

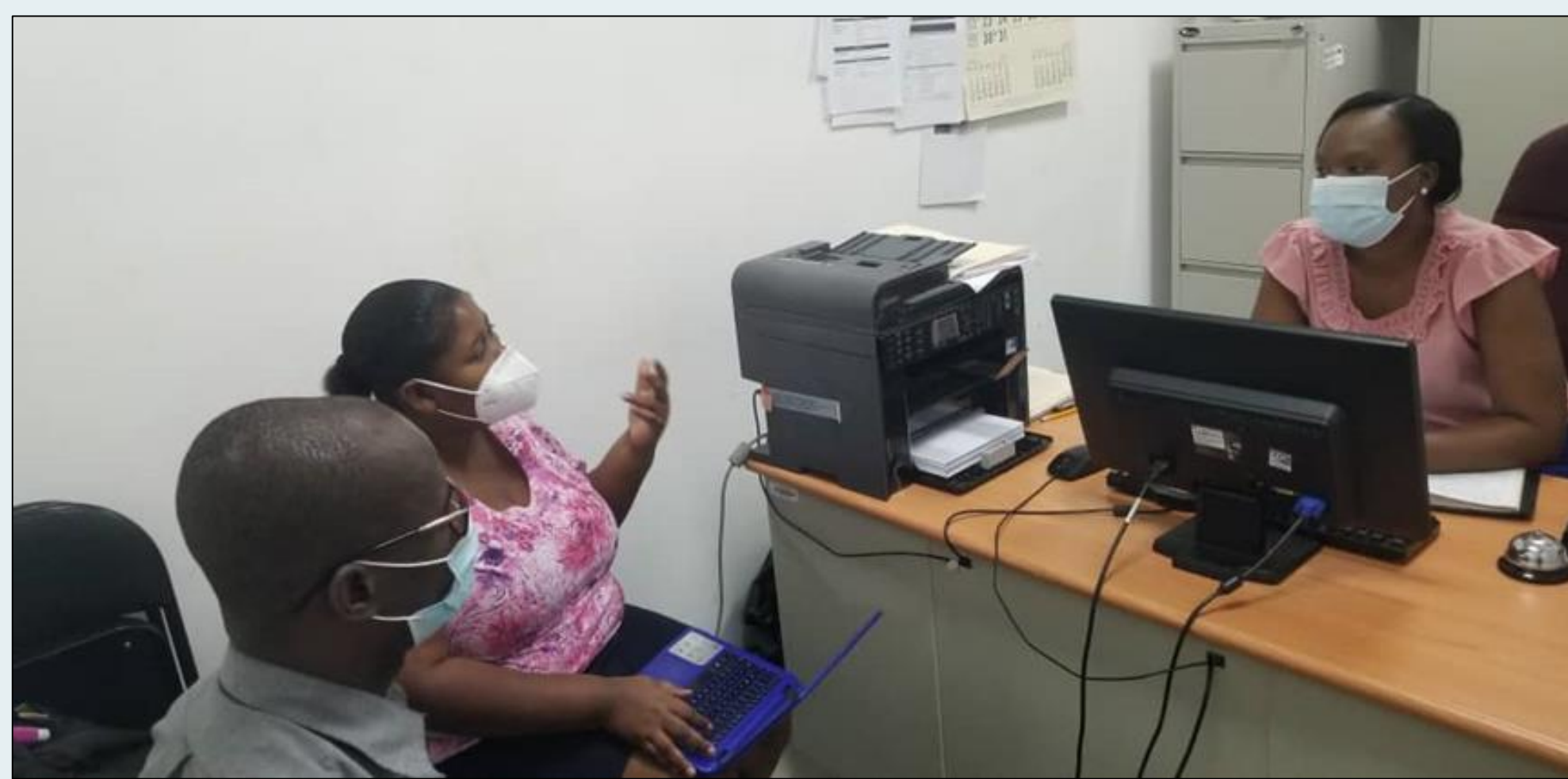
Barriers impeding care for people living with HIV: Early findings from Community-Led Monitoring in Haiti

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Introduction

Community-led monitoring (CLM) is an emerging and powerful approach to improving the quality of healthcare services for people with HIV (PWH), and members of key populations (KP) and other affected groups. CLM consists of a routine cycle of civil society-led monitoring and advocacy to continuously support the HIV program in improving services for PWH and promote accountability to communities and service users.

