

# Enhancing HIV data systems in South Africa: Integrating key population identifiers for inclusive health monitoring

Mashudu Rampilo<sup>1</sup>, Edith Phalane<sup>1</sup>, Edmond Mpho Shinwana<sup>2</sup>, Regina Maithufi<sup>3</sup>, Refilwe Nancy Phaswana-Mafuya<sup>1</sup>

## AFFILIATION

**1** South African Medical Research Council, University of Johannesburg Pan African Centre for Epidemics Research Extramural Unit, Johannesburg, South Africa

**2** Limpopo Department of Health, Polokwane, South Africa

**3** National Department of Health, Pretoria, South Africa

## CORRESPONDENCE TO

Mashudu Rampilo. South African Medical Research Council, University of Johannesburg Pan African Centre for Epidemics Research Extramural Unit, 2092, Johannesburg, South Africa

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E-mail: [rampilomi@gmail.com](mailto:rampilomi@gmail.com)

ORCID iD: <https://orcid.org/0009-0004-3570-0602>

## KEYWORDS

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## ABSTRACT

**INTRODUCTION** Accurate collection of sexual orientation and gender identity (SOGI) data is essential to identify and address disparities in the HIV treatment cascade. In many countries, routine health information management systems (RHIMS) record gender using limited categories such as 'male', 'female', or 'unknown', which fail to adequately capture the diversity of gender identities of transgender and gender-diverse populations. This study aimed to analyze the structure and content of the routine HIV program dataset within the South African routine health information management system for the inclusion of key population unique identifier codes.

**METHODS** A retrospective, exploratory analysis was conducted using routinely collected HIV program data from Limpopo Province. The dataset comprised 37934 records of individuals who underwent HIV testing between April and June 2023. A cohort extract was obtained from the national standard TIER.Net system and analyzed to describe the structure and content of routine HIV data and to assess how the system supports cascade reporting. The analysis,

performed in STATA 17, included descriptive statistical procedures such as frequencies, proportions, and cross-tabulations to examine HIV testing outcomes, ART initiation, retention, and viral load monitoring.

**RESULTS** The RHIMS comprised 37 934 records and 95 HIV-related variables. The overall HIV positivity rate was 2.3%, with ART initiation at 94.6%, viral load testing at 93.9%, viral suppression at 85.1%, and 12-month retention at 61.2%. When comparing male and female outcomes, HIV positivity was 2.8% and 2.2%, ART initiation (94.5% and 96.2%), retention (59.3% and 60.0%), and viral suppression (79.8% and 88.2%), respectively. Disaggregation by sexual orientations could not be done as there were no unique identifiers for them.

**CONCLUSIONS** The RHIMS allows only male-female disaggregation, which is limiting. Integrating key populations' unique identifier codes and gender identity would enable KP-specific data, supporting more targeted interventions, effective resource allocation, and stronger monitoring and evaluation for an inclusive HIV response.

## INTRODUCTION

South Africa, like many countries, is striving to achieve the Joint United Nations Program on HIV/AIDS (UNAIDS) 95–95–95 targets: ensuring that 95% of people living with HIV know their status, 95% of those diagnosed receive antiretroviral therapy (ART), and 95% of those on ART achieve viral suppression<sup>1</sup>. Achieving these targets requires inclusive and targeted strategies, particularly for key populations who

remain disproportionately affected by HIV. This includes 'Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, and other sexual and gender minority groups' (LGBTQI+). The routine collection of sexual orientation and gender identity (SOGI) data is increasingly recognized as essential for addressing health disparities among LGBTQI+ individuals, monitoring rights-based policy implementation, and informing equitable health responses<sup>2–4</sup>. The South African National Strategic Plan (NSP 2023–2028) for HIV, TB, and

STIs prioritizes five key populations: female sex workers (FSW) and their clients, transgender (TG) and gender-diverse individuals, gay men and other men who have sex with men (MSM), people who use drugs (PWUD), and those in prisons or closed settings<sup>5</sup>.

According to the Thembisa Model version 4.8, South Africa has achieved 95% diagnosis, 82% ART coverage, and 92% viral suppression<sup>6</sup>. While the overall national HIV prevalence is estimated at 12.7%, it is significantly higher among key populations, with reported prevalence rates of 55% among PWUD, 40% among TG women, 56% among FSW, and 27% among MSM<sup>6,7</sup>. The Botshelo Ba Trans study highlighted the disproportionate burden among transgender women, with HIV prevalence estimates ranging from 37% in Cape Town and 50% in Buffalo City to 63% in Johannesburg<sup>7</sup>. In response, the UNAIDS Global AIDS Strategy 2021–2026 calls for 90% of transgender people to have access to HIV services, integrated with mental health support, gender-affirming care, services for intimate partner violence and sexual and gender-based violence, and access to post-exposure prophylaxis, emergency contraception, and psychological first aid<sup>8</sup>.

