

# Colombian HIV/AIDS registry and health risk management

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## Abstract

HIV/AIDS information systems are a critical tool for keeping track of the HIV pandemic in any country, leading to the AIDS elimination to 2030 and achievement of the 95-95-95 goals set by 2025. In this article, we describe the data management process of the Colombian National HIV/AIDS registry, its epidemiological results and contributions to research and health risk management. This registry is a longitudinal database. Variables and periodicity are defined by The Ministry of Health and Social Protection. Reporting is done by health insurers and their healthcare providers on annual bases. The information is uploaded through a web platform run by the High-Cost Diseases Fund, in charge of the validation, auditing process, consolidation, analysis and publication of the data. Security and confidentiality of the information is also taken care of by the High-Cost Disease Fund. Main results include epidemiological follow up of the epidemic, periodic evaluation of 25 risk management indicators, publication of research studies and the calculation of an economic incentive for insurers to improve health risk management. The registry has shown to be useful not only for the management of clinical information but also for administrative purposes.

**Keywords:** Health information systems, Registries, HIV, Risk Management, Information Management.

## Registro colombiano de VIH/SIDA y gestión del riesgo en salud

## Resumen

Los sistemas de información sobre el VIH/SIDA son una herramienta fundamental para realizar el seguimiento de la pandemia del VIH en cualquier país, con miras a la eliminación del SIDA hasta el 2030 y al logro de las metas 95-95-95 establecidas para el 2025. En este artículo se describe el proceso de gestión de datos del Registro Nacional de VIH/SIDA de Colombia, sus resultados epidemiológicos, sus aportes a la investigación y a la gestión del riesgo en salud. Este registro es una base de datos longitudinal. Las variables y la periodicidad son definidas por el Ministerio de Salud y Protección Social. Los reportes son realizados por las aseguradoras de salud y sus prestadores de servicios de salud sobre bases anuales. La información se carga a través de una plataforma web gestionada por el Fondo de Enfermedades de Alto Costo, encargado del proceso de validación, auditoría, consolidación, análisis y publicación de los datos. El Fondo de Enfermedades de Alto Costo también se encarga de la seguridad y la confidencialidad de la información. Los principales resultados son el seguimiento epidemiológico de la epidemia, la evaluación periódica de 25 indicadores de gestión del riesgo, la publicación de estudios de investigación y el cálculo de un incentivo económico para que las aseguradoras mejoren la gestión del riesgo sanitario. El registro ha demostrado ser útil no sólo para la gestión de la información clínica, sino también para fines administrativos.

**Palabras clave:** Sistemas de información en salud, Registros, VIH, Gestión de riesgos, Gestión de la información.

## Introduction

Monitoring HIV results is a critical step for countries to achieve the Sustainable Development Goals to 2030 and to end inequalities as stated in the 2021 Political Declaration on HIV and AIDS agreed at the High-Level Meeting on AIDS of the United Nations General Assembly<sup>1</sup>.

Epidemiological surveillance systems and disease-specific registries provide tools that allow this monitoring, however, the data and its results will always rely on the quality of the in-

formation reported by the healthcare providers or institutions performing the care and reporting of the data<sup>2</sup>. Awareness of the importance of HIV registries as platforms for research is growing and contributes to knowledge generation. Many reports are the result of government policies, public organizations such as academia or medical research associations<sup>3</sup>. Health-information systems offer the potential to improve quality of care and population health by informing clinical decision-making and policy formulation, sector surveillance, health risk management and resource allocation. However, to achieve these goals, key features need to be in place: popula-

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tion definition, temporal elements of data reporting, core data, appropriate terminology, quality and safety in data analysis, and governance, as stated in the framework for high-quality data collection developed by the European Medical Agency<sup>4</sup>.

A review by Craig et al. aimed to assess the elements that make up a registry and whether they contain research data. This identified 13 HIV registries that include specific-registry information, collaboration processes and research data<sup>5</sup>. Examples of these registries or observational cohorts were EMBRACE (USA)<sup>6</sup>, CFAR Registry (USA)<sup>7</sup>, CCR/HIV of the VA Department (USA)<sup>8</sup>, San Francisco HIV/AIDS Surveillance Registry<sup>9</sup>, New York City HIV/AIDS Surveillance Registry<sup>10</sup>, Sticking HIV Monitoring in Netherlands<sup>11</sup>, HARS in Missouri<sup>12</sup>, Australian National HIV Registry<sup>13</sup>, InfCare HIV (Sweden)<sup>14</sup>, Minnesota HIV Surveillance Registry<sup>15</sup>, leDEA (Rwanda)<sup>16</sup> and others<sup>5,17,18</sup>.

