to those without another option. When necessary, focus groups included professional translation services. In-person and virtual sessions were recorded using digital voice recorders. Participants received a $30 Visa gift card as an incentive for participating. Additionally, in cases where researchers met with participants in-person a meal was provided. For virtual focus groups, participants received a second $30 Visa gift card to cover the cost of a nice meal. Participation was voluntary and confidential. The research team relied on partner organizations throughout Indiana to promote the study and interested individuals were directed to complete a brief interest survey if they wanted to participate.

Key Partners

The study was led by the IDOH Division of HIV/STD/Viral Hepatitis, with technical support from a research team at Community Solutions, Inc. The Institutional Review Board (IRB) of the Indiana University School of Medicine provided study oversight, and Matthew Holley, Ph.D., Assistant Professor of Clinical and Family Medicine, served as the principal investigator.

An Advisors Group composed of PLWH/A, HIV service and care professionals, and community advocates from across the state provided valuable insight and feedback throughout the project on priority populations to engage, outreach and recruitment strategies, focus group locations, timing and questions, communication strategies, and study findings and recommendations.

The 10 Regional ZIP Coalitions were key recruitment partners. AIDS Serving organizations (ASOs) and other types of organizations represented in Indiana’s ZIP Coalitions recruited at their facilities and through their networks using resources provided by the research team. These organizations advertised the opportunity to participate in focus groups to their staff and clients.

Timeline

Study design launched in April 2022 and participant recruitment began in September. Interviews and focus groups were conducted from September through November. The Needs Assessment Advisory Group met monthly from June – December 2022.

Timeframe	Tasks
April – August 2022	Develop Survey Approach Design methodology and focus group administration plan. Engage necessary partners for focus group administration. Develop, test, and revise the focus group format and questions. Create a draft Focus Group moderator guide (includes the questions to ask and facilitation guidance completed) Provide draft facilitator guide to IDOH and partners for review and testing. Test with 8-12 consumers Edit/Finalize survey instrument (English and Spanish) Create and implement a communication plan. Submit study to IRB for review
August – September 2022	Partner outreach and session scheduling Begin outreach with partner organizations assisting with recruitment and hosting. Schedule all focus group sessions
September-November 2022	Launch focus groups. Ongoing outreach and recruitment Administer focus groups. Facilitate sessions and record data as outlined. Deliver Focus group incentives
December 2022	Analyze and summarize data. Clean and code all focus group data. Analyze survey data. Draft and submit HIV Needs Assessment 2022 Report

Table 2: Study timeline.

Focus Group Design

Based on guidance provided by IDOH, the research team developed proposed interview questions which were reviewed and edited by the HIV Needs Assessment Advisors Group to ensure they would elicit feedback from PLWH/A. The approach included two types of focus groups: in-person groups of 8 – 12 participants and virtual sessions using Zoom with participant-to-respondent ratios of 10-to-1. Ten (10) focus groups were to be geographically based, with one in each of the 10 ZIP Coalition regions, and 10 were to be focused on priority population members in an affinity group approach. Participation was open to all adults (18+ years of age) living with HIV and living in Indiana.

Priority Populations

To best understand the service needs and challenges of PLWH/A in Indiana, the IDOH and HIV Needs Assessment Advisors Group identified priority populations for additional inquiry by looking at data trends and reflecting on their knowledge and experience in the field (Table 3). These priority populations informed the design and implementation of the focus groups as well as informed outreach and recruitment strategies and tools. The information necessary to identify PLWH/A as members or the priority populations was collected in the interest survey.

Priority Populations
Black/African American women living with HIV
Heterosexual Black/African American men living with HIV
Black/African American Men who have Sex with Men (MSM) living with HIV
Young Adults (Ages 18-24) living with HIV
Transgender people living with HIV
Latina/Hispanic females living with HIV
Latino/Hispanic MSM living with HIV
PLWH/A who have experience using illegal drugs with a needle
PLWH/A who have experience using illegal drugs without a needle
PLWH/A who have experience with a coinfection of HIV and HCV
PLWH/A who have experience being treated for a mental health disorder
PLWH/A who have experience with homelessness or housing instability
PLWH/A who have experience with sex-work
PLWH/A who have experience being treated for a substance use disorder
PLWH/A who have experience coming to the US from another country to live/work.
PLWH/A who live in Marion County
PLWH/A who live in rural counties

Table 3: Priority populations.

Participant Protections

Throughout the study, the confidentiality and security of participants' information and identity were paramount. While study participants were not promised complete confidentiality, the study design was intended to protect confidentiality in every phase.

Prospective participants did not need to share identifying information to indicate interest in participation. If selected, detailed information about how to participate was shared with the participant via phone or email with the date, time, and overall expectations for participation. Prospective participants were encouraged to use an alias and/or create a unique email address through which to send or receive any electronic correspondence.

Before each focus group, the research team shared the Study Information Sheet with each participant. This document outlined the purpose of the research, the risks of participation, and the rights and responsibilities of participants. Facilitators at each focus group reviewed this document and ensured that all participants agreed and understood what was in the document. Participants were also given the chance to opt out of the research after this review of the study information sheet and before the beginning of the focus groups. All participants were informed that their participation in this research was completely voluntary and that they could leave at any time until the focus group is complete.

Due to the nature of focus groups, participants may have recognized one another during or at any point after the focus group. All subjects agreed to keep the information shared in the focus group confidential. They were reminded before and after the focus group that the information discussed during the focus group must remain confidential. Participants were also encouraged to limit the number of personal identifiers they used in discussions.

The research team used digital voice recordings at each session. The recording devices and the recordings themselves remained in the possession of the researchers for the duration of the project. Any personally identifying information drawn from the notes or transcripts of the focus groups was removed prior to its inclusion in this report and it was never shared outside the research team.

All members of the research team were certified by the Collaborative Institutional Training Initiative (CITI Program) before having access to any potentially identifying data. This training is required by the IRB for all researchers prior to conducting research and covered research best practices and standards including how to protect the confidentiality and security of participants.

Outreach and Recruitment

Recruiting and enrolling the participants was a key part of this study. The research team created promotional materials for a variety of distribution methods. These included physical materials like pocket cards, brochures, and flyers. These materials were sent via mail to all ASOs and other partner organizations that requested them. The research team also widely distributed virtual copies of the printed materials. The team also created digital materials and template language for emails and social media postings. All resources included information about the Visa gift card and meal to incentivize participation. In addition, the resources were designed to be easy to understand and included images of people of a variety of races and genders. All materials were available in English and Spanish. The translation of the materials was conducted by a professional translation service.

ZIP Coalitions were a partner in distributing recruitment materials and messaging to the organizations that serve PLWH/A in Indiana. ASOs shared outreach and recruitment messaging with their constituents and many organizations allowed the research team to meet with their client-facing staff to discuss and encourage recruitment. Community partners assisted with outreach and recruitment. HMM was a referral partner helping recruit dozens of potential participants. Other community organizations shared outreach messaging with PLWH/A in their networks.

Interest Survey

The research team collected information from potential participants in an online Interest Survey (Appendix D). The interest survey presented a summary of the study aims, potential risks, and potential benefits, collected key information to screen for the inclusion criteria, and for those who met the eligibility requirements, the survey then asked respondents to provide demographic and contact information so researchers can sort them into appropriate focus groups and to follow up with relevant logistics information to attend a focus group. None of these questions were required and participants were encouraged to share only what they were comfortable sharing. If they did not want to provide their real name, participants were given the option to use an alias and set up an email account so the researchers could contact them about the focus group. The survey asked about the following topics:

- County of residence
- Race and ethnicity
- Gender
- The gender of people who they are sexually attracted to
- The year they were told that they were HIV positive
- The county where they receive HIV services and care
- The ASOs where they have received care
- Key lived experiences that are considered to influence a person's ability to access care and services
- Preferred language
- The preferred name they want the research team to use
- Preferred contact method
- Preferred time/date to participate in a focus group

If respondents did not meet the eligibility criteria, they were politely informed that they were not eligible and directed out of the survey and were not asked for any demographic or contact information.

In cases where potential participants did not have access to the interest survey link or were not comfortable using it, participants were able to indicate their interest in participating by contacting the researchers directly via email or phone. The research team maintained a cell phone number and email address for this purpose.

The research team reviewed the interest survey data regularly and used it to contact and invite participants to focus groups. In addition to region (geographic) focus groups and priority population (affinity) focus groups, the research team held virtual sessions for any eligible participant regardless of geography, interviewed participants individually, and held 3 in-person focus groups that were recruited for and hosted by partner ASOs.

Researchers worked with ASOs to schedule meetings with staff to inform them about the study and explore opportunities to collaborate with them in participant recruitment. Members of the research team met with the client-facing staff of more than a dozen ASOs. During these meetings, two ASOs offered to recruit and host in-person focus groups on behalf of this project. In partnership with these ASOs, the research team implemented 3 separate in-person focus groups. To ensure other ASOs had the same opportunity the research team asked all other ASOs to also recruit and host a focus group.

The research team also enlisted help recruiting from HMM. The organization has many trusted relationships in Indiana with PLWH/A and agreed to help get more PLWH/A involved in the study. They provided contact information for interested individuals from their network (with their expressed permission). The research team then worked with those who were referred to ensure that they met the eligibility criteria and then scheduled them into focus groups.

Data Collection

Focus groups, whether they were held virtually or in-person, all followed the same basic protocol. The protocol included reviewing the Study Information Sheet, ensuring all participants understood their rights and responsibilities, and offering the opportunity for participants to decline. Those that stayed were then asked a series of 8 questions related to HIV care, services, and supports.

Each focus group was led by a trained facilitator who asked follow-up questions and encouraged engagement from all participants. In addition to the facilitator, each focus group had another researcher audio recording the focus group and taking notes of the responses. At the end of the focus group, the participants were given their gift cards. If the focus group was virtual the researchers asked the participants how they wanted to receive their incentive. Virtual participants were given the option to have a physical gift card mailed to them or to have a virtual gift card sent to their email.

When the focus group included Spanish-speaking participants, the research team worked with an Indiana-based, professional interpretation service. Interpreters joined the focus group via Zoom and provided simultaneous interpretation services from English-to-Spanish and Spanish-to-English. In addition, a bilingual member of the research team participated and took detailed notes.

Data Analysis

The researchers took notes during each focus group and interview. These notes were cleaned, coded, and analyzed using common qualitative data analysis methods. First, researchers familiarized themselves with the data by reviewing the notes and listening to the recording of the focus group, as necessary. They took notes on initial impressions, looked for key themes, and ensured that what was recorded in the notes reflected what the participant said in the recording to check for bias. In each notes document, the researchers attempted to directly attribute responses to participants.

The data were then organized for full coding and review. Copies of all notes were made and placed in a new folder to preserve all raw data. The comments were categorized by four basic research questions:

1. What has been easy about getting care, services, and supports?
2. What has been hard about getting care, services, and supports?
3. What has been the Impact of COVID-19 on services, care, and supports for PLWH/A?
4. What is the impact of stigma on services, care, supports, and the lives of PLWH/A?

Next, the data were organized into spreadsheets, with a row for each comment that included the unique identifier of the participant who made the comment, their demographic information, and key characteristics (based on interest survey responses). The research team analyzed responses to address each of the basic research questions, overall, as well as by priority populations. The themes were further refined and organized into 3 overarching categories: HIV Prevention and Care Workforce, Healthcare, and Social Determinates of Health.

- Healthcare Access
    - Insurance
    - Mental Health Services
    - Social Support and Support Groups
    - Medication
    - Culturally Responsive, Accessible Care
- Social Determinants of Health
    - Transportation
    - Food
    - Housing
    - Employment
    - Accessibility of Social Supports
- HIV Prevention and Care Workforce
    - Experiences and Provider Interactions at Diagnosis
    - Language that Stigmatizes
    - Consistency of Personnel
    - Communication and Consumer Education
    - Self-Advocacy

Through the analysis, researchers generated a list of findings for each theme, in general, and noted instances for which priority populations were uniquely impacted or for which members of a priority population group cited a particular need that is common to members of their group.

Limitations

The methodology for the needs assessment posed several limitations. While focus groups are an excellent way to hear directly from those impacted and to provide context and meaning, they present several challenges for researchers and participants, alike. In total, 82 PLWH/A participated in the study, which is well short of the goal of 200 respondents. While this methodology was never intended to provide statistically significant, generalizable conclusions, there was a great deal of interest in ensuring broad representation in the conversation and opportunities to have deeper discussions among people who may have overlapping or shared experiences due to geographic proximity or socio-demographic characteristics. While the information collected is still valuable for program and service planning and decision-making, some information for smaller subsets of respondents that would have provided additional detail or insight could not be commented on.

Low participation overall means that it is more difficult to explore similarities or differences across priority populations. While the study participants represent the diversity of the community of PLWH/A and included members from all 17 priority populations identified by the Advisors and key partners, seven (7) priority populations did not reach the threshold to be analyzed separate from the full sample. These sub-populations not meeting the threshold were:

- Heterosexual Black/African American men living with HIV,
- Young adults (18-24 yrs. old) living with HIV,
- Transgender population living with HIV,
- Latina/Hispanic females living with HIV,
- Latino/Hispanic MSM living with HIV,
- PLWH/A with experience coming to the US from another country to live/work
- PLWH/A with who live in rural counties.

Outreach to PLWH/A in the state may have been a limiting factor. Many of these groups represent an overall small number of PLWH/A in Indiana. They are also groups of people that tend to be the most impacted by social determinates of health and stigma. These groups are often the most likely to be missing from care and services due to these barriers. Because much of the research team’s outreach was primarily through ASOs and other similar organizations, these groups may have been less likely to receive the outreach materials. The research team worked to counteract the outreach limiting factors by sharing outreach materials with many non-traditional organizations that engage with these populations and by making the interest survey publicly available on the internet.

Other limitations are due to literacy and the language of the initial interest survey. Because it was an online, written survey, participants had to be able to access the internet and read and comprehend the survey's background, instructions, and questions. Similarly, the survey materials were offered in English and Spanish but no other languages. Individuals who were not able to read the survey materials in English or Spanish would have been precluded from participation. The research team worked to counteract these limits by lowering the reading level of all survey materials and by assisting participants to complete the survey over the phone when necessary.

Physical Barriers to Participation

Participation in focus groups or interviews is time-consuming, and there are often barriers to overcome. The focus groups were held in-person and virtually using Zoom. The in-person format presented barriers for people who do not have reliable transportation, barriers to those not comfortable meeting in-person due to stigma or fear of COVID-19 or other contagious illnesses, and other scheduling conflicts. The virtual format presents barriers for people who do not have the equipment or technical expertise to attend a Zoom meeting. The research team worked to counteract these barriers by doing the following:

- Enlisting partner organizations to help with transportation.
- Offering transportation assistance to participants including subsidizing the cost of the transportation services when necessary
- Locating in-person focus groups in more densely populated areas.
- Ensuring whenever possible that in-person groups were located near public transit.
- Setting up in-person focus group space to allow for social distancing whenever possible.
- Providing tablets to those that wanted to attend virtually but do not have a smart phone.
- Providing a telephone-only (call-in) option for all virtual focus groups

Opportunities for Bias

There are also opportunities for bias and differences in executing this methodology. There may be bias among respondents due to the use of incentives. Those most interested in the gift card would have been more likely to participate. Focus groups being a discussion format tend to be biased towards outspoken people and can tend towards only addressing socially acceptable topics.[12]

Since the focus groups were facilitated by different researchers there was also the potential for the different researchers to bring their own biases into the research. The research team attempted to counteract these biases and differences by implementing a specific focus group protocol to guide the conversation, by training all researchers in our protocol before leading a focus group, and by actively encouraging participation from participants who were quiet or not engaged during the focus groups.

Challenges with Outreach and Recruitment

Early in the recruitment phase of the study, there was a very large influx in the number of survey respondents. In less than 24 hours more than 900 respondents claiming to be

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[12] https://www.sfu.ca/~palys/Smithson-2000-Using&AnalysingFocusGroups.pdf

adults living with HIV in Indiana responded to the survey. Over the next few weeks, the number of survey respondents swelled to over 2900 respondents. This influx of respondents was of keen interest to the research team. When the research team examined these responses nearly all were highly suspicious. The survey captured general IP addresses and a vast majority were IP addresses not located in Indiana and a large portion originated outside of the United States. There were also very suspicious survey completion patterns that became apparent. There were a large number of respondents who recorded the first available answer to each survey question. Many respondents also indicated that they lived in an Indiana county in northeast Indiana but received all their services at ASOs in southwest Indiana. Another suspicious trend was that these respondents exclusively communicated via email and gave phone numbers that when called were not real or associated with themselves.

The research team spent dozens of hours sifting through the survey responses to find people who they believed to be eligible for the invitation to a specific focus group. The team worked diligently to exclude those who appeared to be lying. To help with this, the team established a short follow-up survey that asked respondents to confirm a detail from their original survey. This helped reduce the number of respondents as many could not confirm simple details from their original survey.

During the first virtual group, nearly all the participants did not appear to be who they claimed to be. Participants lacked basic knowledge of the vocabulary and abbreviations commonly used by the healthcare system, in general, and this HIV care system, more specifically, in the U.S. For example, several people were unfamiliar with the terms “non-profit organization” and “ASOs” and asked if those were similar to NGOs (Non-Governmental Organizations). When answering questions about their experiences, they provided information that conflicted with what they indicated in their survey and/or what they shared earlier in the conversation. Because protecting participants from harm was the highest priority, the facilitators did not want to subject the real participants to people who were very obviously lying about their identities. Participants whose responses suggested that they were misrepresenting their identity were removed from the discussion immediately and not allowed to return. In subsequent virtual focus groups, the research team brought participants into the virtual “room” one at a time and screened the participant to see if they were who they said they were (based on their responses to interest survey questions and not in a manner that discloses their actual identity). In these cases, many participants could not confirm simple details about themselves from the interest survey and were dismissed before the focus group began. Participants who were being honest were placed in a separate Zoom room to prevent them from being exposed to people who were lying about their identities.

To address these challenges, the research team consulted the Advisors Group and sought input from other researchers with similar experiences conducting online surveys and focus groups. Their input helped the research team shift their outreach strategy. A new interest survey link was created and shared with the recruitment partners, but the team specifically asked that the partners not post the link on social media or the web. The link was only shared in offices and directly between staff and clients. The research team also shifted away from communicating by email as the primary form of contact with potential participants as much as possible. The research team developed new outreach and recruitment materials that encouraged participants to call or text the research team to get involved. The time and effort used to address the problems created by the misuse of the interest survey link would have been better used in other, more effective outreach and recruitment activities.

Results and Discussion

This section of the report presents information about the study participants and key findings.

Participant Characteristics

In total, 82 unique individuals participated in this study from across the state of Indiana. Table 4 presents the characteristics of the individuals who participated in this study. The characteristics include basic demographic information as well as factors that are related to priority population categories (age, race & ethnicity, gender, preferred language, years living with HIV, the county where the individual receives most of their HIV healthcare services, ZIP region, and risk factors). To protect the identity of participants, the research team suppressed numbers if there were fewer than 5 participants that met an individual characteristic (denoted by a "-"). Blank fields indicate that there were zero participants. A range was used in place of an exact number whenever using the exact number would enable the calculation of a suppressed value.

Participant Characteristic	Total	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10	N/A
# Participants	82	5	12	-	-	-		39	-	-	13	-
Age												
18-24	-										-	
25-34	14	-		-				8			-	
35-44	16	-	5		-			6	-	-	-	
45-54	23		-	-				11		-	5	-
55-64	23	-	-	-		-		10	-		-	
65-74	5		-					-				
Race & Ethnicity												
Hispanic or Latino/a/x	6		-					-				
American Indian/Alaskan Native	-		-								-	
Asian												
Black/African American	37	-	-	-		-		22	-		-	-
Native Hawaiian/Pacific Islander												
White/Caucasian	41	-	-	-	-			17	-	-	9	-
I prefer not to answer	-							-				
Other (Self-Identified)	-		-					-			-	
Gender												
Male	58	-	8	-	-			28	-	-	7	-
Female	21	-	-					9			6	-
Transgender - male to female	-							-				
Transgender - female to male												
Gender non-conforming/genderqueer	-							-				
Identity Not Listed	-					-						
Years of living with HIV												
0-2												
0-5	13	-		-				6		-	-	
6-10	20	-	-	-	-			9	-		5	
11+	46	-	9	-		-		24	-		-	-
(blank)	-		-								-	-

Participant Characteristic	Total	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10	N/A
County Where the Participant Receives a Majority of Their HIV Services												
Allen	-			-								
Clark	-										-	
Elkhart	-		-									
Hamilton	-					-						
Jennings	-										-	
Lake	-	-										
Lawrence	-									-		
Marion	39			-				34-38				
Monroe	-							-		-		
Scott	9										9	
St. Joseph	10	-	5-9									
Tippecanoe	-				-							
Vanderburgh	-								-			
Risk Factors and Challenges Experienced:												
Have used illegal drugs with a needle	20		-					5-9		-	5-9	
Have used illegal drugs without a needle	40	-	-	-	-	-		22	-		5	-
Have experience with sex-work	25	-	-		-			13	-		5	-
Have been treated for a substance use disorder	31	-	-					19	-	-	7	
Have been treated for a mental health disorder	39	-	-	-		-		22	-	-	-	-
Have been homelessness or housing instability	39	-	-	-	-	-		22		-	5	-
Came to the US from another country to live/work	-							-				-
Have had a coinfection of HCV	12			-				1-6			1-6	
Preferred Language												
English	81	5	11	-	-	-		39	-	-	13	-
Spanish	-		-									

Table 4: Participant characteristics.

Note: Values <5 suppressed (indicated as "-")

Most focus group participants were aged 45 or older (62%), including five participants in the 65 – 74 age group. Fifteen participants were aged 18 – 34 (18%).

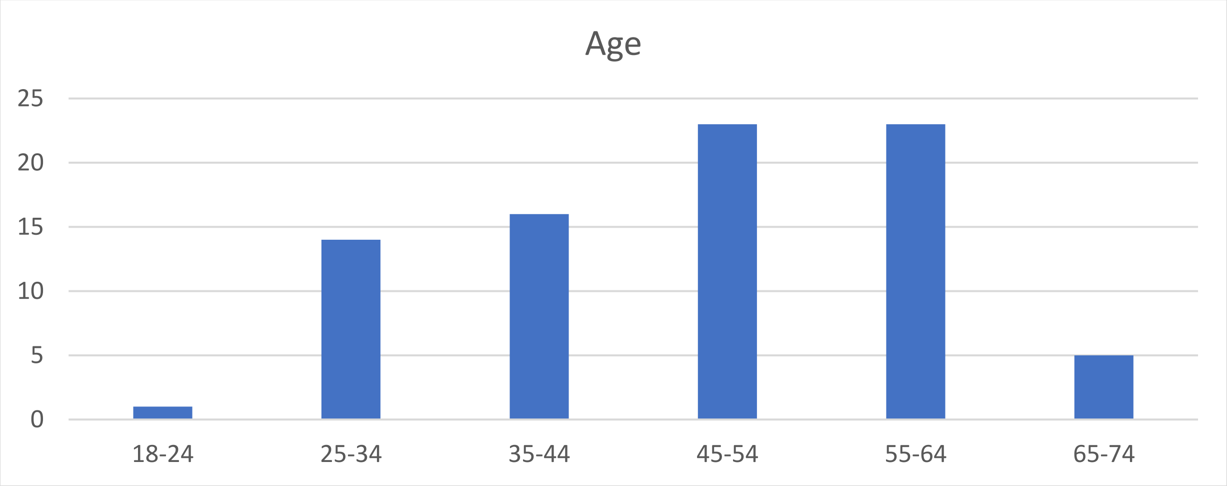

Figure 2: Count of participants in age ranges.

While many of the participants identified with more than one racial or ethnic identity, 50% selected white/Caucasian and nearly as many participants (37 people) selected Black/African American as at least one racial or ethnic identity. Six participants identify as Hispanic or Latinx (7%), one of whom indicated Spanish as a preferred language for focus group participation. At least one participant identifies as American Indian/Alaska Native while none of the participants identify as Asian or Native Hawaiian/Pacific Islander.