In South Africa, gender-affirming healthcare services remain a challenge, with limited provision of these services within the public health system. In October 2021, the South African Clinicians Society publicized much-needed guidelines for the provision of gender-affirming healthcare<sup>9</sup>. The guidelines address significant gaps in knowledge and skills of healthcare providers in providing services to transgender and diverse persons, although hormones are outlined as part of the essential drug list; the service is only available at the tertiary-level hospitals<sup>9</sup>.

Despite this progress, routine health information management systems (RHIMS) in South Africa do not disaggregate data by key population groups, including LGBTQI+ individuals. This makes it difficult for program managers and policymakers to allocate resources effectively or tailor interventions to meet their needs. Collecting SOGI data in healthcare settings is critical for identifying and addressing health disparities, particularly among TG individuals. A study by Mulemfo et al.<sup>10</sup> in South African PHC facilities in Gauteng reported frequent misgendering and administrative erasure, with forms limited to binary options and staff assuming gender based on appearance rather than self-identification. These findings are aligned with the study by Ruberg and Ruelos<sup>11</sup> which reported that traditional demographic categories often fail to capture the complexity and fluidity of transgender identities, highlighting the need for inclusive and flexible data practices that respect self-identification. These limitations undermine efforts to provide responsive care, support monitoring and evaluation, guide public health planning, and inform policy decisions affecting gender-diverse individuals<sup>12</sup>.

The country uses three interlinked electronic registers (TIER.Net) to capture patient-level HIV information at the facility level, and it is integrated with the district health

information system (DHIS-2) for reporting data from the sub-district to the national level<sup>13</sup>. However, TIER.Net currently lacks fields for collecting SOGI information and does not include unique identifier codes for key populations, resulting in HIV data that cannot be disaggregated by key population group. To address these gaps, experts have recommended the adoption of a two-step method, which involves asking about both current gender identity and sex assigned at birth, as a best practice for accurately capturing transgender identities<sup>14</sup>. Some countries have adopted a two-step question approach to enable the collection and documentation of gender identity information<sup>15–18</sup>. This approach involves first asking individuals about their current gender identity, followed by a question about the sex assigned at birth<sup>19</sup>. By prioritizing gender identity as the initial question, this method underscores its significance from the perspective of transgender individuals, affirming their lived identity before referencing assigned sex at birth. This approach allows for greater inclusivity, reduces misclassification, and reflects the diverse lived experiences of gender-diverse individuals<sup>2,14,20</sup>.

The need to strengthen the government's RHIMS has become urgent, particularly following the termination of PEPFAR-funded key populations programs in South Africa, due to the global freeze on US-funded aid announced in January 2025<sup>21</sup>. As external support diminishes, national ownership of key populations data collection anchored in government-managed tools and robust monitoring and evaluation systems capable of disaggregating data by key populations is critical for sustaining service delivery, ensuring accountability, and guiding effective resource allocation.

Countries such as Kenya and Ghana offer practical lessons for integrating key populations' unique identifier codes into RHIMS. The two countries' success was driven by strong political will, investment in digital infrastructure, training of healthcare workers, and active engagement with the key population community to build trust and reduce stigma<sup>22–24</sup>. South Africa could adopt similar strategies by embedding unique identifier codes into existing platforms like TIER.Net or the national health insurance system while ensuring inclusive design through collaboration with key population-led organizations. Hence, understanding the current structure and variables within TIER.Net is essential for assessing how the system can be adapted to collect those missing variables, reduce misclassification, and support person-centered care. Within this context and framework, this study aimed to analyze the structure and content of routine HIV program datasets within the South African RHIMS for the inclusion of Key Populations Unique Identifier Codes.

## METHODS

### Study design

The study employed a secondary dataset analysis of

descriptive design to assess the structure and content of HIV data captured by the RHIMS. The dataset included 37934 individual-level records of clients who accessed HIV testing services and were enrolled in HIV care at public health facilities between 1 April and 30 June 2023. The detailed protocol for this study was published in 2024<sup>22</sup>. The extracted data comprised demographic information (age, sex, and identifiers), HIV testing outcomes, antiretroviral therapy initiation, treatment history, laboratory indicators (including CD4 count and viral load), and treatment outcomes. Among these, individuals who tested HIV positive were followed through the HIV care cascade to assess treatment initiation, retention, and viral suppression outcomes.

