

# Breaking barriers: Using evidence from a Community Treatment Observatory (CTO) to enhance uptake of HIV services in Sierra Leone

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**SUMMARY**

Sierra Leone has a low HIV prevalence (1.5 per cent) but is faced with low uptake of HIV services, including testing, treatment, and treatment monitoring. The Network of HIV Positives in Sierra Leone (NETHIPS) established a Community Treatment Observatory (CTO) with support from its partners to generate evidence and engage duty bearers in improving service delivery. The CTO provides the unique advantage of galvanising efforts of civil society actors and affected populations on ways to tackle new infections and improve care for selected key populations in Sierra Leone.

**Key Words**

Community Treatment Observatory; People living with HIV; PLHIV; HIV support group; Sierra Leone

## INTRODUCTION

Uptake of HIV services is critical in responding to HIV as a global public health problem. This suggests that people should be able to test, receive antiretroviral treatment, and monitor their treatment outcomes in a conducive, social, and legal environment.<sup>1</sup> Additionally, the health system should be resilient and responsive to the needs of people that access HIV services. Control of any epidemic becomes difficult when health service delivery and uptake are challenged.<sup>2</sup> To complement efforts of the National AIDS Control Programme in Sierra Leone, a Community Treatment Observatory (CTO) was established through a three-year project funded by the Global Fund with International Treatment Preparedness Coalition (ITPC) as the principal recipient. The CTO is a community-monitoring mechanism that systematically collects data on stock out of antiretroviral therapy and monitors trends on treatment access along the HIV cascade for targeted action. It is led by People Living with HIV (PLHIV) to improve access to quality treatment and uninterrupted access to HIV services in Sierra Leone.

## DESIGN SUMMARY

In addition to low coverage in testing and treatment, health and community systems required for delivery of HIV services remain weak leading to low uptake of HIV services in Sierra Leone.<sup>3</sup> Specifically, adult HIV prevalence stands at 1.5 per cent<sup>4</sup> in a population estimated at 7 million. This suggests that 61,000 people are living with HIV in Sierra Leone. Out of 61,000 PLHIV, only 47 per cent know their HIV status, and only 39 per cent of those who know their status received treatment in 2017.<sup>5</sup> This suggests that Sierra Leone has to do more to achieve the UNAIDS “90–90–90” ambitious targets by 2020: 90 per cent of PLHIV will know their HIV status; 90 per cent of these PLHIV will receive sustained antiretroviral therapy; and 90 per cent of all PLHIV receiving antiretroviral therapy will achieve viral suppression.

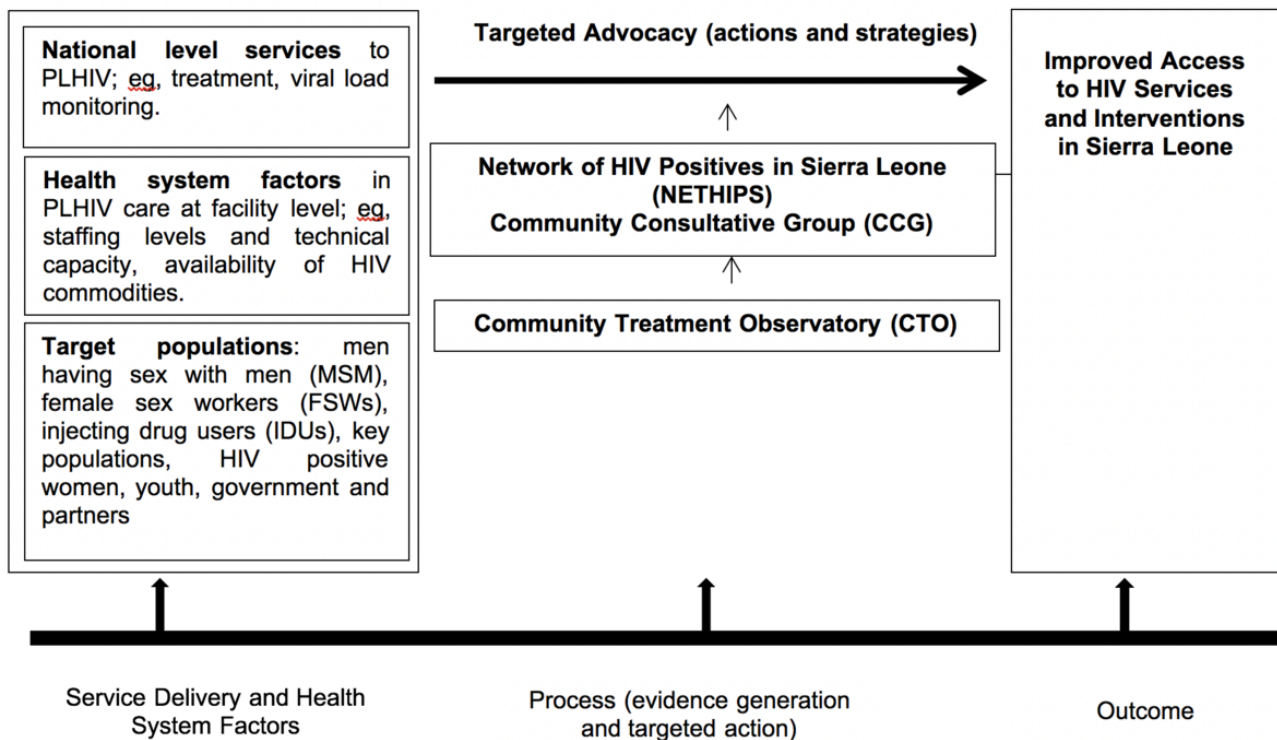
The Community Treatment Observatory was established to enhance the awareness of recipients on delivery of HIV services through collecting and analysing data from health facilities about treatment access trends along the HIV cascade of care. A population sample of 10 per cent of HIV patients on treatment in Sierra Leone was targeted through selection