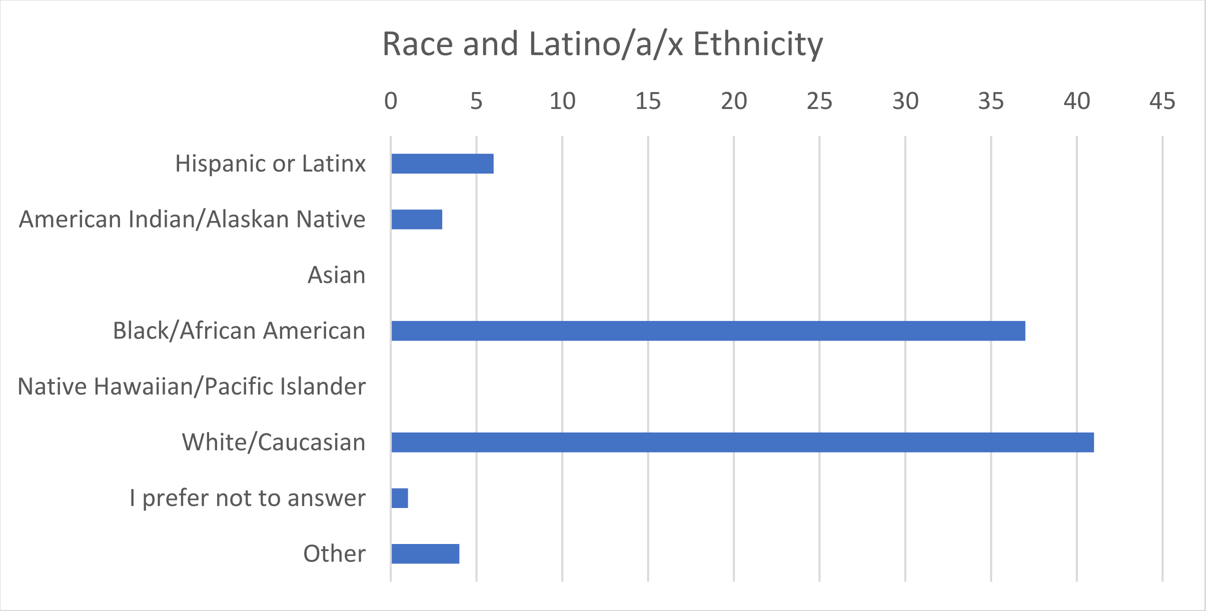

Figure 3: Count of participants by race and Hispanic ethnicity.

Participants were asked to share information regarding gender identity by selecting one or more options from a list and/or writing in an identity that was not listed. Just over 70% of participants identify as male and nearly 27% identify as female. Fewer than five participants identify as transgender, gender non-conforming/genderqueer, or an identity that was not listed.

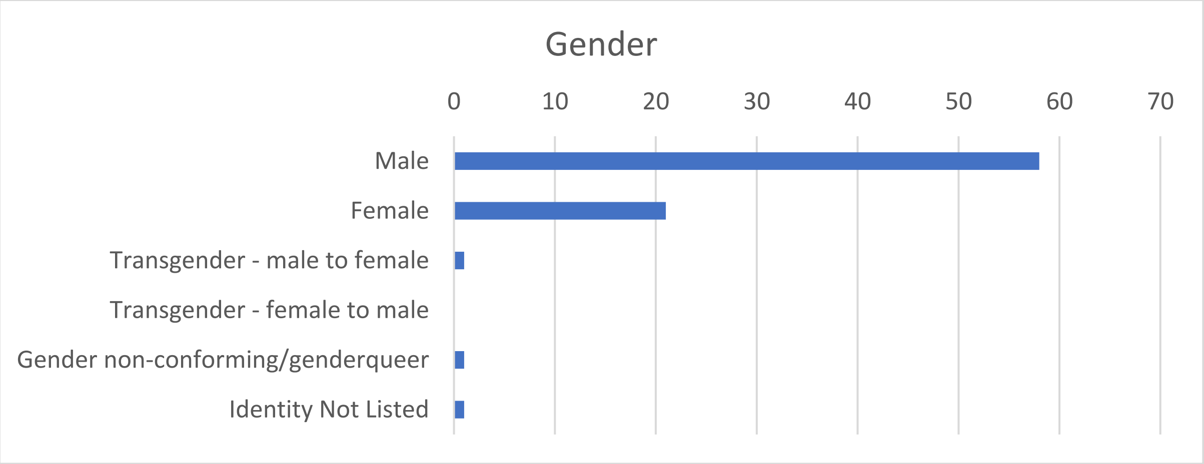

Figure 4: Count of participants by gender.

Participants were asked to share information about their sexual attraction. Most participants reported sexual attraction to men, with 79% of male participants and 86% of female participants reporting attraction to men. Only responses by people who selected "Male" or "Female" as their gender identity are included in Figure 5 because responses are suppressed for members of groups of fewer than five (5) participants.

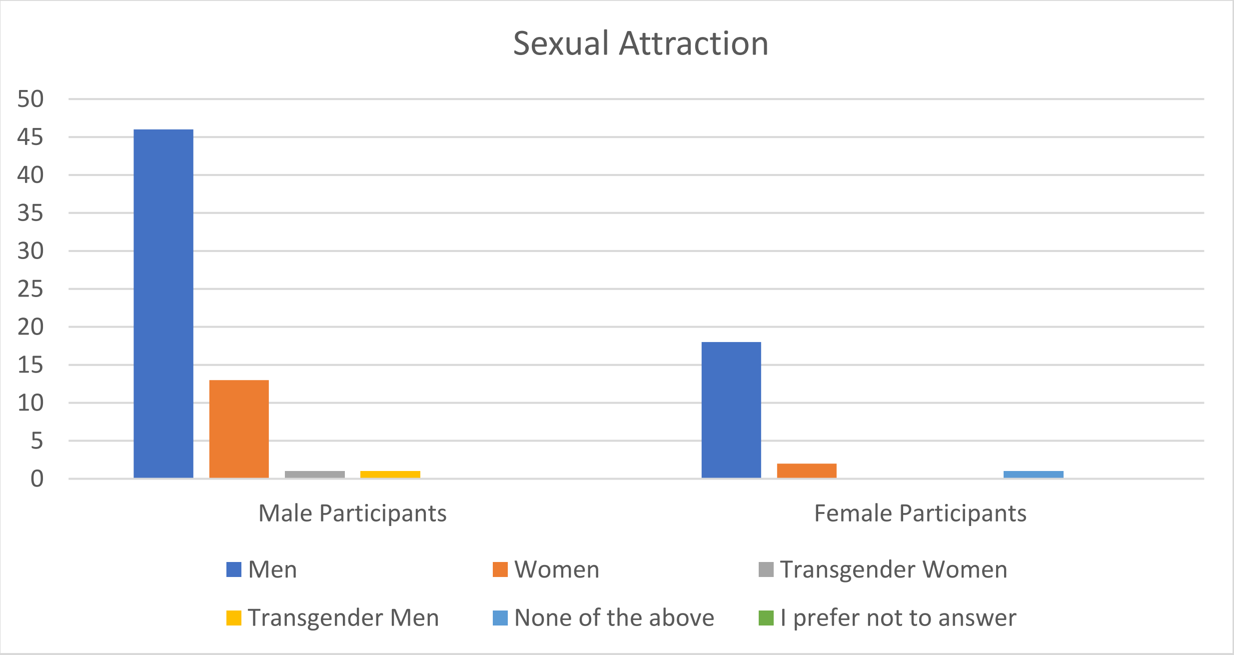

Figure 5: Sexual attraction of participants, by gender.

Among the participants who shared the number of years since receiving an HIV diagnosis, only 7% had received an HIV diagnosis within the prior two years, while over one-half have been living with HIV for over a decade.

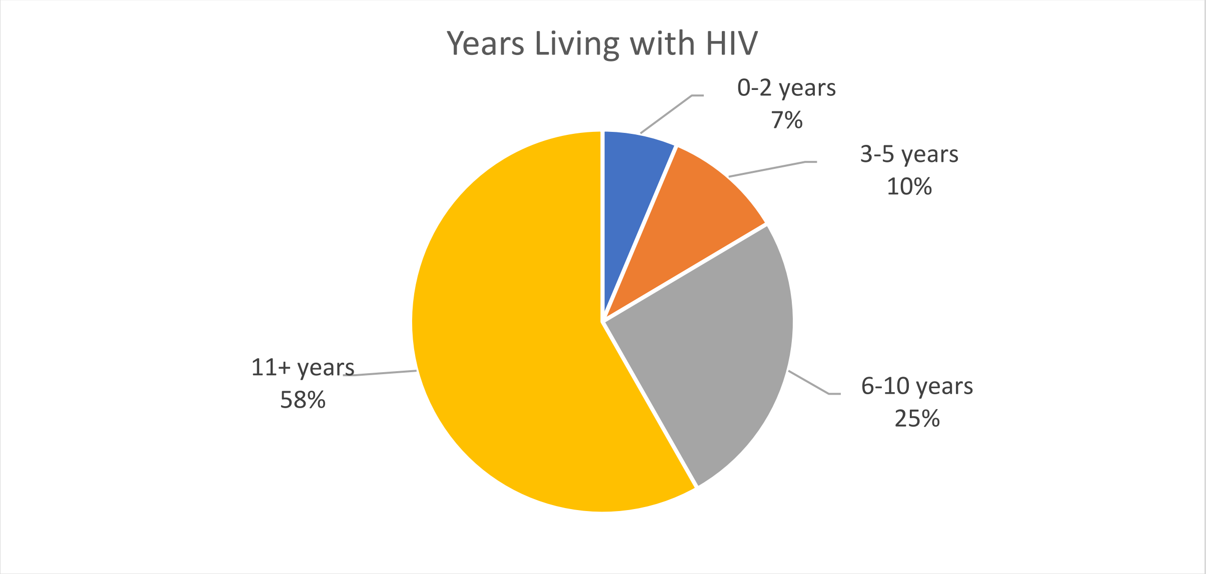

Figure 6: Number of years living with HIV.

Participants were asked to share in which county they receive most of their HIV-related healthcare. Nearly one-half of participants reported receiving care in Marion County, followed by St. Joseph County, Scott County, Lake County, and Vanderburgh County.

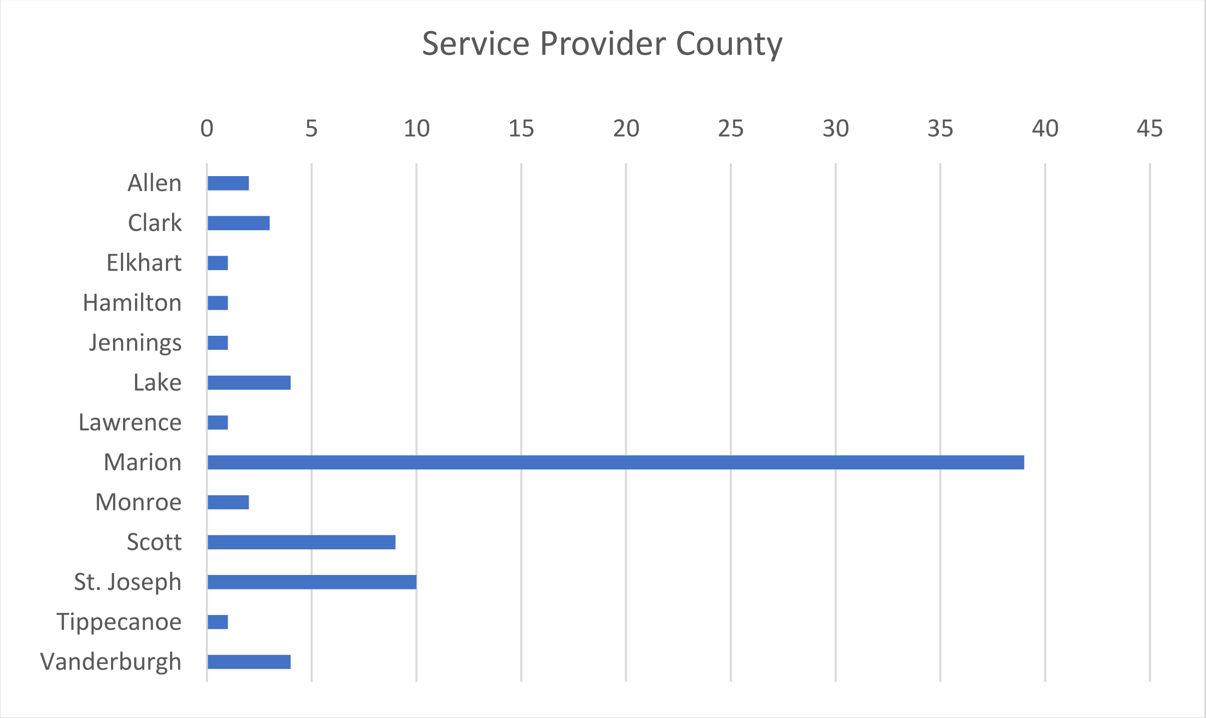

Figure 7: Service provider location (county).

In order to inform affinity group assignments and gather information specific to the priority populations, participants were asked to indicate whether they have had life experiences that may place them at a higher risk of coming into contact with HIV and/or that may impact their ability to get the services or care they need. Many participants reported experience with illegal drugs (both with and without the use of injection drugs), mental health and substance use disorder treatment, and housing instability and homelessness. Over 30% of participants reported experience with sex work and 15% of participants have experienced a co-infection of hepatitis C. Several participants shared that they are immigrants.

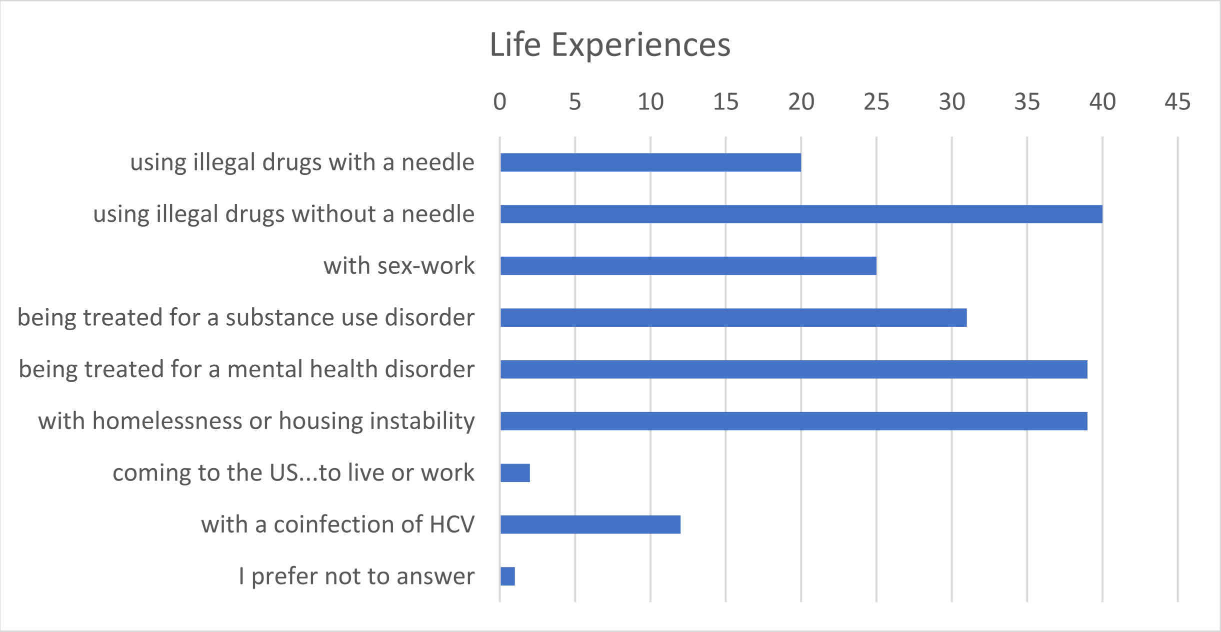

Figure 8: Life experiences of participants.

Priority Populations

The IDOH and HIV Need Assessment Advisors Group identified priority populations for the research team to target for this research. These sub-groups of people living with HIV in Indiana were chosen based on the disproportionate impact of HIV on various communities and known risk factors contributing to HIV transmission and incidence. People from every priority population participated in this research. The research team included all feedback and information shared by these individuals in the overall analysis, findings, and recommendations. However, to protect the identity of participants the research team did not generate findings, or recommendations for priority populations if less than 10 individuals from a priority population participated in the study. Additionally, in the table below the research team suppressed the number of participants if there were less than 5 participants that met an individual characteristic. A "-" indicates that the number was suppressed.

Priority Populations	# Participants
Black/African American women living with HIV	11
Heterosexual Black/African American men living with HIV	-
Black/African American MSM living with HIV	19
Young adults (18-24 yrs. old) living with HIV	-
Transgender people living with HIV	-
Latina/Hispanic females living with HIV	-
Latino/Hispanic MSM living with HIV	-
PLWH/A who have experience using illegal drugs with a needle	20
PLWH/A who have experience using illegal drugs without a needle	40
PLWH/A who have experience with a coinfection of Hepatitis C (HCV)	12
PLWH/A who have experience being treated for a mental health disorder	39
PLWH/A who have experience with homelessness or housing instability	39
PLWH/A who have experience with sex-work	25
PLWH/A who have experience being treated for a substance use disorder	31
PLWH/A who have experience coming to the US from another country to live/work.	-
PLWH/A who live in Marion County	37
PLWH/A who live in rural counties	-

Table 5: Priority population members included in the sample.

Note: Values <5 suppressed (indicated by "-").

Findings

The needs assessment yielded a great deal of information about the service needs and barriers to resources PLWH/A face in Indiana. The data collected were used to identify key findings and develop recommendations for the IDOH and partners to consider for planning and decision-making for HIV programs and services in Indiana. This information is organized into three categories:

- Healthcare Access
- Social Determinates of Health
- Prevention and Care Workforce Issues.

Healthcare Access

Respondents identified a number of barriers to accessing the care they need to support their physical and mental health, such as cost-related burdens, difficulty navigating complex systems, and limited access to mental health supports. Participant feedback regarding access to healthcare is summarized in the following:

This section refers to information that PLWH/A shared related to their medical care and their interactions with the healthcare system. Participants shared themes related to insurance, mental health care, social support and support groups, accessing medication, and access to care, services, and support that meets all the needs of PLWH/A.

Insurance

Finding: Insurance is often a barrier for PLWH/A. Insurance coverage is often complex and confusing, a major financial strain, and not comprehensive enough to cover all their needs.

It was common for participants to describe frustrations with understanding what is covered and what is not. One female participant reported that she needed help understanding her benefits and co-pay so that she could manage her care. Another participant shared that Ryan White insurance supports are good, but it is offered as a secondary insurance requiring a different primary insurance. This was confusing and a challenge to navigate.

Insurance is a major financial strain for PLWH/A. One participant described that insurance and healthcare costs forced him to file for bankruptcy before he could become eligible for the services he needed. Another pointed out that the cost of living is rising, and this makes it harder to afford insurance. A participant receiving state insurance said that even with the insurance benefits he receives, the cost of his medication is unfair given his financial situation and inability to work due to a disability.

Insurance often isn't comprehensive to the needs of PLWH/A. Multiple participants pointed out that they cannot find dentists in their areas who accept their state insurance or Medicaid. Other participants shared that the insurance they receive through their employers does not cover all their medical needs. One participant shared that he does not receive vision benefits through his employer and is forced to use free care from a school of optometry. The soonest he could get an appointment for routine eye care was four months in the future. For others, the insurance did not cover all of their lab work. One participant noted that he is now $1,000 in debt from lab work that wasn't covered.

Insurance experiences were not all bad. When insurance worked well, participants highlighted it as something they liked about their care and services. One participant told the researchers that under his new insurance, he has "no out-of-pocket costs." Another said that with insurance "accessing care is much easier."

Mental Health Services

Finding: Mental Health services are a critical need for PLWH/A. There are limited mental health providers and high turnover rates with providers when PLWH/A do find care.

Participants often shared that mental health care and services were critical, particularly with their co-occurring mental health illnesses. One participant noted that when his mental health needs are not being met, he falls out of HIV care. Another said that his mental health diagnosis, when untreated, can lead him to forget his HIV medication. Participants also noted limited access for newly diagnosed patients. One participant shared the importance of mental health support at that time saying that PLWH/A "feel very alone” when they are first diagnosed. For those without co-occurring mental health illnesses, mental health services are still critical. When asked about the personal needs that he had the hardest time meeting, one participant shared that his mental state was the biggest challenge. He said that having someone to talk to and vent to would be very helpful.

Participants reported that there were a limited number of mental health providers available, and they experienced a high turnover rate with staff. Multiple participants noted that there is a shortage of therapists available. Another participant recommended hiring more mental health professionals. He said every time he made headway with one, they would leave. Both men and women noted the challenge of starting over with a new therapist. The stress of having to retell your issues and traumas to another person prevents people from seeking mental health care after a therapist leaves.

Social Support and Support Groups

Finding: Support groups fill an important need for PLWH/A. Support groups help PLWH/A deal with stigma, help PLWH/A connect with people with similar experiences, and help people navigate care.

Data indicated the need for social and emotional support groups for PLWH/A. Participants cited a lack of support groups available to PLWH/A. One participant asked for consistently available support groups. He said, “It would be nice to be around other people (living with HIV).” One participant stated his wish to have more conversations with other people with HIV. He wished more people were not scared to be open and pointed out that stigma is the reason folks are scared. He said, “Stigma is horrible.” Another participant put it simply “…getting a support group is very important. I feel isolated by it (HIV).” One woman described how she isolated herself after her diagnosis and did not have a good relationship with her doctors. She shared that after more than 10 years of self-imposed isolation, it was joining a support group that gave her the ability to engage with her doctors positively. Similar positive impacts of support groups were noted on several occasions. One participant credited support groups for bringing him out of his shell. He reported that they allowed him to make more friends.

The desire for support tailored to specific populations such as women living with HIV was cited. One woman noted that she would like support groups for women who are HIV-positive and for pregnant women or mothers who have had HIV-negative babies. Another shared that she wanted to see her local ASO offer women’s group meetings and long-term survivor meetings.

Support groups helped individuals navigate the complexities of an HIV diagnosis. During one focus group, a man shared that he felt lucky to know lots of people who are older and living with HIV. They helped him with guidance on how to move forward. One woman said that what helped her deal with having HIV was that they sent her to a support group. It was this community that she credited with helping her navigate her care. Other participants stated they found out about new resources for PLWH/A through participating in support groups.

Finding: COVID-19 heavily and negatively impacted support groups.

When asked about the impact of COVID-19, one participant shared that support groups ended because everything had to go virtual. Highlighting that virtual support groups during COVID were not as well attended or engaging, one participant noted that "...we struggle with Zoom. Many of us are isolated. Some of us went back to using drugs. Staying in the house was a struggle."

Accessing Medication

Finding: Medication is often unaffordable for PLWH/A both with and without insurance.

Even with insurance, for PLWH/A with complex medical needs, the cost of the medications they need to be healthy can be unaffordable. One participant recounted that it was an insurance company, not her doctor, who decided to stop covering a medicine that was helping her manage her appetite and nausea. After her insurance coverage stopped for these medications, she could not afford them out-of-pocket and her issues with appetite and nausea returned. Like the challenge of general affordability shared in the Insurance section of these findings, many participants reported that without insurance they would not be able to afford their medication. Participants told researchers about PLWH/A that they knew who did not have access to insurance and that these people pay thousands of dollars out-of-pocket for their medication or go into debt. The reality of medication access for those without insurance was plainly stated by one participant. He said that without insurance "you can't get the medicine you need to survive."

Finding: PLWH/A favor medication delivery services and large supplies of medicine (more than 30 days of medicine) to improve medication adherence.

PLWH/A reported the utility of medication delivery services as well as large supplies of medicine as helpful for their medication adherence. Multiple participants praised their pharmacies for having a delivery service. Many participants talked about the challenge of only being able to get a 30-day supply of medicine. Without reliable transportation, getting to the pharmacy every month at the correct time was a major barrier for them. Other participants noted how this was changing for the better. One participant shared how helpful it is to him to be able to get a 90-day supply of medication. Having a 90-day supply, he reported, was due to a change in his insurance.

Care Coordination

Finding: PLWH/A need providers within a comprehensive health system that can meet their needs and coordinate their care.

PLWH/A need providers within a comprehensive health system that can meet their complex needs, or they need better care coordination across the existing systems. Participants with co-occurring diagnoses described that they were not able to be treated by the same doctor or health systems for all their needs. One woman talked about her co-occurring condition and shared that her biggest concern is that many doctors do not concern themselves with her other medical conditions. It was common to hear from participants that they changed doctors many times before finding one who could manage their needs. Another described that people are lost to care when they have to go to different places for different aspects of care.

The need for better care coordination across existing systems was also highlighted by participants. One participant shared that services are dependent on each ASO or provider. He said that this creates an environment where there is no coordination between ASOs and providers. Many participants also described negative experiences with their overall care coordination from ASOs. One shared that not all ASOs he has worked with had linkages to care. Another shared that his care coordinator wouldn’t call him unless he first reached out and requested services.

Finding: PLWH/A need care within a centralized location to reduce barriers to access.

