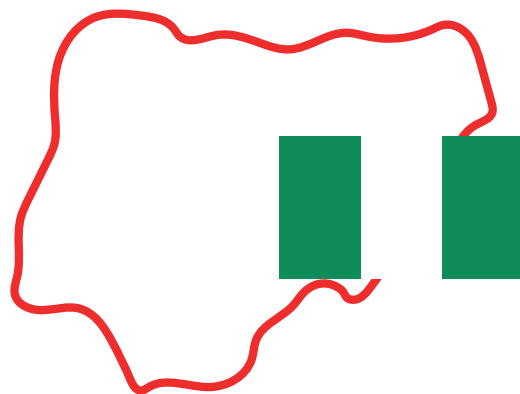


# 'We are family': Supporting retention among key populations living with HIV in Nigeria



Implementation story of the YouthRISE  
Nigeria Stay On project supported  
by Aidsfonds (2020-2023)

Sitting outside the youth clinic in Abuja, Federal Capital Territory (FCT) of Nigeria, a support group facilitator laughs with a group of people who have gathered to meet. They haven't always laughed, but today feels light and they share jokes and chat together after receiving their ART refills. When the group first started, after diagnosis or disclosure, support group facilitators led discussions and health talks to help everyone understand that being HIV positive is not the end of the road. People living with HIV joined the group to find connection and to feel less isolated in their journey with HIV. Defined as "key populations", they often feel stigmatised and excluded, but in this space, they say they feel safe and belong.

One support group facilitator explained their role: "Just counsel and first of all be their friend. They need that friendship... People upon testing and realising they are positive for the first time, they feel devastated, they feel downcast. They need time to heal, they need to be comforted, loved and supported."

## Background and context

HIV prevalence in Nigeria is low at 1.4%, but this represents an estimated 1,800,000 people living with HIV<sup>1</sup> and the fourth highest HIV burden globally.<sup>2</sup> Within key populations HIV prevalence is much higher: 10.9% among people who inject drugs and 15.5% among female sex workers. Antiretroviral therapy (ART) coverage among people who inject drugs is 25% and 12% among female sex workers. Nationally, 63% of people living with HIV are on antiretroviral therapy and 74.6% are virally suppressed.<sup>3</sup>

YouthRISE wanted to see key populations, including adolescent and young people, female sex workers and people who inject drugs linked to care, retained in care for the long-term and ultimately virally suppressed.

To ensure that these groups remained in care, YouthRISE Nigeria implemented an innovative strategy that prioritised improvements in the quality of care available; individual-level support and peer-driven group interventions; alongside advocacy to reduce structural barriers to retention faced by key populations.

The Stay On project, known as the Integrated HIV Care and Support for PLHIV in Nigeria (InCASP) project was implemented between 2020-2023 in six area councils of the federal capital territory, Abuja and neighbouring Nassarawa State. It was supported by Aidsfonds.

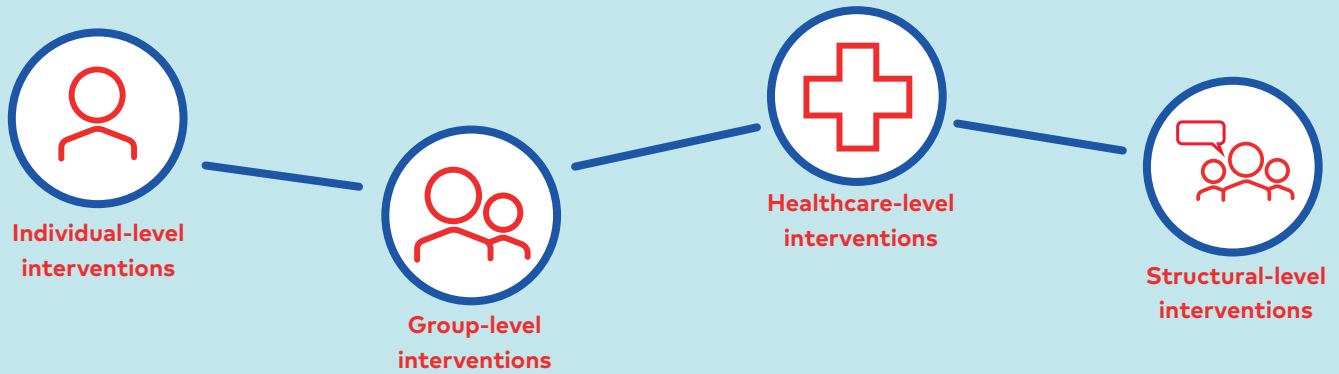
<sup>1</sup>Federal Ministry of Health, Nigeria. Nigeria HIV/AIDS Indicator and Impact Survey (NAIIS) 2018: Technical Report. Abuja, Nigeria. October 2019.

