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### Challenges Of Integrating Community Health Workers (chws) Into Health Systems To Improve Hiv Care Engagement: A Qualitative Study

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**Challenges of Integrating Community Health Workers (CHWs) into Health Systems to  
Improve HIV Care Engagement: A Qualitative Study**

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A Thesis Submitted in Candidacy for the Degree of Master of Public Health

Department of Social and Behavioral Sciences

Yale School of Public Health

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## Abstract

CHWs provide valuable support to individuals managing chronic diseases, especially populations encountering stigma, discrimination, and other services barriers. CHWs effectively improve HIV outcomes for PLWH, and innovative approaches are needed to maximize their impact on self-management by strengthening their roles as liaisons between clinical services and community resources.

Four clinical providers, five community leaders, six CHWs/supervisors in HIV services, and twelve PLWH from St. Louis, Missouri participated in semi-structured interviews, and twelve front-line health workers participated in one of two focus groups. Discussions explored employing CHWs for enhancing HIV care management and retention. Rapid qualitative analysis methods were used to analyze findings.

The study has identified six main challenges that exist at both institutional and systemic levels: (1) CHWs' limited scope of practice, (2) an unsustainable workforce, (3) obstacles in building professional relationships, (4) structural racism in healthcare, (5) dominance of the hierarchical Western European model in HIV care, and (6) inconsistent CHW program implementation efforts. Four recurring themes emerged across the identified challenges: (1) unclear and undervalued CHW roles, (2) insufficient infrastructure for a sustainable CHW workforce, (3) power dynamics within the hierarchical healthcare system, and (4) structural racism perpetuating regional racial trauma. These salient themes highlight the complexity and interdependence of the challenges in integrating CHWs and promoting equitable healthcare delivery.

Strengthening effectiveness of CHW programs requires improving integration of CHWs into the healthcare system. A systematic, collaborative, contextually appropriate and adaptive response is necessary to scale up CHW programs, ensuring quality service delivery and long-term career viability for CHWs.

## Acknowledgement

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## INTRODUCTION

Community Health Workers (CHWs) are trained members of the community who work in various capacities to provide health education, outreach, and support services to their peers and neighbors. Recognizing the crucial role CHWs play in reducing health disparities, health systems are increasingly employing CHW models as a strategy to improve access to healthcare, increase patient satisfaction, reduce healthcare cost, and improve health outcomes. [1] Experts have identified CHWs as an 'emerging healthcare workforce' and have predicted their growing prominence in chronic disease management within the US healthcare system. [2] [3] [4]

Overall, CHWs are essential in managing chronic diseases, as they bridge the gap between healthcare providers and patients, promote self-management, and address social determinants of health. In addition to their involvement in care management for chronic diseases such as hypertension, diabetes, and asthma, CHWs have been involved in Human Immunodeficiency Virus (HIV) care management since the early years of the epidemic. They focus on activities such as prevention, testing, linkage to care, retention in care, and comprehensive referrals for mental health, social and economic services, and substance use treatment. CHWs working in the HIV space possess an exceptional ability to connect with communities that are often hard to reach or underserved by traditional healthcare services.

In response to the ongoing public health concern of HIV in the US, which sees approximately 38,000 new cases nationwide each year, the US Department of Health and Human Services (DHHS) introduced the ten-year Ending the HIV Epidemic Initiative (EtHE) in 2019, with the goal of reducing new HIV infections by 90% by 2030. Identified as one of the seven priority states, Missouri carries a significant HIV burden and lags behind other states in progress along the HIV care continuum, particularly in care retention. Adherence to antiretroviral therapy

(ART) is crucial for achieving viral suppression, which improves health outcomes for individuals living with HIV and reduces the risk of transmission.

Improving personal contact, whether through patient navigators, peer support, or trained interventionists, can increase retention in HIV care. As an evidence-based strategy for enhancing personal contact with hard-to-reach clients in chronic disease management and care activities, CHWs are valued for their intimate knowledge of the populations and communities they serve, acting as bridges between the community and healthcare services. [5] CHWs are uniquely positioned to assist marginalized populations in navigating the social and structural barriers for accessing healthcare services due to the lived experiences they share with their clients. However, challenges in implementation can lead to inconsistencies in the quality of CHWs' service delivery, ultimately preventing them from maximizing their potential and impact on clients and the community.

Research indicates that integrating CHWs within the healthcare system is vital for program effectiveness. [2-10] However, there is no agreed upon process for CHW integration, nor guidance on how to achieve it. A significant question at hand is how to balance CHWs' community and clinic-facing priorities during integration, as the process of bridging two sectors—with distinct cultures, priorities, and procedures—could potentially present challenges for both CHWs and the healthcare context they are embedded in. [3]

A qualitative study allows for a deeper understanding of the complex and interrelated systems-level factors that may be associated with CHW integration, and thus offers the potential for unique insights into the field through two unique aims. This research aims to understand the critical factors for effective CHW integration in HIV care in St. Louis, Missouri, a city with the highest rates of new diagnoses and people living with HIV (PLWH) in one of the seven priority



states identified by EtHE. Additionally, this research aims to understand the challenges associated with employing CHWs and to explore opportunities for enhancing St. Louis's CHW program implementation, optimizing CHW engagement, and ultimately improving health service delivery for the most vulnerable populations.

The extant literature on CHW programs offers insights into the key factors that contribute to CHW integration in both community and clinical contexts. This research further examines CHW implementation in the context of St. Louis, a major metropolitan area that bears a high HIV burden and exhibits significant intersectional disparities. With a marked history of structural racism and economic inequities, St. Louis epitomizes many urban areas in America with underserved populations and communities facing stigma, discrimination, and barriers to services. In addition to exploring CHW integration in HIV care in St. Louis, the study's findings can provide insights into developing implementation strategies for a CHW-centered approach to HIV/AIDS outreach and care across the nation.

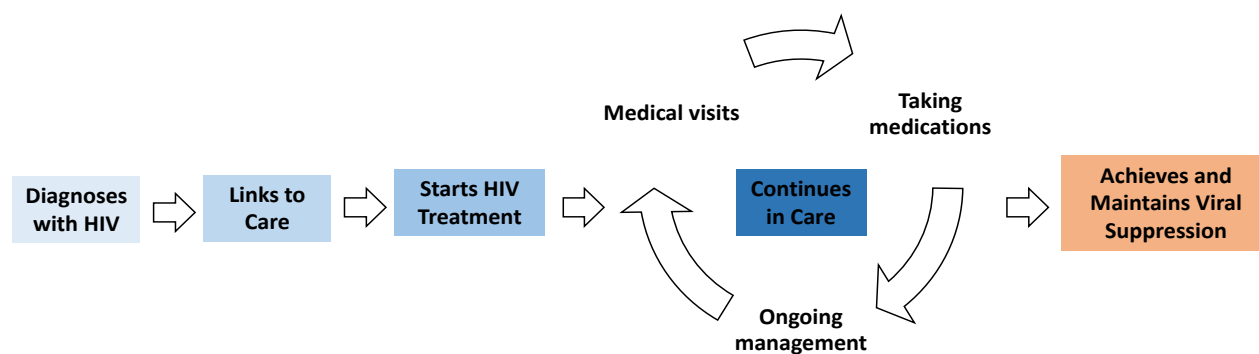
## BACKGROUND

### The state of the HIV epidemic in Missouri

The Human Immunodeficiency Virus (HIV) remains a significant public health concern, with approximately 38,000 new diagnoses in the United States annually. [11] [12] In response, the US Department of Health and Human Services (DHHS) launched the ten-year Ending the HIV Epidemic Initiative (EtHE) in 2019, aiming to reduce new HIV infections by 90% by 2030. [13] Areas with high HIV prevalence play a significant role in the overall national HIV epidemic. Phase one of the EtHE identified fifty city/county-level and seven priority state-level jurisdictions with substantial HIV burdens. The initiative's "four pillars" include 1) Diagnosis, 2) Treatment, 3) Prevention, and 4) Response. By focusing on these strategies, the EtHE initiative aims to reduce the incidence of HIV infections and improve health outcomes people living with HIV (PLWH).

Missouri is one of the seven priority states bearing a significant HIV burden. [14] By the end of 2021, there were 13,856 people living with diagnosed HIV in Missouri, where an estimated 559 new HIV diagnoses were reported in the same year. [15] Consistent with the national pattern, the HIV epidemic in Missouri disproportionately affects minority populations with intersectional social identities. Among the newly diagnosed PLWHs in 2021, the rate of new HIV cases was 7.4 times as high among males and 7.7 times as high among females who were Blacks/African Americans compared to whites. [16] Men who have sex with men (MSM) continue to account for the majority of new HIV diagnoses, while heterosexual contact was the primary mode of transmission among women. [16] In 2021, there were 260 newly diagnosed cases of HIV among MSM, with 49% of the cases attributed to Blacks/African Americans. [16]

**Figure 1** below illustrates the HIV care continuum, which comprises a series of steps that outline the progression of PLWH from their initial diagnosis to achieving viral suppression. [17] Engagement across the HIV care continuum is crucial for PLWHs to initiate and maintain adherence to antiretroviral therapy (ART), an essential aspect of HIV treatment and management. Care retention generally refers to the continued engagement with medical services at a healthcare institution after the initial linkage. Formal definitions and metrics often involve mandatory follow-up at specified intervals to determine retention, which is usually based on either missed appointments or attended medical visits at regular intervals. Adherence to ART is a key factor for PLWHs in achieving viral suppression, a state where their viral load falls below a detectable level (<200 copies/mL). PLWH who are virally suppressed experience longer life expectancy, improved quality of life, slowed illness progression, and a significantly reduced risk of transmitting the virus to HIV-negative partners. [18]



**Figure 1.** HIV care continuum

Missouri's progress along the HIV care continuum falls short of the UNAIDS 90/90/90 target, which aims for 90% PLWH to be aware of their status, 90% of those who are aware of their status to be on ART, and 90% of those on ART to achieve viral suppression. [19] In 2020, 18.1% of newly diagnosed HIV cases in Missouri were classified as late diagnoses (i.e., with an

AIDS diagnosis within three months of initial HIV diagnosis), while 79.4 % of newly diagnosed individuals were linked to care (i.e., had a visit with an HIV health care provider) within one month. In the same year, only 75.9% of PLWH in Missouri received medical care and underwent testing (i.e., at least one CD4 count or HIV viral load test), and 64.8% achieved viral suppression. [20]

Missouri's historically marginalized communities experience significant disparities in HIV care engagement. [16] According to data published by state health department in 2021, Black PLWH had the lowest rates of linkage to care within 90 days at 86%, while Hispanic PLWH had the lowest rates of retention in care at 36%.<sup>1</sup> [16] Furthermore, both Black and Hispanic PLWH had lower rates of viral suppression, at 51% and 46% respectively, compared to White PLWH at 57%. [16]

Gender disparities among PLWH in Missouri are also evident, with women consistently having lower rates of care retention and viral suppression compared to men. [16] There are also significant disparities across age, with 13-24 years old having a rate of being linked to care within 30 days that is more than 10% lower than those aged 25-45 and 7% lower than those aged 45 and above. [16]

Missouri Department of Health and Senior Services, Bureau of HIV, STD, and Hepatitis is partnering with local health departments, community-based organizations (CBOs), health care providers, and other stakeholders to end the HIV epidemic in the state. [14] These efforts aim to increase HIV testing and awareness of one's status, improve access to ART and maintain viral

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<sup>1</sup> From Missouri DHSS's HIV care continuum report, linkage to care within 90 days pertains to the attainment of a CD4 or viral load lab result within three months of diagnosis, while retention in care is defined as having at least two CD4 or viral load lab results within a year that were obtained at intervals of at least three months.

suppression, reduce new infections through pre-exposure prophylaxis (PrEP), and enhance capacity to identify and respond to HIV transmission clusters and outbreaks.[21]

### **HIV burden in St. Louis and the city's history of HIV activities**

Active cases of HIV disproportionately occur in Missouri's two major metropolitan areas, St. Louis and Kansas City, where the highest rates of new diagnoses and PLWH are found. As of the end of 2021, St. Louis City had the highest rate of newly diagnosed individuals who remained classified as HIV cases, at 30.6 per 100,000, and the highest rate of those classified as stage 3 (AIDS) cases, at 5.3 per 100,000. [15]

Despite St. Louis having a high 89% linkage to care rate within 90 days, only 45% of PLWH in St. Louis were retained in care in 2021, and only 53% achieved viral suppression.[16] Similar to the state, St. Louis residents living with HIV from historically marginalized communities experience disparities in engagement along the care continuum. In 2021, women had lower retention and viral suppression rates than men, and Black and Hispanic PLWH had the lowest linkage to care rates of any racial group. Additionally, PLWH aged 13-24 had substantially lower rates of retention compared to those aged 25 and older, and PLWH who use injection drugs (IDU) had the lowest retention and viral suppression rates compared to groups at-risk of transmission via heterosexual contact (HRH) and men who have sex with men (MSM). [16]

St. Louis has a long history of combating the HIV epidemic, with numerous organizations and initiatives playing a key role in a multifaceted effort focusing on prevention, education, testing, treatment, and support for affected individuals and families. In the early 1980s, CBOs such as the St. Louis Effort for AIDS (EFA) and Doorways emerged in response to the first reported cases of HIV/AIDS in the city. EFA, founded in 1985, aimed to provide

comprehensive services and prevention education, while Doorways, established in 1988, focused on providing housing and related support to PLWH. [22] [23]

As the HIV epidemic continued to grow, St. Louis expanded its HIV medical care and support services, including medical case management, counseling, housing assistance, and youth programs. Several notable programs and organizations in the St. Louis region provide these services to improve health outcomes for PLWH, including Project ARK, Places for People, Vivent Health, Williams and Associates, and many others. [24] Striving to enhance the quality of life for individuals living with HIV, many organizations focus on addressing the specific needs of underserved minority populations who are at the highest risk of receiving a diagnosis and falling out of care retention.