Colombia has a solidarity-based health insurance system, regulated by the Ministry of Health and Social Protection (MHSP) with two main regimens (Contributive and Subsidized, according to payment capacity of their affiliates) that covers nearly 97.64% of the population<sup>19</sup>, but include the same services, procedures, medicines, and interventions for their users. Insurers are responsible for managing resources, paying to healthcare providers<sup>20</sup> and data reporting to most of health information systems.

The MHSP delegated to the High-Cost Diseases Fund (CAC, in Spanish), a technical organization of the health system, the monitoring of this disease through the National HIV/AIDS registry. We aimed to describe the data management process of the Colombian registry, its epidemiological results and contributions to research and health risk management.

## Methods

### 1. Background and national policies

The MHSP established the legal framework of the national HIV/AIDS registry (resolutions 4725 of 2011, 0783 of 2012 and 0273 of 2019)<sup>21–23</sup>. These norms include the periodicity, form and content of the information to be reported by all insurance companies and healthcare providers. The annual report covers the cases enrolled and cared for by the insurance companies along a year that starts February 1<sup>st</sup> of any reporting year to January 31<sup>st</sup> of the following year. The variables are adjusted periodically according to new clinical guidelines, country information needs, and lessons learned from the implementation.

### 2. Contents of the registry

#### 2.1. Patients included in the HIV/AIDS registry

The national HIV/AIDS registry is a longitudinal database containing data of two types of populations: 1. pregnant women, children born to mothers living with HIV/AIDS and people reported with active tuberculosis (TB) that were negative to the HIV test or do not have HIV test results at the

time of reporting, and 2. People diagnosed with HIV/AIDS including pregnant women, children born to mothers living with HIV/AIDS and TB patients already diagnosed with HIV. The reason for these two types of reporting is to follow the adherence of the health insurers and healthcare providers to the national HIV/AIDS guidelines and national strategies. The HIV diagnosis is based on the algorithm defined by the national clinical guidelines<sup>24,25</sup>.

#### 2.2. Registry files

Health insurers and healthcare providers collect and summarize the data from the two types of populations in two different files, one for people living with HIV/AIDS (PLWHA) and the other one for the non-HIV or unknown HIV status patients that are followed. Sociodemographic, clinical, and administrative variables are collected for the reporting period. The CAC provides all entities with reporting instructions and an auditing manual as recommended by the MHSP.

#### 2.3. Structure of the database

Registry structure includes 193 variables, grouped in subsections like: identification data, demographics, and administrative updates for all patients; clinical information, current ART, AIDS-defining clinical conditions, current clinical status, prevention interventions and prophylaxis for the HIV/AIDS patients; pregnant women, children born to mothers living with HIV/AIDS and people with active TB with unknown HIV diagnosis or negative HIV test have their own registry files, that cover only 43 variables.

The sociodemographic data (personal identification, date of birth, sex, etc.) are crucial for cross-checking with other official sources of information like the “Unique Affiliated Database” (BDUA, in Spanish) to verify the reliability of the patient’s status as vital statistics are updated on the last date of the period.

The clinical section includes variables related with the diagnosis (date of diagnosis, transmission mechanism, reason for testing, clinical stage, CD4 T-cell count and viral load at diagnosis); treatment (initial and current treatment, substitution therapies, reasons for switching ART, among others) and follow up (success of ART therapy determined by suppression of viral load, most recent CD4 T-cell count, AIDS-related diseases, opportunistic infections and presence of coinfections developed along the care) are also requested. Administrative variables updates refer to PLWHA status in the health system (insured, disaffiliated, change of healthcare provider, i.e.) and the cost of HIV/AIDS care services (total costs of hospital care and total costs of non-hospital care). In addition, if the patient has died, the cause and date of death are recorded.

#### 3. Software: Interconnection System and Health Information Exchange (SISCAC, in Spanish)

SISCAC is the platform set up by the CAC for healthcare insurers and their providers to upload their reports. It is implemented on SharePoint; storage is done in Structured Query Language and MongoDB databases as well as cognitive ser-

vices for artificial intelligence and Power BI are in the Azure cloud, which are Microsoft® services. This platform has a simple interface and can be adapted to the technological characteristics of each healthcare provider in the country. The portal offers notifications, system, and web services and two main menus: apps and microservices.