### Study setting

The original data collection was conducted in Limpopo Province, one of the nine provinces of South Africa. Limpopo Province is situated in the northernmost part of the country. Limpopo shares international borders with Mozambique, Zimbabwe, and Botswana, as well as domestic borders with the provinces of Mpumalanga, Gauteng, and North-West<sup>25</sup>. The province covers an area of approximately 125754 km<sup>2</sup> and is home to an estimated population of 6572720 people, according to the 2022 Census<sup>26</sup>. The province is divided into five district municipalities: Capricorn, Mopani, Sekhukhune, Vhembe, and Waterberg.

### Data extraction

Permission to access TIER.Net cohort data was granted by the NDoH and Limpopo provincial DoH (PMREC 30 October UL 2024/A). A standard data extraction tool was used to abstract data from the TIER.Net cohort report. No patient files or electronic medical records were retrieved or accessed at any stage.

### Data analysis

Data analysis was conducted using STATA 17. The analysis included frequencies and percentages presented through tables and figures.

### Ethical considerations

The study obtained approval from the University of Johannesburg Higher Degrees Committee and Research Ethics Committee (REC-2518-2023). The study was also approved by the Limpopo, Polokwane Mankweng Research Ethics Committee (PMREC) with project number: PMREC 30 October UL 2024/A. Individual patient consent was not required, as no original data were collected for this secondary dataset analysis.

## RESULTS

### Dataset overview

The HIV dataset comprised nearly 95 variables, capturing patient-level information across the HIV care continuum (Supplementary file Table S1). It covers a broad range of

data points designed to monitor patient information for HIV prevention, care, and treatment programs. Key variables included HIV and TB testing details (e.g. testing dates and results), treatment start dates, ART history and regimens, HIV and TB treatment outcomes, pre-exposure prophylaxis usage, CD4 counts, cotrimoxazole prescriptions, viral load measurements, pregnancy status, World Health Organization staging, and patient treatment adherence information. Additionally, the system collects demographic and identifying information such as folder numbers, names, dates of birth, ID numbers, age (in years and months), gender, and contact details to ensure the unique identification of individuals.

Although the system captures a wide range of essential variables, the analysis revealed important gaps within the RHIMS, particularly the absence of disaggregated data for key populations and gender identity. The system is restricted to the sex assigned at birth (male or female). It does not accommodate gender with categories such as transgender male, transgender female, or gender non-conforming.

### Overall HIV cascade

Supplementary file Figure S1 presents the overall HIV treatment cascade, highlighting a strong initial linkage to care and notable attrition before 12 months. Out of 885 individuals who tested HIV positive, 94.6% initiated ART, with only 61.2% remaining active at 12 months. Among those retained, 93.9% received a viral load test, and 85.1% were virally suppressed.

### HIV cascade disaggregated by sex

Supplementary file Table S2 shows the descriptive analysis of the sampled clients according to the HIV care cascade disaggregated by sex. Of the 37934 individuals tested for HIV, 885 tested positive, resulting in an overall positivity rate of 2.3%, with 2.2% in females and 2.8% in males. Of those who tested positive, 94.6% initiated ART, with 96.2% of females and 94.5% of males. At the end of their first 12 months, 61.2% were still on ART, with 60.0% of females and 59.3% of males. Viral load testing at 12 months was done on 93.9% of individuals who were still active, with 93.0% being females and 95.8% males of those tested. The overall viral load suppression was 85.1%, comprising 88.2% of females and 79.8% of males. The viral load suppression by other sexual orientations is unknown, as no unique identifier code was provided for these.

### HIV cascade disaggregated by age categories

As reflected in Supplementary file Table S3, of the 37934 individuals tested for HIV during the selected period, the positivity rate was low at 0.6% in children under 15 years, 1.1% in those aged 15–24 years, and 3.4% in those >24 years, resulting in an overall positivity rate of 2.3%. The ART initiation rates were high across all age groups: 96.6% in children under 15 years, 95.6% in the year group of 15–24 years, and 94.7% in those aged >24 years, with an overall

initiation rate of 94.6%. At 12 months, 67.0% of those aged <15 years, 55.9% of those aged 15–24 years, and 62.0% of those >24 years remained active on ART, giving an overall retention rate of 61.2%. Viral load testing coverage at 12 months was 93.8% for those aged <15, 93.5% for the 15–24 years age group, and 93.6% for those >24 years, with an overall rate of 93.9%. Among those tested, viral suppression rates were 85.6% in those <15 years, 86.8% in the 15–24 years group, and 84.9% in those >24 years, resulting in an overall suppression rate of 85.1%.