Various governmental agencies have also played a critical role in combating the HIV epidemic in St. Louis. The St. Louis County Department of Public Health operates a clinic that provides free HIV testing and counseling services, as well as medical care and case management for individuals living with HIV/AIDS. [25] The St. Louis City Department of Health also provides free HIV testing and prevention education through its STI/HIV Prevention Program. Both agencies have collaborated with CBOs to implement prevention and care strategies. For instance, they work with CBOs to administer the Ryan White HIV/AIDS Program (RWHAP), which provides funding for HIV medical care and support services to low-income PLWH. [26]

In St. Louis, a collaborative environment exists among local organizations, notably exemplified by the St. Louis HIV Health Services Planning Council, which plays a crucial role within the Ryan White HIV/AIDS Program (RWHAP) Part A. RWHAP is a federal program administered under HRSA, providing funds to Eligible Metropolitan Areas (EMA) and Transitional Grant Areas (TGAs) that are most affected by the HIV epidemic. Under Part A, St.

Louis is categorized as a TGA and the Planning Council was created to plan, coordinate, and prioritize HIV-related healthcare and support services within St. Louis. Working in partnership with the Ryan White Part A grantee to distribute federal funds from the RWHAP, the Planning Council conducts needs assessments, sets priorities for funding allocation, distributes funds among the prioritized service categories, develops a comprehensive plan for HIV healthcare service delivery, improves care coordination, and evaluates the effectiveness of funded service providers. Through the collaborative involvement of community members, particularly people living with HIV/AIDS, service providers, and other stakeholders, the Planning Council ensures that their perspectives and needs are considered during the decision-making process, creating a more responsive, equitable, and effective HIV healthcare system in the St. Louis region. [27]

### **Existing strategies for promoting engagement along the HIV care continuum**

Over the years, numerous interventions have been developed and implemented to promote engagement along the HIV care continuum, drawing on insights from implementation science to optimize the adoption, adaptation, and sustainability of evidence-based patient engagement strategies within diverse HIV care contexts. Various strategies and care models have demonstrated efficacy, including multidisciplinary team-based care, integrated care models, and electronic health (E-health) communication.

Multidisciplinary team-based care involves a diverse group of medical and case management personnel, comprising prescribers, nurses, social workers, and CHWs. [28] Such teams offer comprehensive support to patients, addressing their medical needs, external barriers to care, and facilitating patient engagement in chronic disease management. [29] [30] A randomized controlled trial conducted in St. Louis demonstrated the efficacy of this approach. Patients assigned to multidisciplinary teams, including a peer navigator, community HIV nurse,

and intensive case management staff, exhibited higher rates of viral suppression, higher CD4 counts, and better overall perceptions of their health. [31] The intervention employed flex funds to alleviate some of the financial stressors associated with accessing care, such as transportation and rent assistance, highlighting the importance of such support. [31] [32] [33] [34]

In addition to the multidisciplinary, team-based approaches, integrated care models have also shown to be an effective intervention. [34] Combining HIV care with other healthcare services such as mental health care, substance use treatment, or reproductive health services, integrated care offers comprehensive care in a single location, and can improve engagement along the HIV care continuum by reducing the need for patients to navigate multiple providers and systems. [31] [32] [33] [34] As PLWH are disproportionately affected by comorbidities, providing integrated care can improve patient outcomes by addressing the interrelated health issues that many PLWH face. The demonstrated efficacy of multidisciplinary team-based and integrated care models suggests that addressing non-HIV related concerns is critical for facilitating progression along the HIV care continuum. Implementing these evidence-based strategies across HIV-providers can help bridge the gaps in the continuum, ultimately improving health outcomes for PLWH.

The COVID-19 pandemic has presented unprecedented challenges in healthcare service delivery to individuals with HIV. [35] [36] As a result, electronic health communication (E-Health) approaches such as Telehealth and mHealth have become popular among clients to compensate for the reduced face-to-face interactions. E-health communication has proven effective in facilitating HIV care engagement through remote consultations, medication reminders, appointment scheduling, and adherence support. For example, text-based appointment reminders have been shown to improve medication adherence and reduce missed visits. [37]



These technologies can help reach individuals who may face barriers to accessing traditional healthcare services, such as those experiencing transportation obstacles, rural PLWH with limited access to local HIV services, and PLWH who may be hesitant to enter a clinic due to stigma. [38]

Notwithstanding the apparent advantages of e-health, the utilization of technology among PLWH is significantly influenced by social determinants of health, and broad implementation could potentially exacerbate existing disparities. [38] [39] Elderly individuals, Black populations, and PLWH on Medicaid exhibit a lower propensity to engage with telemedicine, an E-health modality entailing provider consultations via phone or video calls. Additionally, PLWH residing above the federal poverty level (FPL) demonstrate a higher likelihood of employing the internet to access health information. [40] A study evaluating technology usage among St. Louis PLWH discovered that the most prevalent users were White, male, employed individuals with higher education and income levels. [39] A more recent investigation revealed that approximately 89% of PLWH utilize cell phones with text messaging capabilities, indicating that E-health communication strategies accounting for disparities in technology usage could be advantageous in St. Louis clinics. [38]

Missouri's EtHE plan encompasses the exploration of telehealth and electronic reminders as potential interventions. The implementation of these strategies in a clinic catering to rural Missourians living with HIV proved successful during the pandemic. Given this evidence, it is essential to further investigate the impact of existing E-health interventions on the progression along the HIV care continuum among Missourians living with HIV.

## **Overview of the CHW intervention**

## **CHW intervention in chronic disease management**

Community Health Workers (CHWs) serve as an evidence-based approach to enhance personal contact with hard-to-reach clients in chronic disease management and care activities, while also addressing social and structural barriers to care. [2] In the US, CHW interventions have mainly been investigated in the context of chronic disease management and healthcare service utilization. Multiple studies have demonstrated the effectiveness of CHW interventions in managing various chronic conditions, such as diabetes, hypertension, and cardiovascular disease. [2] [41] [42] These studies have shown improved glycemic control, self-care behaviors, reduced blood pressure, and decreased hospital readmissions among patients who participated in CHW-led program.

CHWs often work in interdisciplinary teams, collaborating with healthcare providers and serving as liaisons between patients and providers to coordinate care and bridge gaps in communication. [43] Also central to CHW interventions are the deployment of trained CHWs, who may function as outreach workers, peer counselors, and educators. Through home visits, group education sessions, and one-on-one coaching and other services, CHWs provide personalized support tailored to the needs of the patients. [44] This effectively empowers patients to better manage complex chronic conditions through self-care and strengthened connections to the medical care system. [31] [45] [46] Together, by helping patients address social and economic factors that impact their health, overcome barriers to accessing care, navigate the healthcare system, understand their diagnoses, and adhere to treatment plans, CHWs address social determinants of health and facilitate patient navigation, ultimately improving access to care and ensuring care continuity.

CHWs are particularly well-suited to address the unique challenges faced by historically marginalized populations in accessing healthcare services. The mechanism through which CHWs achieve these positive outcomes can be attributed to several factors. Sometimes CHWs share cultural, linguistic, and socioeconomic backgrounds with the clients they serve, which can build trust, facilitate communication, and provide culturally sensitive care. [47] [48] The shared lived experiences between CHWs and clients serve as a foundation for developing trusting relationships and providing tailored support. This rapport enables CHWs to identify and address social determinants of health that may hinder clients from seeking or receiving appropriate care, thereby facilitating patient engagement in self-management, enhancing adherence to treatment plans and lifestyles, leading to improved health outcomes.

### **Integrating Community-based Participatory Research (CBPR), Implementation Science (IS), and Participatory Planning for Effective HIV/AIDS Interventions**

The fight against HIV/AIDS necessitates the implementation of collaborative, evidence-based, and context-specific interventions to address the unique challenges encountered by diverse communities. The integration of Community-Based Participatory Research (CBPR), Implementation Science (IS), and participatory planning has the potential to facilitate the development and implementation of HIV/AIDS interventions that are effective, sustainable, and culturally appropriate.

Prioritizing the involvement of both researchers and community members in the research process, CBPR aims to enhance the community's capacity, foster community-driven change, and respond to health disparities. [49] This methodology supports the integration of community knowledge, cultural practices, and ethical values into the research methodology, thereby ensuring that interventions are relevant and adaptive to the contexts of the intended communities.

CBPR has been utilized in the field of HIV/AIDS to create prevention and treatment interventions that address the distinct barriers faced by marginalized communities, such as individuals who engage in sex work, people who inject drugs, and men who have sex with men. [50] By promoting active involvement and empowerment of the community, CBPR leads to increased accountability and sustainability in the process of intervention development.

The field of IS applies to the study of methodologies and strategies that facilitate the integration of evidence-based interventions into real-life practices. [51] In the context of the HIV/AIDS epidemic, the IS helps identify and address barriers that hinder the adoption, adaptation, and expansion of interventions. The integration of IS principles and the CBPR allows academics and professionals to collaboratively formulate regional strategies for implementing evidence-based HIV/AIDS interventions. CBPR prioritizes the intervention's cultural appropriateness and relevance, while IS focuses on navigating challenges and optimizing the intervention's intended impact in real-world settings. [52]

Furthermore, the decision-making methodology participatory planning entails the active involvement and empowerment of local communities in the process of planning the HIV/AIDS interventions. By working on the design and implementation of interventions in collaboration with affected communities, this approach leads to greater relevance, acceptability, and effectiveness of the interventions. [53] The inclusion of participatory planning in the design and implementation of HIV/AIDS interventions has the potential to foster a sense of community ownership and promote the long-term program sustainability. [54] [55] In addition, this methodology can effectively address the social determinants of health that are affecting the new HIV/AIDS diagnoses and care management.

By combining the respective strengths of each method, the integration of CBPR, IS, and participatory planning therefore assist the development and execution of successful interventions for combating the HIV epidemic, leading to successful implementation of interventions that are culturally appropriate, empirically grounded, and tailored to the specific needs of the affected communities.

## METHOD

This study was conducted as part of the St. Louis Enhancing Engagement and Retention in HIV/AIDS Care (STEER) Project. Project STEER aimed to develop novel implementation strategies to end the HIV epidemic in St. Louis, Missouri, by addressing the gaps in access, care retention, and viral suppression outcomes among hard-to-reach populations. The project's partnership includes the Center for Interdisciplinary Research on AIDS (CIRA) at Yale University, the Brown School of Social Work at Washington University in St. Louis (WUSTL), Vivent Health (an HIV/AIDS service community-based organization serving the St. Louis PLWH community), and the Bureau of STDs, HIV, and Hepatitis in Missouri.