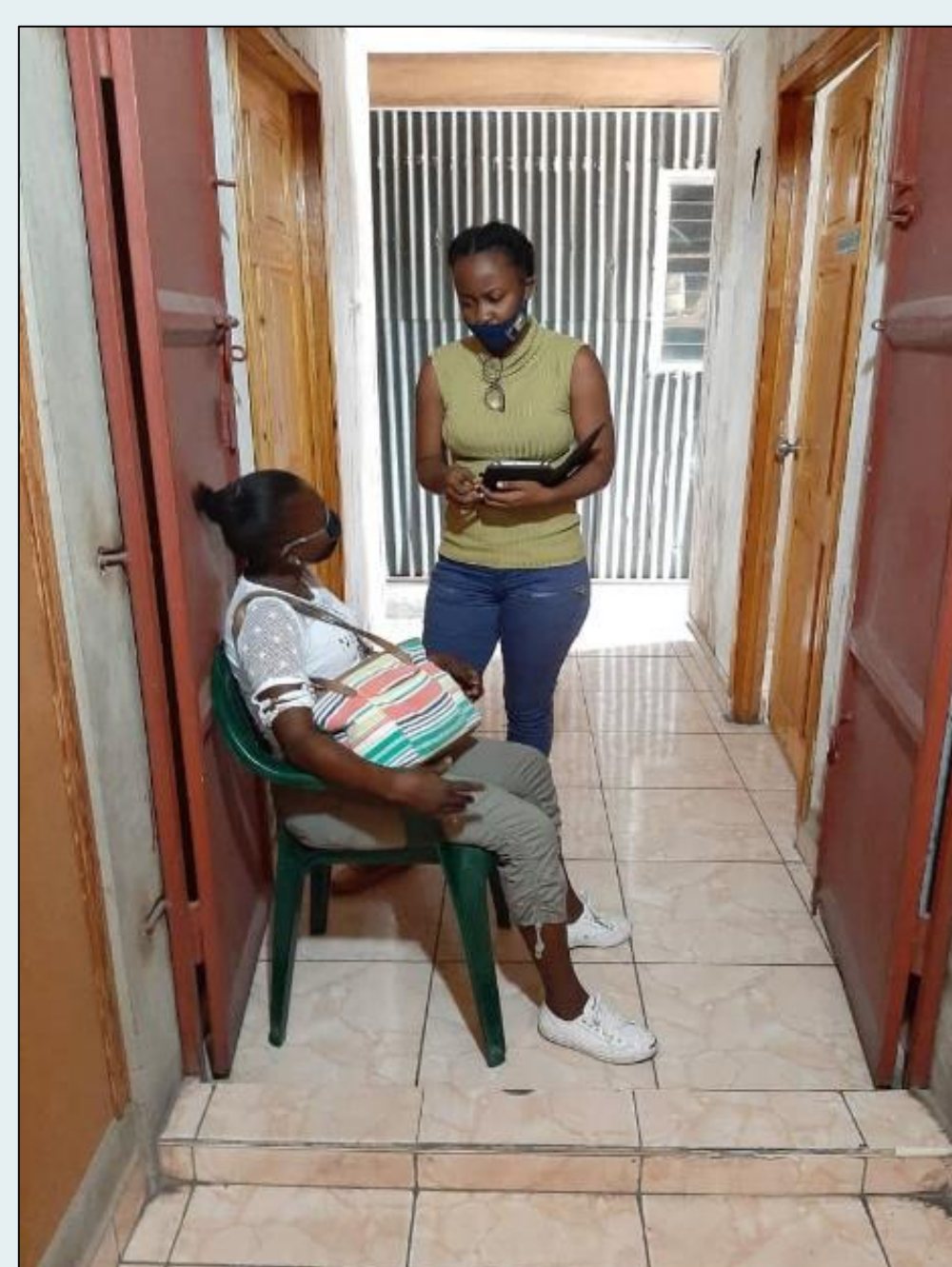


In 2019, representatives of the Haitian Civil Society Forum, led an advocacy campaign for the establishment of CLM in Haiti. This effort, supported by UNAIDS, Housing Works, and other global activists, led to the successful launch in December 2020 of one of the first PEPFAR-supported CLM projects. After a successful pilot, the project has been gathering facility- and community-level data and conducting advocacy since 2021.