of three key population drop-in centers and 17 conventional health facilities providing HIV services in the Western Area Districts of Sierra Leone.

Twelve volunteers were selected from PLHIV support groups within the designated catchment area and trained to collect data monthly from the selected health facilities using data collection tools developed by ITPC. Three of the data collectors were appointed unanimously as team leaders to provide field support and ensure data quality. The health facilities covered in the intervention were put into three zones, each zone manned by a team leader who received, validated, and submitted field data to the National Focal Person, who further scrutinised data before analysis to produce a quarterly Community Treatment Observatory report. In addition, the quarterly Community Treatment Observatory report is forwarded to the Community Consultative Group (CCG), which comprises key selected strategic stakeholders in the national HIV response. These include representatives of People Living with HIV and targeted key and priority population groups, namely, men who have sex with men, sex workers, injecting drug users, pregnant women, and young people (aged 15–24 years). It is important to note that institutions operating in the HIV response (eg, National AIDS Secretariat, National AIDS Control Programme, UNAIDS) were co-opted into the CCG by NETHIPS based on their technical expertise in health and community systems strengthening, ability to drive advocacy and influence policy, and willingness to voluntarily participate in the CCG forums.

The CCG meets quarterly to interrogate CTO reports, and discuss and prioritise advocacy issues and strategies. The purpose of the meeting is to position the CCG strategically to engage relevant authorities, including policy makers on HIV treatment access trends evidenced. The CCG is guided by a terms of reference that was developed by NETHIPS and validated by the CCG members. The operations of the CTO were designed to engage in targeted advocacy pursued by the CCG as depicted in Figure 1.

Figure 1: Framework/Design–Community Treatment Observatory (CTO), Sierra Leone



### LESSONS LEARNED

The CTO has been successful in generating evidence on treatment access trends and has provided opportunities for PLHIV and key populations to engage duty bearers and key opinion leaders on improving access to quality, uninterrupted HIV treatment in Sierra Leone. Although practices/activities of key populations are criminalised in

Sierra Leone,<sup>6</sup> evidence from the CTO galvanises actors, including civil society organizations, on ways to tackle new HIV infections and improve services within the cascade of care for key and priority populations in Sierra Leone. The CTO has demonstrated that a patient-led approach in monitoring HIV services enhances dialogue between service providers and service users on ways to improve care.

By end of year one (June 2017 to May 2018), there was an increase in the uptake of HIV services by the key and prioritised patient populations at the health facilities. For example, the data shows that HIV testing and treatment uptake increased among MSM, IDU, pregnant women, and youth (15-24) from baseline (Figures 2 and 3).<sup>7</sup>