### Study Population

This study employed a qualitative research design to gather insights from 39 stakeholders involved in HIV care both within and outside of Missouri. Five key stakeholder groups were approached for primary data collection: (1) key informant interviews with CHWs/supervisors drawn from a previous multisite Health Resources Service Administration (HRSA)-funded CHW pilot intervention (three CHWs and three supervisors); (2) key informant interviews with community leaders who interact with PLWH in St. Louis (five participants); (3) key informant interviews with clinical providers who interact with PLWH in St. Louis (four clinicians); (4) two focus groups with frontline lay health workers who interact with PLWH in St. Louis (twelve participants total); and (5) semi-structured interviews with PLWH from St. Louis (twelve PLWH).

## **Recruitment**

CHWs/supervisors who participated in the previous multisite HRSA-funded CHW pilot project were recruited through direct outreach via email with the assistance of the PI from the previous study. Community leaders and clinical providers engaging with PLWH were recruited via email referrals and direct outreach through the Fast Track St. Louis Steering Committee, a group of experts and community leaders involved in the HIV community in St. Louis, Missouri and Vivent Health. Frontline health workers engaging with PLWH in St. Louis were recruited in partnership with Vivent and the WUSTL HIV/AIDS clinic via email outreach to those staff. PLWH were recruited using outreach flyers distributed by Vivent. Once potential participants contacted the research team through the contact information provided on the flyer (email and/or telephone), they were screened for eligibility and provided with additional information about the study, the interview process, and informed consent procedures. Those who met the eligibility criteria and agreed to participate were then scheduled for interviews.

## **Participant Demographics**

Of the six CHWs/Supervisors who participated in the interviews, all were African American, with four identifying as cisgender female and two as cisgender male. The average age of participants was 54 years old. Half of them had worked in their role for over 5 years. All participants were employed by organizations receiving Ryan White funding, and these organizations had an average size of 28 employees.

Of the five community leader participants who participated in the interviews, four were African American, with three identifying as cisgender female and two as cisgender male. The average age of the community leader participants was 40 years old. 60% of the participants had

worked in their role for over five years. All participants were employed by organizations receiving Ryan White funding, and these organizations had an average size of 61 employees.

Of the four clinical providers who participated in interviews, three were non-Hispanic White and one was African American, with one identifying as cisgender female, two as cisgender male, and one as gender non-conforming. The clinicians were two nurse practitioners, one surgeon, and one professor of medicine. The average age of the clinicians was 53 years old. All but one had worked in their role for more than five years. Half of these clinicians were employed by organizations receiving Ryan White funding, and these organizations had an average size of 200 employees.

Of the twelve front-line health workers who participated in the focus group, eight were African American and four were non-Hispanic White, with half identifying as cisgender female, one as transgender female, three as cisgender male, and one as gender non-conforming. The average age of the focus group participants was 43 years old. Job titles for the participants included early intervention services specialist, clinic case manager, linkage to care coordinator, team supervisor, prevention supervisor, health navigator, health coach, outreach specialist, engagement specialist, and community outreach worker. Four of the participants had worked in their role for less than a year, six participants between one and five years, and two participants for more than five years. All participants were employed by organizations receiving Ryan White funding, and these organizations had an average size of 146 employees.

Of the twelve PLWH who participated in interviews, eleven were African American and one was non-Hispanic White, with seven identifying as cisgender female, one as transgender female, and four as cisgender male. The average age of the PLWH participants was 52 years old.



## **Data Collection**

Interviews and focus groups ranged from 60 to 90 minutes and were conducted virtually over Zoom. A trained interviewer/facilitator led the interviews and focus groups, while a note-taker documented the discussions. Open-ended interview and focus group guides were employed to offer general guidance for the conversations, ensuring that key topics were addressed while simultaneously preserving the participants' freedom to express their thoughts and opinions on matters they considered significant. Baseline questions covered topics such as experiences with peer navigators, barriers and facilitators for HIV care management, and strengths, challenges, and suggestions for employing CHWs in St. Louis.

During the interviews and focus groups, the interviewer recorded the sessions using Zoom's meeting recording feature and a notetaker took notes on a computer. Upon completion of the interview or focus group, participants were asked to complete a brief anonymous demographic questionnaire electronically via Qualtrics. Participants were offered compensation of \$60 upon the completion of the interview/focus group and questionnaire, either through a gift card or an e-gift card.

After the interview/focus group, recorded audio files were uploaded to a secure server and shared with Transcribeme, a company specializing in HIPAA-compliant transcription. Transcripts were reviewed and de-identified as necessary. The transcripts were stored on a password-protected computer and a secure server.

## **Data Analysis**

After reading the transcripts and reviewing field notes, the findings from interviews and focus groups were analyzed deductively using a rapid qualitative analysis approach. [56] Key

findings from each interview and focus group were described in a Rapid Assessment Procedure (RAP) sheet. [57] The RAP sheet included notes on key observations, quotes, and emerging themes from interviews and focus groups. The RAP sheets were compiled into a matrix, where summaries were synthesized within and across stakeholder groups to identify key patterns and insights for subsequent analysis. All summaries were cross-checked by a team member who did not participate in the interview. Community members serving on Project STEER's planning team supported data analysis to enhance rigor, offer coding insights and to minimize bias.

### **Ethical Consideration**

The study adhered to ethical guidelines for qualitative research. Informed consent was obtained from all participants, and confidentiality was maintained throughout the study. The Yale University Institutional Review Board determined that the study posed minimal risk to participants and met the criteria for exemption.

## FINDINGS

The participants in our study, including community leaders, clinical providers, and front-line health workers who engage with PLWH in St. Louis, possessed a broad range of experience with peer navigators and CHWs in the context of HIV care engagement. Most of the participants had familiarity with the CHW intervention program, with some having previous experience as CHWs. This section presents the findings on the challenges encountered in integrating CHWs into the health system. The results are presented in tables, and the key themes are subjected to a thorough analysis with supported quotes from interviews and focus group.

### **Participants identified institutional and systemic challenges for integrating CHWs into the health system**

In the study, community leaders, front-line health workers, and clinical providers who engage with PLWH in St. Louis identified institutional and systemic challenges related to the utilization of CHWs for HIV care in the context of St. Louis or a broader implementation environment. The six main challenges are summarized in **Table 1**. The institutional challenges included constraints on the CHW's scope of practice, an unsustainable CHW workforce, and obstacles in establishing professional relationships with other members of the care team. Specifically, the participants reported confusion regarding job titles for various CHW-like positions, restrictions imposed by grant-defined roles and guidelines, insufficient salaries, constraints on recruitment, limited opportunities for professional development, a lack of support and resources, inadequate CHW representation in leadership and decision-making positions, a professional hierarchy within healthcare institutions, and silos within the care team that led to a lack of communication, interaction, and transparency among care team members and CHWs.

The systemic challenges associated with the utilization of CHWs for HIV care include pervasive structural racism in the healthcare system, the dominance of the hierarchical Western European model in HIV/AIDS care, and inconsistent momentum and consistency in CHW program implementation efforts. Participants emphasized challenges that encompass a wide range of concerns related to historical and ongoing racialized trauma, workplace cultures that marginalize minority groups, stigma and discrimination, power differentials, siloed organizations, and a lack of prioritization for St. Louis by external stakeholders. Additionally, the COVID-19 pandemic has imposed new constraints on CHW roles and activities, exacerbating existing challenges and hindering progress in implementing effective CHW programs.

As shown in **Table 2**, four recurring themes emerged across the challenges identified by the participants: 1) The roles of CHWs are not well-understood by care team members and are often undervalued, 2) The health system lacks the necessary infrastructure to properly support a sustainable CHW workforce, 3) The power dynamics within the hierarchical structure of the Western healthcare system lead to silos in care delivery that marginalize roles that do not require formal education, and 4) Structural racism in the healthcare system reinforces regional racialized trauma. These themes highlight the complexity and interconnectedness of the challenges for integrating CHWs as well as promoting equity and inclusivity in healthcare delivery. In the following section, we will undertake a detailed analysis of these themes to gain a better understanding of the challenges.

**Table 1.** Challenges of integrating CHWs

| <b>Institutional challenges</b>   |   |
|---|---|
| 1. Constraints on CHW's scope of practice   | a) Lack of standardized titles for diverse CHW-like positions and role ambiguity  |
|   | b) Impediments for CHWs to address community needs due to constraints imposed by grant-defined roles and guidelines <ul style="list-style-type: none"> <li>i) Confinement to working in healthcare settings limits CHW's community engagement</li> <li>ii) Conventional full-time work schedule imposes limitations on the availability of CHWs for community outreach</li> </ul>                                 |
| 2. Unsustainable CHW workforce  | a) Insufficient remuneration  |
|   | b) Constraints on recruitment resulting in a narrow pool of qualified CHWs  |
|   | c) Limited opportunities for professional development   |
|   | d) Lack of support and resources for achieving high-quality performance by CHWs <ul style="list-style-type: none"> <li>i) Inadequate access to resources for addressing the health and social needs of their clients</li> <li>ii) Limited standardization of community resource knowledge</li> <li>iii) Burnout among CHWs</li> </ul>   |
|   | e) Inadequate representation in leadership and decision-making positions  |
| 3. Obstacles in fostering professional relationships with other care team members | a) Professional hierarchy within healthcare institutions <ul style="list-style-type: none"> <li>i) Assumptions of low educational qualifications for CHW positions</li> <li>ii) Lack of understanding and recognition of CHW role and responsibilities</li> </ul>   |
|   | b) Silos in the care team: Lack of communication, interaction, and transparency among care team members and CHWs <ul style="list-style-type: none"> <li>i) Distrust of physicians by CHWs (i.e. perceived lack of empathy, high physician turnover)</li> <li>ii) Disconnection between care team members and CHWs' agendas due to limited understanding of each other's roles and differing priorities</li> </ul> |
| <b>Systemic challenges</b>  |   |
| 4. Pervasive structural racism in the healthcare system                           | a) Historical and present racialized trauma in St. Louis  |
|   | b) Predominance of White health professionals, compared to predominantly African American CHWs, leads to a racialized workplace culture that further marginalizes minority groups   |
|   | c) Stigma and discrimination <ul style="list-style-type: none"> <li>i) HIV-related stigma</li> </ul>  |

|  |  |
|--|--|
|  | ii) Professional stigma  |
|  | d) Underappreciation and lack of recognition for the impact of minority-led organizations employing CHWs   |
| 5. Dominance of the hierarchical Western European Model in HIV/AIDS care       | a) Tension between limited acceptance of non-traditional knowledge sources and concerns about CHWs' qualifications to provide health information |
|  | b) Organizations working in silos limit the potential for collaboration and resource-sharing for care provision                                  |
|  | c) External stakeholders' lack of prioritization for the region  |
| 6. Insufficient momentum and consistency in CHW program implementation efforts | a) Inconsistent stakeholder support for the continuum of CHW programs  |
|  | b) Pandemic-related constraints on CHW roles and activities  |

**Table 2.** Recurring Themes Across the Six Identified Challenges

| Theme   | Sub sections   | Refer to Table 1                |
|---|--|---------------------------------|
| #1 The roles of CHWs are not well-understood by care team members and are often undervalued.  | Inconsistent CHW titles and role ambiguities<br><br>Professional hierarchy within healthcare institutions<br><br>Disconnection among the care team members | 1a<br>3a, 3b                    |
| #2 The health system lacks the necessary infrastructure to properly support a sustainable CHW workforce.  | Constraints on CHW's scope of practice<br><br>Unsustainable CHW workforce  | 1b<br>2a-2e<br>5b, 5c<br>6a, 6b |
| #3 The power dynamics within the hierarchical structure of the Western healthcare system lead to silos in care delivery that marginalize roles that do not require formal education |  | 2e<br>3a, 3b<br>5a, 5b          |
| #4 Structural racism in the healthcare system reinforces regional racialized trauma   |  | 4a-4d                           |

**1) The roles of CHWs are not well-understood by care team members and are often undervalued.** [See **Table 1:** 1a, 3a, 3b]

“There is not really a lot of recognition of us, except for among us.”  
 --- Health Coach (from Focus Group)

**Inconsistent CHW titles and role ambiguity**

The term "Community Health Worker" (CHW) encompasses a wide range of roles and responsibilities. According to a community leader, CHW was used as an umbrella term:

In the CHW space... like the first two years, 2018 to 2020, we used to say CHWs are an umbrella term. And you can think about them as navigators and support specialist and case managers, so we were kind of put everybody in one umbrella. (Commlead5)

This diversity in CHW titles, roles, and responsibilities, which can vary depending on the healthcare setting and community needs, however, can lead to confusion among other healthcare professionals in understanding the scope of work for CHWs on their care team and in effectively collaborating with them. As support resources in the clinical setting continue to expand, CHWs are entering with new roles and titles. A clinical provider noted that CHWs are an emerging cadre, and that some care team members may not be as familiar with their roles compared to other support roles that have existed for a longer period:

I've been working with case managers in Ryan White clinics since 1993, but I've worked with health coaches for about six, seven years, okay? And case managers did everything before. I mean we asked them to do everything, you know, enroll people insurance and take care of all kinds of paperwork, and providing enough mental health counseling. The difference now is that our resources have expanded, so we also have mental specialist too... insurance specialist. But I think in my experience, I've worked with case managers

far longer than anyone else, and I have always relied on them to help with anything that's non-medical.” (Clinlead4)

However, while some new titles have been created to reflect the distinct services provided by certain CHWs, a front-line health worker also pointed out that CHWs with overlapping roles are working under different position titles due to funding restrictions:

I think we have this very like peer or non-peer mindset right now, where you know some of these folks are doing very similar things. Like early intervention service is doing very similar things to health coach, but we have them separated right now, because we have this peer/non-peer dichotomy because of funding restrictions. (Director from the focus group)

The diversity in roles and responsibilities among CHWs presents a challenge in creating standardized titles and clearly delineating their responsibilities and scope of practice. While the overlapping roles of CHWs under different position titles may demonstrate their versatility and adaptability in addressing various community health issues, it can also lead to confusion regarding their responsibilities, making it difficult for CHWs to establish their identity within the health system. Furthermore, the absence of standardized titles and role ambiguity presents a challenge for healthcare professionals in understanding the services provided by CHWs on their care team and in effectively collaborating with them.