The initial findings of the CLM project present an assessment of the quality of HIV services and care in Haiti, based on data collected by community monitors in health facilities and communities. This analysis describes both barriers to care and enablers of engagement in HIV services. These findings provide an important roadmap for improving the quality of service delivery and care in HIV facilities in Haiti, with concrete recommendations for the public health system, their implementing partners, international donors, health care providers, and other stakeholders.

Description and methods

Surveys were conducted in 41 healthcare facilities in the Nord, Artibonite, and Ouest departments from April to June 2021, including 41 observation-based surveys of facilities, 41 facility manager interviews, and 980 patient surveys (including 689 PWH). Data were collected by a team mainly composed of PWH and KP community monitors. Separately, 6 focus groups and 45 semi-structured individual interviews were conducted in the broader community. Qualitative data were analyzed using a thematic codebook developed by the monitors and other CLM team members.



Conclusions

Barriers to care for PLHIV and key populations in Haiti are deep and numerous. Services will never be of good quality without continuous monitoring of quality in clinics and in the community. This advocacy to introduce and cultivate better quality services, led by and for the community and all patients, is just beginning. The CLM Haiti structure will continue to make the voices of the voiceless heard so that all patients know that they are entitled to the best services in the establishments, and that it is not because they are PLHIV or members of key population that they have to endure daily humiliations, invasions of privacy and insults from health workers and other staff who work in the clinics.