#### 4. Data management

##### 4.1. Data collection

Data from clinical records of the reporting populations (described above) is extracted by health care providers to the standardized registry files once a year and reported to the health insurers. These ones collect the data from different providers, review the data and fill the gaps according to the services supplied along the year. On the reporting dates, when data is considered complete, they upload the information into the SISCAC platform established by the CAC and run an automated validation mesh prior to sending the data.

##### 4.2. Data validation

The platform contains an automatic validator mesh to check security, structure, consistency, and confidentiality of registered data. This validation is done at the time of reporting. Consolidated data is cross-checked by the CAC professionals with an official database of persons affiliated in the health system to verify the insurer and vital status of the reported patients. After this step, the data management coordinator approves the dataset to be audited.

##### 4.3. Data auditing

As reporting is done based on medical records, this information is sent later to an auditing process, conducted by health professionals with experience in clinical auditing. They compared the database information against the clinical records. If the information reported is different from the available registers, an adjustment is requested based on the registers.

According to the findings, the information is classified in three groups: conforming data (CD) when reported information was the same found in medical records; non-conforming data (NCD) when reported information was different from the one registered on medical records, but adjustments can be done; and original data not available (ODNA), when the information is not found on clinical records. In the last case, the information is not taken into account for the analysis. This classification is considered in the rating process for health insurers.

##### 4.4. Data analysis

After the auditing process, a single database is consolidated. Sometimes a patient could be reported by two insurers that had the patient at different times along the year or that provided different services. In those cases, the patient is counted only once for epidemiological indicators. Cases that died outside the period are excluded from analysis. Crude and standardized measures are estimated for the epidemiological indicators defined below. Numeric data are presented as me-

dians and interquartile ranges (IQR) or media and standard deviation (SD) according with distributions. Category data sets are presented as frequencies and proportions.

HIV prevalent cases are all the ones reported in the period; HIV Incident cases are the ones that were diagnosed within the reporting period; and mortality cases are those reported by health insurers within the period and verified with external sources from the MHSP. Finally, 25 HIV risk management indicators are estimated to evaluate the quality of care provided by insurers and health care institutions. These indicators were chosen after a literature review and agreed by expert's consensus<sup>26</sup>.

##### 4.5. Data dissemination and use

When information is ready, an annual report is prepared and published through the CAC's website. Information is also presented through technical documents, research publications and conferences to HIV/AIDS partners in the country that can use it for knowledge management and decision-making at the local and national levels and for international reporting.

#### 5. Distribution mechanism

With the results of the indicators, the CAC calculates an ex-post incentive mechanism for the contributive and subsidized insurers following the provisions of current regulations (Resolution 1912 of 2015 - MHSP<sup>27</sup>). This mechanism seeks to improve risk management of this disease and is based on four indicators: screening for HIV in pregnant women, early detection of PLWHA, undetectable viral load and HIV prevalence. Those healthcare insurers that achieve the highest results receive the resources established for the mechanism, while those that get the lowest results are the ones that deliver those resources.

#### 6. Security and confidentiality

All records in the database are numbered with a unique identifier number to ensure data anonymization and the follow-up across the years. This database is stored on the SISCAC platform, which has strict controls for each user to ensure that only those who have authorization can access the information.