### **Professional hierarchy within healthcare institutions**

In addition to inconsistent CHW titles and role ambiguity, the professional hierarchy within healthcare institutions greatly contributes to the lack of understanding and recognition of CHW roles and responsibilities. This creates obstacles in fostering professional relationships with other care team members and in effectively integrating CHWs into the healthcare team. The



healthcare system often features a hierarchical structure that is differentiated by educational and training backgrounds. CHWs may have different educational backgrounds compared to other healthcare professionals, which can result in misunderstandings about their roles and responsibilities. When asked about their thoughts on employing CHWs to assist PLWH with care management, a clinical provider who had limited experience working with CHWs expressed concerns about CHW qualifications for engaging patients on health information.

Well, hmmm...What would the education level of that person be? Would that be somebody that was like an MA, or an LPN, or a nurse, or you know, Because I mean that's the issue... Like I mean if they're out of their element and the patients are asking questions that they can't answer...To me that would be more of a disservice than a service because they're asking about well, what do I do if I miss my meds, are these side effects of my meds, and if they can't answer it, you know that could go either way. I mean they might be able to help with transportation or bus passes, or you know, whatever. But as far as answering side effects or medication questions, you're talking two different levels of expertise. (Clinlead3)

The concerns expressed by the clinical provider reflect limited exposure among some healthcare professionals to CHWs, their work, and their impact on patient care, which can result in misunderstandings about the CHW profession. This may involve assumptions about low educational qualifications and an incapacity for communicating with PLWH on medical-related information (discussed further in Crosscutting Theme #3). The professional hierarchy in the healthcare system, which prioritizes knowledge from an educational paradigm, can lead to biases among some professionals who assume CHWs with low educational qualifications cannot perform higher-level responsibilities within the care team, resulting in exclusion from patient

care in clinical settings. This lack of familiarity and limited awareness of CHW roles exacerbates the professional hierarchy.

### **Disconnection among the care team members**

Additionally, the disconnection between care team members and CHWs exists both between CHWs and healthcare professionals and also support staff. This disconnection can arise from differing priorities, limited understanding of each other's roles, different approaches to care, and communication barriers. For example, when describing the challenges of obtaining resources for client's non-medical needs, a community leader who was a CHW shared their frustration working with case managers in supporting their clients:

And that's it, that's all we've heard. We just have to tell the clients that and it's kind of difficult working alongside a case manager who's kind of fragile with the delivery of telling the client what's really going on in a professional manner. You know you can't text the client this: oh, your bus pass ain't coming in indefinitely. You got to get on the phone, you got to have a conversation, you got to lean into the client. Because you know what? That's a deterrent, it's a trauma, and it's emotionally driven... like I don't have no access to get around. I can't get my next appointment, which I don't do, you know. So we have to really [unintelligible] when we deliver information. (Commlead3)

CHWs may have different focuses and approaches to care compared to case managers. In the example mentioned above, the case manager informed clients that the bus pass was no longer available via a text, but the CHW considered the emotional stress this information can inflict the client and took a further step to call the clients to explain the situation. The case manager, however, did not understand why the CHW would take such extra effort. The community leader shared the case manager's reaction:

“The case managers, yeah, are saying you know...you're doing too much you guys baby them...” (Commlead3)

The differing approaches to client interactions highlight the challenge for care team members and CHWs to align their efforts and collaborate effectively.

The disconnection within the care team is also due to limited understanding of each other's roles and responsibilities. A clinical director shared the challenge of introducing a new role like CHWs to an already complex team:

I think it's much harder than people recognize to actually introduce a new role in a medical setting. I mean there's certain roles that are long standing that anyone has some understanding about, physician, nurse practitioner, nurse, medical assistant... So I think one of the disadvantages of Ryan White programs is that the funding allows us to provide a lot of support staff, but with the more granularity in the staffing, it's more difficult to be sure all the providers know who these people are and how to use them. (Clinlead4)

Many participants noted a lack of communication, interaction, and transparency among care team members and CHWs. A clinical provider identified silos in clinical practice that limit the integration of CHWs into the care team:

Unfortunately, for the time in which I've worked in HIV, there hasn't been a great inter-departmental reliance on other people's specialties, whether it be professionally or working with lay individuals. (Clinlead2)

Participants identified several factors that can lead to silos in the care team. The clinical director highlighted the difficulty for members to establish connections and develop familiarity with one another in a large healthcare team.

I think getting that information out so people understand who these people are and what they can offer is not easy. I struggle with that just in my clinic because I have 25 physician providers, and none of them are there five days a week. If someone was in clinic five days a week, it's a little bit easier to sort of say yeah this face you're going to see. But if you're only coming Monday afternoon, trying to get that one person to really understand that there's someone available...(Clinlead4)

Furthermore, large healthcare teams may experience high employee turnover. According to a clinical provider, 12 providers have worked in his office over the past eight years. Trust is built through consistent interactions and relationship-building over time. When there is a high provider turnover rate, it becomes challenging for CHWs to establish long-lasting relationships with healthcare providers. The inability to form strong connections may result in mistrust and hinder effective collaboration. Additionally, CHWs who are often deeply invested in the well-being of their communities may lose trust in healthcare providers from perceiving a lack of commitment when providers frequently change and disrupt continuity of care for patients and communities. A community leader shared her frustrations with the physicians they have interacted with:

“But again, the barrier is, we love our physicians, but they ain’t gonna do the extra work. They gonna say they got rounds at the hospital this week, the second-year medical students and the other one's going to Haiti or Brazil, and they said, you know, they are going on vacation...So if they don't feel like it's a concern, how do we feel like it's a concern?” (Commlead3)

The absence of standardized titles and role ambiguity, along with the professional hierarchy within healthcare institutions and silos in the care team, leads to a lack of

understanding and recognition of the CHW profession. This makes it challenging for CHWs to establish strong relationships with other care team members and results in them not being well integrated into the health system.

2) **The health system lacks the necessary infrastructure to properly support a sustainable CHW workforce.** [See Table 1: 1b, 2a-2e, 5b, 5c, 6a, and 6b]

“What I’m trying to say is, [CHWs] are only as powerful as the system within which they can refer to and connect with.”

--- Clinical Leader

The effective integration of CHWs into the health system is a crucial element in building a sustainable CHW workforce. However, such integration cannot be maintained unless organizations have established the necessary infrastructure to properly support CHWs. A front-line health worker spoke in favor of strengthening support by emphasizing the negative consequence of an unsustainable workforce:

“You want a strong person, and you don’t want a lot of turnovers.” (Care Coordinator from the focus group)

Such caution against high turnover among CHWs and the potential for negative consequences highlights the detrimental effects of an unsustainable CHW workforce. This not only hinders the formation of relationships between CHWs and other care team members but can also erode trust between CHWs and the communities they serve. Unfortunately, the current health system does not provide CHWs with the necessary support to realize their full potential and establish long-term, viable careers. A clinical provider expressed concerns over the current infrastructure for CHW employment in St. Louis:

We’ve been worried that so many organizations are adding community health workers without themselves having the infrastructure and what it takes to properly support a

community health worker so that they're able to do what they're so incredibly capable of doing. (Clinlead1)

As the integration of CHWs would be facilitated by a flourishing and viable profession as a foundation, the study's participants identified gaps in the existing infrastructure for supporting CHWs that negatively affect the long-term viability of the workforce. These challenges include constraints on CHW's scope of practice, as well as an unsustainable workforce that fails to equip and empower CHWs to address the diverse and complex health needs of their communities.

### **Constraints on CHW's scope of practice**

Most CHW roles are outlined and funded by specific grants or funding sources, often with specific objectives. While grant-defined roles and responsibilities can provide structured guidelines for CHWs, enabling more efficient use of resources and facilitating performance evaluation for improvements, several participants pointed out the limitations and constraints that grant-defined roles can impose on CHWs. For example, a community leader noted that the conventional full-time work schedule set by most grant guidelines imposes limitations on the availability of CHWs for community outreach. This rigid work schedule may not be compatible with the needs of the communities they serve, as medical and non-medical-related concerns may arise outside of typical working hours. The community leader who worked as a CHW shared their experience of having to work extra hours to help clients:

I have literally outgrown my organization. I'm just, you know I'm doing it because I care, I do it because we're saving lives, we are changing the narrative, we're trying to end the epidemic, this is why I'm doing it. (Commlead3)

Unlike the community leader who went the extra mile to meet clients outside of working hours, many CHWs are unable to deliver services outside of working hours. As a result, they may be

unable to address urgent or pressing needs of their clients in a timely manner, which can negatively impact the overall effectiveness of the program. In addition to the time constraints imposed by grant and organizational guidelines, a community leader noted that many programs confine CHWs to working strictly within healthcare settings such as clinics and hospitals:

Missouri is a show-me state, we're also a very verbally red state. So if we say we need CHWs, and they fund CHWs in our hospital or health center, they will think that they funded all CHWs. So when you have someone who is HIV positive but they are inside of the jails, and they can't get their medication...And my CHW is in the jail. But because they can't sign off on CMS and get reimbursed, we can't provide that service. The government has just done a disservice because they only funded the hospital and the health center. (Commlead5)

The CHW role, as the community leader further noted, remains unfulfilled when their services are limited to clinical settings:

If I can't go to their home, I can't sit at a table where decisions are being made, to advocate for the places that I know they'll never see, I feel unfulfilled as a CHW because my job title is that. (Commlead5)

As CHWs are often members of the same community and have a cultural understanding of their clients, they are uniquely positioned to provide assistance to the most vulnerable individuals who may have lost touch with traditional healthcare due to access barriers or other reasons:

I think for the care you're talking about for very, very marginalized, and vulnerable communities, [CHWs] are not going to get into those nooks and crannies being inside those healthcare systems. (Clinlead1)

Confining CHWs to work only within healthcare settings limits their ability to reach and engage with these marginalized populations who are struggling the most, hindering their ability to maximize their potential to bridge the divide between communities and healthcare institutions.

Grant-defined roles, as the community leader also pointed out, confine more than CHW's scope of practice:

That actually did a disservice, because now, the broad reach the CHWs used to have, they no longer had it because not only were you confined by the actual [insurance] billing, but you are confined by the cultures and the rules and the regulations of what they will allow. So while CHWs who was helping a diabetes patients might have been used not only helping them in their appointments but also traveling to their home in order to show them how to use the groceries that we just told you to buy and what's the five minute meal, because I recognize the church electricity is kind of wanted off, so you might not always have you know your refrigerator to keep things cool. That was limited when we put them into certain system. (Commlead5)

Under responsibilities delineated by funders, CHWs are primarily confined to front-line roles. Crosscutting Theme #3 and #4 delves into the underlying factors behind this role confinement. Nonetheless, as noted by the community leader above, this confinement also restricts opportunities for CHW career development and hinders the expansion of the CHW workforce:

So we've worked to make sure that the way in which the region views this workforce and peer navigators is expanding, because it has done us a disservice when peer navigators are only looked at as that direct service provider or case managers, when they have the ability to mobilize, they have the ability to advocate, and they have the ability to translate. (Commlead5)



The limitations imposed by grant guidelines detract CHWs from the authentic role of the CHW profession in addressing the unmet needs of marginalized populations and facilitating effective engagement in HIV care.