PLWH/A need care within a centralized location to reduce barriers to access. Participants expressed interest in more “one-stop shops” for PLWH/A. Places where they can get all the care they need at one time. Participants shared that some ASOs, particularly in central Indiana have this model and it is very positive. Those outside of central Indiana cited this as highly desired in their areas. When one participant heard about the number of services at one organization in central Indiana, he called it “amazing” and said, “We don’t have anything like that here,” referring to northwest Indiana.

PLWH/A shared a barrier that could be reduced through a centralized model. As outlined in the Social Determinates of Health section, transportation barriers are reduced if you only have to go to one location. This model also makes it easier to manage time off with employers. If you can get everything done in one place and in one day you are likely to miss fewer days of work. These improvements also likely mean that PLWH/A would miss fewer appointments, be dropped less by providers, and stay linked to care.

Social Determinants of Health

People experiencing poverty and others facing difficulty in meeting the basic needs of daily living face enormous barriers to care. Concerns over limited or inadequate access to transportation, nutritious food, safe and affordable housing, gainful employment, and supportive services were cited by many focus group participants. Participant feedback regarding unmet foundational needs that create barriers to prevention and care is summarized in the following:

Transportation

Finding: Participants struggled with acquiring transportation for medical, employment, support groups, and basic needs.

Transportation is an essential need for PLWH/A to access care and basic needs. PLWH/A in Indiana struggle with accessing transportation to reach their medical appointments and pharmacies for medication. One participant commented that “I was diagnosed in 2009, I had a hard time staying consistent with care, going to the doctor. I had lots of obstacles as far as transportation.” Participants also reported that public transit systems are not a reliable or viable option for people in Indiana. Participants commented that the bus routes are confusing and time-consuming and only beneficial for people living in downtown Indianapolis. One participant commented that “Transportation was tough because the bus system is crazy. I have to catch multiple buses to get where I’m going.” Another participant commented, “Public transit is limited so it does nothing for people living outside of downtown Indianapolis.”

Finding: Participants appreciate transportation services provided by ASOs but have cited the need for more flexibility in when those services are available.

Participants generally had favorable comments regarding transportation services provided by ASOs and insurance. Many participants were appreciative of ASOs that offered transportation services but wished for more expanded days and times when transportation is available. Limited schedules for transportation may not align with accessing medical appointments and basic needs. Focus group participants also cited a need for an increase in gas cards for people outside of service providers to assist them with transportation needs. One participant commented “(I need) gas cards, I don’t drive but I need them for people to take her to where she needs to be. I haven’t been able to find them or receive them.”

Food Access

Finding: PLWH/A reported that SNAP enrollment is complex and renewal is difficult.

Focus group participants reported overall frustrations and challenges in accessing food. Participants reported that the process to access SNAP benefits involves too much “red tape.” Many felt that the program benefits should be streamlined for PLWH/A. A participant commented that “(With) SNAP you have to do everything with a mail or fax. Can’t do it online. It’s ridiculous.” Another participant commented that “There is too much red tape. There should be an easier way for folks with HIV, it should be automatic. Auto-renewal (for SNAP benefits).”

Finding: Food banks don’t always have the food that PLWH/A need. Food banks are hard to rely on if you have complex dietary or medical needs.

Food banks are a reliable source of groceries for PLWH/A in Indiana. Participants discussed frustrations with the lack of options for diverse and nutritious food at food banks. One participant commented, “Food banks are inconsistent and that’s super hard. You risk wasting your voucher if there isn’t anything there that’s good.” Research has shown that populations who receive food from food banks prefer to receive meat, poultry, fish, and produce over less nutritional items.[13]

Finding: There is no consistent awareness among PLWH/A of the food benefits and resources available to them through services and ASOs.

The study also revealed many of the focus group participants were unaware of the services and options available to reduce food insecurity. Participants reported that they often found that their peers were unaware that their ASO had a food pantry or other services available. One participant commented that “His peers did not know about the (ASO)’s food pantry and other resources. He just learned about (program). Wants to get knowledge about what’s available to more people.”

Housing

Finding: Housing is often in unsafe areas and not safe or welcoming for queer and older people.

Many participants of the study had frustration with acquiring safe housing. Participants living in Marion County cited that housing placements are often unsafe and not appropriate for the lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA) community or older residents. Participants also reported experiences of being placed in housing that was near drug users and other illegal activities. One participant commented, “The housing I have been connected with hasn’t been livable. Not safe for queer people or older people.” Another participant stated, “Someone was murdered in my building ten feet from my bedroom window, and they don’t understand why I want to move.”

Finding: Public housing assistance is difficult to navigate and slow to materialize for PLWH/A.

Housing assistance programs have been reported to be confusing and difficult to access. Participants reported either being unaware of what programs and assistance are available or they are currently experiencing delays due to long waitlists. The process throughout Indiana to obtain housing was often described as slow, with rigid requirements causing a barrier to access. One participant commented, “Right now we are homeless. Trying to keep up with housing has been the biggest challenge for me and my husband. We are not working with anyone at the moment, (we) have never heard of any of the places that others have mentioned (at the focus group).” Another participant stated “I’ve asked for help with that through (ASO), and the people I have asked don’t

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[13] Levi, R., Schwartz, M., Campbell, E. *et al.* Nutrition standards for the charitable food system: challenges and opportunities. *BMC Public Health* 22, 495 (2022). https://doi.org/10.1186/s12889-022-12906-6

seem to have any idea about what is available. It’s on me to figure out if I’m eligible, like with section 8, etc.”

Finding: Public housing resources are generally limited.

Participants discussed limited resources for those facing housing insecurity. Participants living outside of Indianapolis cited that there are no housing options outside Indianapolis and participants have been told to seek housing in more urban areas. One participant commented, “Here are lots of people who are homeless, if you ask about housing here, they will tell you to go to Indy to find housing and you have to come up with the deposit and first month’s rent before Ryan White will kick in. There are no resources for housing.”

Employment

Finding: PLWH/A experience stigma in the workplace.

Stigma is a barrier to employment as many participants felt the need to hide their status to maintain their employment. Participants have reported negative interactions after disclosing their status at their place of employment. One participant commented, “When diagnosed, I was working at a hospital and some other nurses campaigned for me to be fired, which I was.” Another participant stated “I don’t tell people at my job that I’m positive because I’m afraid of what people would think of me. It could be my own thoughts but not sure. COVID set us back a little bit, people were leery about you coughing around them, let alone having HIV.”

Finding: PLWH/A want to work but can’t always find jobs or employers who are supportive and flexible enough to meet their unique needs.

Participants cited needing resources to support PLWH/A in accessing employment. Many focus group participants discussed a desire to work but need employers that understand the complex medical needs of PLWH/A. One participant commented, “We educate the community about HIV, but the general public is not educated on HIV. Like employers don’t understand that people with HIV have specific appointments (we) have to make. Create an optional program for employers to learn.”

Participants who aren’t working requested access to the workforce and asked for services to help PLWH/A find work in Indiana. Another participant commented, “I really think we need some sort of workforce help. Helping people in the community who are struggling to find jobs, find work. It’s not something offered…A lot of people who might be under disability are still wanting to work. They want something to do. They are not ready to retire… Also finding them a workplace that is not going to judge someone who is living with HIV working in that environment.”

Language Barriers

Finding: There is a need for resources for non-English speakers, particularly Spanish speakers.

Participants reported that within Latino/a/x communities, language is a key barrier to care. As of 2020 Latino/a/x residents account for 10.8% (N=1,282) of the total number of people living with HIV in Indiana.[14] As the Latino/a/x population grows we will need multilingual literature and services to support this population reaching viral suppression. Participants report that most of the information was provided only in English. As a result, some PLWH/A choose not to receive care or to go to another state. One participant said "In Indiana, there is a lack of resources and services available to Latinos. Latinos are looking elsewhere for care because Indiana is not appreciative of the Latino community."

Mixed Rural/Suburban Communities

Finding: PLWH/A in mixed rural/suburban counties often must travel to other more populated areas to receive services for fear of stigma and to have better access to services.

Participants living in mixed rural/urban counties often experience stigma as a barrier to care as well as stigma resulting in negative experiences in their personal and professional relationships. Participants cited having to travel to other more populated areas to receive services for fear of stigma and to have better access to services.

"If I didn't receive services in Bloomington, I would have had to go to Paoli. I chose to receive services in Bloomington because there would have been barriers and definitely stigma in other places."

Findings: Housing and medical services have also been reported to be limited within mixed rural/urban counties.

Housing and medical services have also been reported to be limited within mixed rural/urban counties. There was a limited number of participants who reported positive experiences in receiving access to housing, though participants cited that the rental assistance programs in Jefferson and Scott County have been helpful, many people in need are unaware of this service. Other participants cited that they were unable to find specialists, counselors, and housing within mixed rural/urban counties.

"Stigma around HIV/AIDS is crazy. Nobody knew what to do, no specialists, no counselors so I had to go to Louisville. Before I got with (my doctor) there was a time when I wasn't taking meds…There are lots of people who are homeless (living on couches, at friends' houses)—if you ask about housing here, they will tell you to go to Indy to find housing and you have to come up with the deposit and first month's rent

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[14] Emory University. (2022). Local Data: Indiana. AIDSVu. https://aidsvu.org/local-data/united-states/midwest/indiana/

before Ryan White will kick in. There are no resources for housing, etc. I have other health challenges I need help with."

Urban Communities

Finding: Participants living in urban counties reported positive experiences regarding the number of services available and that access to these services is easier in urban counties.

Participants living in urban counties reported positive experiences regarding the number of services available and that access to these services is easier in urban counties. Participants reported that transportation services and food assistance programs within these counties have been easy to access.

During COVID-19 participants reported that ASOs offering gift cards for food, delivery services, and basic needs was helpful during the pandemic. Others commented that having a tablet provided to them allowed them to maintain contact with others and take part in services.

"Prior to COVID, I was already experiencing social distancing because of my immune system. During the pandemic, (ASO) provided me services; delivering food, meals on wheels, they have a pantry, they sent me a tablet that allowed me to stay in contact with the real world, they offer yoga and classes/gatherings, you just Zoom in. It keeps you in contact. I would like it to continue."

HIV Prevention and Care Workforce

Focus group participants shared a full range of experiences engaging with the system of care. A core component of those experiences is often the direct interaction with frontline staff, as well as the impact of the culture, policies, and practices of their employers. The themes that were identified were: experiences and provider interactions at diagnosis, language that stigmatizes, consistency of personnel, knowledge about and access to the services available to PLWH/A, and self-advocacy. Participant feedback that may be reflective of workforce development and training needs and opportunities for the HIV prevention and care workforce is summarized in the following:

Experiences and Provider Interactions at Diagnosis

Finding: Many participants reported negative experiences with providers because of poor bedside manners, lack of support from providers, and a general sense of dismissiveness towards people living with HIV at the time of diagnosis.

PLWH/A that have a negative experience at diagnosis reported difficult transitions into care. Participants reported negative experiences with providers because of poor bedside manners, a lack of support from providers, and a sense of dismissiveness from providers. One participant recalled feeling like everything "was shoved down his throat" and he was expected to "just deal with it." Another recalled how at his diagnosis the doctor made assumptions about his sexuality and life choices that made him very uncomfortable.

In addition to these negative experiences with providers at diagnosis, many participants reported feeling like they were not supported when they were initially diagnosed, which caused confusion and trauma. One woman shared her experience as this: “It was scary. I didn’t know what was up, what was down, who to ask, what to ask. I wasn’t given any type of pamphlet…. I didn’t even know about care coordinators.” Others reported that they did not receive any resources on where to go or who to connect with following their diagnosis. Some shared that the information they received was difficult to understand. Participants offered these suggestions: “(I) would like to see clients get a checklist of ‘to-do’ at diagnosis so they know right away what they need to do and who to contact.” Focus group participants recommended that once a person is diagnosed with HIV, providers should get them the information they need right away.

Participants talked about feeling a sense of dismissiveness from providers at diagnosis. For some, it was plainly stated. One participant shared that when he was diagnosed, his provider informed him he could no longer be seen at the facility because they were “not prepared to provide care for a patient who tested positive.” One man shared that when his friends were diagnosed, they were simply handed off and not supported by their primary care doctor. When talking about their negative experiences at diagnosis, many participants expressed a need for training opportunities for providers.

Finding: PLWH/A that have positive experiences at diagnosis often transition into HIV care with fewer challenges.

Several participants reported positive experiences with providers and care staff at diagnosis. One participant said he felt “lucky” because he was immediately referred to care and his doctors handled all the bloodwork and connections to further care. He noted that his experience at diagnosis meant he didn’t have to deal with the challenges of finding care and support at the same time as dealing with his life-changing diagnosis.

Stigmatizing Language

Finding: PLWH/A have experienced providers that use offensive or stigmatizing language during care appointments.

Stigmatizing experiences shared during focus groups included assumptions made by providers about the PLWH/A, stigmatizing language being used by providers and staff at appointments, and perceived judgments about lifestyle choices when talking about care and services.

Finding: The language used in communications from providers and ASOs to describe resources and services can be stigmatizing and/or deter people from seeking care and services.

The language used in communications from ASOs and other providers to describe resources and services can be stigmatizing and/or deter people from seeking care and services. Some participants shared that the word “AIDS” is heavily associated with stigma and reported not wanting to associate with organizations that have the word "AIDS" in their name or that use "AIDS" to publicly describe available resources or services.

Participants suggested that sensitivity training for case managers was important. One participant said "I would work on training. Most case managers are not HIV positive."

Consistency of Personnel

Finding: Staff retention and consistency leads to positive experiences with HIV care and services.

Many focus group participants discussed challenges with providers, care coordinators, and mental health professionals due to the high rate of turnover of employees. One participant summed up the issue this way, "they (ASO) change case workers so often that you have no idea who is in charge of your care." As one participant noted, "The rotation of case managers and lack of communication does seem to cause a feeling of unease...Transferring of case managers without communication makes transitions difficult. Communication is really important."

Participants described feeling like they had to "start over" with a new staff member because the previous one left. One participant said, "It's a challenge to tell your story over and over again." Several participants discussed how having to repeat their stories with new providers, particularly mental health providers and case managers, often resulted in having to re-live traumas. When talking about turnover, some participants noted that they thought that their care coordinator/case manager was overloaded with clients. One said that the state mandates care coordinators carry a client load of 30 which isn't always feasible because they try and individualize care.

It is important to note that PLWH/A shared that long-term relationships with providers and care coordinators are an important positive for them. Several participants noted that they had been with their providers or care coordinators for a long time and were pleased with the care they were receiving. One participant, when asked what was going well with his care, said he has had the same general provider for 20 years and the provider has always been supportive and welcoming to him. Multiple participants shared that they liked their current care coordinator/case manager and hope that they stay in their position.

Communication and Consumer Education

Finding: PLWH/A are not aware of all the resources that they are eligible for that support their health and wellbeing.

Beyond the time of their initial diagnosis and linkage to care, participants in the focus groups often talked about being unaware of all the services and resources available to them. They reported that it wasn't until they asked for resources specifically or shared specific barriers with their care coordinators/case managers that they were told about key resources. One participant recalled that to get help "you have to ask for the help and give your exact needs..." Another participant mentioned that it wasn't until he mentioned to his case manager that he was struggling to pay his utility bills that he found out about a program to help PLWH/A with their bills. He said "It'd be more helpful if they had it on the website what they could assist with... They need to improve communications." Another participant shared that "They don't tell you about the services they have until you ask. Sometimes they do laptop giveaways, and I didn't know they could do that. They should let us know when the funding comes in so we can ask for services." Many described not learning about important supports and resources until long after their diagnosis. Other participants recalled that she learned she was eligible for care coordination and financial assistance years after her diagnosis.

It was common for participants to tell the researchers that they learned about support or resources from another PLWH/A and not from someone at an ASO or provider. One participant recalled that if he had not been involved in a program with other PLWH/A, he would not have known there was funding for housing. He said, "We rely on other people to tell us what these resources are." Participants recommended that ASOs and other providers be more transparent about what resources and supports are available and share more information with clients about how to access them.

Self-Advocacy

Finding: There is a disconnect between what is available and how hard PLWH/A need to work/self-advocate to get them. PLWH/A often feel forced to self-advocate with their ASOs or providers to survive.

Many participants described that if they did not ask questions or if they did not continuously reach out to their care coordinators/providers they would not have received services and care. One person described their experience with getting care at an ASO saying that "If I didn't call and request services, they wouldn't call me... Sometimes it takes a whole week to hear back from people..." Another participant said that it was not until he asked a lot of questions that he was able to navigate and get the care he needed. Another participant lamented that his other friends living with HIV were not in the focus group to share their experiences. He described himself as a go-getter but said his friends "aren't the same, and it's much harder for them."

The underlying sentiment from many PLWH/A was that being connected with an ASO or having a care coordinator is not enough to receive the resources and support you are eligible for. At times participants described ASOs or care coordinators as gatekeepers. One participant summed it up as "Some people are put in certain positions to be gatekeepers of money that's not theirs, it's for us clients... there are many people who are struggling with different issues and providers overlook people on purpose."

Conclusions and Recommendations

The purpose of this study is to learn about the priorities, interests, challenges, and needs of PLWH/A through conversation and dialogue. The needs assessment yielded a great deal of information from PLWH/A about the service needs and barriers to resources that they face in Indiana.

This information can be used by anyone who manages and facilitates resources, supports, and services to make their offerings more accessible and useful. Those who work in the system of care should review the findings and reflect on their own practices and spheres of influence. What can each of us do differently now that we know a little more about the experiences that have been shared?

The data collected were used to identify the following recommendations for the IDOH and partners to consider for planning and decision-making for HIV programs and services in Indiana. Many of the recommendations are based on insights provided by focus group participants. Additionally, several recently completed assessments and plans were consulted in the development of these recommendations, including *What Matters to YOU? Needs Assessment for People Living with HIV in Indiana* (2019), *Zero is Possible – Indiana's Plan for Ending HIV and HCV* (2020), and the *Indiana HIV Integrated Prevention and Care Plan* (2022).

Healthcare Access

Regarding the findings discussed in the healthcare section, funding and programming decisions should be made to:

- Create clear and easy-to-understand information about what resources, supports, and services are available to PLWH/A from insurance providers and Managed Care Entities (MCEs) and ensure this information is shared with clients at ASOs.
- Encourage ASOs to partner with existing health insurance navigation programs to help PLWH/A better navigate their health insurance.
- Encourage and incentivize partnerships and programs that provide more mental health services to PLWH/A.
- Increase the number and type of support groups available for PLWH/A and ensure PLWH/A know about and are accessing these groups.
- Help PLWH/A pay for medication.
- Allow medication needed by PLWH/A to be filled for 90-day periods by working with providers, pharmacies, and insurance companies.
- Implement or expand home delivery of medications for PLWH/A by working with pharmacies and healthcare providers.
- Improve linkages to care when people are first diagnosed with HIV.
- Create locations of "one-stop shops" for comprehensive care and services for PLWH/A in all parts of Indiana.
- Reduce costs for people who are un/underinsured by working with health insurance navigation and enrollment in programs.

Social Determinants of Health

Regarding the findings discussed in the social determinates of health section, funding and programming decisions should be made to:

- Increase the accessibility of all HIV services and supports in languages other than English with special attention paid to Spanish language services and supports.
- Increase overall support for transportation services and expand the availability of transportation services to accommodate the needs of PLWH/A.
- Promote awareness and education about food benefits, particularly SNAP benefits, and access to food banks/food vouchers.
- Ensure that PLWH/A know about and are accessing all resources available, not just services and supports funded by HIV funding.
- Streamline enrollment and reauthorization for PLWH/A who are accessing all resources available, not just services and supports funded by HIV funding.
- Increase resources that support housing for PLWH/A including financial support for mortgage/rent and utilities.
- Expand the availability of safe and welcoming housing for PLWH/A with particular attention paid to the needs of LGBTQIA people and older adults.
- Support PLWH/A who want to work or are currently working but face challenges related to their diagnosis (e.g., side effects of medication) and stigma from employers.

HIV Prevention and Care Workforce

Regarding the findings discussed in the workforce section, funding and programming decisions should be made to:

- Increase the expertise of medical providers, especially those in private practice, at hospitals, or in community health clinics, around treating PLWH/A to reduce stigma and improve their discussion of sensitive topics, such as substance use, mental health, and sexual health.
- Create comprehensive guides about the types of HIV and social support services available to PLHW/A in Indiana. Work with ASOs to ensure they are used and accessed by PLWH/A.
- Support efforts that help retain mental health providers in Indiana.
- Create avenues for PLWH/A to better advocate for changes to care and services from their providers.
- Recruit and hire people with lived experience (HIV positive, experience utilizing the system) to serve as case managers and navigators within ASOs.
- Provide support services and warm handoffs between agencies and providers through navigation, case management, and care coordination.

Future Assessment

The 2022 Needs Assessment for PLWH/A in Indiana is an important step in centering the voices of PLWH/A to understand the needs, experiences, and barriers to service many people face, but it was not designed to be the sole instrument of assessment.

Rather, it is one avenue through which important perspectives from diverse individuals across the state were gathered, summarized, and shared.

Fortunately, there are many ways in which those with responsibility for stewardship of the available resources and supports to listen and learn from those living with HIV. State and local public health agencies have access to data and information that points to disparities in health outcomes that result from inequitable systems. Coalitions and advocacy groups, such as the Indiana Statewide Advisory Council, the ten regional ZIP Coalitions, and HMM rely on the leadership of PLWH/A and utilize a variety of practices to gather voice and input from their respective communities. ASOs and providers should collect customer/patient satisfaction and feedback on a regular, ongoing basis, and weave the use of that information into their performance management processes.

While those who facilitate the system of care should be careful and dedicated listeners to the community of PLWH/A, formal studies remain a useful tool. As the population of PLWH/A in Indiana changes and their service needs, resources, and issues accessing services change, regular assessment must be done for use in program and service planning. Listed below are recommendations for future periodic needs assessment studies:

- Conduct a formal assessment of needs every 2 – 4 years, depending on the depth, quality, and comprehensiveness of consumer input collected through funded programs and partners.
- Engage grassroots groups, community advocates, and frontline service providers in study design, participant recruitment, and developing findings and recommendations.
- Utilize a mix-methods approach, specifically a convergent parallel design, through which quantitative and qualitative data are collected simultaneously and later merged to produce results to answer the research question.
- Oversample for priority populations such as Black MSM, Black Women who have Sex with Men (WSM), People Who Inject Drugs (PWID), youth, those currently or recently incarcerated, and so forth.
- Blend random sample methodology with other approaches to collect information from hard-to-reach populations, including individuals who are not stably housed, immigrants, and those with lower reading levels than the survey may accommodate. Examples include working through grassroots organizations and administering surveys at care sites serving large shares of clients in the oversample categories.
- Increase outreach efforts for priority populations and consider non-traditional means of engaging with priority populations including through organizations and events related to arts and culture.
- Review and compare information from this and other recent needs assessments to review findings, recommendations, and assessment samples for patterns,

trends, and gaps. (i.e., Marion County EHE Needs Assessments, 2019 “What Matters to YOU?” Needs Assessment for People Living with HIV in Indiana)

There remain several priority areas of exploration that were touched upon in the current study and should continue to be investigated in future research, including:

- Specific barriers in access to services for non-majority populations, specifically people of color, females, and individuals who are non-MSM.
- Specific barriers and lived experiences of Latino/a/x and Black populations.
- Overall utilization of services by PLWH/A and priority populations to ensure equitable access and use of services and supports.
- The specific role and impact of race and racism within systems of HIV prevention and care.
- The role of family (birth or chosen) in PLWH/A seeking care or services for HIV

Appendix A: Abbreviations

Abbreviations	
ADAP	AIDS Drug Assistance Program
AIDS	Acquired Immunodeficiency Syndrome
ASO	AIDS Serving Organizations
CITI	Collaborative Institutional Training Initiative
COVID-19	Coronavirus Disease 2019
EHE	Ending the HIV Epidemic
HCV	Hepatitis C Virus
HIAP	Health Insurance Premiums and Cost-Sharing Assistance Program
HIV	Human Immunodeficiency Virus
HMM	HIV Modernization Movement Indiana
HRSA	Health Resources and Services Administration
HSP	HIV Services Program of the Indiana Department of Health
IDOH	Indiana Department of Health
IP	Internet Protocol
IRBI	Institutional Review Board
LGBTQIA	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual
MCEs	Managed Care Entities
MSM	Men who have Sex with Men
NGOs	Non-Governmental Organizations
PLWH/A	People/person living with HIV
PrEP	Pre-Exposure Prophylaxis
PWID	People Who Inject Drugs
SNAP	Supplemental Nutrition Assistance Program
SSPs	Syringe Services Programs
STD	Sexually Transmitted Diseases
SUDs	Substance Use Disorders
WSM	Women who have Sex with Men
ZIP-IN	Zero is Possible - Indiana

Appendix B: Glossary

Acquired Immunodeficiency Syndrome (AIDS): A chronic, potentially life-threatening condition caused by HIV.