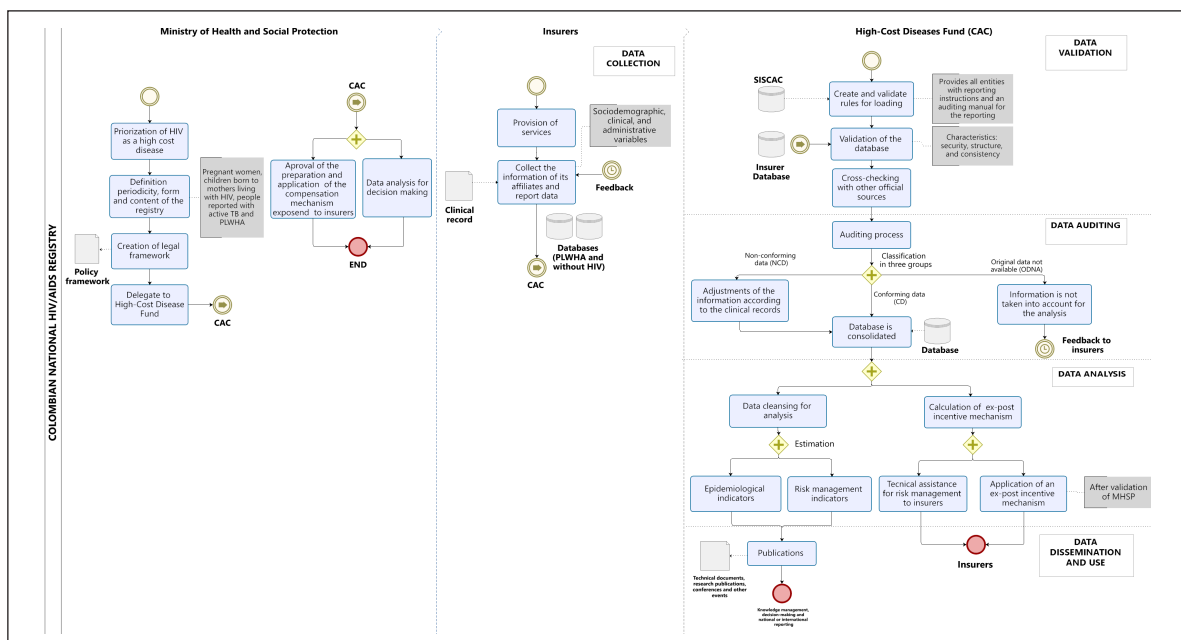
Figure 1 illustrates the complete process of building the national registry from data collection to data dissemination

## Results

### 1. Epidemiological situation of the HIV/AIDS in Colombia, 2012-2019

From 2012 to 2019, the country has seen a 300% increase in the reported cases to the registry, going from 37,325 to 109,056. Prevalence increased from 0.09% to 0.22%. Mortality went up from 1.1 per 100,000 population to 3.6 per 100,000 population, and the incidence increased from 13.8 per 100,000 population to 21.9 per 100,000 population (Figure 2).

Data showed that in Colombia HIV affects men in a major proportion (75.8%) than women. The male/female ratio was 3.14:1. The mean age of diagnosis for men was 32.6 years (SD



**Figure 1.** Illustrates the complete process of building the national registry from data collection to data dissemination.

Construction process of the HIV/AIDS national registry from the normativity of the MHSP until the publication of the information and use of data for decision-making. Abbreviations: MHSP: Ministry of Health and Social Protection, PLWHA: People living with HIV/AIDS, SISAC: Interconnection system and health information exchange, TB: Tuberculosis.

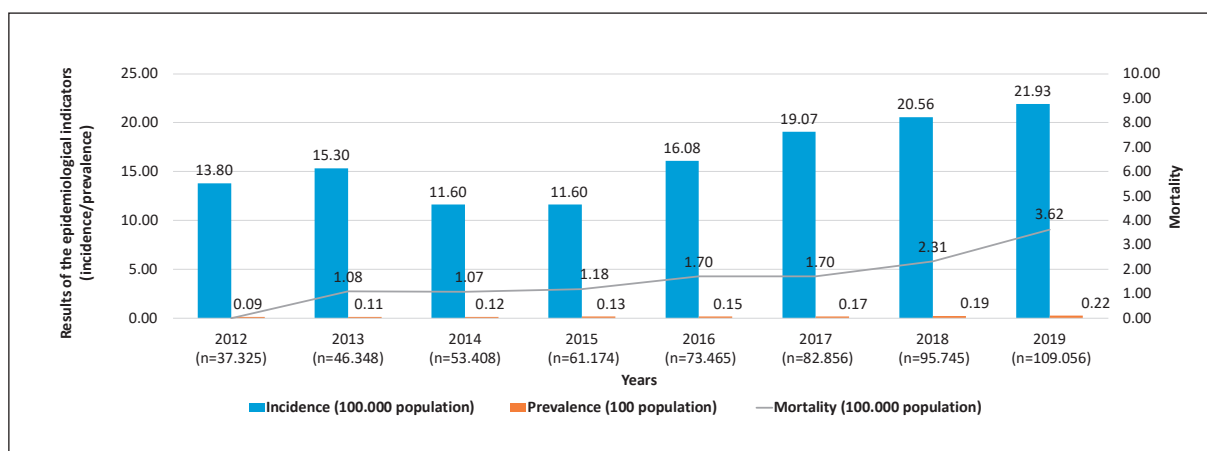
$\pm 11.7$ ) while in women was 36.1 years ( $SD \pm 13.5$ ). The highest incidence and prevalence by geographical regions were observed in Bogotá, while the highest mortality was seen in the Caribbean and the Central regions (Figure 3). The main way of transmission was sexual (90.3% of cases) and 56.5% of all reported cases were diagnosed on stage 3 (AIDS) 2014 CDC's classification<sup>28</sup>, with AIDS wasting syndrome (13.7%) and TB (7.3%) being the most frequent opportunist infections.