Besides the constraints imposed by grant guidelines, participants also observed that the pandemic has further restricted the roles and activities of CHWs:

You know I think we've hired more health coaches in the last three, four years, but with the pandemic now you know going on over two years, it's changed everything. And if the pandemic hadn't happened, I'm not sure if we would have tried to broaden their scope a lot sooner. But we certainly focused on patients who are struggling, and that's where I've used them the most...With the pandemic, they were virtual not even in clinic for I think almost 14 or 15 months. (Clinlead4)

Together, the limitations imposed by grant-defined roles and guidelines and the pandemic have constricted the scope of CHWs' practice and detracted them from fulfilling their authentic role within the profession, thereby impeding their ability to improve health outcomes in underserved populations and promote health equity.

### **Unsustainable CHW workforce**

An unsustainable CHW workforce poses significant challenges to the successful integration of CHWs into the health system, as it undermines the quality of care and overall effectiveness of CHW programs. The underlying causes of this workforce unsustainability are multifaceted, encompassing both institutional and systemic factors. Several participants highlighted key features of the current CHW program that contribute to an unsustainable CHW workforce.

To begin, the inadequate compensation of CHWs poses a significant challenge to the sustainability of the workforce. As underscored by a community leader who has previously worked as a CHW, many individuals in CHW and CHW-like roles receive low wages that make it difficult to make ends meet:

What I was saying is affording you know the income, you know the cost of living goes up every day and we individuals with lived experiences or peers or content experts, community health worker, we should be afforded the value of someone that has a degree.  
(Commlead3)

The financial burden placed on CHWs make it challenging to attract and retain qualified individuals, as it negatively impacts their well-being and job satisfaction. This, in turn, presents a challenge in maintaining a stable workforce and contributes to inequities within the healthcare system. High turnover rates are also impediments to sustaining CHW programs. However, inadequate salaries are not the only factor contributing to insufficient staffing. A community leader noted that the recruitment of CHWs with the necessary lived experience and qualifications to meet funders' expectations is a challenging process.

So through the years we've learned that because of the organization that I work for being a, you know, medical clinic...we felt it important to ask if [CHW candidates] at least have a bachelor's degree... I've heard from other health coaches, we would get so many more people, you know, if they could just have a high school [degree] but, there's been issues in the past and there's a lot of documentation that comes with this job, just like the case managers and, as you know, the funders want to see the numbers. So documentation seems to be a challenge...So having that minimum educational requirement has helped a

little bit, but I also...If they don't have that, if they have experience...it's just challenging sometimes to find the right people. (Commead4)

The emphasis on formal education and credentials over expertise in HIV/AIDS care, which reflects the dominance of the hierarchical Western European model, is further explored in Crosscutting Theme #3.

Furthermore, several participants highlighted the insufficient support and lack of professional development opportunities for CHWs who are employed within the system. These factors create challenges in both sustaining and expanding the workforce:

“Well, I think [CHWs] have to have a home, they have to have support, they have to have structure, and they have to have community. The community health workers have to have all those things. I do not believe they have that within most healthcare systems. They are used, they are not actualized. (Clinlead1]

Participants identified the lack of support and resources available to CHWs to achieve high-quality performance. This includes limited access to resources for effectively addressing the health and social needs of their clients, a lack of standardized guidelines for community resources, and inadequate support for burnout (refer to Table 2d). For example, a community leader emphasized the necessity of ongoing trainings for CHWs and the development of a comprehensive resource manual that all CHWs can utilize in their practice:

But I think after you're done with the program, keeping the fervor together and keeping people trained, and I think even during the program we developed a resource manual and I think that it's good, but I think it would be great to have like the collective CHWs to have just a resource guide, like virtual maybe, maybe where we all are working in and like having those meetings together. (Commlead2)

However, such collaborative efforts to “keep the fervor together” and develop resource manuals are often hindered by the presence of silos among disciplines and agencies. A clinical leader highlighted the fragmentation of care resulting from organizations operating in silos:

Because we know systems themselves are siloed. I can only see you about your HIV, I can only see you about your substance abuse, I can only see you about your mental health concerns, I can only see you about your foot wounds. I can only see you about your housing concerns. I can only see you about your legal concerns...So that silo-ing is the problem. (Clinlead2)

Several factors contribute to the formation of silos. In addition to the hierarchical structure of the care team and organization, which creates barriers between departments and competing priorities as discussed in Crosscutting Theme #1 and Theme #3, a community leader has revealed that competition across agencies for funding is a primary underlying factor contributing to the formation of silos:

...You know we don't want to hurt nobody feeling, we don't want to step on anybody's toes...We work in silos most often. And that's not helping us, working in silos and we're competing for the same parts of money you know all of that. That puts a damper on delivery of helping people right. (Commlead3)

A director working with front-line health workers shared that the competition across agencies is not always implicit:

There does become a disparity between agency and because some agencies have other funding sources, where they can supplement, like the money that they're getting for a case manager from Part A, or B or C or D. And some don't and some have excellent benefits that they can offer that kind of balance maybe lower pay. And so having equity

across the agencies is also an important issue to think about, because then we also have folks that move to other agencies, because this is the same job, but it's being paid or benefited differently. (Director from the focus group)

Silos can result in duplication of efforts and limit the potential for collaboration and resource-sharing. Such practices can lead to a waste of valuable resources and impede CHWs' ability to provide accessible, high-quality and consistent care to their clients.

The combination of low compensation, insufficient resources and support, inadequate training and limited opportunities for career growth can lead to financial stress, make CHWs feel ill-equipped to address evolving community health needs, and contribute to feelings of stagnation and frustration. Further challenges stemming from CHW's dual identity as both members of the community they serve and individuals with shared diagnoses are discussed in Crosscutting Theme #4. Nonetheless, participants emphasized that the emotionally demanding nature of CHW work, coupled with high workloads and inadequate infrastructure for sustaining a viable workforce, can contribute to burnout. A front-line health worker called out the need for more institutional support for CHW's well-being:

Times have changed, we are coming out, still in COVID. I think things that need to be incorporated when we're talking about finances, because I'm not afraid to talk about it either, that is, we need mental health days, we need days as employees. Because when you're dealing with this stuff, when you're dealing with someone and everything that they're dealing with, now when you leave, but when your work becomes what you're dealing with. That stress...I don't think you get... stressed an hour about it and you need time to kind of reflect and get your own mental health back in place. So not only do we need salaries that that match what we do with... match what's going on, but we also need

time you know we need time to be able to you know to replenish and refocus and get back to what would what we do best which is helping people (Care Coordinator from the focus group)

Finally, considering the numerous gaps in the current support infrastructure for CHWs, as outlined by participants, it is still noteworthy that CHW program implementation efforts are not consistent across settings. A community leader cautioned against the inconsistency in supporting the continuum of CHW programs, arguing that haphazard efforts could exacerbate harm for the community:

What you'll have to think about is everyone's going to love your idea. I spent the first year and a half doing that, like everyone's like 'yes, I support. I want to be a part of it... This makes sense, the region needs it.' And you're going to be successful for a little while when you have the startup funds. But similar to like what you just asked me in three years, what do we do next, how do we not just bring a program that looks good, feel good, and work good and then two years later, we have to take it away. So that actually does more harm than never bringing it in the first place right. (Commlead5)

In summary, the current health system lacks the necessary infrastructure to support CHWs adequately. This results in a constrained scope of practice dictated by grant-defined roles and guidelines, and an unsustainable workforce experiencing low compensation, limited resources, and insufficient professional development opportunities. Furthermore, the presence of silos among disciplines and agencies, fueled by competition for funding and differing priorities, hinders collaboration and resource-sharing. Therefore, the CHW workforce encounters institutional and systemic obstacles in realizing its full potential and fostering long-term, viable careers, making the integration of CHWs into the health system a challenging process.

**3) The power dynamics within the hierarchical structure of the Western healthcare system lead to the silos in care delivery that marginalize roles that do not require formal education.** [See **Table 1:** 2e, 3a, 3b, 5a, and 5b]

“We are trying to put together a job description for health workers and every position always says you have to have a degree. But a degree, when does life experience overwrought a degree? At what point is that held at the same way of having a degree? When is life experience going to be looked upon at the same eyes as a degree?”

--- Prevention Specialist (from the focus group)

Participants’ responses of their perceived challenges of integrating CHWs revealed the tension between Western healthcare system’s limited acceptance of non-traditional knowledge sources and concerns about CHWs’ qualifications to provide health information. A clinical leader pointed out that the educational and formal training requirements within the healthcare system serve to exclude community members from being considered for employment opportunities:

The formally trained folks have more system knowledge and are often hired by systems of care versus the ones that we work with would never ever get a job in a system of care, but their knowledge of the community is generally richer because they're generally more closely tied to it. (Clinlead1)

Nonetheless, CHWs who have undergone training and been hired by the system also experience under-recognition of their contributions. A front-line health worker highlighted a workplace culture that prioritizes formal education over lived experience:

I do everything that someone with a master’s or a bachelor's would have to do, and I promise you I’m not being grandiose or anything like that, but I can do better. Like, if you would just listen to my viewpoints, and this strategic outlook, I’m going to be able to have the outcomes right because I have the lived experience. And that lived experience that we have, that’s a degree. And that pain doesn't come with it, it goes unnoticed. And

sometimes that's kind of like burnout too in a sense, for I love what I do. I'm very passionate about it and I've learned like sometimes people don't look at the work that we do with the lived experience behind it. It goes off the accolades and that kind of like to be a barrier for some very good future workers. (Engagement Specialist from the Focus Group)

The contributions CHWs make in addressing health disparities for HIV care lies primarily in their shared experiences and comprehensive understanding of the communities they serve, as opposed to the knowledge derived from formal training. A clinical leader emphasized CHWs' ability to meet people where they are is particularly valuable for community engagement in disadvantage populations:

What I find our community health advocates can do, that systems of care and anyone inside system of care can't do, is they can reach folks who are beyond socialized care. They cannot either because of transportation, communication, or simply the fact that their lives are so defined by their trauma they cannot even engage with as much as a single appointment in the clinic, even if everything's paid for, and everything's free and everything's accessible, they cannot do it, they cannot do it. And so, where our community health advocates, what they do, and what our clinic does is it truly meets people where they are. And that's what makes it so different. (Clinlead2)

However, non-traditional knowledge sources, such as lived experience as a CHW or shared diagnosis and cultural experiences, and community-based knowledge, are frequently undervalued by many healthcare providers. Recalling from Theme #1, the concerns expressed by a provider regarding the inability of CHWs to communicate effectively with PLWH regarding medical information underscore the preference given to the Western European healthcare model



that does not fully recognize the validity of knowledge beyond the traditional education paradigm. A clinical leader provided a satirical comment on the hierarchical structure of knowledge within the healthcare system:

Yeah, because right, think about it, community engagement is not seen as a developed skill that is just as complex as an aortic surgery, right? (Clinlead2)

Additionally, it is important to note that healthcare providers are not the only individuals concerned about the lack of formal education among CHWs. A community leader, while acknowledging the critical front-line role played by CHWs, expressed concerns over their qualifications for performing tasks requiring professional skills, such as report writing:

But when we talk about community health workers who are indigenous leaders from the community, they don't always come with those skill sets that we're looking for that we think we need. I'll put it that way because we're looking for is someone to connect with the community and they come with that, you know they have that but they don't always have those other skill sets and some, and as a manager I find it challenging sometimes because I am responsible for reporting to funders what we are doing, how we are doing our outcomes, and sometimes I can't rely on the community health worker or the peer navigator to be able to write up that report. You know I have to kind of like provide some professional development training. (Commlead1)

Moreover, for some individuals, even the "professional development training" can be limited. As noted by another community leader:

One of my supervisors, she is an MSW. And for her, the fact that like right now there's not like a four-year program to become a CHW, it's just like this beautiful training that

we do, or whatever and it's very intense, but for her, she felt like it was very limited at the same time. (Commlead2)

The perceived lack of credibility of CHWs in performing advanced responsibilities hinders them from taking up leadership and decision-making positions. However, many participants disagreed with the notion that their lack of formal higher education background makes them incapable of performing more professional and specialized tasks. According to a community leader:

We individuals with lived experiences or peers or content experts, community health worker, we should be afforded the value of someone that has a degree. You know, it's a lot of work that's being done, and we do most of the work. We lay the foundation for that work to be built. We are capable of being supervisors or capacity builders with or without a degree, I do believe that, I've watched it be manifested in over the last 25 years, good key people that I worked alongside of, to say the least. (Commlead3)

Nevertheless, the tension between limited acceptance of non-traditional knowledge sources and concerns about CHWs' qualifications reflects the dominance of the hierarchical Western European model in HIV/AIDS care, which reinforces power dynamics that prioritize formal education and credentials over lived experiences and other non-traditional knowledge sources.