AIDS Drug Assistance Program (ADAP): provides FDA-approved medications to low-income people with HIV. These people have limited or no health insurance. Grant recipients can also use ADAP funds to buy health insurance for eligible clients, and provide services that improve access to, adherence to, and monitoring of, drug treatments.[i][15]

Human Immunodeficiency Virus (HIV): A disease that attacks the body's immune system. It targets CD4 cells which are meant to help the immune system fight off infection.

Health Resources and Services Administration (HRSA): A division of the U.S. Department of Health and Human Services. It is the primary federal agency for improving healthcare access to uninsured, isolated, or vulnerable individuals.

Managed Care Entities: Insurance providers that serve Medicaid and Medicare patients in Indiana.

Ryan White Program: A federal program administered by the HRSA that provides a comprehensive system of HIV medical care, support services, and medications for individuals who are low-income, underserved, or uninsured.

Section 8: One way to refer to the Housing Choice Voucher Program. This is the "federal government's major program for assisting very low-income families, the elderly, and the disabled to afford decent, safe, and sanitary housing in the private market."[16]

Stigma: "HIV stigma is negative attitudes and beliefs about people with HIV. It is the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable.[17]"

Viral Load: A measure of the HIV particles in a milliliter (mL) of blood.

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[15] Health Resources & Services Administration (2022, February) *Part B: AIDS Drug Assistance Program (ADAP)* https://ryanwhite.hrsa.gov/about/parts-and-initiatives/part-b-adap

[16] U.S. Department of Housing and Urban Development, *Housing Choice Vouchers Fact Sheet* https://www.hud.gov/topics/housing_choice_voucher_program_section_8

[17] Centers for Disease Control and Prevention (2021, June 1) *HIV Stigma and Discrimination* https://www.cdc.gov/hiv/basics/hiv-stigma/index.html

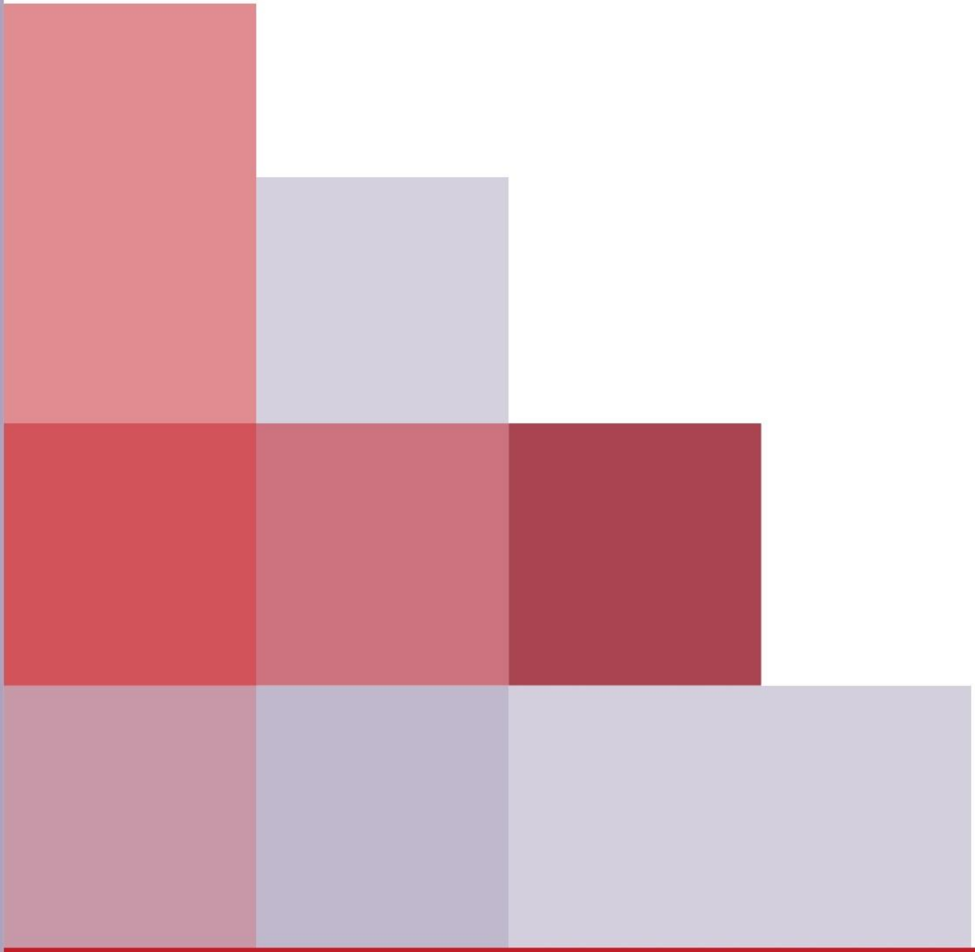
Appendix C: Focus Group Protocol

Appendix D: Interest Survey

December 2022

Needs Assessment of People Living with HIV/AIDS

Indiana Department of Health



Prepared by:
Community Solutions, Inc.

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Acknowledgments

The study was led by the Indiana Department of Health (IDOH) Division of HIV/STD/Viral Hepatitis, with technical support from a research team at Community Solutions, Inc. The Institutional Review Board of Indiana University School of Medicine provided study oversight and Matthew Holley, Ph.D., Assistant Professor of Family Medicine at the Indiana University School of Medicine, served as the principal investigator. Input and guidance were generously provided by the Statewide Advisory Council of the IDOH HIV/STD/Viral Hepatitis Division and a team of advocates and leaders who served on an ad hoc Needs Assessment Advisors Group.

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Jose Arguellez, Community Advocate
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Michael Butler, Marion County Public Health Department
Josh Dowell, IDOH Division of HIV/STD/Viral Hepatitis
Stacey Easley, AIDS Resource Group
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Jennifer Jerger, Matthew 25 AIDS Services
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Eric Pfleider – HIV Modernization Movement – Indiana
Kathy Thornson, Allen County Department of Health
Jill Stowers, IU Health Positive Link
Nick Voyles, Indiana Recovery Alliance

Their wisdom made this effort possible and their dedication to ensuring that all people living with HIV are supported by their communities is an inspiration.

Executive Summary

In 2021, just over 13,000 PLWH/A were living in Indiana, 519 of whom were newly diagnosed. The share of people who were newly diagnosed with HIV in 2021 who were connected to care within 30 days was higher than that of previous years (3,100 of whom were people not actively engaged in care (84% compared with 56% of all PLWH/A in Indiana). Just over two-thirds of PLHIV in Indiana in 2021 have suppressed viral load and 3,100 PLWH/A were not engaged in care – which indicates that 24% of PLWH/A have unmet needs.[1]

The purpose of the 2022 Indiana Department of Health (IDOH) HIV/STD/Viral Hepatitis Division - Consumer Needs Assessment of people living with HIV/AIDS (PLWH/A) was to learn from PLWH/A in Indiana about the care system barriers they face and the priorities they have for their own health and wellness. This information will be used by the IDOH to inform their strategy for funding and deploying supports and services aimed at the following: the prevention of HIV infection in Indiana, increasing the share of PLWH/A in Indiana who achieve and maintain viral load suppression, and serving people in Indiana living with the co-infection of hepatitis C (HCV). In addition, IDOH hopes to increase understanding of how the stigma still surrounding HIV impacts the availability of services and resources, how the COVID-19 pandemic has impacted people and services, and how PLWH/A can be supported to receive the care they need and want.

The study centered on the overall question, “What would it take for all PLWH/A to get the care they need to achieve and maintain viral load suppression?” It was designed to collect information from PLWH/A in Indiana about barriers to resources and service needs through in-person focus groups, virtual focus groups, and one-on-one interviews. Participants were asked to share perspectives on the stigma surrounding HIV, how it can be eliminated, how the COVID-19 pandemic impacted their ability to access resources and services, and what can be done to empower PLWH/A to live their best lives.

The study was led by the IDOH Division of HIV/STD/Viral Hepatitis, with technical support from a research team at Community Solutions, Inc. The Institutional Review Board (IRB) of the Indiana University School of Medicine provided oversight, and Matthew Holley, Ph.D., Assistant Professor of Clinical and Family Medicine, served as the principal investigator. An Advisors Group comprised of PLWH/A, HIV service and care professionals, and community advocates from across the state provided input and guidance throughout the study.

Focus group participants were recruited by the ten regional ZIP Coalitions, AIDS serving organizations (ASOs), and other organizations represented in the ZIP Coalitions. A total of 82 PLWH/A participated in the study. Data were collected using a semi-structured protocol at virtual focus groups, in-person focus groups, and one-on-one interviews. Sessions were no more than two hours in length. For virtual sessions, the facilitators

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[1] Indiana Department of Health. (2022). Integrated HIV Prevention and Care Plan for the State of Indiana.

provided the use of a web-enabled tablet to those without another option. When necessary, focus groups included professional translation services. All sessions were recorded using digital voice recorders. Due to the low participation rate, among other factors, there are limitations to how well the data represents all PLWH/A in Indiana. However, the information collected is still valuable for program and service planning, and decision-making.

Findings and Recommendations

The needs assessment yielded a great deal of information about the service needs and barriers to resources PLWH/A face in Indiana. The data collected were used to identify key findings and develop recommendations for the IDOH and partners to consider for planning and decision-making for HIV programs and services in Indiana. This information is organized into three categories:

- Healthcare Access
- Social Determinates of Health
- HIV Prevention and Care Workforce

Healthcare Access

Respondents identified a number of barriers to accessing the care they need to support their physical and mental health, such as cost-related burdens, difficulty navigating complex systems, and limited access to mental health supports. Participant feedback regarding access to healthcare is summarized in the following:

- Insurance coverage issues were frequently cited as a barrier. Insurance coverage is often complex and confusing, a major financial strain, and not comprehensive enough to cover all health-related needs.
- Mental health services are a critical need. In addition to a general shortage of available providers, participants noted high turnover rates among mental health providers as a challenge.
- Support groups meet multiple needs/interests. Support groups help PLWH/A deal with stigma, connect with people with similar experiences, and navigate the system of care.
- COVID-19 heavily and negatively impacted support groups.
- Medication is often unaffordable for PLWH/A – among people with insurance coverage as well as those without insurance.
- Many respondents favor medication delivery services and large supplies of medicine (more than 30 days of medicine).
- PLWH/A need providers within a comprehensive health system that can meet their needs and coordinate their care.
- PLWH/A need care within a centralized location to reduce barriers to access.

Based on the findings related to healthcare access, funding and programming decisions should be made to:

- Create clear and easy-to-understand information about what resources, supports, and services are available to PLWH/A from insurance providers and Managed Care Entities (MCEs) and ensure this information is shared with clients at ASOs.
- Encourage ASOs to partner with existing health insurance navigation programs to help PLWH/A better navigate their health insurance.
- Encourage and incentivize partnerships and programs that provide more mental health services to PLWH/A.
- Increase the number and type of support groups available for PLWH/A and ensure PLWH/A know about and are accessing these groups.
- Help PLWH/A pay for medication.
- Allow medication needed by PLWH/A to be filled for 90-day periods by working with providers, pharmacies, and insurance companies.
- Implement or expand home delivery of medications for PLWH/A by working with pharmacies and healthcare providers.
- Improve linkages to care when people are first diagnosed with HIV.
- Create locations of “one-stop-shops" for comprehensive care and services for PLWH/A in all parts of Indiana.
- Reduce costs for people who are un/underinsured by working with health insurance navigation and enrollment in programs.

Social Determinates of Health

People experiencing poverty and others facing difficulty in meeting the basic needs of daily living face enormous barriers to care. Concerns over limited or inadequate access to transportation, nutritious food, safe and affordable housing, employment, and supportive services were cited by many focus group participants. Participant feedback regarding unmet foundational needs that create barriers to prevention and care is summarized in the following:

- Transportation
    - Participants struggled with acquiring transportation for medical, employment, support groups, and basic needs.
    - Participants appreciate transportation services provided by ASOs but also shared the need for more flexibility in when those services are available.
- Food Access
    - Food access is a commonly-cited concern, as food banks don’t always have appropriate food – particularly for people who have complex dietary or medical needs.
    - SNAP enrollment is complex, and renewal is difficult.
    - Many participants were unaware of nutrition support resources that may be available to them through services and ASOs.
- Housing
    - Housing is often in unsafe areas and not safe or welcoming for queer and/or older people.
    - Public housing resources are generally limited, difficult to navigate, and slow to materialize.

- Employment
    - PLWH/A experience stigma in the workplace.
    - Some participants shared that they want to work but have difficulty finding jobs or employers who are supportive and flexible enough to meet their unique needs.
- Group-Specific Challenges
    - There is a need for resources for people who do not speak English, particularly Spanish speakers.
    - PLWH/A in mixed rural/urban[2] counties often have to travel to other more populated areas to receive services for fear of stigma and to have better access to services.
    - Housing and medical services have also been reported to be limited within mixed rural/urban counties.
    - Participants living in urban counties reported positive experiences regarding the number of services available and that access to these services is easier in urban counties.

Based on the findings related to social determinants of health, funding and programming decisions should be made to:

- Increase overall support for transportation services and expand the availability of transportation services to accommodate the needs of PLWH/A.
- Promote awareness and education about food benefits, particularly SNAP benefits, and access to food banks/food vouchers.
- Ensure that PLWH/A know about and are accessing all resources available, not just services and supports funded by HIV funding.
- Streamline enrollment and reauthorization for PLWH/A who are accessing all resources available, not just services and supports funded by HIV funding.
- Increase resources that support housing for PLWH/A including financial support for mortgage/rent and utilities.
- Expand the availability of safe and welcoming housing for PLWH/A with particular attention paid to the needs of LGBTQIA people and older adults.
- Support PLWH/A who want to work or are currently working but face challenges related to their diagnosis (e.g., side effects of medication) and stigma from employers.
- Increase the accessibility of all HIV services and supports in languages other than English with special attention paid to Spanish language services and supports.

HIV Prevention and Care Workforce

Focus group participants shared a full range of experiences engaging with the system of care. A core component of those experiences is often the direct interaction with frontline staff, as well as the impact of the culture, policies, and practices of their

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[2] The research team used the Purdue University system of county classification to distinguish rural, mixed (rural/urban), and urban Indiana counties. For more information about this classification please see: https://www.extension.purdue.edu/extmedia/EC/EC-766-W.pdf

employers. Participant feedback that may be reflective of workforce development and training needs and opportunities for the HIV prevention and care workforce is summarized in the following:

- Many participants reported negative experiences with healthcare providers because of poor bedside manners, lack of support from providers, and a general sense of dismissiveness at the time of diagnosis.
- People who shared their positive experiences with providers at the time of initial diagnosis also reported a transition into HIV care with fewer challenges.
- PLWH/A have experienced providers that use offensive or stigmatizing language during care appointments.
- The language used in communications from healthcare providers and ASOs to describe resources and services can be stigmatizing and/or deter people from seeking care and services.
- Staff retention and consistency leads to positive experiences with HIV care and services.
- PLWH/A are not aware of all the resources that they are eligible for that support their health and wellbeing.
- There is a disconnect between what is available and how hard people need to work/self-advocate to get them. Many participants shared that they often feel forced to self-advocate with their ASOs or healthcare providers to survive.

Based on the findings related to participants' difficulties in navigating the system of care, funding and programming decisions should be made to:

- Increase the expertise of medical providers, especially those in private practice, at hospitals, or in community health clinics, around treating PLWH/A to reduce stigma and improve their discussion of sensitive topics, such as substance use, mental health, and sexual health.
- Create comprehensive guides about the types of HIV and social support services available to PLHW/A in Indiana. Work with ASOs to ensure they are used and accessed by PLWH/A.
- Support efforts that help retain mental health providers in Indiana.
- Create avenues for PLWH/A to better advocate for changes to care and services from their providers.
- Recruit and hire people with lived experience (HIV positive, experience utilizing the system) to serve as case managers and navigators within ASOs.
- Provide support services and warm handoffs between agencies and providers through navigation, case management, and care coordination.

Recommendations for Future Assessment

The 2022 Needs Assessment for PLWH/A in Indiana was an important step in centering the voices of PLWH/A to understand the needs, experiences, and barriers to service faced by PLWH/A in Indiana, but it was not designed to be the sole instrument for future assessment. Fortunately, there are many ways in which those with responsibility for stewardship of the available resources and supports to listen and learn from those living with HIV.

While those who facilitate the system of care should be careful and dedicated listeners to the community of PLWH/A, formal studies remain a useful tool. As the population of PLWH/A in Indiana changes and their service needs, resources, and issues accessing services change, regular assessment must be done for use in program and service planning. Listed below are recommendations for future periodic needs assessment studies:

- Conduct a formal assessment of needs every 2 – 4 years, depending on the depth, quality, and comprehensiveness of consumer input collected through funded programs and partners.
- Engage grassroots groups, community advocates, and frontline service providers in study design, participant recruitment, and developing findings and recommendations.
- Utilize a mix-methods approach, specifically a convergent parallel design, through which quantitative and qualitative data are collected simultaneously and later merged to produce results to answer the research question.
- Oversample for priority populations such as Black MSM, Black Women who have Sex with Men (WSM), People Who Inject Drugs (PWID), youth, those currently or recently incarcerated, and so forth.
- Blend random sample methodology with other approaches to collect information from hard-to-reach populations, including individuals who are not stably housed, immigrants, and those with lower reading levels than the survey may accommodate. Examples include working through grassroots organizations and administering surveys at care sites serving large shares of clients in the oversample categories.
- Increase outreach efforts for priority populations and consider non-traditional means of engaging with priority populations including through organizations and events related to arts and culture.
- Review and compare information from this and other recent needs assessments to review findings, recommendations, and assessment samples for patterns, trends, and gaps. (i.e., Marion County EHE Needs Assessments, 2019 “What Matters to YOU?” Needs Assessment for People Living with HIV in Indiana)

There remain several priority areas of exploration that were touched upon in the current study and should continue to be investigated in future research, including:

- Specific barriers in access to services for non-majority populations, specifically people of color, females, and individuals who are non-MSM.
- Specific barriers and lived experiences of Latino/a/x and Black populations.
- Overall utilization of services by PLWH/A and priority populations to ensure equitable access and use of services and supports.

- The specific role and impact of race and racism within systems of HIV prevention and care.
- The role of family (birth or chosen) in PLWH/A seeking care or services for HIV

Background and Introduction

HIV in Indiana

Human Immunodeficiency Virus (HIV) is a virus that attacks the CD4 (T-cells) of the body's immune system, damaging the immune system and making it more difficult for people living with HIV (PLWH/A) to fight off infection and disease.[3] HIV has three phases: acute HIV infection, the first two-to-four weeks after transmission; clinical latency, asymptomatic HIV or dormancy; and Acquired Immunodeficiency Syndrome (AIDS), the final and most severe stage.[4] Approximately 1.2 million people in the United States are living with HIV, with 30,000-40,000 new diagnoses each year.[5] With early diagnosis and proper medical care, progression to AIDS is almost completely preventable, and the life expectancy among PLWH/A is comparable to that of the rest of the population.[6]

In 2021, just over 13,000 PLWH/A were living in Indiana, 519 of whom were newly diagnosed. The share of people who were newly diagnosed with HIV in 2021 who were connected to care within 30 days was higher than that of previous years (3,100 of whom were people not actively engaged in care (84% compared with 56% of all PLWH/A in Indiana). Just over two-thirds of PLHIV in Indiana in 2021 have suppressed viral load and 3,100 PLWH/A were not engaged in care – which indicates that 24% of PLWH/A have unmet needs.[7]

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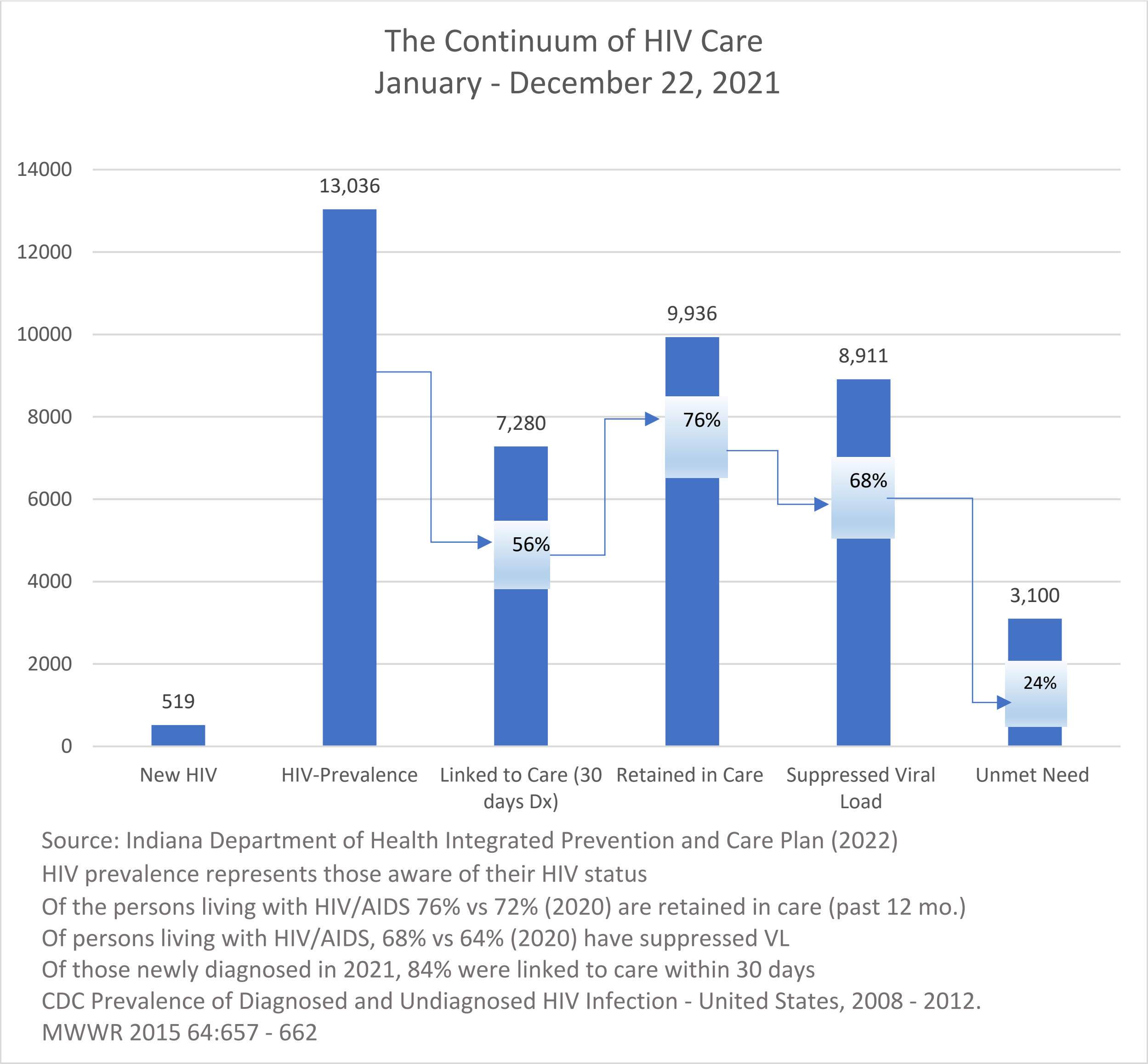
[3] Centers for Disease Control and Prevention. (2019). About HIV/AIDS. Retrieved from https://www.cdc.gov/hiv/basics/whatishiv.html

[4] Ibid.

[5] HIV.gov. (2019). U.S. Statistics. Retrieved from https://www.hiv.gov/hiv-basics/overview/data-and-trends/statistics

[6] Deeks, S. G., Lewin, S. R., & Havlir, D. V. (2013). The end of AIDS: HIV infection as a chronic disease. *Lancet (London, England)*, *382*(9903), 1525–1533. doi:10.1016/S0140-6736(13)61809-7

[7] Indiana Department of Health. (2022). Integrated HIV Prevention and Care Plan for the State of Indiana.



Source: Indiana Department of Health Integrated Prevention and Care Plan (2022)
HIV prevalence represents those aware of their HIV status
Of the persons living with HIV/AIDS 76% vs 72% (2020) are retained in care (past 12 mo.)
Of persons living with HIV/AIDS, 68% vs 64% (2020) have suppressed VL
Of those newly diagnosed in 2021, 84% were linked to care within 30 days
CDC Prevalence of Diagnosed and Undiagnosed HIV Infection - United States, 2008 - 2012.
MWWR 2015 64:657 - 662

Figure 1: Continuum of HIV Care (2021).