Since 2019, data on key populations is being recorded, finding that 43.1% of new HIV infections in 2019 were diagnosed on men who have sex with men. The median lymphocyte count at diagnosis increased from 249 cells/ $\mu$ l (IQR 106–440) in 2012 to 329 cells/ $\mu$ l. (IQR 309–686) in 2019. The proportion of people

with viral suppression ( $VL < 50$  copies/ml) increased from 50.8 % in 2012 to 63.9% in 2019. This data is published annually at <https://cuentadealcosto.org/site/publicaciones/>.

## 2. Risk management indicators

Over the 2012–2019 period, we have measured 25 national level indicators. 18 indicators have shown an increase in performance compared to the baseline (median 16.9%; IQR 1.7% - 26.5%). The biggest difference was seen with the indicators: proportion of HIV exposed children under 6 months tested for HIV (23.5% versus 98.0%), proportion of PLWHA with annual Tuberculin Skin Test (TST) (18.8% versus 61.4%), and proportion of PLWHA in latent tuberculosis therapy (14.6% versus 48.7%). Instead, two indicators saw a poorer perfor-



**Figure 2.** Epidemiological situation of the HIV/AIDS in Colombia, 2012–2019

Epidemiological indicators of the national HIV/AIDS registry in Colombia: incidence, prevalence and mortality from the beginning of the registry in 2012 up to the most recent measurement.

mance: Coverage of antiretroviral therapy in line with National Clinical Guidelines, decreasing 2.4%, and the proportion of PLWHA, not on antiretroviral therapy, with a CD4 count done in the reporting period, decreasing by 17.8%.

In 2019, 3 risk management indicators met the established target: proportion of HIV exposed children under 6 months tested for HIV (>95%), proportion of PLWHA on antiretroviral therapy with a viral load done in the reporting period ( $\geq 95$ ) and the proportion of PLWHA with antiretroviral therapy switch (<30). Table 1 shows the results of the indicators since the establishment of the registry and the percentage difference between the baseline in 2012 and the last measurement in 2019.

Likewise, the Colombian registry has made possible to monitor Colombia's progress towards the UNAIDS 90-90-90 targets. Of the estimated 119,000 PLWHA that know their HIV status in 2019 (information given by the MHSP), 84,992 (71.4%) were on ART treatment, and 72,272 of them (85.0%) were virologically suppressed (<1,000 copies/ml).

### 3. Research

With the HIV/AIDS registry information, three scientific articles have been produced describing the situation of PLWHA in Colombia: *"Burden and magnitude of risk in HIV/AIDS in the Colombian health system: a real-world data approach"*<sup>29</sup>, *"Epidemiological and clinical characterization in minors under 13 years living with HIV in Colombia. 2018: a cross-sectional study"*<sup>30</sup>, and *"Survival in people living with HIV in the framework the Colombian health system: 2011-2018 in the pediatric population"*<sup>31</sup>, which shows the multiples sub-analyses that can be done with the wide range of variables collected.