Apart from the emphasis on formal education that marginalizes individuals with non-traditional knowledge sources, participants also brought attention to other challenges resulting from the Western European healthcare model. Recalling from Theme #1 and #2, several participants underscored the presence of silos within the healthcare system, evident in clinical care teams and across various agencies, that pose significant challenges to effective communication, collaboration, and resource sharing (refer to **Table 1 3b** and **5b**). As each

discipline operate independently with separation of roles, silos can make it difficult to integrate innovation such as new roles like CHWs into the health system.

4) **Structural racism in the healthcare system reinforces regional racialized trauma** [See **Table 1: 4a-4d**]

“The problem is not the Community Health Worker; the problem is a system of care that is based on white body supremacy in which hierarchy is supreme in that relationship.”

--- Clinical Leader

The challenges associated with the integration and sustainability of CHWs at the systemic level, as identified by the participants, are multifaceted and emanate from the pervasive structural racism deeply ingrained in the healthcare system. A clinical leader acknowledged the significance of racialized trauma prevalent in the St. Louis region, and further noted that a racialized healthcare workforce perpetuates this trauma, fostering distrust and disconnect between healthcare professionals and support workers:

So, here's where I see the biggest disconnects. I see white dominant health professions and health facilities trying to interact with community health workers that reflect the St Louis city population, which is mostly black folks. And so, you have that hierarchy, that's a massive problem because of the all the racialized trauma in this region and segregation.”

(Clinlead1)

While CHWs' backgrounds are highly valued for their intrinsic knowledge of the community they serve, they are predominantly confined to front-line roles and are noticeably underrepresented from leadership positions. A Black female community leader expressed such concern regarding the underrepresentation of CHWs in leadership positions:

Again, how do we apply best practices to remove the white elephant in the room? In a sense, like you have to make sure that blended diversity and inclusion piece is well received and not overlooked. Do you see people that look like me? Do you see people that feel like me? Do you see the people that look like me or feel like me in higher leadership roles? (Commlead3)

Additionally, this quote underscored the barriers CHWs confront, particularly given their dual identity as both members of the community they serve and individuals with shared diagnoses. Multiple participants who have previously worked as a CHW or other front-line health staff roles shared the stigma and discrimination they experienced:

You know, we got to get screening and testing too, we have unprotected sex, and sometimes, it comes back right? And we got to go in here and now I got to face people who I worked with out in the field, because I made a mistake. That's just like being re-diagnosed all over again. (Engagement Specialist from the focus group)

When discussing their past experiences with professional stigma, a community leader revealed the pressure CHWs face while working in HIV care, which is a particularly sensitive space due to the stigmatization of the disease:

But have let us have one slip up and the word gets out, then it's like, oh, what are they doing over here? You know, people's biases start to show up, you know, and I tell my staff this all the time. We can't afford to make the mistakes. Or have the slip-ups that the majority agencies have. I know that's a lot of pressure for people. (Commlead1)

The stigma associated with the CHW profession is deeply rooted in racial biases and manifests the pervasive structural racism in healthcare. A community leader highlighted the racialized power dynamics that severely undervalue the impact of minority-led organizations employing CHWs:

Everybody who works for minority agency know, there seems to be this lack of respect, for lack of a better word, black authority, if I can say that. And I know deep in my heart that all of this is part of the systemic racism thinking, and how people were brought up, what people consciously and subconsciously believe about minorities, and even the internalize racism that comes along with it. One of the challenges I find is that getting people to respect the work...you know the values and beliefs of the agency. Because I have seen behavior be display there I know would not happen somewhere else. (Commlead1)

The duality of identity experienced by CHWs presents unique challenges, rendering them vulnerable to stigma and discrimination in both their personal and professional lives. In healthcare settings where CHWs predominantly belong to minority communities, this stigma can reinforce racialized workplace cultures, giving rise to power imbalances and microaggressions that marginalize minority CHWs. In St. Louis, a region that has experienced severe racialized trauma, stigma against CHWs is compounded by racial biases and contributes to the perpetuation of health disparities by undermining the effectiveness of CHW-led interventions and creating barriers to professional development. The underrepresentation of CHWs in leadership positions can additionally weaken their credibility within the clinical care team and the communities they serve, thereby impeding their full integration into the health system.

## DISCUSSION

### Implications for the intervention

Participants in this study recognized numerous and interconnected challenges in the integration of CHWs into the health system, highlighting the need for a comprehensive approach to achieve successful integration. To address many components of the problem, such as infrastructure, care team dynamics, and workforce development, this approach necessitates joint efforts from community stakeholders, healthcare institutions, and policy makers. This section details how the study's results may inform CHW interventions at the institutional and systemic levels.

### Emphasize the value of CHWs beyond their role as front-line service providers

Acceptance and integration of non-traditional information sources can have far-reaching implications for the design, implementation, and integration of CHW interventions within the larger health system. CHWs often come from the communities they serve and have an intimate understanding of the issues that community members living with a stigmatizing condition experience. The current hierarchical structure of Western European healthcare systems prioritizes formal education over lived experience, thereby overlooking CHWs' immense capacity to perform advanced responsibilities such as leveraging their knowledge of local contexts and relationships with community members to facilitate the design, implementation, and evaluation of health programs, as well as advocating for policy changes. [3]

By valuing and integrating CHWs' lived and shared experiences, the intervention can become more culturally sensitive and appropriate, enhancing the acceptability and effectiveness of health services and fostering trust between healthcare providers and communities.

Acknowledging the diverse roles CHWs can play, and their unique skills and experiences

provide policymakers and healthcare leaders with a better understanding of the value of CHW programs and may lead to increased investment and expansion of the scope of CHW interventions.

### **Maintain an equilibrium between standardization and flexibility in CHW roles**

Establishing standardization of CHW roles and responsibilities is crucial to promote clarity and consistency in their scope of practice, facilitating effective collaboration with other members of the care team, and ensuring that CHWs work within their areas of expertise. However, rigid standardization may restrict the ability of CHWs to address the diverse and unique needs of the communities they serve. Hence, it is essential to adopt strategies that promote flexibility in grant-defined roles, allowing CHWs to adjust their responsibilities to meet the specific needs of their clients while remaining within their overall scope of practice. Striking a balance between standardization and flexibility can facilitate CHW's integration into the health system and optimize their impact on improving health outcomes in their communities. [3]

Intervention developers may consider collaborating with stakeholders such as health departments, community-based organizations, CHW associations, and community members to develop a regional framework that defines CHW titles, roles, and responsibilities. Such regional framework should be flexible enough to accommodate the unique needs of different communities and allow for adaptation at the local level. The framework could outline the core competencies and tasks expected of CHWs, regardless of their specific roles or titles. These core competencies can serve as a foundation for training and capacity-building efforts while also allowing for additional tasks and responsibilities based on local needs and resources.

Additionally, it is crucial to work with grantors and funding agencies to promote flexibility in grant-defined roles, enabling CHWs to adjust their responsibilities based on community needs and priorities. This may involve revising grant guidelines, developing flexible funding models, or advocating for policy changes to support a more adaptive approach to CHW roles.

Furthermore, periodic review and updates of the guidelines for CHW roles and responsibilities are necessary to ensure they remain relevant and responsive to changing community needs, healthcare innovations, and policy developments. This process should involve ongoing engagement with CHWs, community members, and other key stakeholders.

### **Strengthen infrastructure capacity for a sustainable CHW workforce**

A sustainable CHW workforce requires deep investment from multilateral stakeholders to enhance the infrastructure's capacity for equitable compensation, equip CHWs with the necessary resources and competencies, establish a non-hierarchical supervision system that fosters trust, empowerment and ownership, and provide opportunities for career advancement.

Ensuring fair compensation is a critical factor in promoting motivation and job satisfaction among CHWs. When CHWs feel that their work is recognized and adequately remunerated, they are more likely to feel valued and invested in their role. Such compensation ensures that CHWs can meet their basic needs and achieve financial stability, ultimately reducing stress and enhancing overall well-being. Additionally, fair and equitable compensation is essential for sustaining a stable workforce by reducing turnover rates and recognizing the value of CHWs, which helps legitimize their roles within the health system and the communities they serve.



To ensure consistent delivery of high-quality performance, CHWs need to be equipped with knowledge and skills through comprehensive training and capacity building that includes tailoring the training curriculum to meet the specific needs of the communities they serve. Such training should address the diverse roles and responsibilities that CHWs undertake while incorporating hands-on training and experiential learning opportunities. Additionally, the training should focus on capacity building in communication, problem-solving, and leadership to enable CHWs to build strong relationships with communities, navigate complex situations, and coordinate care with other healthcare providers effectively. Ongoing learning and skill development opportunities such as refresher courses, workshops, and seminars should be provided to CHWs to keep them updated on current best practices, guidelines, and innovations in their field.

In response to the concerns of inadequate access to resources and limited standardization of community resource knowledge expressed by many participants, several strategies can be implemented. To begin, an integrated resource database of community resources, including health and social services, may be sought out, allowing CHWs to easily locate and connect clients with appropriate resources. Subsequently, community resource training could be included in CHW training curriculum to ensure that CHWs are well-informed about available resources and understand how to access and utilize them efficiently. Furthermore, established procedures and standards for referring clients to community services might be explored, ensuring that CHWs use consistent and successful approaches. This has the potential to reduce misunderstandings, improve communication, and streamline the referral process.

While many existing CHW programs have developed supervision structures that include regular feedback, mentorship, and coaching, more enhancements are required to enable

collaborative engagement with CHWs. Recognizing that CHWs have a wide range of needs, skills, and challenges, supervision approaches should be adaptable and flexible, giving personalized guidance and encouragement. [58] Creating open lines of two-way communication, encouraging supervisors to involve CHWs in decision-making processes such as program planning, implementation, and evaluation, and facilitating peer support networks among CHWs are some strategies for establishing a non-hierarchical approach to supervision. CHWs may be empowered to take ownership of their positions and foster a supportive work culture that recognizes the emotional intensity of their job by developing a bottom-up supportive supervisory environment.

Furthermore, it is imperative that the infrastructure supporting the CHW workforce establish a clear career pathway to enable CHWs to grow within their profession. The process of establishing a career ladder includes examining existing CHW roles and responsibilities to identify areas for expansion, creating a competency framework adaptable to the community's unique needs that outlines the knowledge and skills required for varying CHW roles and responsibilities, defining the different levels within the CHW career ladder and their corresponding advancement criteria, creating opportunities for specialized roles, and offering ongoing training and professional development. [59]

In the context of professionalizing the CHW workforce, it is essential to note that while this approach has the potential to sustain and upscale CHW programs in a more Eurocentric model of care, there are also potential unintended consequences that could erode community trust and identification. One of the potential risks is that professionalization may lead to a disconnect between CHWs and the communities they serve, particularly if CHWs are perceived as being too closely aligned with the formal health system. Additionally, the professionalization

process may result in the exclusion of individuals who possess valuable community-based knowledge and experience but lack formal education or credentials. Moreover, increased bureaucracy resulting from professionalization may redirect resources away from direct service delivery, thereby diminishing the effectiveness of CHW programs. Therefore, it is crucial to professionalize the CHW workforce in a manner that preserves the unique strengths and contributions of CHWs and maintains their relationships with the communities they serve.

Lastly, sustainable CHW programs require long-term investment to secure adequate funding for training, supervision, program development as well as financial incentives such as salaries and benefits. [61] A strong advocacy campaign is essential to raise awareness about the role and contributions of CHWs, increase political will to support CHW programs, and advocate for policy changes that recognize and integrate CHWs into the health system. Additionally, finding alternative funding mechanisms for CHW programs beyond grants is essential for ensuring their sustainability and adaptability. Diversifying funding sources can help create resilient CHW programs that can better respond to the evolving needs of communities.