The majority of PLWH/A in Indiana are male, with the greatest share of cases being males ages 40 years or older. African Americans are the most disproportionately impacted demographic group and account for almost one-half of those newly diagnosed. Almost one-half of PLWH/A in Indiana and new diagnoses live in the central region of the state, specifically Boone, Hamilton, Hancock, Hendricks, Johnson, Marion, Morgan, and Shelby counties, with the greatest share living in Marion County. More than two-in-five PLWH/A in Indiana live in Marion County.[8]

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[8] Ibid.

HIV System of Care

Living with HIV can affect many aspects of a person’s life, resulting in unique service needs. These service needs may be related to housing, employment, accessing and paying for HIV care, adhering to HIV-related care and medications, side effects from HIV or medications, other health problems, mental health issues, substance use, stigma, and discrimination. For these reasons, effective primary prevention strategies are critical as they can prevent new cases of HIV infection. Available and accessible support services for PLWH/A, including HIV medical care, case management, and social support are important in the long-term quality and duration of life of PLWH/A in Indiana.

The current system of HIV care includes services that help PLWH/A meet their unique medical and support needs. This system aims to help individuals maintain continued care services by minimizing the barriers that inhibit access and supporting resources to increase access to HIV-related services. The US Health Resources and Services Administration (HRSA) provides grants to states, cities, counties, and community-based groups to help provide care, medication, and essential support services to PLWH/A through the Ryan White HIV/AIDS Program (RWHAP).

The IDOH receives funding through RWHAP Part B to fund core medical and supportive services that aim to improve HIV-related health outcomes. PLWH/A who meet eligibility requirements may enroll in the HIV Services Program (HSP) to access these services at state-funded, community-based clinics and sites.

Core Medical Services	**Support Services**
Early Intervention Services	Emergency Financial Assistance
Medical Nutrition Therapy	Foodbank / Home-delivered Meals
Medical Case Management	Health Education / Risk Reduction
Mental Health Services	Housing
Outpatient/Ambulatory Health Services	Linguistic Services
Substance Use Services (outpatient)	Medical Transportation
AIDS Drug Assistance Program Treatments	Referral for Health Care and Support Services
Health Insurance Premium and Cost-Sharing Assistance for Low-Income Individuals	Outreach Services
	Psychosocial Support
	Non-medical Case Management
	Other Professional Services
	Substance Use Services (residential)

Table 1: Indiana HIV Services Program Core Medical and Support Services.

There are three eligibility requirements for HSP enrollment: one must by living with HIV, be an Indiana resident, and have a household income no greater than 300% of the federal poverty level.

PLWH/A who are enrolled in an HSP and are not eligible for Medicare, Medicaid, or an employer-based health insurance program may also enroll in comprehensive health insurance coverage through Health Insurance Premiums and Cost Sharing Assistance (HIAP) during open enrollment. For those needing coverage starting outside of the open enrollment window, they may enroll in ADAP, a temporary insurance program that covers HIV-related medical care.

Any PLWH/A in Indiana, regardless of income level, may access nonmedical case management services funded through IDOH. Nonmedical case management is the delivery of a range of client-centered activities that focus on improving access and adherence to core medical and supportive services. These services include coordination, guidance, and assistance in accessing medical, social, community, legal, financial, employment, vocational, or other needed services.

Services funded through the Ryan White Part B grants managed by the IDOH are not the only services available to PLWH/A in Indiana. Regional or local institutions may provide additional services for PLWH/A in their communities with funding support from RWHAP Parts A, C, and D, as well as a multitude of other publicly funded grants, community and private foundations, and individual donors.

While HRSA provides the largest direct investment in HIV prevention and care among the U.S. Department of Health and Human Services operating divisions, several other agencies play a significant role, as well. In 2019, HHS launched the *Ending the HIV Epidemic in the U.S.* (EHE) initiative[9] to streamline federal efforts to leverage the powerful data and tools now available to reduce new HIV diagnoses in the United States by 75% by 2025 and by 90% by 2030. The 10-year EHE effort is working to accelerate progress toward this goal by directing new funds to those communities most impacted by HIV in a phased approach, starting with the geographic areas facing the highest burden. Communities are encouraged to facilitate state and local strategic partnerships and planning in four areas to achieve the ambitious goals of the EHE:

1. **Diagnose** all people with HIV as early as possible.
2. **Treat** people with HIV rapidly and effectively to reach sustained viral suppression.
3. **Prevent** new HIV transmissions by using proven interventions, including pre-exposure prophylaxis (PrEP) and syringe services programs (SSPs).
4. **Respond** quickly to potential HIV outbreaks to get needed prevention and treatment services to people who need them.

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[9] Ending the HIV Epidemic in the U.S. (EHE). (2022, June 7th). Center for Disease Control and Prevention. Retrieved December 8th, 2022, from www.cdc.gov/endhiv

In response to the EHE call to action, the Indiana Department of Health Division of HIV/STD/Viral Hepatitis developed the statewide Zero is Possible – Indiana (ZIP-IN) initiative, which aims to reduce HIV incidence rates by 90% by the year 2030. The work to do so is guided by the *ZIP-IN Plan* which sets a decades-long course of action to guide collective efforts to eliminate the transmission of HIV and ensure optimal quality of life for PLWH/A in Indiana.[10] One of the key strategies of the ZIP-IN plan is the creation of ZIP Coalitions. There are ten ZIP Coalitions in Indiana, each responsible for leading regional efforts to end the HIV epidemic, including the engagement of diverse partners—especially PLWH/A. ZIP Coalitions receive financial support from IDOH to offset costs associated with coalition management and engagement, as well as assistance from IDOH staff.

In addition, Marion County was selected by the Department of Health and Human Services (DHHS) as one of the priority jurisdictions to receive Ending the HIV Epidemic (EHE) investments. The Marion County Ending the HIV Epidemic (EHE) Task Force developed a 5-year plan (2021-2025) focused on the Ending the HIV Epidemic efforts for Marion County. This planning process engaged more than 50 governmental and non-governmental organizations and hundreds of people across Marion County. The resulting plan was designed to monitor and track progress on the four state and national EHE pillars of Diagnose, Prevent, Treat, and Respond. Efforts specific to the Marion County EHE Plan are ongoing.[11]

The IDOH Division of HIV/STD/Viral Hepatitis evaluates progress toward public health goals as well as the quality and accessibility of services, resources, and supports using a variety of strategies. One key strategy is to conduct a periodic assessment of needs and barriers experienced by PLWH/A in Indiana. A 2019 study utilized a two-phase, random sample survey approach that yielded responses from nearly 300 PLWH/A in Phase 1 (short-form survey) and nearly 200 responses from PLWH/A in Phase 2 (long-form survey). While the study generated useful information, there were limitations to the utility due to methodological constraints and low participation rates. Community partners, advisors, and the research team agreed that future inquiries should include qualitative research in the form of individual interviews or focus groups.

Purpose of this Study

The objective of the 2022 Needs Assessment of PLWH/A in Indiana is to inform the IDOH strategy for funding and deploying supports and services aimed at the following: the prevention of HIV infection in Indiana, increasing the share of PLWH/A in Indiana who achieve and maintain viral load suppression, and serving people in Indiana living with the co-infection of HCV. In addition, IDOH hopes to increase understanding of how the stigma still surrounding HIV impacts the availability of services and resources, how

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[10] Zero is Possible – Indiana's Plan to End HIV and HCV, 2021-2030. https://www.zipindiana.org/

[11] Marion County Ending the HIV Epidemic (EHE), https://thfgi.org/marion-county-ending-the-hiv-epidemic/

the COVID-19 pandemic has impacted people and services, and how PLWH/A can be supported to live their best lives.

Study Approach

The study centered on the overall question, “What would it take for all PLWH/A to get the care they need to achieve and maintain VL suppression?” and was designed to collect information about service needs and barriers to resources from approximately 200 PLWH/A in Indiana through in-person and virtual focus groups and key informant interviews. Participants were asked to share perspectives on the stigma surrounding HIV, how it can be eliminated, how the COVID-19 pandemic has impacted people and services, and what can be done to empower PLWH/A to live their best lives.

Data were collected through focus groups and key informant interviews using a semi-structured protocol (Included in Appendix C: Focus Group Protocol). Sessions were no more than 2 hours in length. For virtual sessions, the facilitators provided the use of a web-enabled tablet to those without another option. When necessary, focus groups included professional translation services. In-person and virtual sessions were recorded using digital voice recorders. Participants received a $30 Visa gift card as an incentive for participating. Additionally, in cases where researchers met with participants in-person a meal was provided. For virtual focus groups, participants received a second $30 Visa gift card to cover the cost of a nice meal. Participation was voluntary and confidential. The research team relied on partner organizations throughout Indiana to promote the study and interested individuals were directed to complete a brief interest survey if they wanted to participate.

Key Partners

The study was led by the IDOH Division of HIV/STD/Viral Hepatitis, with technical support from a research team at Community Solutions, Inc. The Institutional Review Board (IRB) of the Indiana University School of Medicine provided study oversight, and Matthew Holley, Ph.D., Assistant Professor of Clinical and Family Medicine, served as the principal investigator.

An Advisors Group composed of PLWH/A, HIV service and care professionals, and community advocates from across the state provided valuable insight and feedback throughout the project on priority populations to engage, outreach and recruitment strategies, focus group locations, timing and questions, communication strategies, and study findings and recommendations.

The 10 Regional ZIP Coalitions were key recruitment partners. AIDS Serving organizations (ASOs) and other types of organizations represented in Indiana’s ZIP Coalitions recruited at their facilities and through their networks using resources provided by the research team. These organizations advertised the opportunity to participate in focus groups to their staff and clients.

Timeline

Study design launched in April 2022 and participant recruitment began in September. Interviews and focus groups were conducted from September through November. The Needs Assessment Advisory Group met monthly from June – December 2022.

Timeframe	Tasks
April – August 2022	Develop Survey Approach Design methodology and focus group administration plan. Engage necessary partners for focus group administration. Develop, test, and revise the focus group format and questions. Create a draft Focus Group moderator guide (includes the questions to ask and facilitation guidance completed) Provide draft facilitator guide to IDOH and partners for review and testing. Test with 8-12 consumers Edit/Finalize survey instrument (English and Spanish) Create and implement a communication plan. Submit study to IRB for review
August – September 2022	Partner outreach and session scheduling Begin outreach with partner organizations assisting with recruitment and hosting. Schedule all focus group sessions
September-November 2022	Launch focus groups. Ongoing outreach and recruitment Administer focus groups. Facilitate sessions and record data as outlined. Deliver Focus group incentives
December 2022	Analyze and summarize data. Clean and code all focus group data. Analyze survey data. Draft and submit HIV Needs Assessment 2022 Report

Table 2: Study timeline.

Focus Group Design

Based on guidance provided by IDOH, the research team developed proposed interview questions which were reviewed and edited by the HIV Needs Assessment Advisors Group to ensure they would elicit feedback from PLWH/A. The approach included two types of focus groups: in-person groups of 8 – 12 participants and virtual sessions using Zoom with participant-to-respondent ratios of 10-to-1. Ten (10) focus groups were to be geographically based, with one in each of the 10 ZIP Coalition regions, and 10 were to be focused on priority population members in an affinity group approach. Participation was open to all adults (18+ years of age) living with HIV and living in Indiana.

Priority Populations

To best understand the service needs and challenges of PLWH/A in Indiana, the IDOH and HIV Needs Assessment Advisors Group identified priority populations for additional inquiry by looking at data trends and reflecting on their knowledge and experience in the field (Table 3). These priority populations informed the design and implementation of the focus groups as well as informed outreach and recruitment strategies and tools. The information necessary to identify PLWH/A as members or the priority populations was collected in the interest survey.

Priority Populations
Black/African American women living with HIV
Heterosexual Black/African American men living with HIV
Black/African American Men who have Sex with Men (MSM) living with HIV
Young Adults (Ages 18-24) living with HIV
Transgender people living with HIV
Latina/Hispanic females living with HIV
Latino/Hispanic MSM living with HIV
PLWH/A who have experience using illegal drugs with a needle
PLWH/A who have experience using illegal drugs without a needle
PLWH/A who have experience with a coinfection of HIV and HCV
PLWH/A who have experience being treated for a mental health disorder
PLWH/A who have experience with homelessness or housing instability
PLWH/A who have experience with sex-work
PLWH/A who have experience being treated for a substance use disorder
PLWH/A who have experience coming to the US from another country to live/work.
PLWH/A who live in Marion County
PLWH/A who live in rural counties

Table 3: Priority populations.

Participant Protections

Throughout the study, the confidentiality and security of participants' information and identity were paramount. While study participants were not promised complete confidentiality, the study design was intended to protect confidentiality in every phase.

Prospective participants did not need to share identifying information to indicate interest in participation. If selected, detailed information about how to participate was shared with the participant via phone or email with the date, time, and overall expectations for participation. Prospective participants were encouraged to use an alias and/or create a unique email address through which to send or receive any electronic correspondence.

Before each focus group, the research team shared the Study Information Sheet with each participant. This document outlined the purpose of the research, the risks of participation, and the rights and responsibilities of participants. Facilitators at each focus group reviewed this document and ensured that all participants agreed and understood what was in the document. Participants were also given the chance to opt out of the research after this review of the study information sheet and before the beginning of the focus groups. All participants were informed that their participation in this research was completely voluntary and that they could leave at any time until the focus group is complete.

Due to the nature of focus groups, participants may have recognized one another during or at any point after the focus group. All subjects agreed to keep the information shared in the focus group confidential. They were reminded before and after the focus group that the information discussed during the focus group must remain confidential. Participants were also encouraged to limit the number of personal identifiers they used in discussions.

The research team used digital voice recordings at each session. The recording devices and the recordings themselves remained in the possession of the researchers for the duration of the project. Any personally identifying information drawn from the notes or transcripts of the focus groups was removed prior to its inclusion in this report and it was never shared outside the research team.

All members of the research team were certified by the Collaborative Institutional Training Initiative (CITI Program) before having access to any potentially identifying data. This training is required by the IRB for all researchers prior to conducting research and covered research best practices and standards including how to protect the confidentiality and security of participants.

Outreach and Recruitment

Recruiting and enrolling the participants was a key part of this study. The research team created promotional materials for a variety of distribution methods. These included physical materials like pocket cards, brochures, and flyers. These materials were sent via mail to all ASOs and other partner organizations that requested them. The research team also widely distributed virtual copies of the printed materials. The team also created digital materials and template language for emails and social media postings. All resources included information about the Visa gift card and meal to incentivize participation. In addition, the resources were designed to be easy to understand and included images of people of a variety of races and genders. All materials were available in English and Spanish. The translation of the materials was conducted by a professional translation service.

ZIP Coalitions were a partner in distributing recruitment materials and messaging to the organizations that serve PLWH/A in Indiana. ASOs shared outreach and recruitment messaging with their constituents and many organizations allowed the research team to meet with their client-facing staff to discuss and encourage recruitment. Community partners assisted with outreach and recruitment. HMM was a referral partner helping recruit dozens of potential participants. Other community organizations shared outreach messaging with PLWH/A in their networks.

Interest Survey

The research team collected information from potential participants in an online Interest Survey (Appendix D). The interest survey presented a summary of the study aims, potential risks, and potential benefits, collected key information to screen for the inclusion criteria, and for those who met the eligibility requirements, the survey then asked respondents to provide demographic and contact information so researchers can sort them into appropriate focus groups and to follow up with relevant logistics information to attend a focus group. None of these questions were required and participants were encouraged to share only what they were comfortable sharing. If they did not want to provide their real name, participants were given the option to use an alias and set up an email account so the researchers could contact them about the focus group. The survey asked about the following topics:

- County of residence
- Race and ethnicity
- Gender
- The gender of people who they are sexually attracted to
- The year they were told that they were HIV positive
- The county where they receive HIV services and care
- The ASOs where they have received care
- Key lived experiences that are considered to influence a person’s ability to access care and services
- Preferred language
- The preferred name they want the research team to use
- Preferred contact method
- Preferred time/date to participate in a focus group

If respondents did not meet the eligibility criteria, they were politely informed that they were not eligible and directed out of the survey and were not asked for any demographic or contact information.

In cases where potential participants did not have access to the interest survey link or were not comfortable using it, participants were able to indicate their interest in participating by contacting the researchers directly via email or phone. The research team maintained a cell phone number and email address for this purpose.

The research team reviewed the interest survey data regularly and used it to contact and invite participants to focus groups. In addition to region (geographic) focus groups and priority population (affinity) focus groups, the research team held virtual sessions for any eligible participant regardless of geography, interviewed participants individually, and held 3 in-person focus groups that were recruited for and hosted by partner ASOs.

Researchers worked with ASOs to schedule meetings with staff to inform them about the study and explore opportunities to collaborate with them in participant recruitment. Members of the research team met with the client-facing staff of more than a dozen ASOs. During these meetings, two ASOs offered to recruit and host in-person focus groups on behalf of this project. In partnership with these ASOs, the research team implemented 3 separate in-person focus groups. To ensure other ASOs had the same opportunity the research team asked all other ASOs to also recruit and host a focus group.

The research team also enlisted help recruiting from HMM. The organization has many trusted relationships in Indiana with PLWH/A and agreed to help get more PLWH/A involved in the study. They provided contact information for interested individuals from their network (with their expressed permission). The research team then worked with those who were referred to ensure that they met the eligibility criteria and then scheduled them into focus groups.

Data Collection

Focus groups, whether they were held virtually or in-person, all followed the same basic protocol. The protocol included reviewing the Study Information Sheet, ensuring all participants understood their rights and responsibilities, and offering the opportunity for participants to decline. Those that stayed were then asked a series of 8 questions related to HIV care, services, and supports.

Each focus group was led by a trained facilitator who asked follow-up questions and encouraged engagement from all participants. In addition to the facilitator, each focus group had another researcher audio recording the focus group and taking notes of the responses. At the end of the focus group, the participants were given their gift cards. If the focus group was virtual the researchers asked the participants how they wanted to receive their incentive. Virtual participants were given the option to have a physical gift card mailed to them or to have a virtual gift card sent to their email.

When the focus group included Spanish-speaking participants, the research team worked with an Indiana-based, professional interpretation service. Interpreters joined the focus group via Zoom and provided simultaneous interpretation services from English-to-Spanish and Spanish-to-English. In addition, a bilingual member of the research team participated and took detailed notes.

Data Analysis

The researchers took notes during each focus group and interview. These notes were cleaned, coded, and analyzed using common qualitative data analysis methods. First, researchers familiarized themselves with the data by reviewing the notes and listening to the recording of the focus group, as necessary. They took notes on initial impressions, looked for key themes, and ensured that what was recorded in the notes reflected what the participant said in the recording to check for bias. In each notes document, the researchers attempted to directly attribute responses to participants.

The data were then organized for full coding and review. Copies of all notes were made and placed in a new folder to preserve all raw data. The comments were categorized by four basic research questions:

1. What has been easy about getting care, services, and supports?
2. What has been hard about getting care, services, and supports?
3. What has been the Impact of COVID-19 on services, care, and supports for PLWH/A?
4. What is the impact of stigma on services, care, supports, and the lives of PLWH/A?

Next, the data were organized into spreadsheets, with a row for each comment that included the unique identifier of the participant who made the comment, their demographic information, and key characteristics (based on interest survey responses). The research team analyzed responses to address each of the basic research questions, overall, as well as by priority populations. The themes were further refined and organized into 3 overarching categories: HIV Prevention and Care Workforce, Healthcare, and Social Determinates of Health.

- Healthcare Access
    - Insurance
    - Mental Health Services
    - Social Support and Support Groups
    - Medication
    - Culturally Responsive, Accessible Care
- Social Determinants of Health
    - Transportation
    - Food
    - Housing
    - Employment
    - Accessibility of Social Supports
- HIV Prevention and Care Workforce
    - Experiences and Provider Interactions at Diagnosis
    - Language that Stigmatizes
    - Consistency of Personnel
    - Communication and Consumer Education
    - Self-Advocacy

Through the analysis, researchers generated a list of findings for each theme, in general, and noted instances for which priority populations were uniquely impacted or for which members of a priority population group cited a particular need that is common to members of their group.

Limitations

The methodology for the needs assessment posed several limitations. While focus groups are an excellent way to hear directly from those impacted and to provide context and meaning, they present several challenges for researchers and participants, alike. In total, 82 PLWH/A participated in the study, which is well short of the goal of 200 respondents. While this methodology was never intended to provide statistically significant, generalizable conclusions, there was a great deal of interest in ensuring broad representation in the conversation and opportunities to have deeper discussions among people who may have overlapping or shared experiences due to geographic proximity or socio-demographic characteristics. While the information collected is still valuable for program and service planning and decision-making, some information for smaller subsets of respondents that would have provided additional detail or insight could not be commented on.

Low participation overall means that it is more difficult to explore similarities or differences across priority populations. While the study participants represent the diversity of the community of PLWH/A and included members from all 17 priority populations identified by the Advisors and key partners, seven (7) priority populations did not reach the threshold to be analyzed separate from the full sample. These sub-populations not meeting the threshold were:

- Heterosexual Black/African American men living with HIV,
- Young adults (18-24 yrs. old) living with HIV,
- Transgender population living with HIV,
- Latina/Hispanic females living with HIV,
- Latino/Hispanic MSM living with HIV,
- PLWH/A with experience coming to the US from another country to live/work, and
- PLWH/A with who live in rural counties.

Outreach to PLWH/A in the state may have been a limiting factor. Many of these groups represent an overall small number of PLWH/A in Indiana. They are also groups of people that tend to be the most impacted by social determinates of health and stigma. These groups are often the most likely to be missing from care and services due to these barriers. Because much of the research team’s outreach was primarily through ASOs and other similar organizations, these groups may have been less likely to receive the outreach materials. The research team worked to counteract the outreach limiting factors by sharing outreach materials with many non-traditional organizations that engage with these populations and by making the interest survey publicly available on the internet.

Other limitations are due to literacy and the language of the initial interest survey. Because it was an online, written survey, participants had to be able to access the internet and read and comprehend the survey's background, instructions, and questions. Similarly, the survey materials were offered in English and Spanish but no other languages. Individuals who were not able to read the survey materials in English or Spanish would have been precluded from participation. The research team worked to counteract these limits by lowering the reading level of all survey materials and by assisting participants to complete the survey over the phone when necessary.

Physical Barriers to Participation

Participation in focus groups or interviews is time-consuming, and there are often barriers to overcome. The focus groups were held in-person and virtually using Zoom. The in-person format presented barriers for people who do not have reliable transportation, barriers to those not comfortable meeting in-person due to stigma or fear of COVID-19 or other contagious illnesses, and other scheduling conflicts. The virtual format presents barriers for people who do not have the equipment or technical expertise to attend a Zoom meeting. The research team worked to counteract these barriers by doing the following:

- Enlisting partner organizations to help with transportation.
- Offering transportation assistance to participants including subsidizing the cost of the transportation services when necessary
- Locating in-person focus groups in more densely populated areas.
- Ensuring whenever possible that in-person groups were located near public transit.
- Setting up in-person focus group space to allow for social distancing whenever possible.
- Providing tablets to those that wanted to attend virtually but do not have a smart phone.
- Providing a telephone-only (call-in) option for all virtual focus groups

Opportunities for Bias

There are also opportunities for bias and differences in executing this methodology. There may be bias among respondents due to the use of incentives. Those most interested in the gift card would have been more likely to participate. Focus groups being a discussion format tend to be biased towards outspoken people and can tend towards only addressing socially acceptable topics.[12]

Since the focus groups were facilitated by different researchers there was also the potential for the different researchers to bring their own biases into the research. The research team attempted to counteract these biases and differences by implementing a specific focus group protocol to guide the conversation, by training all researchers in our protocol before leading a focus group, and by actively encouraging participation from participants who were quiet or not engaged during the focus groups.

Challenges with Outreach and Recruitment

Early in the recruitment phase of the study, there was a very large influx in the number of survey respondents. In less than 24 hours more than 900 respondents claiming to be

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[12] https://www.sfu.ca/~palys/Smithson-2000-Using&AnalysingFocusGroups.pdf

adults living with HIV in Indiana responded to the survey. Over the next few weeks, the number of survey respondents swelled to over 2900 respondents. This influx of respondents was of keen interest to the research team. When the research team examined these responses nearly all were highly suspicious. The survey captured general IP addresses and a vast majority were IP addresses not located in Indiana and a large portion originated outside of the United States. There were also very suspicious survey completion patterns that became apparent. There were a large number of respondents who recorded the first available answer to each survey question. Many respondents also indicated that they lived in an Indiana county in northeast Indiana but received all their services at ASOs in southwest Indiana. Another suspicious trend was that these respondents exclusively communicated via email and gave phone numbers that when called were not real or associated with themselves.