## DISCUSSION

As countries work toward achieving the 95–95–95 HIV targets and ending the HIV/AIDS epidemic as a public health threat by 2030, strengthening RHIMS is essential for robust epidemiological analysis, identifying service delivery gaps, and supporting differentiated HIV care tailored to the needs of key populations. The observed patterns in HIV positivity, retention, and viral suppression are broadly consistent with findings reported in the Limpopo. According to the Limpopo Department of Health Annual Performance Plan 2024/25, the HIV test positivity rate was 0.5% among children aged 12–59 months, 1.1% among children aged 5–14 years, 1.2% among youth aged 15–24 years (excluding ANC), 2.7% among adults aged 25–49 years (excluding ANC), and 4.4% among adults aged ≥50 years (excluding ANC). Retention on ART at 12 months stood at 65.2% among adults and 75.9% among children<sup>25</sup>. The province recorded an 84% viral load testing rate at 12 months, with 89% of those tested achieving viral suppression<sup>25</sup>. Similar trends of relatively low HIV positivity, high ART initiation, and suboptimal retention at 12 months have been documented, underscoring persistent challenges in sustaining long-term engagement in care. The comparatively lower retention observed in this study may reflect contextual differences in service delivery or limitations inherent in routine health information systems, particularly in tracking patient continuity across facilities. Viral suppression outcomes are largely comparable to provincial estimates, indicating effective treatment among individuals retained in care. However, the persistence of sex-based disparities in treatment outcomes is consistent with existing evidence and highlights the need for targeted, differentiated interventions. Collectively, these findings emphasize the importance of strengthening retention strategies and enhancing routine data systems to improve longitudinal monitoring of HIV outcomes.

The continued reliance on binary sex and gender fields in RHIMS renders transgender individuals largely invisible within health data systems, contributing to inappropriate clinical decision-making and missed opportunities for essential preventive screenings for those with non-binary or transitioned anatomy<sup>4</sup>. A study by Mulemfo et al.<sup>10</sup> found that healthcare workers in South African primary healthcare facilities often assumed patients' gender based on appearance, contributing to misgendering, the exclusion

of LGBTQI+ identities in health records, and limited access to appropriate services.

This study assessed the opportunities for incorporating key populations' unique identifier code and gender identity into the national RHIMS to strengthen the monitoring of the HIV care cascade in South Africa. Our findings confirmed that the current health information systems cannot capture key population identifiers, making it difficult to track continuity of care and assess true engagement across the HIV care cascade. This undermines programmatic planning, limits responsiveness to equity gaps, and prevents accurate monitoring of differentiated HIV services. Our study found that RHIMS can currently disaggregate HIV cascades only by sex and age groups. Meanwhile, in South Africa, estimates suggest there are 87214 transgender women, 28065 transgender men, and 66076 gender non-conforming individuals<sup>27</sup>, who remain largely invisible in routine data systems. While it is well established that key populations carry a higher HIV burden than the general population, routine data-derived HIV cascades are frequently based on proxy indicators, making it impossible to track individuals across the cascade without the use of unique identifier codes<sup>15</sup>. This deficiency is particularly concerning given the intersectional vulnerabilities of key populations to HIV, which are exacerbated by stigma, discrimination, and other health-seeking barriers<sup>28</sup>. According to the Ritshidze<sup>29</sup> report, 75% of the key populations who participated in the community-led monitoring survey indicated they accessed public health facilities, but the data collection tools at these facilities could not indicate their key populations status. In trying to assist countries in closing this gap, the WHO released consolidated strategic information guidelines focusing on improving individual-level routine data to strengthen person-centered services for HIV and other related infections<sup>4</sup>. Yet the current South African health information systems still have critical limitations.