### **Adopt a relationship-based care team model**

Integrating CHWs into health systems requires implementation strategies that involve both CHWs and other care team members. A relationship-based care model, which resembles the non-hierarchical supervision system discussed earlier, can promote collaboration, communication, and mutual understanding among all members of the care team. [60]

One of the key elements for creating a relationship-based care model is to establish a shared understanding of the goals and objectives of the care team, including the roles of CHWs, which can foster a sense of unity and commitment among all team members. [62] Establishing channels for open and transparent communication among care team members is also vital to

building trust and encouraging collaborative problem-solving. This may include regular team meetings or communication platforms that enable real-time collaboration and information sharing. In addition, interprofessional education and training, as well as opportunities for job shadowing or mentoring, can also be utilized to encourage care team members to learn about each other's roles, expertise, and perspectives. This approach could enhance the traditional continuing medical education framework, which typically focuses on offering specialized training for individual professions. [63] By deepening their understanding of each other's responsibilities, care team members can better appreciate the value that each member brings to the team and work together more effectively.

Creating formal frameworks, such as joint case conferences and multidisciplinary rounds where all team members may interact to address the health and social needs of their clients and establish integrated care plans, can also help to achieve a team-based approach to care. [64] [65] [66] The care team may provide a more holistic approach to care by incorporating all members in decision-making and leveraging the specific qualities and knowledge of CHWs. Such a relationship-based model implementation could help healthcare institutions in better integrating CHWs into their services and promoting higher satisfaction among care team members and clients alike.

### **Shifting the narrative away from individual-level factors**

The shift in focus from individual-level factors to addressing structural barriers is crucial for the effective integration of CHWs into healthcare systems. Structural barriers, which originate from racialized trauma, systemic policies, white supremacy/medical racism, and organizational practices hinder CHWs' ability to contribute effectively to the care team.

As previously discussed, improving organizational structures to enhance the capacity of the infrastructure supporting CHWs and advocating for policies that acknowledge and support their roles can validate their contributions, provide necessary resources, support, and transform the culture and practices of healthcare institutions, thereby fostering greater acceptance and integration of CHWs into the health system.

To break down the professional hierarchy within healthcare institutions, implementation strategies can focus on fostering interprofessional education, and creating opportunities for joint training and decision-making. Importantly, healthcare systems must address the pervasive structural racism and discrimination that marginalizes CHWs, particularly those from Black and Brown backgrounds. This can involve hosting anti-racism training for healthcare professionals, promoting cultural competency and humility, acknowledging the legitimacy of non-traditional knowledges sources, and ensuring that organizational policies and practices are equitable and inclusive.

Finally, to overcome structural barriers, healthcare institutions should invest in strengthening relationships with the communities they serve. Potential strategies include collaboration with community-based organizations in decision-making processes and ensuring that services provided are responsive to the needs of the community. [67] [68] [69] By fostering strong community relationships, healthcare systems may establish a more inclusive approach to care. Furthermore, encouraging collaboration among organizations, such as resource sharing, might help overcome structural barriers by pooling information, knowledge, and resources, thereby reducing duplicative and siloed efforts. [70]

By focusing on these potential solutions, healthcare systems can shift their narrative from addressing individual-level factors and establish an environment that is favorable to the effective integration of CHW programs.

### **Significance of the current investigation**

This study investigates the challenges of CHW integration from the perspectives of stakeholders engaging with PLWH in St. Louis, Missouri. The stakeholders' involvement and contributions to the research process ensure that findings are grounded in the lived experiences and knowledge of those directly impacted by the challenges being explored. Because St. Louis is a major metropolitan area with high HIV burdens and significant intersectional disparities and challenges stemming from a long history of structural racism and economic inequities, this study provides insights for the challenges encountered in various regions across the United States, especially in areas with diverse demographics and communities facing stigma, discrimination, and other obstacles to accessing services.

While regional contexts in St. Louis may not be the same as those in other areas across the country, the lessons learned from this study can inform the design and implementation of CHW programs in other cities that share similar characteristics and challenges related to structural inequities, healthcare disparities, and the need for community-based solutions. The findings and solutions offered by this study remain relevant and generalizable, offering useful insights into the challenges of integrating CHWs into a hierarchical health system. The findings can help build CHW-centered implementation strategies for HIV/AIDS outreach and care, as well as guide policies and interventions focused on addressing structural barriers and promoting health equity in a variety of urban contexts.

## Limitations

This study should be interpreted considering its limitations. The recruitment of community leaders, clinical providers, and front-line health workers for interviews and focus groups may introduce social desirability bias, as participants could provide responses they perceive to be socially desirable or expected. This may result in an over-optimistic or critical portrayal of the existing CHW intervention.

The small sample size of community leaders and clinical providers interviewed may limit the robustness and generalizability of the findings, particularly for the clinical leader group. Recruiting clinical providers proved more difficult than recruiting other stakeholder groups, and two of the four providers interviewed had limited experience with peer-led interventions in their clinics. Consequently, the study's findings may not be fully representative of the broader population of clinical providers. While the study aims to capture the challenges of CHW integration at a more institutional and systemic level, it also records participants' concerns regarding challenges at an individual level. It is important to consider these limitations when interpreting the study's findings and applying them to the broader context of CHW interventions.

## Conclusions

In this study, we examined the challenges related to utilizing Community Health Workers (CHWs) for HIV care in St. Louis, as reported by community leaders, front-line health workers, and clinical providers. We identified six key challenges: constraints on CHWs' scope of practice, an unsustainable CHW workforce, obstacles in establishing professional relationships, structural racism in healthcare, the dominance of the hierarchical Western European model in HIV/AIDS care, and inconsistent momentum and consistency in CHW program implementation efforts.

Our findings revealed four recurring themes, including unclear and undervalued CHW roles, lack of necessary infrastructure for a sustainable CHW workforce, power dynamics within the hierarchical Western healthcare system, and structural racism perpetuating regional racialized trauma. These themes underscore the complexity and interconnectedness of the challenges faced in integrating CHWs and promoting equity and inclusivity in healthcare delivery.

The present investigation focused on a segment of the qualitative findings from Project STEER's intervention planning process. Qualitative research offers a platform for documenting and preserving the narratives, experiences, and viewpoints of underrepresented communities. Given the richness of responses regarding the challenges of integrating CHWs, we chose to specifically focus on this topic to ensure a comprehensive and nuanced portrayal of participants' stories and perspectives.

Additional analyses are required to examine other themes addressed within the qualitative data, such as barriers and facilitators to HIV care, recommendations for employing CHWs, and the exploration of distinct contexts that shape individual participants' experiences and viewpoints.

By combining the insights from this study with future research findings, we aim to inform the adaptation of the CHW intervention in St. Louis, enhancing its effectiveness, equity, and sustainability. Ultimately, this comprehensive understanding will contribute to improved HIV care outcomes within the region and beyond.



## REFERENCE

- [1] Javanparast, S., Windle, A., Freeman, T., & Baum, F. (2018). Community Health Worker Programs to Improve Healthcare Access and Equity: Are They Only Relevant to Low- and Middle-Income Countries?. *International journal of health policy and management*, 7(10), 943–954. <https://doi.org/10.15171/ijhpm.2018.53>
- [2] Kangovi, S., Mitra, N., Grande, D., Huo, H., Smith, R. A., & Long, J. A. (2017). Community health worker support for disadvantaged patients with multiple chronic diseases: A randomized clinical trial. *American Journal of Public Health*, 107(10), 1660-1667. doi: 10.2105/AJPH.2017.303980
- [3] Malcarney, M. B., Pittman, P., Quigley, L., Horton, K., & Seiler, N. (2017). The Changing Roles of Community Health Workers. *Health services research*, 52 Suppl 1(Suppl 1), 360–382. <https://doi.org/10.1111/1475-6773.12657>
- [4] Perry, H. B., Zulliger, R., & Rogers, M. M. (2014). Community health workers in low-, middle-, and high-income countries: an overview of their history, recent evolution, and current effectiveness. *Annual review of public health*, 35, 399-421.
- [5] Gómez, C. A., Tat, S. A., Allen, D., Gordon, D., & Browe, D. (2017). What will it take to end the HIV/AIDS epidemic? Linking the most disenfranchised into care through outreach. *AIDS patient care and STDs*, 31(3), 122-128.
- [6] Collinsworth A. W., Vulimiri M., Schmidt K. L., Snead C. A. (2013). Effectiveness of a community health worker-led diabetes self-management education program and implications for CHW involvement in care coordination strategies. *Diabetes Educator*, 39, 792-799.
- [7] Findley, S., Matos, S., Hicks, A., Chang, J., & Reich, D. (2014). Community health worker integration into the health care team accomplishes the triple aim in a patient-centered medical home: a Bronx tale. *The Journal of ambulatory care management*, 37(1), 82–91. <https://doi.org/10.1097/JAC.0000000000000011>
- [8] Johnson, S. L., & Gunn, V. L. (2015). Community Health Workers as a Component of the Health Care Team. *Pediatric clinics of North America*, 62(5), 1313–1328. <https://doi.org/10.1016/j.pcl.2015.06.004>
- [9] Martinez LS, Davoust M, Rajabiun S, Baughman A, Bachman SS, Bowers- Sword R, et al. “Part of getting to where we are is because we have been open to change” integrating community health workers on care teams at ten Ryan White HIV/AIDS program recipient sites. *BMC Public Health*. (2021) 21:1–11. doi: 10.1186/s12889-021-10943-1
- [10] Wennerstrom, A., Hargrove, L., Minor, S., Kirkland, A. L., & Shelton, S. R. (2015). Integrating Community Health Workers Into Primary Care to Support Behavioral Health

- Service Delivery: A Pilot Study. *The Journal of ambulatory care management*, 38(3), 263–272. <https://doi.org/10.1097/JAC.0000000000000087>
- [11] Centers for Disease Control and Prevention. (2020). HIV surveillance report, 2019 (32), 123.
- [12] Office of Infectious Disease and HIV/AIDS Policy. (2021, June 2). About Ending the HIV Epidemic in the US. HIV.gov. <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview>
- [13] Khazanchi R, Sayles H, Bares SH, Swindells S, Marcelin JR. Neighborhood Deprivation and Racial/Ethnic Disparities in Human Immunodeficiency Virus Viral Suppression: A Single-center, Cross-sectional Study in the United States Midwest. *Clin Infect Dis*. 2021;72(10):e642-e645. doi:10.1093/cid/ciaa1254
- [14] Missouri Department of Health and Senior Services. (2021). Ending the HIV epidemic A plan for Missouri <https://health.mo.gov/living/healthcondiseases/communicable/hivaids/pdf/ending-draft-plan.pdf>
- [15] Missouri Department of Health and Senior Services. (2021). Epidemiologic Profiles of HIV, STD, and Hepatitis in Missouri 2021. <https://health.mo.gov/data/hivstdaids/pdf/mo-hiv-std-2021.pdf>
- [16] Missouri Department of Health and Senior Services. (2021). Missouri HIV care continuum. <https://health.mo.gov/data/hivstdaids/pdf/2021-hiv-continuum-care.pdf>
- [17] Centers for Disease Control and Prevention. (2019). Understanding the HIV Care Continuum. <https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf>
- [18] Algarin, A. B., Sheehan, D. M., Varas-Diaz, N., et al. (2020). Health care-specific enacted HIV-related stigma's association with antiretroviral therapy adherence and viral suppression among people living with HIV in Florida. *AIDS Patient Care and STDs*, 34(7), 316-326. <https://doi.org/10.1089/apc.2020.0031>
- [19] Joint United Nations Programme on HIV/AIDS (UNAIDS). (2018). 90–90–90: An ambitious treatment target to help end the AIDS epidemic. <https://www.unaids.org/en/resources/909090>
- [20] AIDSVu. (n.d.). Missouri HIV data. <https://aidsvu.org/local-data/united-states/midwest/missouri/>
- [21] Fauci AS, Redfield RR, Sigounas G, Weahkee MD, Giroir BP. Ending the HIV Epidemic: A Plan for the United States. *JAMA*. 2019;321(9):844–5. doi: 10.1001/jama.2019.1343.
- [22] Doorways. (n.d.). History & mission. <https://doorwayshousing.org/about/history-mission/>