Figure 2: Comparison of HIV testing at baseline and end of year 1

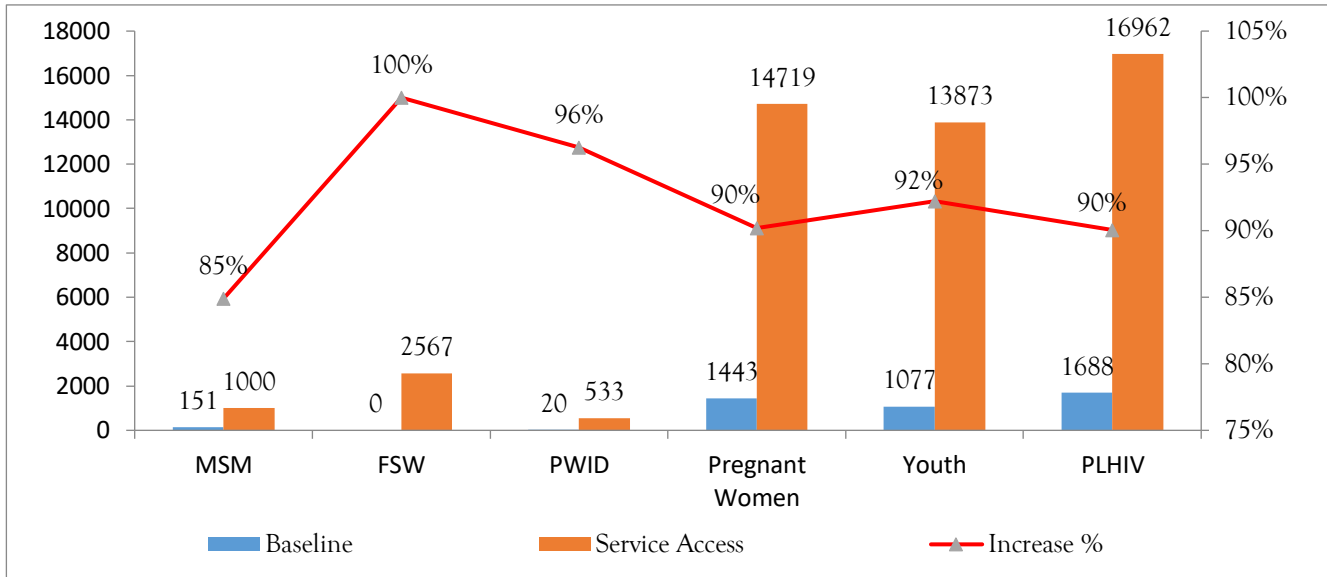
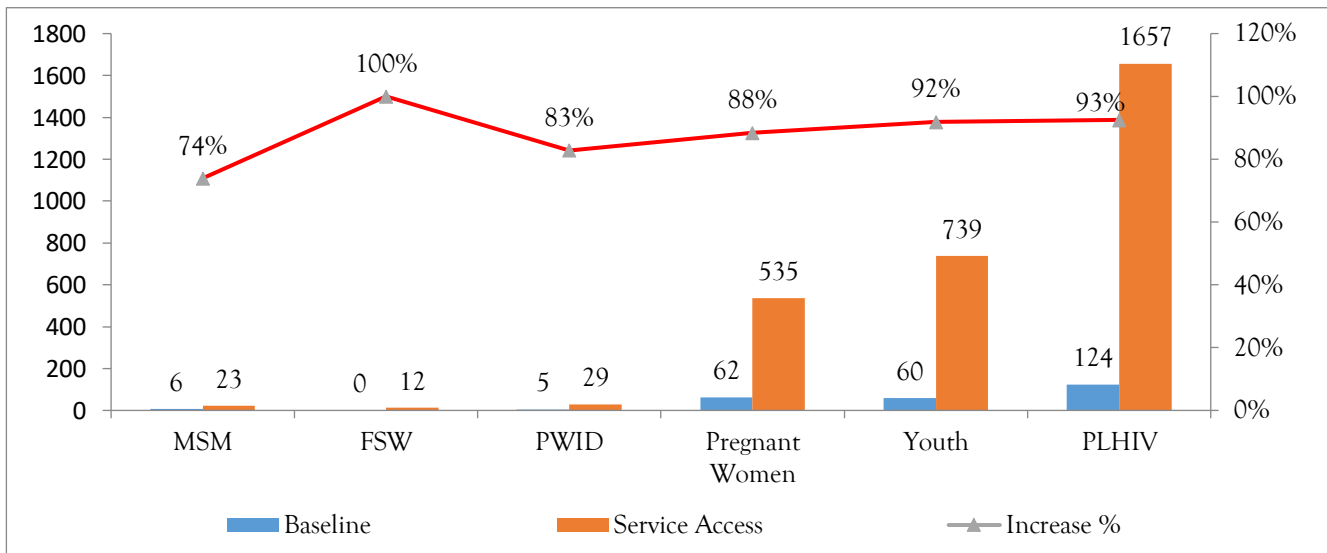


Figure 3: Comparison of ART Uptake at baseline and end of year 1



The CTO has provided a platform that brings national partners and civil society together for HIV advocacy while monitoring the performance and commitment of service providers and duty bearers to the HIV response. Importantly as well, data review processes have brought forth the need to revise and include metrics aligned to the entirety of the HIV testing to treatment cascade.