The research team spent dozens of hours sifting through the survey responses to find people who they believed to be eligible for the invitation to a specific focus group. The team worked diligently to exclude those who appeared to be lying. To help with this, the team established a short follow-up survey that asked respondents to confirm a detail from their original survey. This helped reduce the number of respondents as many could not confirm simple details from their original survey.

During the first virtual group, nearly all the participants did not appear to be who they claimed to be. Participants lacked basic knowledge of the vocabulary and abbreviations commonly used by the healthcare system, in general, and this HIV care system, more specifically, in the U.S. For example, several people were unfamiliar with the terms “non-profit organization” and “ASOs” and asked if those were similar to NGOs (Non-Governmental Organizations). When answering questions about their experiences, they provided information that conflicted with what they indicated in their survey and/or what they shared earlier in the conversation. Because protecting participants from harm was the highest priority, the facilitators did not want to subject the real participants to people who were very obviously lying about their identities. Participants whose responses suggested that they were misrepresenting their identity were removed from the discussion immediately and not allowed to return. In subsequent virtual focus groups, the research team brought participants into the virtual “room” one at a time and screened the participant to see if they were who they said they were (based on their responses to interest survey questions and not in a manner that discloses their actual identity). In these cases, many participants could not confirm simple details about themselves from the interest survey and were dismissed before the focus group began. Participants who were being honest were placed in a separate Zoom room to prevent them from being exposed to people who were lying about their identities.

To address these challenges, the research team consulted the Advisors Group and sought input from other researchers with similar experiences conducting online surveys and focus groups. Their input helped the research team shift their outreach strategy. A new interest survey link was created and shared with the recruitment partners, but the team specifically asked that the partners not post the link on social media or the web. The link was only shared in offices and directly between staff and clients. The research team also shifted away from communicating by email as the primary form of contact with potential participants as much as possible. The research team developed new outreach and recruitment materials that encouraged participants to call or text the research team to get involved. The time and effort used to address the problems created by the misuse of the interest survey link would have been better used in other, more effective outreach and recruitment activities.

Results and Discussion

This section of the report presents information about the study participants and key findings.

Participant Characteristics

In total, 82 unique individuals participated in this study from across the state of Indiana. Table 4 presents the characteristics of the individuals who participated in this study. The characteristics include basic demographic information as well as factors that are related to priority population categories (age, race & ethnicity, gender, preferred language, years living with HIV, the county where the individual receives most of their HIV healthcare services, ZIP region, and risk factors). To protect the identity of participants, the research team suppressed numbers if there were fewer than 5 participants that met an individual characteristic (denoted by a "-"). Blank fields indicate that there were zero participants. A range was used in place of an exact number whenever using the exact number would enable the calculation of a suppressed value.

Participant Characteristic	Total	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10	N/A
# Participants	82	5	12	-	-	-		39	-	-	13	-
Age												
18-24	-										-	
25-34	14	-		-				8			-	
35-44	16	-	5		-			6	-	-	-	
45-54	23		-	-				11		-	5	-
55-64	23	-	-	-		-		10	-		-	
65-74	5		-					-				
Race & Ethnicity												
Hispanic or Latino/a/x	6		-					-				
American Indian/Alaskan Native	-		-								-	
Asian												
Black/African American	37	-	-	-		-		22	-		-	-
Native Hawaiian/Pacific Islander												
White/Caucasian	41	-	-	-	-			17	-	-	9	-
I prefer not to answer	-							-				
Other (Self-Identified)	-		-					-			-	
Gender												
Male	58	-	8	-	-			28	-	-	7	-
Female	21	-	-					9			6	-
Transgender - male to female	-							-				
Transgender - female to male												
Gender non-conforming/genderqueer	-							-				
Identity Not Listed	-					-						
Years of living with HIV												
0-2												
0-5	13	-		-				6		-	-	
6-10	20	-	-	-	-			9	-		5	
11+	46	-	9	-		-		24	-		-	-
(blank)	-		-								-	-

Participant Characteristic	Total	R1	R2	R3	R4	R5	R6	R7	R8	R9	R10	N/A
County Where the Participant Receives a Majority of Their HIV Services												
Allen	-			-								
Clark	-										-	
Elkhart	-		-									
Hamilton	-					-						
Jennings	-										-	
Lake	-	-										
Lawrence	-									-		
Marion	39			-				34-38				
Monroe	-							-		-		
Scott	9										9	
St. Joseph	10	-	5-9									
Tippecanoe	-				-							
Vanderburgh	-								-			
Risk Factors and Challenges Experienced:												
Have used illegal drugs with a needle	20		-					5-9		-	5-9	
Have used illegal drugs without a needle	40	-	-	-	-	-		22	-		5	-
Have experience with sex-work	25	-	-		-			13	-		5	-
Have been treated for a substance use disorder	31	-	-					19	-	-	7	
Have been treated for a mental health disorder	39	-	-	-		-		22	-	-	-	-
Have been homelessness or housing instability	39	-	-	-	-	-		22		-	5	-
Came to the US from another country to live/work	-							-				-
Have had a coinfection of HCV	12			-				1-6			1-6	
Preferred Language												
English	81	5	11	-	-	-		39	-	-	13	-
Spanish	-		-									

Table 4: Participant characteristics.

Note: Values <5 suppressed (indicated as "-")

Most focus group participants were aged 45 or older (62%), including five participants in the 65 – 74 age group. Fifteen participants were aged 18 – 34 (18%).

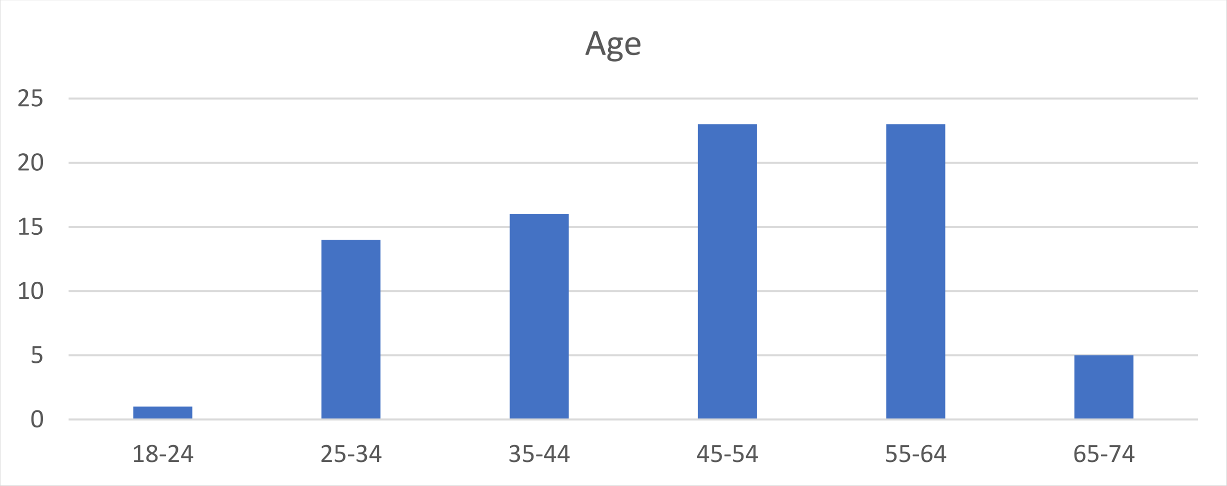

Figure 2: Count of participants in age ranges.

While many of the participants identified with more than one racial or ethnic identity, 50% selected white/Caucasian and nearly as many participants (37 people) selected Black/African American as at least one racial or ethnic identity. Six participants identify as Hispanic or Latinx (7%), one of whom indicated Spanish as a preferred language for focus group participation. At least one participant identifies as American Indian/Alaska Native while none of the participants identify as Asian or Native Hawaiian/Pacific Islander.

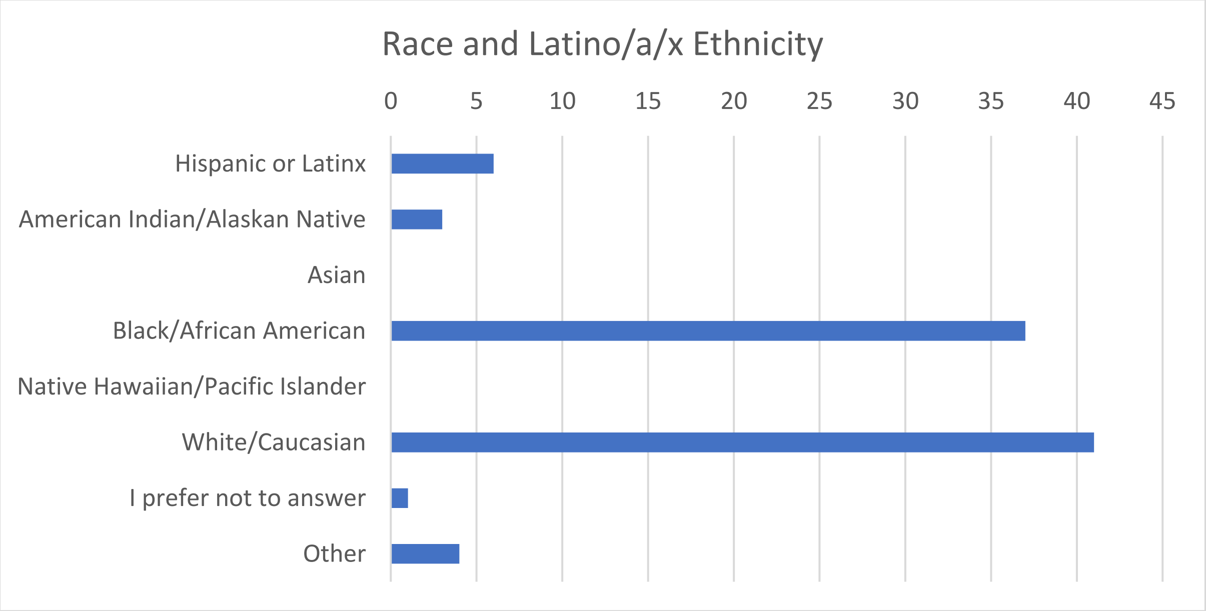

Figure 3: Count of participants by race and Hispanic ethnicity.

Participants were asked to share information regarding gender identity by selecting one or more options from a list and/or writing in an identity that was not listed. Just over 70% of participants identify as male and nearly 27% identify as female. Fewer than five participants identify as transgender, gender non-conforming/genderqueer, or an identity that was not listed.

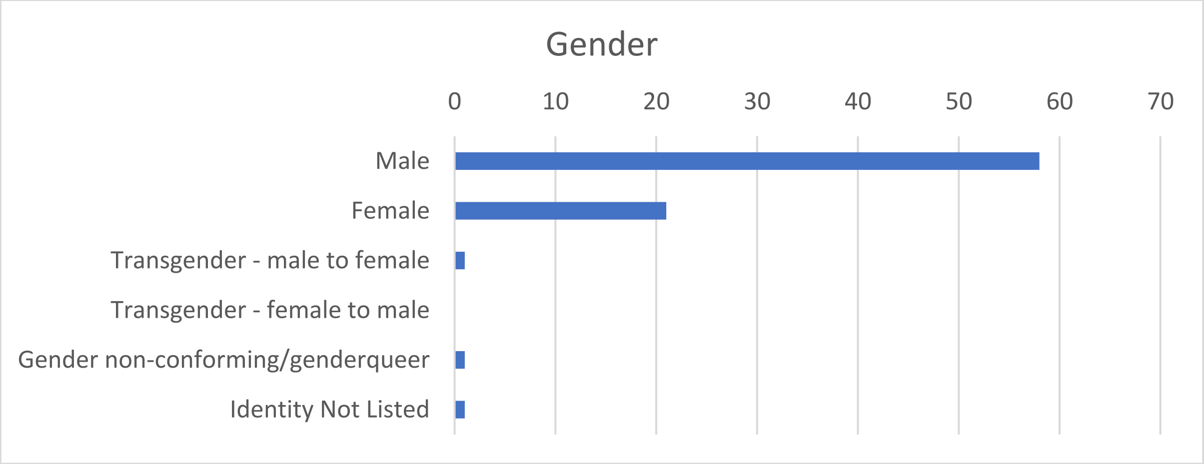

Figure 4: Count of participants by gender.

Participants were asked to share information about their sexual attraction. Most participants reported sexual attraction to men, with 79% of male participants and 86% of female participants reporting attraction to men. Only responses by people who selected "Male" or "Female" as their gender identity are included in Figure 5 because responses are suppressed for members of groups of fewer than five (5) participants.

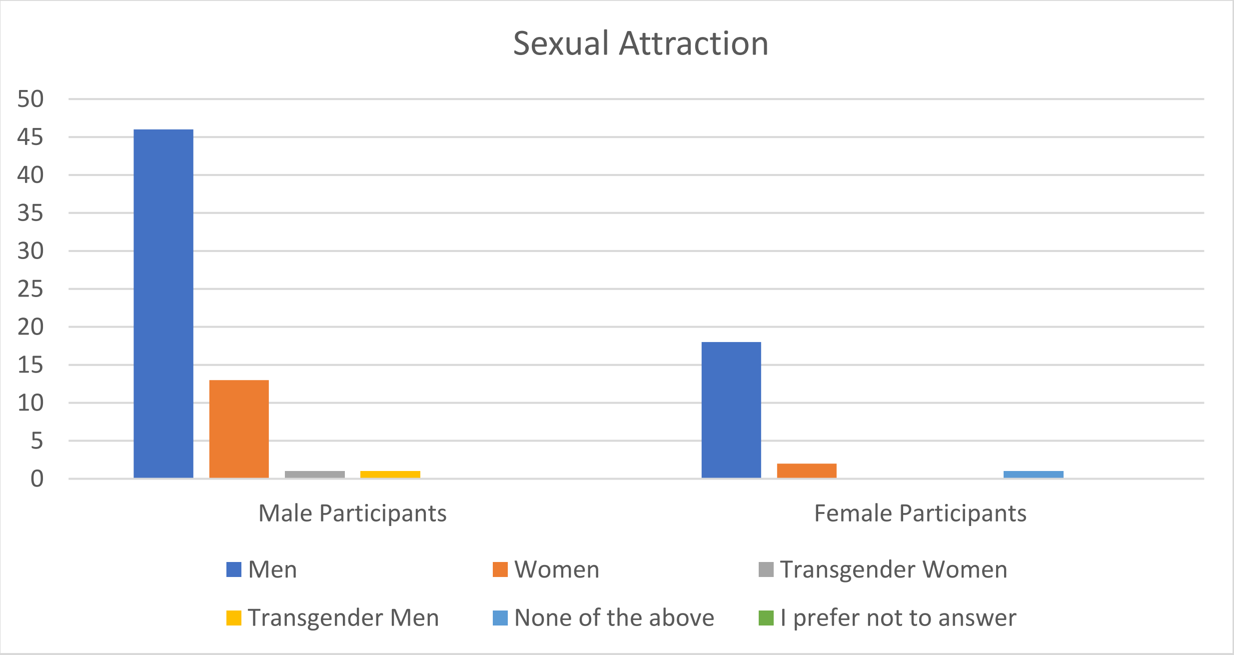

Figure 5: Sexual attraction of participants, by gender.

Among the participants who shared the number of years since receiving an HIV diagnosis, only 7% had received an HIV diagnosis within the prior two years, while over one-half have been living with HIV for over a decade.

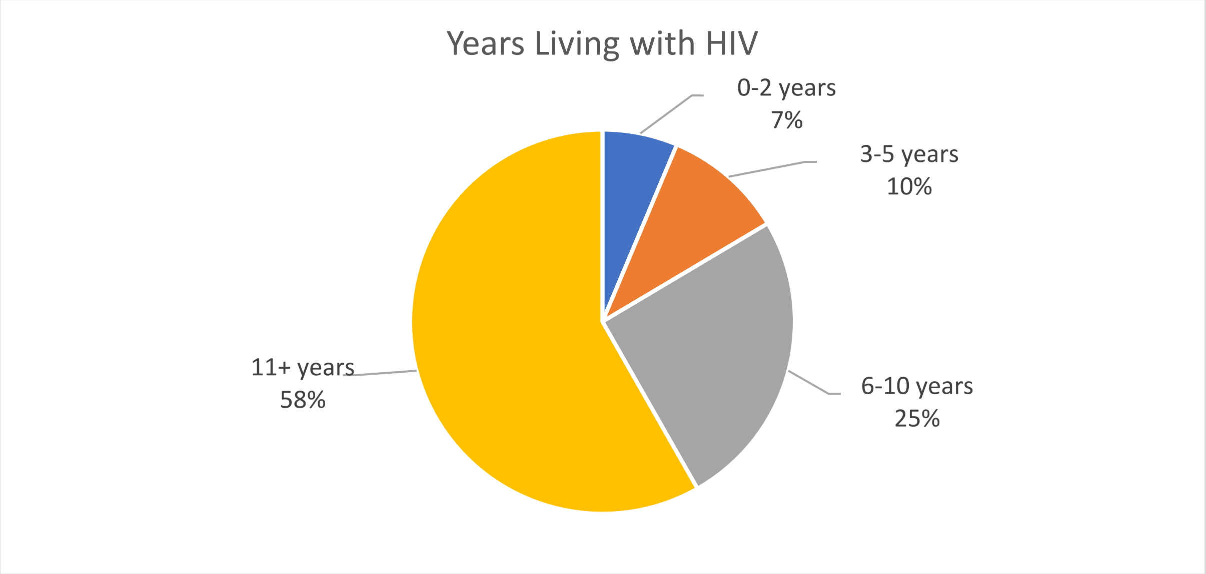

Figure 6: Number of years living with HIV.

Participants were asked to share in which county they receive most of their HIV-related healthcare. Nearly one-half of participants reported receiving care in Marion County, followed by St. Joseph County, Scott County, Lake County, and Vanderburgh County.

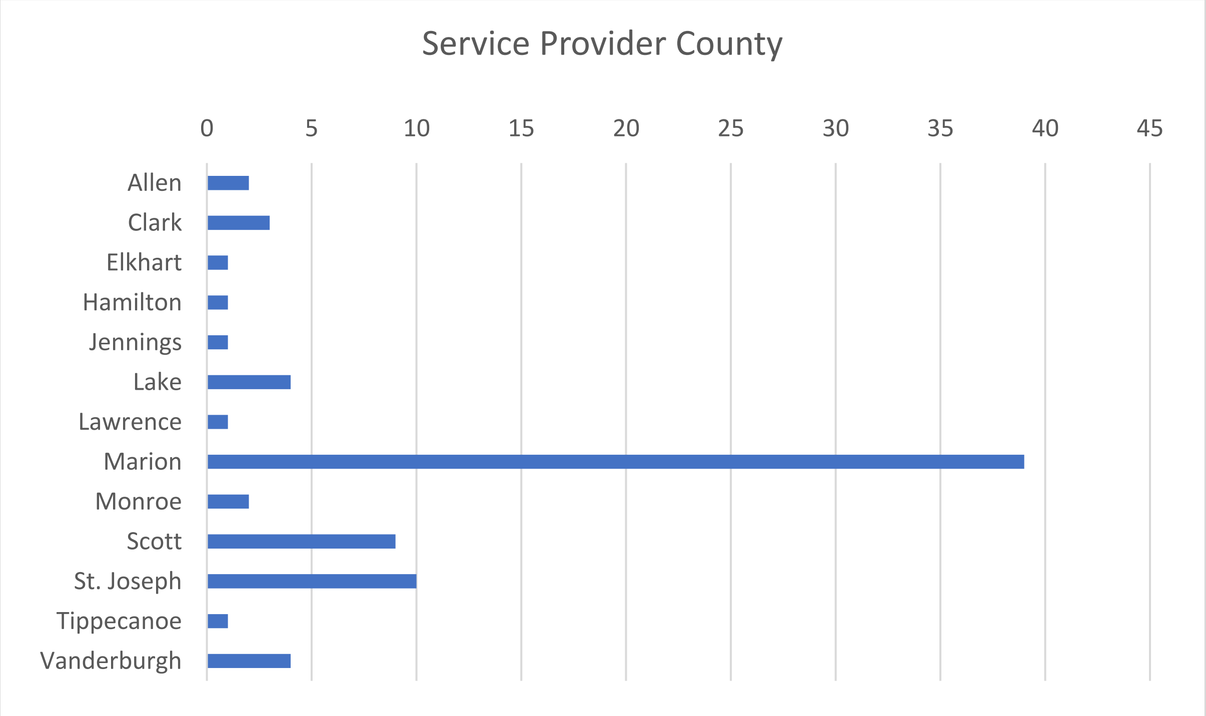

Figure 7: Service provider location (county).

In order to inform affinity group assignments and gather information specific to the priority populations, participants were asked to indicate whether they have had life experiences that may place them at a higher risk of coming into contact with HIV and/or that may impact their ability to get the services or care they need. Many participants reported experience with illegal drugs (both with and without the use of injection drugs), mental health and substance use disorder treatment, and housing instability and homelessness. Over 30% of participants reported experience with sex work and 15% of participants have experienced a co-infection of hepatitis C. Several participants shared that they are immigrants.

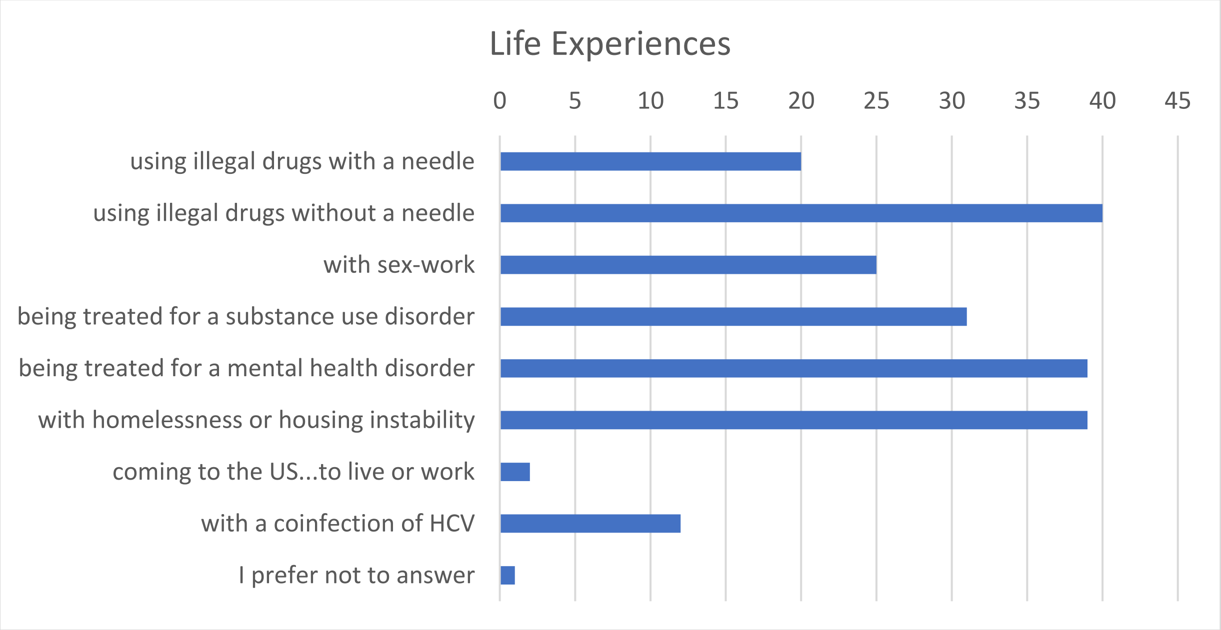

Figure 8: Life experiences of participants.

Priority Populations

The IDOH and HIV Need Assessment Advisors Group identified priority populations for the research team to target for this research. These sub-groups of people living with HIV in Indiana were chosen based on the disproportionate impact of HIV on various communities and known risk factors contributing to HIV transmission and incidence. People from every priority population participated in this research. The research team included all feedback and information shared by these individuals in the overall analysis, findings, and recommendations. However, to protect the identity of participants the research team did not generate findings, or recommendations for priority populations if less than 10 individuals from a priority population participated in the study. Additionally, in the table below the research team suppressed the number of participants if there were less than 5 participants that met an individual characteristic. A “-” indicates that the number was suppressed.

Priority Populations	# Participants
Black/African American women living with HIV	11
Heterosexual Black/African American men living with HIV	-
Black/African American MSM living with HIV	19
Young adults (18-24 yrs. old) living with HIV	-
Transgender people living with HIV	-
Latina/Hispanic females living with HIV	-
Latino/Hispanic MSM living with HIV	-
PLWH/A who have experience using illegal drugs with a needle	20
PLWH/A who have experience using illegal drugs without a needle	40
PLWH/A who have experience with a coinfection of Hepatitis C (HCV)	12
PLWH/A who have experience being treated for a mental health disorder	39
PLWH/A who have experience with homelessness or housing instability	39
PLWH/A who have experience with sex-work	25
PLWH/A who have experience being treated for a substance use disorder	31
PLWH/A who have experience coming to the US from another country to live/work.	-
PLWH/A who live in Marion County	37
PLWH/A who live in rural counties	-

Table 5: Priority population members included in the sample.