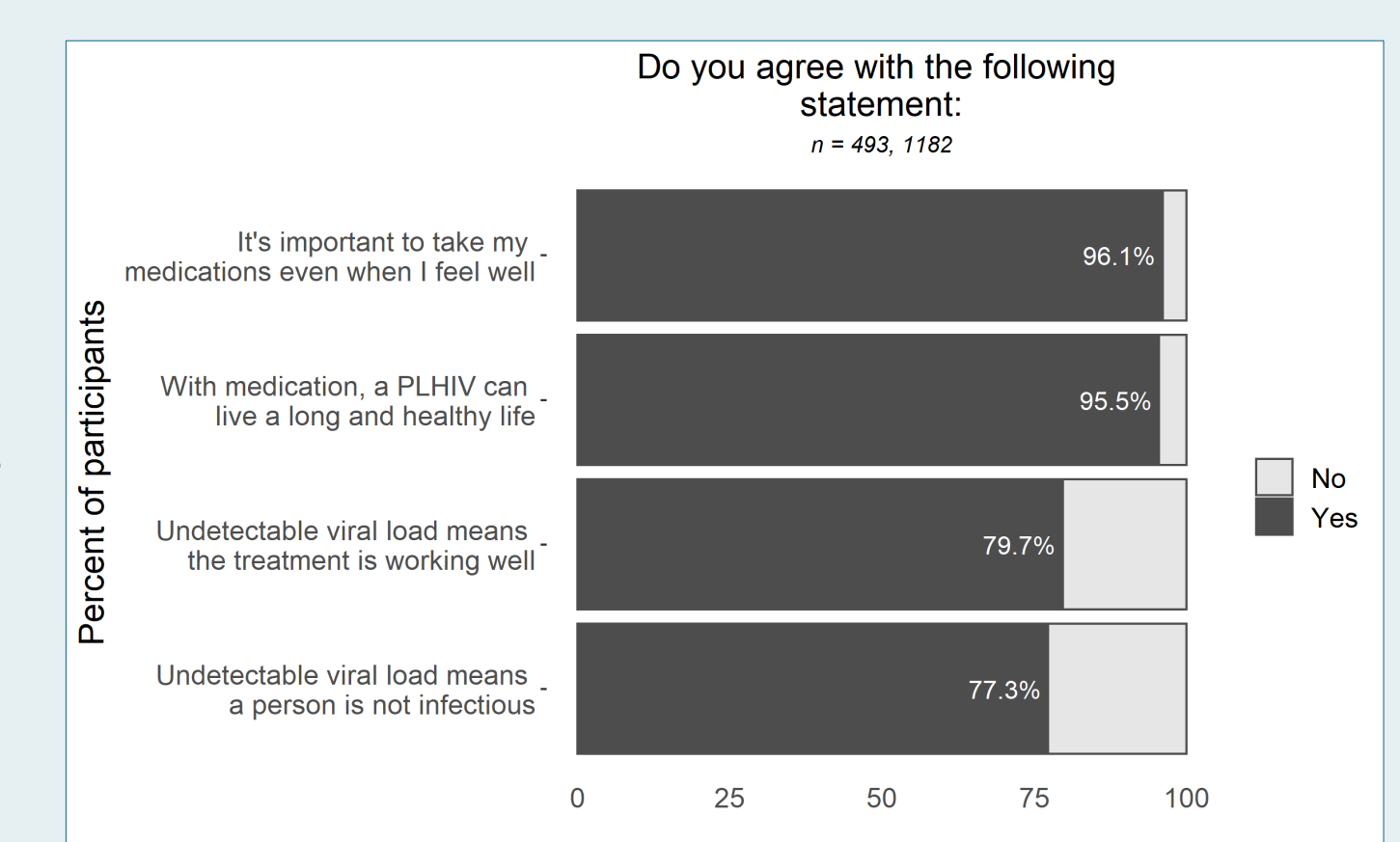
Lessons Learned

High patient literacy, but gaps in awareness of some services

According to 493 surveyed respondents, 96% know the importance of taking their medications even when feeling well and 96% know that people living with HIV (PLHIV) can live a long and healthy life (Fig. 1). Out of 1,182 respondents, 77% knew about U=U.

While participants knew the importance of treatment, many patients were not aware of key clinical and support services. Although 94% of facility managers report that their clinic offers adherence clubs, only 55% of patients knew they existed. Similarly, although 46% of facility managers said their clinics offered PrEP, only one-quarter of patients surveyed had ever heard of the medication.

Figure 1. Survey responses on measures of treatment literacy



Reports of rude and abusive behavior from staff & privacy violations

Figure 2. Advocates conducting visits with clinics to propose solutions to problems identified during data collection



Respondents in clinics described facility staff as being friendly (95%) and professional (84%). However, in interviews and focus groups outside of clinics, 28 respondents described rude or abusive behavior from clinic staff.

Respondents described having limited recourse when mistreated by staff. Only 28% of clinics surveyed had a complaint box for patients to report concerns. Transfers were frequently described as a way of finding care, although 28% of respondents did not feel comfortable requesting a transfer. Interview and focus group participants described denial of transfer requests, giving way to patient transfers without approval, often described as "silent transfers".

"Yes, I have been humiliated, mistreated, disrespected and denigrated."
- Focus group respondent