The points discussed above do not suggest that the CTO has solved the institutional bottlenecks or challenges faced by duty bearers like the National AIDS Secretariat and National AIDS Control Programme; rather, it reveals how service users can support and monitor programme effectiveness and advocate for improvement. Adaption and implementation of the CTO as an initiative for patient-led advocacy in different settings is contingent on understanding the social and legal contexts.

## DESIGN INSIGHT

Efficient public health systems that are accessible and responsive to a community's needs are fundamental for health promotion and disease control, especially the management of epidemics. Involving the consumers of these health systems in their development, in addition to other traditional stakeholders, not only improves efficiency but also makes the systems more user friendly and adaptable. This Design Insight discusses one such effort, the setting up of a Community Treatment Observatory (CTO) led by People Living with HIV (PLHIV), as a part of the National AIDS Control Programme in Sierra Leone. The primary objective of this observatory was to increase the awareness of HIV patients towards the delivery of HIV-related services by analysing healthcare access trends.

The results from this unique program have been very encouraging over a one-year period of its existence. The CTO has not only generated data on healthcare usage and provided an opportunity for PLHIV to engage with healthcare leaders to improve accessibility and quality of care, but it has already led to increased treatment uptake and will undoubtedly lead to improved public health outcomes. What is unique to this program is its simplicity, which promotes user engagement and energises the consumers to access care facilities and improve their experience in doing so.

There are two important lessons to be learnt from this experience:

1. Involving the consumers of a healthcare system in its planning and development is imperative in its successful and efficient implementation.
2. This model can and should be replicated to other healthcare delivery systems. There are a number of healthcare issues that use condition-specific healthcare delivery systems. Vector-borne disease control programs (like malaria) in the developing part of the world and lifestyle-associated disease control programs in developed countries (like cardiovascular diseases and obesity) are just two examples of such dedicated healthcare delivery systems. The model proposed in this paper can be adapted to both those conditions to improve access and usage.

Lastly, it should be noted that although this system appears simple and worked elegantly in this particular scenario, if it is adapted to other health conditions or regions, such adaptations must be evaluated critically for success/impact. Doing so would not only allow for critical appraisal of such an intervention but would also lead to its development as needed.

## REFERENCES

1. UNAIDS. 90-90-90: An ambitious treatment target to help end the AIDS epidemic [Internet]. October 2014 [cited 2018 AUG 14]. Available from: [http://www.unaids.org/sites/default/files/media\\_asset/90-90-90\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf)
2. Gils T, Bossard C, Verdonck K, et al. Stockouts of HIV commodities in public health facilities in Kinshasa: Barriers to end HIV. Bochenek T, editor. PLOS ONE. 2018 Jan 19;13(1):e0191294.
3. Government of Sierra Leone. National Strategic Plan on HIV/AIDS 2016-2020 [Internet]. November 2015 [cited 2018 AUG 14]. Available from: <https://www.childrenandaids.org/sites/default/files/2017-11/Sierra%20Leone%20National%20Strategic%20Plan%202016%20-%202020.pdf>

4. Republic of Sierra Leone. Sierra Leone Demographic and Health Survey 2013 [Internet]. 2013 [cited 2018 AUG 14]. Available from: <https://dhsprogram.com/pubs/pdf/FR297/FR297.pdf>
5. UNAIDS. Country Profile Sierra Leone [Internet]. 2018 [cited 2018 AUG 14]. Available from: <http://www.unaids.org/en/regionscountries/countries/sierraleone>
6. UNDP in Sierra Leone. Reviewing laws and policies for a more effective HIV response in Sierra Leone [Internet]. Feb 8, 2018 [cited 2018 AUG 14]. Available from: <http://www.sl.undp.org/content/sierraleone/en/home/presscenter/articles/2018/02/08/reviewing-laws-and-policies-for-a-more-effective-hiv-response-in-sierra-leone.html>
7. Network of HIV Positives in Sierra Leone. Sierra Leone Community Treatment Observatory (CTO) Data Review 2017/2018 [unpublished report]. Network of HIV Positives in Sierra Leone; July 2018.

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### PEER REVIEW

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### CONFLICTS OF INTEREST

There is no conflict of interest.

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None

### ETHICS COMMITTEE APPROVAL

Not applicable