<sup>2</sup>McIntyre AF, Mitchell A, Stafford KA, Nwafor SU, Lo J, Sebastian V, Schwitters A, Swaminathan M, Dalhatu I, Charurat M. Key Population Size Estimation to Guide HIV Epidemic Responses in Nigeria: Bayesian Analysis of 3-Source Capture-Recapture Data. JMIR Public Health Surveill. 2022 Oct 26;8(10):e34555. doi: 10.2196/34555

<sup>3</sup>UNAIDS (2020), Country progress report - Nigeria: Global AIDS Monitoring.

## Stay On project in Nigeria

Within the InCASP project, the foundational approach was responding to the unique needs of people living with HIV with tailored comprehensive care and support. YouthRISE Nigeria addressed the diverse needs of people living with HIV, especially since among (young) key populations, needs vary widely. To support viral suppression and long-term retention in care, strategies had to be adapted to support the unique needs of different groups and individuals.



**Individual-level interventions** – YouthRISE provided individual-level interventions such as home-based care, mobile outreach clinics, continuous adherence counselling and psychosocial support. It was important to provide services in close proximity to where individuals live.

“Mental health services are very important for people living with HIV because they go through depression. They go through fears, anger, rejection, isolation and emotional issues.”

- Community Health Worker, InCASP project



**Group-level interventions** – YouthRISE initiated peer-to-peer support groups to reduce isolation, stigma and discrimination and promote mutual support for antiretroviral therapy adherence and retention in care. Cluster delivery systems for ART were integrated into peer support groups to reduce travel costs incurred in getting to the clinic for ART refills. Group income-generating activities were also used - particularly with adolescents and young people living with foster parents - to encourage development of life skills, provide an income and improve nutritional status. YouthRISE also engaged with pre-existing female sex worker networks to follow up those in care and reintegrate those lost to follow up.

“We now have our peers as friends and we have this peer network and support system. The relationship is priceless.”

- Support group member



**Healthcare-level interventions** – YouthRISE worked hard to improve the quality of care available for key populations in the target areas. Training and supportive supervision was provided by YouthRISE, together with the Ministry of Health and the state AIDS agency, to deliver humane and right based services that are compassionate and non-judgemental. Adolescents and young people reported improvements in how safe and comfortable they felt when attending clinics, and how service providers listened to and responded to their needs - a significant change from previous experience. In addition, YouthRISE facilitated the transition to adult care classes to support adolescents to successfully make this transition and retain them in care.



**Structural-level interventions** – As drug use is illegal in Nigeria, this creates structural barriers to accessing care and to long-term retention for people who inject drugs. YouthRISE Nigeria continues to advocate for decriminalisation of drug use, evidence-based drug policies, reduction in stigma and discrimination, and a harm reduction approach to improve health outcomes for people who inject drugs. YouthRISE have worked with existing networks to lobby for lower user fees for key populations, which has alleviated the financial burden of health services and encouraged uptake.

## The impact

YouthRISE's comprehensive approach contributed to improved quality of care for key populations by working to shift attitudes of service providers and integrating a non-judgemental approach. YouthRISE lobbied for a specific day for adolescent and young people to attend clinics, while also lobbying for reduced user fees with the patient community and existing networks. In addition, a one-stop-shop for female sex workers was re-opened to create a safe space for service use, retention in care and ART adherence.<sup>4</sup>

YouthRISE used support groups and differentiated service delivery to support ongoing psychosocial needs and to reduce barriers to accessing monthly ART refills. In addition, nutritional and economic support in the form of skill building and microcredit support for business startup (for example poultry, soap-making, fishing, and beauty services) was particularly impactful for adolescents and young people who are emancipated minors<sup>5</sup> and caring for siblings as the head of household.

"Funding for community-based initiatives does not always reach the grassroots and when it does, it is often insufficient, leaving community-based responses under-resourced. However, the InCASP project changed that. Strengthening community structures and embedding support at the local levels, people living with HIV were reintegrated into care and retained in care. Through the project, the visibility of YouthRISE has increased, enabling access to continued resources to meet the needs of key populations in Nigeria living with HIV."

- Group facilitator, InCASP project

The InCASP project reached **2,261** people living with HIV. **100%** of them were linked to care, **97%** achieved ART retention and by the end of the project, **95%** were virally suppressed. These results far exceed national averages (63% of people living with HIV are on ART nationally and 74.6% are virally suppressed).