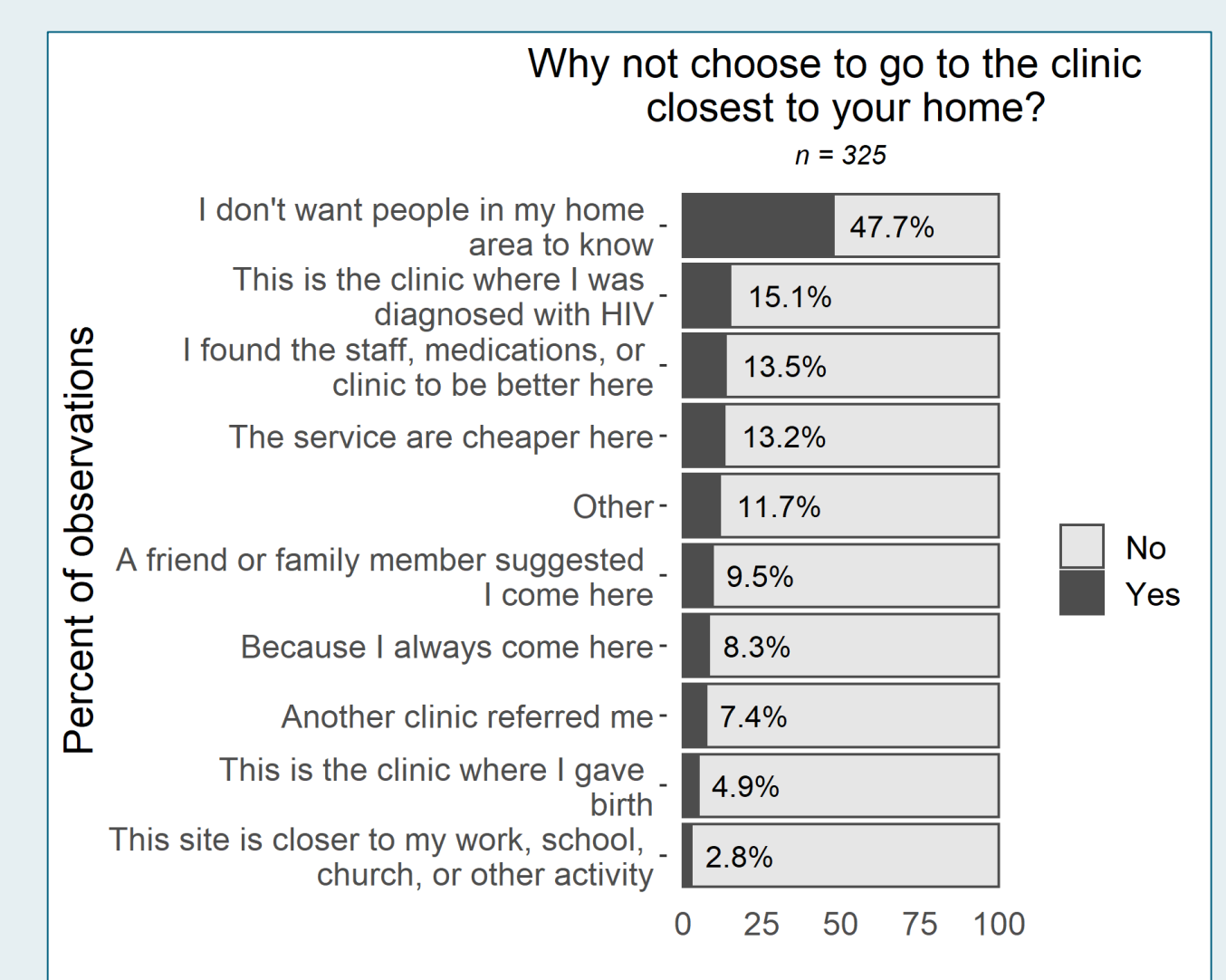
Patients travel long distances to care to avoid privacy violations

Among surveyed respondents, 60% travel long distances to travel to the clinic, with 57% traveling more than one hour. Although 53% of those traveling from far away have clinics closer to home, they primarily avoid nearby clinics to avoid being seen by people they know (Fig. 3).

In interviews and focus groups, respondents commonly described fears of their private health information being released. A primary driver of privacy violations was the separation of PLHIV from other patients in clinic spaces, described by 18 respondents as being inappropriate, contributing to stigma and disclosure, and a driver of clients abandoning clinic-based care.

The delivery of medications to people at home can reduce travel and wait times for PLHIV. However, only 63% of patients were aware of delivery services. The most common reason for choosing not to have medications delivered were concerns about confidentiality.

Figure 3. Reasons respondents choose to travel to more distant clinics



Incentives are inconsistent or insufficient

In interviews and focus groups, respondents described the importance of clinics providing small incentives to patients, such as food or money. Several respondents described discontinuing treatment because of not having food to take the medication.

While 94% of respondents reported receiving reimbursement for travel costs, these were frequently described as being insufficient or not consistently available. Only 20% receive food or meals.

While PLHIV do not pay for HIV treatment in Haiti, 5% of surveyed respondents described paying for some services. In interviews, participants described the need for free wraparound services for PLHIV.



Acknowledgements

We thank all those who have understood that civil society organizations can play an important role in advocating for the improvement of the quality of services in clinics. We thank the global activists, members of Haitian civil society organizations, and Housing Works for their advocacy for CLM in Haiti. We especially thank PEPFAR for understanding the importance of community monitoring in the process of improving the quality of services in clinics and for making funds available to start funding this project in Haiti. Our thanks also go to UNAIDS, OAS, and our technical partners O'Neill Institute and Health GAP, who helped implement



This project, and Housing Works, who ensure the implementation by advancing funds to facilitate the timely completion of activities. Our thanks also go to the member organizations of the Civil Society Forum. We thank the healthcare networks that are beginning to work together to improve the delivery of better services and to the community and patients who are willing to support us in collecting data for analysis for the CLM.