Note: Values <5 suppressed (indicated by "-").

Findings

The needs assessment yielded a great deal of information about the service needs and barriers to resources PLWH/A face in Indiana. The data collected were used to identify key findings and develop recommendations for the IDOH and partners to consider for planning and decision-making for HIV programs and services in Indiana. This information is organized into three categories:

- Healthcare Access
- Social Determinates of Health
- Prevention and Care Workforce Issues.

Healthcare Access

Respondents identified a number of barriers to accessing the care they need to support their physical and mental health, such as cost-related burdens, difficulty navigating complex systems, and limited access to mental health supports. Participant feedback regarding access to healthcare is summarized in the following:

This section refers to information that PLWH/A shared related to their medical care and their interactions with the healthcare system. Participants shared themes related to insurance, mental health care, social support and support groups, accessing medication, and access to care, services, and support that meets all the needs of PLWH/A.

Insurance

Finding: Insurance is often a barrier for PLWH/A. Insurance coverage is often complex and confusing, a major financial strain, and not comprehensive enough to cover all their needs.

It was common for participants to describe frustrations with understanding what is covered and what is not. One female participant reported that she needed help understanding her benefits and co-pay so that she could manage her care. Another participant shared that Ryan White insurance supports are good, but it is offered as a secondary insurance requiring a different primary insurance. This was confusing and a challenge to navigate.

Insurance is a major financial strain for PLWH/A. One participant described that insurance and healthcare costs forced him to file for bankruptcy before he could become eligible for the services he needed. Another pointed out that the cost of living is rising, and this makes it harder to afford insurance. A participant receiving state insurance said that even with the insurance benefits he receives, the cost of his medication is unfair given his financial situation and inability to work due to a disability.

Insurance often isn't comprehensive to the needs of PLWH/A. Multiple participants pointed out that they cannot find dentists in their areas who accept their state insurance or Medicaid. Other participants shared that the insurance they receive through their employers does not cover all their medical needs. One participant shared that he does not receive vision benefits through his employer and is forced to use free care from a school of optometry. The soonest he could get an appointment for routine eye care was four months in the future. For others, the insurance did not cover all of their lab work. One participant noted that he is now $1,000 in debt from lab work that wasn't covered.

Insurance experiences were not all bad. When insurance worked well, participants highlighted it as something they liked about their care and services. One participant told the researchers that under his new insurance, he has "no out-of-pocket costs." Another said that with insurance "accessing care is much easier."

Mental Health Services

Finding: Mental Health services are a critical need for PLWH/A. There are limited mental health providers and high turnover rates with providers when PLWH/A do find care.

Participants often shared that mental health care and services were critical, particularly with their co-occurring mental health illnesses. One participant noted that when his mental health needs are not being met, he falls out of HIV care. Another said that his mental health diagnosis, when untreated, can lead him to forget his HIV medication. Participants also noted limited access for newly diagnosed patients. One participant shared the importance of mental health support at that time saying that PLWH/A "feel very alone" when they are first diagnosed. For those without co-occurring mental health illnesses, mental health services are still critical. When asked about the personal needs that he had the hardest time meeting, one participant shared that his mental state was the biggest challenge. He said that having someone to talk to and vent to would be very helpful.

Participants reported that there were a limited number of mental health providers available, and they experienced a high turnover rate with staff. Multiple participants noted that there is a shortage of therapists available. Another participant recommended hiring more mental health professionals. He said every time he made headway with one, they would leave. Both men and women noted the challenge of starting over with a new therapist. The stress of having to retell your issues and traumas to another person prevents people from seeking mental health care after a therapist leaves.

Social Support and Support Groups

Finding: Support groups fill an important need for PLWH/A. Support groups help PLWH/A deal with stigma, help PLWH/A connect with people with similar experiences, and help people navigate care.

Data indicated the need for social and emotional support groups for PLWH/A. Participants cited a lack of support groups available to PLWH/A. One participant asked for consistently available support groups. He said, "It would be nice to be around other people (living with HIV)." One participant stated his wish to have more conversations with other people with HIV. He wished more people were not scared to be open and pointed out that stigma is the reason folks are scared. He said, "Stigma is horrible." Another participant put it simply "…getting a support group is very important. I feel isolated by it (HIV)." One woman described how she isolated herself after her diagnosis and did not have a good relationship with her doctors. She shared that after more than 10 years of self-imposed isolation, it was joining a support group that gave her the ability to engage with her doctors positively. Similar positive impacts of support groups were noted on several occasions. One participant credited support groups for bringing him out of his shell. He reported that they allowed him to make more friends.

The desire for support tailored to specific populations such as women living with HIV was cited. One woman noted that she would like support groups for women who are HIV-positive and for pregnant women or mothers who have had HIV-negative babies. Another shared that she wanted to see her local ASO offer women's group meetings and long-term survivor meetings.

Support groups helped individuals navigate the complexities of an HIV diagnosis. During one focus group, a man shared that he felt lucky to know lots of people who are older and living with HIV. They helped him with guidance on how to move forward. One woman said that what helped her deal with having HIV was that they sent her to a support group. It was this community that she credited with helping her navigate her care. Other participants stated they found out about new resources for PLWH/A through participating in support groups.

Finding: COVID-19 heavily and negatively impacted support groups.

When asked about the impact of COVID-19, one participant shared that support groups ended because everything had to go virtual. Highlighting that virtual support groups during COVID were not as well attended or engaging, one participant noted that "...we struggle with Zoom. Many of us are isolated. Some of us went back to using drugs. Staying in the house was a struggle."

Accessing Medication

Finding: Medication is often unaffordable for PLWH/A both with and without insurance.

Even with insurance, for PLWH/A with complex medical needs, the cost of the medications they need to be healthy can be unaffordable. One participant recounted that it was an insurance company, not her doctor, who decided to stop covering a medicine that was helping her manage her appetite and nausea. After her insurance coverage stopped for these medications, she could not afford them out-of-pocket and her issues with appetite and nausea returned. Like the challenge of general affordability shared in the Insurance section of these findings, many participants reported that without insurance they would not be able to afford their medication. Participants told researchers about PLWH/A that they knew who did not have access to insurance and that these people pay thousands of dollars out-of-pocket for their medication or go into debt. The reality of medication access for those without insurance was plainly stated by one participant. He said that without insurance "you can't get the medicine you need to survive."

Finding: PLWH/A favor medication delivery services and large supplies of medicine (more than 30 days of medicine) to improve medication adherence.

PLWH/A reported the utility of medication delivery services as well as large supplies of medicine as helpful for their medication adherence. Multiple participants praised their pharmacies for having a delivery service. Many participants talked about the challenge of only being able to get a 30-day supply of medicine. Without reliable transportation, getting to the pharmacy every month at the correct time was a major barrier for them. Other participants noted how this was changing for the better. One participant shared how helpful it is to him to be able to get a 90-day supply of medication. Having a 90-day supply, he reported, was due to a change in his insurance.

Care Coordination

Finding: PLWH/A need providers within a comprehensive health system that can meet their needs and coordinate their care.

PLWH/A need providers within a comprehensive health system that can meet their complex needs, or they need better care coordination across the existing systems. Participants with co-occurring diagnoses described that they were not able to be treated by the same doctor or health systems for all their needs. One woman talked about her co-occurring condition and shared that her biggest concern is that many doctors do not concern themselves with her other medical conditions. It was common to hear from participants that they changed doctors many times before finding one who could manage their needs. Another described that people are lost to care when they have to go to different places for different aspects of care.

The need for better care coordination across existing systems was also highlighted by participants. One participant shared that services are dependent on each ASO or provider. He said that this creates an environment where there is no coordination between ASOs and providers. Many participants also described negative experiences with their overall care coordination from ASOs. One shared that not all ASOs he has worked with had linkages to care. Another shared that his care coordinator wouldn't call him unless he first reached out and requested services.

Finding: PLWH/A need care within a centralized location to reduce barriers to access.

PLWH/A need care within a centralized location to reduce barriers to access. Participants expressed interest in more "one-stop shops" for PLWH/A. Places where they can get all the care they need at one time. Participants shared that some ASOs, particularly in central Indiana have this model and it is very positive. Those outside of central Indiana cited this as highly desired in their areas. When one participant heard about the number of services at one organization in central Indiana, he called it "amazing" and said, "We don't have anything like that here," referring to northwest Indiana.

PLWH/A shared a barrier that could be reduced through a centralized model. As outlined in the Social Determinates of Health section, transportation barriers are reduced if you only have to go to one location. This model also makes it easier to manage time off with employers. If you can get everything done in one place and in one day you are likely to miss fewer days of work. These improvements also likely mean that PLWH/A would miss fewer appointments, be dropped less by providers, and stay linked to care.

Social Determinants of Health

People experiencing poverty and others facing difficulty in meeting the basic needs of daily living face enormous barriers to care. Concerns over limited or inadequate access to transportation, nutritious food, safe and affordable housing, gainful employment, and supportive services were cited by many focus group participants. Participant feedback regarding unmet foundational needs that create barriers to prevention and care is summarized in the following:

Transportation

Finding: Participants struggled with acquiring transportation for medical, employment, support groups, and basic needs.

Transportation is an essential need for PLWH/A to access care and basic needs. PLWH/A in Indiana struggle with accessing transportation to reach their medical appointments and pharmacies for medication. One participant commented that “I was diagnosed in 2009, I had a hard time staying consistent with care, going to the doctor. I had lots of obstacles as far as transportation.” Participants also reported that public transit systems are not a reliable or viable option for people in Indiana. Participants commented that the bus routes are confusing and time-consuming and only beneficial for people living in downtown Indianapolis. One participant commented that “Transportation was tough because the bus system is crazy. I have to catch multiple buses to get where I’m going.” Another participant commented, “Public transit is limited so it does nothing for people living outside of downtown Indianapolis.”

Finding: Participants appreciate transportation services provided by ASOs but have cited the need for more flexibility in when those services are available.

Participants generally had favorable comments regarding transportation services provided by ASOs and insurance. Many participants were appreciative of ASOs that offered transportation services but wished for more expanded days and times when transportation is available. Limited schedules for transportation may not align with accessing medical appointments and basic needs. Focus group participants also cited a need for an increase in gas cards for people outside of service providers to assist them with transportation needs. One participant commented “(I need) gas cards, I don’t drive but I need them for people to take her to where she needs to be. I haven’t been able to find them or receive them.”

Food Access

Finding: PLWH/A reported that SNAP enrollment is complex and renewal is difficult.

Focus group participants reported overall frustrations and challenges in accessing food. Participants reported that the process to access SNAP benefits involves too much “red tape.” Many felt that the program benefits should be streamlined for PLWH/A. A participant commented that “(With) SNAP you have to do everything with a mail or fax. Can’t do it online. It’s ridiculous.” Another participant commented that “There is too much red tape. There should be an easier way for folks with HIV, it should be automatic. Auto-renewal (for SNAP benefits).”

Finding: Food banks don’t always have the food that PLWH/A need. Food banks are hard to rely on if you have complex dietary or medical needs.

Food banks are a reliable source of groceries for PLWH/A in Indiana. Participants discussed frustrations with the lack of options for diverse and nutritious food at food banks. One participant commented, “Food banks are inconsistent and that’s super hard. You risk wasting your voucher if there isn’t anything there that’s good.” Research has shown that populations who receive food from food banks prefer to receive meat, poultry, fish, and produce over less nutritional items.[13]

Finding: There is no consistent awareness among PLWH/A of the food benefits and resources available to them through services and ASOs.

The study also revealed many of the focus group participants were unaware of the services and options available to reduce food insecurity. Participants reported that they often found that their peers were unaware that their ASO had a food pantry or other services available. One participant commented that “His peers did not know about the (ASO)’s food pantry and other resources. He just learned about (program). Wants to get knowledge about what’s available to more people.”

Housing

Finding: Housing is often in unsafe areas and not safe or welcoming for queer and older people.

Many participants of the study had frustration with acquiring safe housing. Participants living in Marion County cited that housing placements are often unsafe and not appropriate for the lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA) community or older residents. Participants also reported experiences of being placed in housing that was near drug users and other illegal activities. One participant commented, “The housing I have been connected with hasn’t been livable. Not safe for queer people or older people.” Another participant stated, “Someone was murdered in my building ten feet from my bedroom window, and they don’t understand why I want to move.”

Finding: Public housing assistance is difficult to navigate and slow to materialize for PLWH/A.

Housing assistance programs have been reported to be confusing and difficult to access. Participants reported either being unaware of what programs and assistance are available or they are currently experiencing delays due to long waitlists. The process throughout Indiana to obtain housing was often described as slow, with rigid requirements causing a barrier to access. One participant commented, “Right now we are homeless. Trying to keep up with housing has been the biggest challenge for me and my husband. We are not working with anyone at the moment, (we) have never heard of any of the places that others have mentioned (at the focus group).” Another participant stated “I’ve asked for help with that through (ASO), and the people I have asked don’t

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[13] Levi, R., Schwartz, M., Campbell, E. *et al.* Nutrition standards for the charitable food system: challenges and opportunities. *BMC Public Health* 22, 495 (2022). https://doi.org/10.1186/s12889-022-12906-6

seem to have any idea about what is available. It’s on me to figure out if I’m eligible, like with section 8, etc.”

Finding: Public housing resources are generally limited.

Participants discussed limited resources for those facing housing insecurity. Participants living outside of Indianapolis cited that there are no housing options outside Indianapolis and participants have been told to seek housing in more urban areas. One participant commented, “Here are lots of people who are homeless, if you ask about housing here, they will tell you to go to Indy to find housing and you have to come up with the deposit and first month’s rent before Ryan White will kick in. There are no resources for housing.”

Employment

Finding: PLWH/A experience stigma in the workplace.

Stigma is a barrier to employment as many participants felt the need to hide their status to maintain their employment. Participants have reported negative interactions after disclosing their status at their place of employment. One participant commented, “When diagnosed, I was working at a hospital and some other nurses campaigned for me to be fired, which I was.” Another participant stated “I don’t tell people at my job that I’m positive because I’m afraid of what people would think of me. It could be my own thoughts but not sure. COVID set us back a little bit, people were leery about you coughing around them, let alone having HIV.”

Finding: PLWH/A want to work but can’t always find jobs or employers who are supportive and flexible enough to meet their unique needs.

Participants cited needing resources to support PLWH/A in accessing employment. Many focus group participants discussed a desire to work but need employers that understand the complex medical needs of PLWH/A. One participant commented, “We educate the community about HIV, but the general public is not educated on HIV. Like employers don’t understand that people with HIV have specific appointments (we) have to make. Create an optional program for employers to learn.”

Participants who aren’t working requested access to the workforce and asked for services to help PLWH/A find work in Indiana. Another participant commented, “I really think we need some sort of workforce help. Helping people in the community who are struggling to find jobs, find work. It’s not something offered…A lot of people who might be under disability are still wanting to work. They want something to do. They are not ready to retire… Also finding them a workplace that is not going to judge someone who is living with HIV working in that environment.”

Language Barriers

Finding: There is a need for resources for non-English speakers, particularly Spanish speakers.

Participants reported that within Latino/a/x communities, language is a key barrier to care. As of 2020 Latino/a/x residents account for 10.8% (N=1,282) of the total number of people living with HIV in Indiana.[14] As the Latino/a/x population grows we will need multilingual literature and services to support this population reaching viral suppression. Participants report that most of the information was provided only in English. As a result, some PLWH/A choose not to receive care or to go to another state. One participant said "In Indiana, there is a lack of resources and services available to Latinos. Latinos are looking elsewhere for care because Indiana is not appreciative of the Latino community."

Mixed Rural/Suburban Communities

Finding: PLWH/A in mixed rural/suburban counties often must travel to other more populated areas to receive services for fear of stigma and to have better access to services.

Participants living in mixed rural/urban counties often experience stigma as a barrier to care as well as stigma resulting in negative experiences in their personal and professional relationships. Participants cited having to travel to other more populated areas to receive services for fear of stigma and to have better access to services.

"If I didn't receive services in Bloomington, I would have had to go to Paoli. I chose to receive services in Bloomington because there would have been barriers and definitely stigma in other places."

Findings: Housing and medical services have also been reported to be limited within mixed rural/urban counties.

Housing and medical services have also been reported to be limited within mixed rural/urban counties. There was a limited number of participants who reported positive experiences in receiving access to housing, though participants cited that the rental assistance programs in Jefferson and Scott County have been helpful, many people in need are unaware of this service. Other participants cited that they were unable to find specialists, counselors, and housing within mixed rural/urban counties.

"Stigma around HIV/AIDS is crazy. Nobody knew what to do, no specialists, no counselors so I had to go to Louisville. Before I got with (my doctor) there was a time when I wasn't taking meds…There are lots of people who are homeless (living on couches, at friends' houses)—if you ask about housing here, they will tell you to go to Indy to find housing and you have to come up with the deposit and first month's rent

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[14] Emory University. (2022). Local Data: Indiana. AIDSVu. https://aidsvu.org/local-data/united-states/midwest/indiana/

before Ryan White will kick in. There are no resources for housing, etc. I have other health challenges I need help with."

Urban Communities

Finding: Participants living in urban counties reported positive experiences regarding the number of services available and that access to these services is easier in urban counties.

Participants living in urban counties reported positive experiences regarding the number of services available and that access to these services is easier in urban counties. Participants reported that transportation services and food assistance programs within these counties have been easy to access.

During COVID-19 participants reported that ASOs offering gift cards for food, delivery services, and basic needs was helpful during the pandemic. Others commented that having a tablet provided to them allowed them to maintain contact with others and take part in services.

"Prior to COVID, I was already experiencing social distancing because of my immune system. During the pandemic, (ASO) provided me services; delivering food, meals on wheels, they have a pantry, they sent me a tablet that allowed me to stay in contact with the real world, they offer yoga and classes/gatherings, you just Zoom in. It keeps you in contact. I would like it to continue."

HIV Prevention and Care Workforce

Focus group participants shared a full range of experiences engaging with the system of care. A core component of those experiences is often the direct interaction with frontline staff, as well as the impact of the culture, policies, and practices of their employers. The themes that were identified were: experiences and provider interactions at diagnosis, language that stigmatizes, consistency of personnel, knowledge about and access to the services available to PLWH/A, and self-advocacy. Participant feedback that may be reflective of workforce development and training needs and opportunities for the HIV prevention and care workforce is summarized in the following:

Experiences and Provider Interactions at Diagnosis

Finding: Many participants reported negative experiences with providers because of poor bedside manners, lack of support from providers, and a general sense of dismissiveness towards people living with HIV at the time of diagnosis.

PLWH/A that have a negative experience at diagnosis reported difficult transitions into care. Participants reported negative experiences with providers because of poor bedside manners, a lack of support from providers, and a sense of dismissiveness from providers. One participant recalled feeling like everything "was shoved down his throat" and he was expected to "just deal with it." Another recalled how at his diagnosis the doctor made assumptions about his sexuality and life choices that made him very uncomfortable.

In addition to these negative experiences with providers at diagnosis, many participants reported feeling like they were not supported when they were initially diagnosed, which caused confusion and trauma. One woman shared her experience as this: “It was scary. I didn’t know what was up, what was down, who to ask, what to ask. I wasn’t given any type of pamphlet…. I didn’t even know about care coordinators.” Others reported that they did not receive any resources on where to go or who to connect with following their diagnosis. Some shared that the information they received was difficult to understand. Participants offered these suggestions: “(I) would like to see clients get a checklist of ‘to-do’ at diagnosis so they know right away what they need to do and who to contact.” Focus group participants recommended that once a person is diagnosed with HIV, providers should get them the information they need right away.

Participants talked about feeling a sense of dismissiveness from providers at diagnosis. For some, it was plainly stated. One participant shared that when he was diagnosed, his provider informed him he could no longer be seen at the facility because they were “not prepared to provide care for a patient who tested positive.” One man shared that when his friends were diagnosed, they were simply handed off and not supported by their primary care doctor. When talking about their negative experiences at diagnosis, many participants expressed a need for training opportunities for providers.

Finding: PLWH/A that have positive experiences at diagnosis often transition into HIV care with fewer challenges.

Several participants reported positive experiences with providers and care staff at diagnosis. One participant said he felt “lucky” because he was immediately referred to care and his doctors handled all the bloodwork and connections to further care. He noted that his experience at diagnosis meant he didn’t have to deal with the challenges of finding care and support at the same time as dealing with his life-changing diagnosis.

Stigmatizing Language

Finding: PLWH/A have experienced providers that use offensive or stigmatizing language during care appointments.

Stigmatizing experiences shared during focus groups included assumptions made by providers about the PLWH/A, stigmatizing language being used by providers and staff at appointments, and perceived judgments about lifestyle choices when talking about care and services.

Finding: The language used in communications from providers and ASOs to describe resources and services can be stigmatizing and/or deter people from seeking care and services.

The language used in communications from ASOs and other providers to describe resources and services can be stigmatizing and/or deter people from seeking care and services. Some participants shared that the word “AIDS” is heavily associated with stigma and reported not wanting to associate with organizations that have the word "AIDS" in their name or that use "AIDS" to publicly describe available resources or services.

Participants suggested that sensitivity training for case managers was important. One participant said "I would work on training. Most case managers are not HIV positive."

Consistency of Personnel

Finding: Staff retention and consistency leads to positive experiences with HIV care and services.

Many focus group participants discussed challenges with providers, care coordinators, and mental health professionals due to the high rate of turnover of employees. One participant summed up the issue this way, "they (ASO) change case workers so often that you have no idea who is in charge of your care." As one participant noted, "The rotation of case managers and lack of communication does seem to cause a feeling of unease...Transferring of case managers without communication makes transitions difficult. Communication is really important."

Participants described feeling like they had to "start over" with a new staff member because the previous one left. One participant said, "It's a challenge to tell your story over and over again." Several participants discussed how having to repeat their stories with new providers, particularly mental health providers and case managers, often resulted in having to re-live traumas. When talking about turnover, some participants noted that they thought that their care coordinator/case manager was overloaded with clients. One said that the state mandates care coordinators carry a client load of 30 which isn't always feasible because they try and individualize care.

It is important to note that PLWH/A shared that long-term relationships with providers and care coordinators are an important positive for them. Several participants noted that they had been with their providers or care coordinators for a long time and were pleased with the care they were receiving. One participant, when asked what was going well with his care, said he has had the same general provider for 20 years and the provider has always been supportive and welcoming to him. Multiple participants shared that they liked their current care coordinator/case manager and hope that they stay in their position.

Communication and Consumer Education

Finding: PLWH/A are not aware of all the resources that they are eligible for that support their health and wellbeing.

Beyond the time of their initial diagnosis and linkage to care, participants in the focus groups often talked about being unaware of all the services and resources available to them. They reported that it wasn't until they asked for resources specifically or shared specific barriers with their care coordinators/case managers that they were told about key resources. One participant recalled that to get help “you have to ask for the help and give your exact needs...” Another participant mentioned that it wasn’t until he mentioned to his case manager that he was struggling to pay his utility bills that he found out about a program to help PLWH/A with their bills. He said “It’d be more helpful if they had it on the website what they could assist with… They need to improve communications.” Another participant shared that “They don’t tell you about the services they have until you ask. Sometimes they do laptop giveaways, and I didn’t know they could do that. They should let us know when the funding comes in so we can ask for services.” Many described not learning about important supports and resources until long after their diagnosis. Other participants recalled that she learned she was eligible for care coordination and financial assistance years after her diagnosis.

It was common for participants to tell the researchers that they learned about support or resources from another PLWH/A and not from someone at an ASO or provider. One participant recalled that if he had not been involved in a program with other PLWH/A, he would not have known there was funding for housing. He said, “We rely on other people to tell us what these resources are.” Participants recommended that ASOs and other providers be more transparent about what resources and supports are available and share more information with clients about how to access them.

Self-Advocacy

Finding: There is a disconnect between what is available and how hard PLWH/A need to work/self-advocate to get them. PLWH/A often feel forced to self-advocate with their ASOs or providers to survive.

Many participants described that if they did not ask questions or if they did not continuously reach out to their care coordinators/providers they would not have received services and care. One person described their experience with getting care at an ASO saying that “If I didn’t call and request services, they wouldn't call me… Sometimes it takes a whole week to hear back from people…” Another participant said that it was not until he asked a lot of questions that he was able to navigate and get the care he needed. Another participant lamented that his other friends living with HIV were not in the focus group to share their experiences. He described himself as a go-getter but said his friends “aren’t the same, and it’s much harder for them.”