- [23] PROMO. (n.d.). Saint Louis Effort for AIDS. <https://promoonline.org/organizations/saint-louis-effort-for-aids/>
- [24] Washington University Infectious Diseases Clinic. (n.d.). Our partners. <https://hiv.wustl.edu/about-us/our-partners/>
- [25] St. Louis County Department of Public Health. (n.d.). Sexual Health Resources. <https://stlouiscountymo.gov/st-louis-county-departments/public-health/sexual-health/>
- [26] City of St. Louis. (n.d.). St. Louis Regional HIV Health Services Planning Council. <https://www.stlouis-mo.gov/government/boards/public-board-detail.cfm?groupID=840917319>
- [27] Health Resources and Services Administration. (2019). Ryan White HIV/AIDS Program Part A manual. <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/resources/manual-part.pdf>
- [28] Kimmel AD, Martin EG, Galadima H, et al. Clinical outcomes of HIV care delivery models in the US: a systematic review. *AIDS Care*. 2016;28(10):1215-1222. doi:10.1080/09540121.2016.1178702
- [29] Scott K, Beckham SW, Gross M, et al. What do we know about community-based health worker programs? A systematic review of existing reviews on community health workers. *Hum Resour Health*. 2018;16(1):39. doi:10.1186/s12960-018-0304-x
- [30] Cabral HJ, Davis-Plourde K, Sarango M, Fox J, Palmisano J, Rajabiun S. Peer Support and the HIV Continuum of Care: Results from a Multi-Site Randomized Clinical Trial in Three Urban Clinics in the United States. *AIDS Behav*. 2018;22(8):2627-2639. doi:10.1007/s10461-017-1999-8
- [31] Shacham E, López JD, Brown TM, Tippit K, Ritz A. Enhancing Adherence to Care in the HIV Care Continuum: The Barrier Elimination and Care Navigation (BEACON) Project Evaluation. *AIDS Behav*. 2018;22(1):258-264. doi:10.1007/s10461-017-1819-1
- [32] Geter A, Sutton MY, Hubbard McCree D. Social and structural determinants of HIV treatment and care among black women living with HIV infection: a systematic review: 2005–2016. *AIDS Care*. 2018;30(4):409-416. doi:10.1080/09540121.2018.1426827
- [33] Aidala AA, Wilson MG, Shubert V, et al. Housing Status, Medical Care, and Health Outcomes Among People Living With HIV/AIDS: A Systematic Review. *Am J Public Health*. 2016;106(1):e1-e23. doi:10.2105/AJPH.2015.302905
- [34] Soto TA, Bell J, Pillen MB, For The Hiv/aids Treatment Adherence HOACSG. Literature on integrated HIV care: a review. *AIDS Care*. 2004;16(sup1):43-55. doi:10.1080/09540120412331315295

- [35] Fadul N, Regan N, Kaddoura L, Swindells S. A Midwestern Academic HIV Clinic Operation during the COVID-19 Pandemic: Implementation Strategy and Preliminary Outcomes. *J Int Assoc Provid AIDS Care JIAPAC*. 2021;20:23259582211041424. doi:10.1177/23259582211041423
- [36] Wood BR, Lan KF, Tao Y, et al. Visit Trends and Factors Associated With Telemedicine Uptake Among Persons With HIV During the COVID-19 Pandemic. *Open Forum Infect Dis*. 2021;8(11):ofab480. doi:10.1093/ofid/ofab480
- [37] Mayer JE, Fontelo P. Meta-analysis on the effect of text message reminders for HIV-related compliance. *AIDS Care*. 2017;29(4):409-417. doi:10.1080/09540121.2016.1214674
- [38] Marhefka SL, Lockhart E, Turner D, et al. Social Determinants of Potential eHealth Engagement Among People Living with HIV Receiving Ryan White Case Management: Health Equity Implications from Project TECH. *AIDS Behav*. 2020;24(5):1463-1475. doi:10.1007/s10461-019-02723-1
- [39] Shacham E, Stamm K, Overton ET. Can you hear me now? Limited use of technology among an urban HIV-infected cohort. *AIDS Care*. 2009;21(8):1000-1006. doi:10.1080/09540120802612832
- [40] Calvert JK, Aidala AA, West JH. An Ecological View of Internet Health Information Seeking Behavior Predictors: Findings from the CHAIN Study. *Open AIDS J*. 2013;7:42-46. doi:10.2174/1874613601307010042
- [41] Balcazar H, Lee Rosenthal E, Nell Brownstein J, Rush CH, Matos S, Hernandez L. Community health workers can be a public health force for change in the United States: three actions for a new paradigm. *Am J Public Health*. (2011) 101:2199–03 doi: 10.2105/AJPH.2011.300386
- [42] Rosenthal EL.,Brownstein JN, Rush CH, Hirsch G. R, Willaert AM, Scott JR, et al. Community health workers: part of the solution. *Health Affairs*. (2010) 29:1338–1342. doi: 10.1377/hlthaff.2010.0081
- [43] Lohr, A. M., Ingram, M., Nuñez, A. V., Reinschmidt, K. M., & Carvajal, S. C. (2018). Community–clinical linkages with community health workers in the United States: a scoping review. *Health promotion practice, 19*(3), 349-360.
- [44] Brownstein, J. N., Chowdhury, F. M., Norris, S. L., Horsley, T., Jack, L., Zhang, X., & Satterfield, D. (2007). Effectiveness of community health workers in the care of people with hypertension.
- [45] Bombard, Y., Baker, G. R., Orlando, E., Fancott, C., Bhatia, P., Casalino, S., ... & Pomey, M. P. (2018). Engaging patients to improve quality of care: a systematic review. *Implementation Science, 13*(1), 1-22.

- [46] Krentz, H. B., McPhee, P., Arbess, G., Jackson, L., Stewart, A. M., Bois, D., & Rourke, S. B. (2021). Reporting on patients living with HIV “disengaging from care”. Who is actually “lost to follow-up”? *AIDS care*, 33(1), 114-120
- [47] TargetHIV. *Using Community Health Workers to Improve Linkage and Retention in Care*. Available from: <https://targethiv.org/chw>
- [48] Jack, H. E., Arabadjis, S. D., Sun, L., Sullivan, E. E., & Phillips, R. S. (2017). Impact of community health workers on use of healthcare services in the United States: a systematic review. *Journal of general internal medicine*, 32(3), 325-344.
- [49] Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: The intersection of science and practice to improve health equity
- [50] Coughlin S. S. (2016). Community-Based Participatory Research Studies on HIV/AIDS Prevention, 2005-2014. *Jacobs journal of community medicine*, 2(1), 019.
- [51] M. Khair ElZarrad, Erin T. Eckstein, Russell E. Glasgow, Applying Chronic Illness Care, Implementation Science, and Self-Management Support to HIV, *American Journal of Preventive Medicine*, Volume 44, Issue 1, Supplement 2, 2013, Pages S99-S107, ISSN 0749-3797, <https://doi.org/10.1016/j.amepre.2012.09.046>.
- [52] Drahota, A., Meza, R. D., Brikho, B., Naaf, M., Estabillo, J. A., Gomez, E. D., ... & Aarons, G. A. (2016). Community-Academic Partnerships: A Systematic Review of the State of the Literature and Recommendations for Future Research.
- [53] Zakus, J. D., & Lysack, C. L. (1998). Revisiting community participation. *Health policy and planning*, 13(1), 1–12. <https://doi.org/10.1093/heapol/13.1.1>
- [54] Laverack, G., & Labonte, R. (2000). A planning framework for community empowerment goals within health promotion. *Health policy and planning*, 15(3), 255–262. <https://doi.org/10.1093/heapol/15.3.255>
- [55] Campbell, C., & Cornish, F. (2012). How can community health programmes build enabling environments for transformative communication? Experiences from India and South Africa. *AIDS and behavior*, 16(4), 847–857. <https://doi.org/10.1007/s10461-011-9966-2>
- [56] Nevedal, A. L., Reardon, C. M., Opra Widerquist, M. A., Jackson, G. L., Cutrona, S. L., White, B. S., & Damschroder, L. J. (2021). Rapid versus traditional qualitative analysis using the Consolidated Framework for Implementation Research (CFIR). *Implementation science : IS*, 16(1), 67. <https://doi.org/10.1186/s13012-021-01111-5>
- [57] Beebe, J. (2001). *Rapid Assessment Process: An Introduction*. AltaMira Press.

- [58] Westgate, C., Musoke, D., Crigler, L. *et al.* Community health workers at the dawn of a new era: 7. Recent advances in supervision. *Health Res Policy Sys* **19** (Suppl 3), 114 (2021). <https://doi.org/10.1186/s12961-021-00754-6>
- [59] Smithwick, J., Nance, J., Covington-Kolb, S., Rodriguez, A., & Young, M. (2023). "Community health workers bring value and deserve to be valued too:" Key considerations in improving CHW career advancement opportunities. *Frontiers in public health*, *11*, 1036481. <https://doi.org/10.3389/fpubh.2023.1036481>
- [60] Baines, D., Dulhunty, A., & Charlesworth, S. (2021, January 31). Relationship-Based Care Work, Austerity and Aged Care. *Work, Employment and Society*, *36*(1), 139–155. <https://doi.org/10.1177/0950017020980985>
- [61] Barbero C, Mason T, Rush C, Sugarman M, Bhuiya AR, Fulmer EB, Feldstein J, Cottoms N and Wennerstrom A (2021) Processes for Implementing Community Health Worker Workforce Development Initiatives. *Front. Public Health* 9:659017. doi: 10.3389/fpubh.2021.659017
- [62] McCarville, E.E., Martin, M.A., Pratap, P.L. *et al.* Understanding the relationship between care team perceptions about CHWs and CHW integration within a US health system, a qualitative descriptive multiple embedded case study. *BMC Health Serv Res* **22**, 1587 (2022). <https://doi.org/10.1186/s12913-022-08723-7>
- [63] Sud, A., Hodgson, K., Bloch, G., & Upshur, R. (2021, August 28). A Conceptual Framework for Continuing Medical Education and Population Health. *Teaching and Learning in Medicine*, *34*(5), 541–555. <https://doi.org/10.1080/10401334.2021.1950540>
- [64] Rosen, M. A., DiazGranados, D., Dietz, A. S., Benishek, L. E., Thompson, D., Pronovost, P. J., & Weaver, S. J. (2018). Teamwork in healthcare: Key discoveries enabling safer, high-quality care. *The American psychologist*, *73*(4), 433–450. <https://doi.org/10.1037/amp0000298>
- [65] Gurses, A. P., & Xiao, Y. (2006). A systematic review of the literature on multidisciplinary rounds to design information technology. *Journal of the American Medical Informatics Association : JAMIA*, *13*(3), 267–276. <https://doi.org/10.1197/jamia.M1992>
- [66] Horberg, M. A., Hurley, L. B., Towner, W. J., Allerton, M. W., Tang, B. T., Catz, S. L., Silverberg, M. J., & Quesenberry, C. P. (2012). Determination of optimized multidisciplinary care team for maximal antiretroviral therapy adherence. *Journal of acquired immune deficiency syndromes (1999)*, *60*(2), 183–190. <https://doi.org/10.1097/QAI.0b013e31824bd605>
- [67] Sprague C, Simon SE. Understanding HIV care delays in the US South and the role of the social-level in HIV care engagement/retention: A qualitative study. *International Journal for Equity in Health* 2014;13:28.

- [68] Bogart LM, Wagner GJ, Mutchler MG, Risley B, McDavitt BW, McKay T, et al. Community HIV treatment advocacy programs may support treatment adherence. *AIDS Education and Prevention* 2012;24(1):1-14.
- [69] Vincent, W., Sevelius, J., Lippman, S. A., Linnemayr, S., & Arnold, E. A. (2019). Identifying Opportunities for Collaboration Across the Social Sciences to Reach the 10-10-10: A Multilevel Approach. *Journal of acquired immune deficiency syndromes (1999)*, 82 Suppl 2(2), S118–S123. <https://doi.org/10.1097/QAI.0000000000002170>
- [70] Taylor, B. S., Fornos, L., Tarbuton, J., Muñoz, J., Saber, J. A., Bullock, D., Villarreal, R., & Nijhawan, A. E. (2018). Improving HIV Care Engagement in the South from the Patient and Provider Perspective: The Role of Stigma, Social Support, and Shared Decision-Making. *AIDS patient care and STDs*, 32(9), 368–378. <https://doi.org/10.1089/apc.2018.0039>