- Total number of people living with HIV reached: **2,261**
- New individuals enrolled in HIV care: **676**
- Number of people reintegrated into care: **736**
- People living with HIV enrolled in support groups: **1,766**
- Referrals for other services: **706**
- Nutritional packs distributed: **2,087**
- Number of people engaged in economic empowerment activities: **180**

<sup>4</sup>UNAIDS (2020), [Country progress report - Nigeria: Global AIDS Monitoring](#).

<sup>5</sup>Emancipated minors refers to people under the age of 18 who meet one of the following criteria: sexually active, engaging in risk practices, married or has given birth. The term 'emancipated minors' is used within the Nigerian national HIV response and within key populations programs.

## Lessons learned

**1. Client-centred and differentiated model of service delivery** provides tailored and specialised approaches rather than generalised care. It recognises the unique needs of each client and provides an array of services to address their needs and to support referrals within the continuum of care. Examples of this include the youth-friendly clinics, one-stop-shop for female sex workers, and advocacy that aligns with needs that emerge.

**2. Group-based approaches** deliver comprehensive care and support mechanisms that are key to adherence among key populations living with HIV. Group-based approaches also contribute to a sense of solidarity, reduce stigma and help to build trust as members share interests, perspectives and experiences.

**3. Mobile service delivery** has proven to be effective in reaching hard-to-reach groups such as key populations. This approach ensures services are delivered to close to home, bridging distance barriers even in emergency situations, such as the COVID-19 lockdown.

**4. Caregiver support is critical to treatment adherence.** YouthRISE worked with caregivers within forums to provide health education on ART adherence and support for disclosure. By the end of the project, caregiver disclosure rates reached 85%, increased from 80% in year 2 and 75% in year 1.

**5. Socio-economic empowerment and food security enhance treatment adherence.**

Working with key populations - especially adolescents and young people - to improve their income and food security had a substantial impact on treatment adherence and retention in care.

**6. Integrated supportive supervision and coordination meetings enhance stakeholder engagement leading to more effective advocacy.** Through integrated supportive supervision and regular coordination meetings, YouthRISE Nigeria developed strong relationships with multi-sectoral stakeholders and government agencies (or coordinating agencies of government) to improve the quality of care, advocating for changes within systems (such as user fees) and strengthening ART facilities. Supportive supervision also provided the opportunity to integrate standardised tools for enhanced data collection, which was used for programme improvement, decision-making, and advocacy for policy reform.

## Challenges and recommendations

Government policies that criminalise drug use create a structural barrier to retention in care for people who inject drugs. Joint advocacy towards the government is needed to address this. YouthRISE works with allies to advocate for decriminalisation of drug use to increase access to services and enable retention in care.

The age of consent in Nigeria to access HIV services without consent of parents or guardians is 18 years and this can create challenges for adolescents and young people who are emancipated minors. The sustained advocacy of YouthRISE and its allies has led to a change in the age of consent, services are provided to people under the age of 18 without parental/legal consent on public health grounds.

It is recommended to collaborate with allies when advocating for challenges such as the age of consent. YouthRISE works with the patient community to advocate for changes to the age of consent to ensure anonymity and autonomy in health decisions among these youth.

Mobility of key populations, low household income and food insecurity contribute to lost to follow up and dropouts in care. Gender-based violence and stigma/discrimination, both of which increased dramatically during COVID-19 lockdowns, also presents challenges to disclosure and adherence. Community-based programming that can strengthen community structures, build trust between community actors and provide long-term support is critical to overcoming these barriers.

## What's next?

Having seen the achievements of the Stay On project, particularly with adolescent and young people in the federal capital territory, a partner of YouthRISE Nigeria has committed to support the youth HIV treatment network (Adolescents and Young People Network) and its activities moving forward.

YouthRISE Nigeria will continue to mobilise resources and work with government agencies and other stakeholders to scale up this successful approach, strengthening partnerships and the capacity of community networks. In particular, the focus will be on expanding ART cluster delivery systems and access to microcredit for key populations. In addition, YouthRISE wants to embed stronger psychosocial support for key populations within both group and individual level interventions.

## About YouthRISE

YouthRISE Nigeria started in 2014, born in response to growing drug use and HIV incidence among people who use/inject drugs in Nigeria. It is an advocacy and service-based organisation with a mandate to promote human rights, access to quality healthcare, harm reduction, social justice, and development for young people, especially those vulnerable to drug use. Through strategic engagement with stakeholders and communities, YouthRISE Nigeria champions drug policy reform and ensures better health outcomes for underserved communities.