This significant disparity necessitates further disaggregation of HIV outcomes by key populations and LGBTQI+ subgroups to identify hidden disparities and ensure equitable care. Global guidance and emerging best practices support the inclusion of SOGI data in RHIMS to improve outcome tracking and health equity<sup>30</sup>. Studies have emphasized the significance of disaggregating HIV viral suppression outcomes by sex assigned at birth, current gender identity, and sexual orientation, as this approach is crucial for identifying hidden disparities, enhancing clinical decision-making, and promoting equitable, person-centered HIV care among sexual and gender minority populations<sup>17</sup>. A study conducted by Shi et al.<sup>16</sup> reported that cisgender sexual minority women had a significantly higher risk of HIV virological failure compared to cisgender heterosexual women, further reinforcing the need for disaggregated data to address inequities in HIV treatment outcomes<sup>16</sup>. The Botshelo Ba Trans study reported high HIV prevalences among transgender women in South Africa, with

63.1% in Buffalo City, 49.4% in Cape Town, and 53.5% in Johannesburg, underscoring the urgent need for targeted, inclusive, and gender-affirming health interventions<sup>7</sup>.

The WHO, UNAIDS, and other global health bodies strongly support the use of the two-step gender identity question, which involves asking both current gender identity and sex assigned at birth, as a best practice for accurately capturing data on transgender and gender-diverse populations and advancing rights-based, inclusive public health responses<sup>8,12,14,31,32</sup>. In South Africa, national policies recognize these needs, but challenges persist in implementation. The South African National LGBTI HIV Plan (2017–2022)<sup>33</sup> and the National Strategic Plan (NSP) 2023–2028<sup>5</sup> acknowledge the challenges faced by key populations, emphasizing person-centered services; however, the current RHIMS cannot provide data to monitor the impact of those policies. South Africa's progress toward inclusive, person-centered HIV care requires urgent RHIMS reform to close visibility gaps for TGs, through the incorporation of both key populations' unique identifier code and gender identities. Incorporating SOGI data and key populations' unique identifier code into RHIMS is both feasible and ethically necessary. Achieving this will require sustained political commitment and multisectoral collaboration, including the involvement of civil society, policymakers, donors, and technical partners to ensure that inclusive data systems are both effectively designed and sustainably implemented.

### Strengths and limitations

A key strength of this study was the use of routinely collected Department of Health data from the national system, which ensured standardized data collection and enabled assessment of system-level performance within the RHIMS. Another strength was the inclusion of a large dataset (n=37934), which enhanced the robustness, reliability, and precision of the findings. However, the study has some limitations. Using data from one district restricts the generalizability of the findings and limits the ability to assess temporal trends; the use of a single time-point dataset limited the ability to assess trends over time. The study relied on a descriptive and exploratory analytical approach, which restricted the depth of inferential analysis.

### CONCLUSIONS

As countries work towards achieving the global HIV targets and ending the HIV/AIDS epidemic by 2030, strengthening routine health information systems remains essential for complete monitoring of progress across the HIV care cascade. This study provided insight into overall program performance, showing evidence of progression from diagnosis through treatment initiation, retention, and viral suppression based on routinely collected service data. However, despite the availability of these key program indicators, the current RHIMS framework does not allow their disaggregation by key population groups because SOGI

variables and KP unique identifier codes are not captured. Given that key populations account for a disproportionate share of HIV infections, incorporating unique identifiers for key populations into the system would enable more targeted interventions, better resource allocation, and improved program management. The country is already one step ahead with the implementation of HPRS and the EMR. It is therefore crucial to consider the inclusion of those missing variables in the new system while it is at the piloting stage.

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#### CONFLICTS OF INTEREST

The authors have each completed and submitted an ICMJE form for disclosure of potential conflicts of interest. The authors declare that they have no competing interests, financial or otherwise, related to the current work. All authors report that since the initial planning of the work, the study was partially supported by funding from the South African Medical Research Council (SAMRC) under Project Code #57035 (File reference: HDID8528/KR/202), awarded through the Division of Research Capacity Development's Mid-Career Scientist Program, with financial backing from the South African National Treasury.

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#### ETHICAL APPROVAL AND INFORMED CONSENT

Ethical approval was obtained from the University of Johannesburg Higher Degrees Committee and Research Ethics Committee (Approval number: REC-2518-2023; Date: 28 November 2023). The study was also approved by the Limpopo, Polokwane Mankweng Research Ethics Committee with project number: (Approval number: PMREC 30 October UL 2024/A; Date: 30 October 2024). Individual patient consent was not required, as no original data were collected for this secondary dataset analysis.

#### DATA AVAILABILITY

The data supporting this research are available from the authors on reasonable request.

#### AUTHORS' CONTRIBUTIONS

MR, RNPM and EP: conceived the idea of the study. MR: initial draft. RNPM and EP: reviewed the manuscript. EP: supervision. RM, MP and JS: contributed to the review of the manuscript. All authors read and approved the final version for submission.

#### PROVENANCE AND PEER REVIEW

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