The underlying sentiment from many PLWH/A was that being connected with an ASO or having a care coordinator is not enough to receive the resources and support you are eligible for. At times participants described ASOs or care coordinators as gatekeepers. One participant summed it up as “Some people are put in certain positions to be gatekeepers of money that’s not theirs, it’s for us clients... there are many people who are struggling with different issues and providers overlook people on purpose.”

Conclusions and Recommendations

The purpose of this study is to learn about the priorities, interests, challenges, and needs of PLWH/A through conversation and dialogue. The needs assessment yielded a great deal of information from PLWH/A about the service needs and barriers to resources that they face in Indiana.

This information can be used by anyone who manages and facilitates resources, supports, and services to make their offerings more accessible and useful. Those who work in the system of care should review the findings and reflect on their own practices and spheres of influence. What can each of us do differently now that we know a little more about the experiences that have been shared?

The data collected were used to identify the following recommendations for the IDOH and partners to consider for planning and decision-making for HIV programs and services in Indiana. Many of the recommendations are based on insights provided by focus group participants. Additionally, several recently completed assessments and plans were consulted in the development of these recommendations, including *What Matters to YOU? Needs Assessment for People Living with HIV in Indiana* (2019), *Zero is Possible – Indiana's Plan for Ending HIV and HCV* (2020), and the *Indiana HIV Integrated Prevention and Care Plan* (2022).

Healthcare Access

Regarding the findings discussed in the healthcare section, funding and programming decisions should be made to:

- Create clear and easy-to-understand information about what resources, supports, and services are available to PLWH/A from insurance providers and Managed Care Entities (MCEs) and ensure this information is shared with clients at ASOs.
- Encourage ASOs to partner with existing health insurance navigation programs to help PLWH/A better navigate their health insurance.
- Encourage and incentivize partnerships and programs that provide more mental health services to PLWH/A.
- Increase the number and type of support groups available for PLWH/A and ensure PLWH/A know about and are accessing these groups.
- Help PLWH/A pay for medication.
- Allow medication needed by PLWH/A to be filled for 90-day periods by working with providers, pharmacies, and insurance companies.
- Implement or expand home delivery of medications for PLWH/A by working with pharmacies and healthcare providers.
- Improve linkages to care when people are first diagnosed with HIV.
- Create locations of "one-stop shops" for comprehensive care and services for PLWH/A in all parts of Indiana.
- Reduce costs for people who are un/underinsured by working with health insurance navigation and enrollment in programs.

Social Determinants of Health

Regarding the findings discussed in the social determinates of health section, funding and programming decisions should be made to:

- Increase the accessibility of all HIV services and supports in languages other than English with special attention paid to Spanish language services and supports.
- Increase overall support for transportation services and expand the availability of transportation services to accommodate the needs of PLWH/A.
- Promote awareness and education about food benefits, particularly SNAP benefits, and access to food banks/food vouchers.
- Ensure that PLWH/A know about and are accessing all resources available, not just services and supports funded by HIV funding.
- Streamline enrollment and reauthorization for PLWH/A who are accessing all resources available, not just services and supports funded by HIV funding.
- Increase resources that support housing for PLWH/A including financial support for mortgage/rent and utilities.
- Expand the availability of safe and welcoming housing for PLWH/A with particular attention paid to the needs of LGBTQIA people and older adults.
- Support PLWH/A who want to work or are currently working but face challenges related to their diagnosis (e.g., side effects of medication) and stigma from employers.

HIV Prevention and Care Workforce

Regarding the findings discussed in the workforce section, funding and programming decisions should be made to:

- Increase the expertise of medical providers, especially those in private practice, at hospitals, or in community health clinics, around treating PLWH/A to reduce stigma and improve their discussion of sensitive topics, such as substance use, mental health, and sexual health.
- Create comprehensive guides about the types of HIV and social support services available to PLHW/A in Indiana. Work with ASOs to ensure they are used and accessed by PLWH/A.
- Support efforts that help retain mental health providers in Indiana.
- Create avenues for PLWH/A to better advocate for changes to care and services from their providers.
- Recruit and hire people with lived experience (HIV positive, experience utilizing the system) to serve as case managers and navigators within ASOs.
- Provide support services and warm handoffs between agencies and providers through navigation, case management, and care coordination.

Future Assessment

The 2022 Needs Assessment for PLWH/A in Indiana is an important step in centering the voices of PLWH/A to understand the needs, experiences, and barriers to service many people face, but it was not designed to be the sole instrument of assessment.

Rather, it is one avenue through which important perspectives from diverse individuals across the state were gathered, summarized, and shared.

Fortunately, there are many ways in which those with responsibility for stewardship of the available resources and supports to listen and learn from those living with HIV. State and local public health agencies have access to data and information that points to disparities in health outcomes that result from inequitable systems. Coalitions and advocacy groups, such as the Indiana Statewide Advisory Council, the ten regional ZIP Coalitions, and HMM rely on the leadership of PLWH/A and utilize a variety of practices to gather voice and input from their respective communities. ASOs and providers should collect customer/patient satisfaction and feedback on a regular, ongoing basis, and weave the use of that information into their performance management processes.

While those who facilitate the system of care should be careful and dedicated listeners to the community of PLWH/A, formal studies remain a useful tool. As the population of PLWH/A in Indiana changes and their service needs, resources, and issues accessing services change, regular assessment must be done for use in program and service planning. Listed below are recommendations for future periodic needs assessment studies:

- Conduct a formal assessment of needs every 2 – 4 years, depending on the depth, quality, and comprehensiveness of consumer input collected through funded programs and partners.
- Engage grassroots groups, community advocates, and frontline service providers in study design, participant recruitment, and developing findings and recommendations.
- Utilize a mix-methods approach, specifically a convergent parallel design, through which quantitative and qualitative data are collected simultaneously and later merged to produce results to answer the research question.
- Oversample for priority populations such as Black MSM, Black Women who have Sex with Men (WSM), People Who Inject Drugs (PWID), youth, those currently or recently incarcerated, and so forth.
- Blend random sample methodology with other approaches to collect information from hard-to-reach populations, including individuals who are not stably housed, immigrants, and those with lower reading levels than the survey may accommodate. Examples include working through grassroots organizations and administering surveys at care sites serving large shares of clients in the oversample categories.
- Increase outreach efforts for priority populations and consider non-traditional means of engaging with priority populations including through organizations and events related to arts and culture.
- Review and compare information from this and other recent needs assessments to review findings, recommendations, and assessment samples for patterns,

trends, and gaps. (i.e., Marion County EHE Needs Assessments, 2019 "What Matters to YOU?" Needs Assessment for People Living with HIV in Indiana)

There remain several priority areas of exploration that were touched upon in the current study and should continue to be investigated in future research, including:

- Specific barriers in access to services for non-majority populations, specifically people of color, females, and individuals who are non-MSM.
- Specific barriers and lived experiences of Latino/a/x and Black populations.
- Overall utilization of services by PLWH/A and priority populations to ensure equitable access and use of services and supports.
- The specific role and impact of race and racism within systems of HIV prevention and care.
- The role of family (birth or chosen) in PLWH/A seeking care or services for HIV

Appendix A: Abbreviations

Abbreviations	
ADAP	AIDS Drug Assistance Program
AIDS	Acquired Immunodeficiency Syndrome
ASO	AIDS Serving Organizations
CITI	Collaborative Institutional Training Initiative
COVID-19	Coronavirus Disease 2019
EHE	Ending the HIV Epidemic
HCV	Hepatitis C Virus
HIAP	Health Insurance Premiums and Cost-Sharing Assistance Program
HIV	Human Immunodeficiency Virus
HMM	HIV Modernization Movement Indiana
HRSA	Health Resources and Services Administration
HSP	HIV Services Program of the Indiana Department of Health
IDOH	Indiana Department of Health
IP	Internet Protocol
IRBI	Institutional Review Board
LGBTQIA	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual
MCEs	Managed Care Entities
MSM	Men who have Sex with Men
NGOs	Non-Governmental Organizations
PLWH/A	People/person living with HIV
PrEP	Pre-Exposure Prophylaxis
PWID	People Who Inject Drugs
SNAP	Supplemental Nutrition Assistance Program
SSPs	Syringe Services Programs
STD	Sexually Transmitted Diseases
SUDs	Substance Use Disorders
WSM	Women who have Sex with Men
ZIP-IN	Zero is Possible - Indiana

Appendix B: Glossary

Acquired Immunodeficiency Syndrome (AIDS): A chronic, potentially life-threatening condition caused by HIV.

AIDS Drug Assistance Program (ADAP): provides FDA-approved medications to low-income people with HIV. These people have limited or no health insurance. Grant recipients can also use ADAP funds to buy health insurance for eligible clients, and provide services that improve access to, adherence to, and monitoring of, drug treatments.[i15]

Human Immunodeficiency Virus (HIV): A disease that attacks the body's immune system. It targets CD4 cells which are meant to help the immune system fight off infection.

Health Resources and Services Administration (HRSA): A division of the U.S. Department of Health and Human Services. It is the primary federal agency for improving healthcare access to uninsured, isolated, or vulnerable individuals.

Managed Care Entities: Insurance providers that serve Medicaid and Medicare patients in Indiana.

Ryan White Program: A federal program administered by the HRSA that provides a comprehensive system of HIV medical care, support services, and medications for individuals who are low-income, underserved, or uninsured.

Section 8: One way to refer to the Housing Choice Voucher Program. This is the "federal government's major program for assisting very low-income families, the elderly, and the disabled to afford decent, safe, and sanitary housing in the private market."[16]

Stigma: "HIV stigma is negative attitudes and beliefs about people with HIV. It is the prejudice that comes with labeling an individual as part of a group that is believed to be socially unacceptable.[17]"

Viral Load: A measure of the HIV particles in a milliliter (mL) of blood.

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[15] Health Resources & Services Administration (2022, February) *Part B: AIDS Drug Assistance Program (ADAP)* https://ryanwhite.hrsa.gov/about/parts-and-initiatives/part-b-adap

[16] U.S. Department of Housing and Urban Development, *Housing Choice Vouchers Fact Sheet* https://www.hud.gov/topics/housing_choice_voucher_program_section_8

[17] Centers for Disease Control and Prevention (2021, June 1) *HIV Stigma and Discrimination* https://www.cdc.gov/hiv/basics/hiv-stigma/index.html

Appendix C: Focus Group Protocol

HIV Needs Assessment Focus Group Protocol

Thank you for being here today to share your wisdom and experience. We are eager to learn from you grateful that you've agreed to join in the conversation about what it would take to have a strong, supportive system of care for people living with HIV in Indiana.

Before we jump in, I want to share some information to be sure that everyone understands the purpose of this conversation and what the risks of participation are, and that we all know our rights and responsibilities are if we agree to participate. You each have a document called the Study Information Sheet, which explains these things in more detail, but I wanted to hit on a few of the high points.

- This focus group is being conducted on behalf of the Indiana Department of Health by a community development and evaluation organization called Community Solutions. (*Introduce staff team names/role for session*)
- The IDOH has asked for our (Community Solutions) help in gathering information from people living with HIV so that they can do a better job at working with organizations across Indiana to provide resources, supports, and services to help people living with HIV achieve and maintain optimal health and wellbeing.
- Your participation in this conversation is totally voluntary and you're not required to share any information that you don't want to share. You do not have to answer every question we pose, and you do not have to disclose any personal details that you don't want to share.
- The discussion will last about 90 minutes. Please feel free to take care of any needs you have, like visiting the restroom or getting something to eat or drink at any time. For the comfort and respect of everyone, please try to be present in the room and avoid distractions from your phone or other devices. *If virtual:* Also, for the comfort and connection of everyone, please leave on your camera throughout the discussion. If you need help figuring out how to do so, ____ can assist you through the chat function.
- The research team will be audio recording this conversation so that we are sure to capture all of the information you share. The audio recordings will never be shared with anyone outside of the research team and will be destroyed after they are transcribed.
- Participants in this discussion will receive a $30 gift card as a token of appreciation for your time and effort to be with us today. *If virtual:* We wish we could all be together in person and share a meal, but since that's not the case, we'll also be providing a $30 gift card for a meal. We will provide instructions for how to get those at the end of the discussion today.
- You may quit this conversation at any point in time. Any thoughts or ideas that you provide to the conversation prior to your exit may be included in the data analysis process, but your identity and any identifying information will never be shared outside of the research team.
- If you share personally identifying information during the course of the discussion, no information about your identity will be shared privately or publicly by the research team with anyone at any time. All participants are asked to keep confidential any personally identifying information shared, including the identities of all participants. However, you are welcome to tell anyone that you participated in this study, if you wish. You just cannot share who else participated, if you do know who others in the room are.
- There are a couple of risks to participation. One is that another participant will break confidentiality and disclose your participation to someone else. There is also the risk of stress, sadness, or other negative emotions coming up for you during the conversation. We will do our best to keep the

conversation on track and engaging. We encourage you to let us know uncomfortable or have concerns at any point in the discussion.

- By participating in this conversation, you are agreeing to provide your input for the community needs assessment we are conducting on behalf of the Indiana Department of Health and indicating your agreement to maintain the confidentiality of the people and information shared during the discussion.
- We have a limited amount of time with you all today and a number of questions for you to consider. We humbly ask that you focus your answers on the questions and topics we are asking about.
- Any questions?
    - *Answer questions*
- Ok, unless anyone would like to decline to participate, let’s get started.

BE SURE TO TURN ON THE RECORDER IF YOU HAVEN’T DONE SO ALREADY

We all know that having access to the healthcare needed to achieve and maintain viral load suppression is critical for people living with HIV. However, many people really struggle to do so for a variety of reasons. We hope to learn more about those reasons today – as well as what would help to break down those barriers.

Let's begin with introductions – please share your first name or the name by which you would like to be addressed for this conversation and why you decided to join this conversation?

1. What are a couple of words that you would use to describe what your experience has been, in terms of getting the care you want?
2. For those of you who named more positive experiences, such as __ or __, why do you think it's been relatively easy?
    a. What was helpful or supportive to you, if anything?
    b. Have you gotten any help in accessing care (formal or informal)?
        i. If so, what kinds of help has been most beneficial, and why?
3. For those of you who named more negative experiences, such as __ or __, what has made it hard?
    a. What do you think causes the difficulties or roadblocks?
    b. *For regional group discussions only:* Do you think those are challenges that a lot of people face?
    c. *For affinity group discussions only*: Many people in this discussion group identify as __. Do you think people who are living with HIV and identify as __ might have a harder time accessing care? If so, why? What are those extra challenges? What causes or creates those extra challenges?
4. What about others? What personal needs do you find you have the hardest time meeting?
5. Are there any resources you use that you think need to be made easier to access?
    a. *For affinity group discussions only*: Are there any specific types of resources or supports that people who are __ might find helpful in overcoming those obstacles?
    b. What are the gaps in services or supports? What is missing?
6. For those of you who have been living with HIV for more than 4 or 5 years, what has been the impact of Covid? Have you seen changes in resources, services, or supports? How have needs changed in the last year or two?
    a. *(If improvement/positive)* What made it easier? (policies, funding, services, etc.)
    b. *(If negative)* What has been hard about it? What caused challenges or difficulties?
7. *If it has not yet been identified/discussed:* How does the stigma still surrounding HIV impact the availability of/access to care, services and supports?
8. If you were in charge, what would you do to make it possible for everyone to get the care they want? Are there things that you think would really help people to access care?

Thank you again for your time and effort today! Please remember to keep confidential any information discussed today, as well as identifying information about those who participated. If you have any questions or concerns at any time, please contact Ashley (handout or put contact info in the chat).

Please accept this token of our appreciation. *Distribute gift cards.*

OR

We will be sending a gift card to the email address you provided for this call today shortly. If you do not receive it, please contact Eric (handout or put contact info in the chat).

Appendix D: Interest Survey

HIV Needs Assessment Interest Survey

If you prefer to take this survey in Spanish, please click here:

If you prefer to take this survey in English, please click here:

Thank you for your interest in the 2022 Needs Assessment for people living with HIV in Indiana focus groups. This research is being conducted by IU School of Medicine and Community Solutions Inc. on behalf of the Indiana Department of Health (IDOH) to help IDOH understand service needs and challenges faced by people living with HIV in Indiana so that they can improve the programs and services that they offer. If you would like to see if there is an upcoming focus group with an open spot for you, please complete this short interest survey.

All of your answers to these questions will remain confidential. You are not required to share any information that could be used to identify you (such as your name, address, or full birthdate) on this survey form if you do want to. You may or may not be selected to participate. The research team will reach out to you to let you know if there is a spot for you in an upcoming group using whatever email address or contact method you provide. If you are selected and participate in a focus group, you will receive a $30 Visa Gift Card.

1. What is your age?
    a. under 18
    b. 18-24
    c. 25-34
    d. 35-44
    e. 45-54
    f. 55-64
    g. 65-74
    h. 75 or older
2. Do you live in Indiana?
    a. Yes
    b. No
3. Has a medical or service provider ever told you that you are HIV Positive?
    a. Yes
    b. No

You may be eligible to participate in a focus group! We need to collect a little more information about you to see if there is a spot available in any of the upcoming sessions. The information you provide is confidential, and you will not be required to provide your name or to share any information that identifies you as part of this survey. Voluntarily sharing the information below with the researchers is very helpful.

4. What county do you live in?
    1. Adams
    2. Allen
    3. Bartholomew
    4. Benton
    5. Blackford
    6. Boone
    7. Brown
    8. Carroll
    9. Cass
    10. Clark
    11. Clay
    12. Clinton
    13. Crawford
    14. Daviess
    15. Dearborn
    16. Decatur
    17. De Kalb
    18. Delaware
    19. Dubois
    20. Elkhart
    21. Fayette
    22. Floyd
    23. Fountain
    24. Franklin
    25. Fulton
    26. Gibson
    27. Grant
    28. Greene
    29. Hamilton
    30. Hancock
    31. Harrison
    32. Hendricks
    33. Henry
    34. Howard
    35. Huntington
    36. Jackson
    37. Jasper
    38. Jay
    39. Jefferson
    40. Jennings
    41. Johnson
    42. Knox
    43. Kosciusko
    44. La Porte
    45. Lagrange
    46. Lake
    47. Lawrence
    48. Madison
    49. Marion
    50. Marshall
    51. Martin
    52. Miami
    53. Monroe
    54. Montgomery
    55. Morgan
    56. Newton
    57. Noble
    58. Ohio
    59. Orange
    60. Owen
    61. Parke
    62. Perry
    63. Pike
    64. Porter
    65. Posey
    66. Pulaski
    67. Putnam
    68. Randolph
    69. Ripley
    70. Rush
    71. St. Joseph
    72. Scott
    73. Shelby
    74. Spencer
    75. Starke
    76. Steuben
    77. Sullivan
    78. Switzerland
    79. Tippecanoe
    80. Tipton
    81. Union
    82. Vanderburgh
    83. Vermillion
    84. Vigo
    85. Wabash
    86. Warren
    87. Warrick
    88. Washington
    89. Wayne
    90. Wells
    91. White
    92. Whitley
    93. I prefer not to answer

5. Are you Hispanic or Latino/a/x?
    a. Yes
    b. No
    c. I prefer not to answer

6. What race or races do you identify with? Select all that apply.
    a. American Indian/Alaskan Native
    b. Asian

   c. Black/African American
   d. Native Hawaiian/Pacific Islander
   e. White/Caucasian
   f. Other (Please specify)

7. Which best describes your gender?
   a. Male
   b. Female
   c. Transgender – male to female
   d. Transgender – female to male
   e. Gender non-conforming/genderqueer
   f. An identity not listed, please specify:

8. Who are you sexually attracted to? Select all that apply.
   a. Men
   b. Women
   c. Transgender Women
   d. Transgender Men
   e. None of the above

9. In what year were you told by a medical or service provider that you have HIV? If you can't remember, please estimate.

10. What county do you receive most of your HIV/AIDS or HCV healthcare services in?
    1. Adams
    2. Allen
    3. Bartholomew
    4. Benton
    5. Blackford
    6. Boone
    7. Brown
    8. Carroll
    9. Cass
    10. Clark
    11. Clay
    12. Clinton
    13. Crawford
    14. Daviess
    15. Dearborn
    16. Decatur
    17. De Kalb
    18. Delaware
    19. Dubois
    20. Elkhart
    21. Fayette
    22. Floyd
    23. Fountain
    24. Franklin
    25. Fulton
    26. Gibson
    27. Grant
    28. Greene
    29. Hamilton
    30. Hancock
    31. Harrison
    32. Hendricks
    33. Henry
    34. Howard
    35. Huntington
    36. Jackson
    37. Jasper
    38. Jay
    39. Jefferson
    40. Jennings
    41. Johnson
    42. Knox
    43. Kosciusko
    44. La Porte
    45. Lagrange
    46. Lake
    47. Lawrence
    48. Madison
    49. Marion
    50. Marshall
    51. Martin
    52. Miami
    53. Monroe
    54. Montgomery
    55. Morgan
    56. Newton
    57. Noble
    58. Ohio
    59. Orange
    60. Owen

61. Parke
62. Perry
63. Pike
64. Porter
65. Posey
66. Pulaski
67. Putnam
68. Randolph
69. Ripley
70. Rush
71. St. Joseph
72. Scott
73. Shelby
74. Spencer
75. Starke
76. Steuben
77. Sullivan
78. Switzerland
79. Tippecanoe
80. Tipton
81. Union
82. Vanderburgh
83. Vermillion
84. Vigo
85. Wabash
86. Warren
87. Warrick
88. Washington
89. Wayne
90. Wells
91. White
92. Whitley
93. I prefer not to answer
94. I receive most of my services outside Indiana.

11. Have you ever received services at any of the following organizations?
    a. AIDS Ministries/AIDS Assist
    b. AIDS Resource Group of Evansville
    c. Aliveness Project of Northwest Indiana
    d. Almost 4 minds Logistics and Transportation INC
    e. Aspire Indiana
    f. BU Wellness Network
    g. Clark County Health Department
    h. Community Health Network – Community Infectious Disease Care
    i. Concord Center
    j. The Damien Center
    k. Eskenazi Health - Infectious Disease Clinic
    l. Indiana Legal Services
    m. IU Health LifeCare
    n. IU Health - Positive Link
    o. Meridian Health Services
    p. Matthew 25 AIDS Services Inc
    q. Meals on Wheels/Partners in Nutrition Indiana
    r. Northeast Indiana Positive Resource Connection
    s. Refresh F5/Foundations Family Medicine
    t. Scott County Health Department - One Stop Shop
    u. Step Up Inc
    v. Volunteers of America Ohio & Indiana
    w. I prefer not to answer

12. We're interested in hearing from people who have had different experiences that influence their ability to get the services and care that they need. Please indicate which experiences apply to you.
    a. I have experience using illegal drugs with a needle.
    b. I have experience using illegal drugs without a needle.

   c. I have experience with sex-work.
   d. I have experience being treated for a substance use disorder.
   e. I have experience being treated for a mental health disorder.
   f. I have experience with homelessness or housing instability.
   g. I have experience coming to the US from another country to live or work.
   h. I have experience with a coinfection of Hepatitis C (HCV).

13. What is your preferred language?
    a. English
    b. Spanish
    c. Burmese
    d. Haitian/Creole
    e. Other language?

Thank you for sharing a bit about you and your background. Now we need to get a little information so that we can follow up with you to see if there is an upcoming focus group that works for you. You are not required to submit any information that could be used to identify you (name, personal phone number, or email), but you can do so, if you prefer. Any information you share will be kept confidential by the research team. However, if you prefer to remain anonymous, you may use a different name than your given name and create/use a new email address for communicating with the research team (free email addresses can be created using platforms like Google, Outlook, or Yahoo).

If you complete the following questions, you will be entered into consideration to be a participant. You may or may not be selected to participate. The research team will follow up with you on next steps using the name and contact method you provide. If you submit this form and are invited to participate in a focus group, you can choose to withdraw at any time prior to or during the focus group.

14. What name would you like us to use for you? (You may use a name other than your own.)

15. What way do you prefer that we communicate with you about the focus group?
    a. EMAIL
    b. PHONE/TEXT

16. What is an email address we should use to communicate with you? (You may use an email address that does not identify you.)

17. What is a phone number where we can contact you?

END OF SURVEY FOR THOSE ELIGIBLE FOR THE FOCUS GROUPS

Thank you for submitting your information to be considered for a focus group. The research team will reach out to you via the method you selected in the next few weeks.

END OF THE SURVEY FOR THOSE NOT ELIGIBLE FOR THE FOCUS GROUPS

Participants must be adults living with HIV in Indiana in order to be eligible to participate in the study. Thank you for your interest.