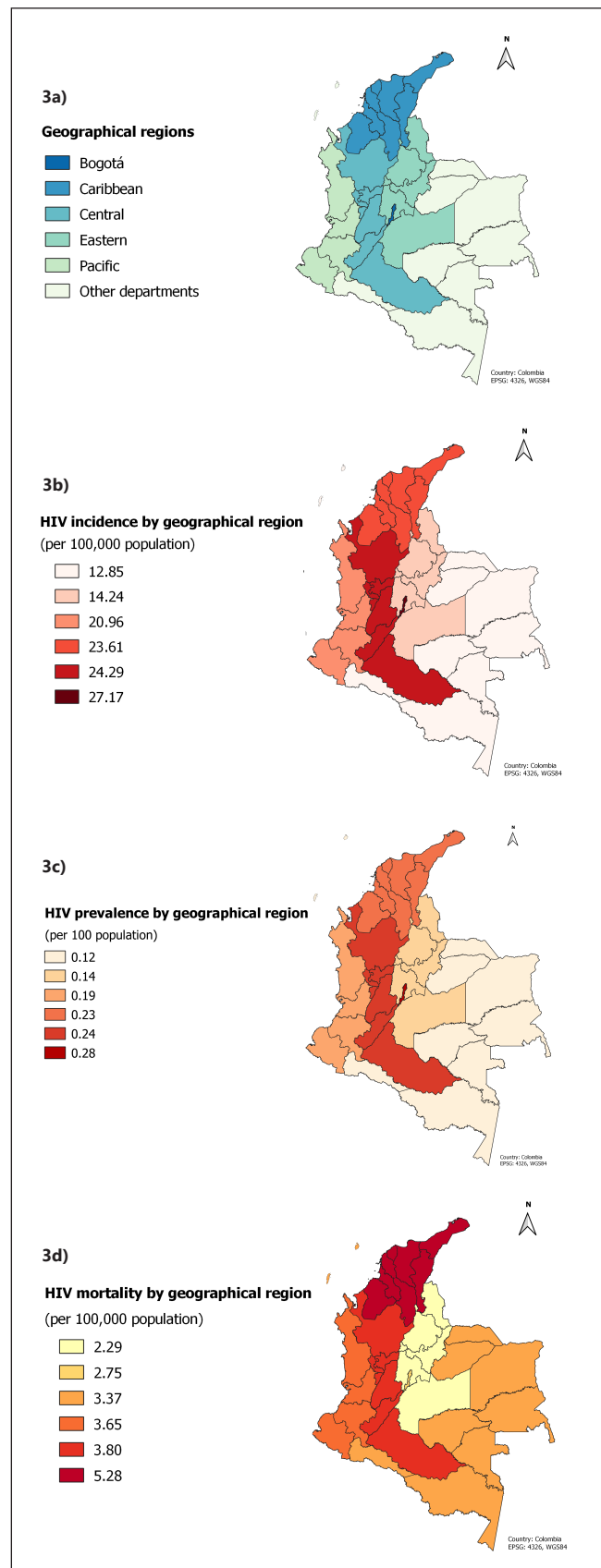
### 4. Distribution mechanism

Implementation of the ex-post incentive mechanism for the contributive and subsidized regimes have increased the performance of the insurers. This is reflected on the key four indicators that are evaluated: screening for HIV in pregnant women, which went up from 61.3% to 92.0%; early detection of PLWHA, that increased mildly from 57.4% to 58.0%; undetectable viral load, from 51.4% to 70.0%; and the HIV prevalence that increased from 0.09% to 0.22%. The best they perform the higher the amount they received. Extra resources are expected to be reinvested in strengthening the insurer's HIV/AIDS programs.

### Discussion

The main results of the National HIV/AIDS registry are: 1. Epidemiological information to follow trends of the HIV epidemic in Colombia; 2. Periodic measurement of risk management indicators; 3. Data for operational research; and 4. Information for an incentive distribution mechanism.

The registry shows the increase in reported HIV cases in the country and improvement of the main risk management indicators to reduce the burden of this disease. While, UNAIDS monitoring shows that since 2010, new HIV infections have



**Figure 3.** Age-standardized epidemiologic indicators of HIV/AIDS by geographical region. Geographical region distribution (3a), age-standardized incidence (3b), age-standardized prevalence (3c) and age-standardized mortality (3d).

**Table 1.** Risk management indicators of Colombian HIV/AIDS Registry, 2012-2019

| Indicators                                                                                         | Rank |            |      | Year of follow-up (%) |      |      |      |      |      |      |      | Difference between baseline and last measurement |
|----------------------------------------------------------------------------------------------------|------|------------|------|-----------------------|------|------|------|------|------|------|------|--------------------------------------------------|
|                                                                                                    | High | Medium     | Low  | 2012                  | 2013 | 2014 | 2015 | 2016 | 2017 | 2018 | 2019 |                                                  |
| Proportion of pregnant women screened for HIV.                                                     | ≥95  | 85 - 94.9  | <85  | 61.3                  | 86.2 | 70.5 | 78.9 | 85.5 | 89.0 | 91.0 | 92.0 | 30.7                                             |
| Proportion of children under 6 months with postnatal prophylaxis for HIV.                          | 100  | *          | <100 | 77.0                  | 82.8 | 96.3 | 96.1 | 92.8 | 86.5 | 91.0 | 96.0 | 19.0                                             |
| Proportion of HIV exposed children under 6 months tested for HIV.                                  | ≥95  | 85 - 94.9  | <85  | 23.5                  | 40.5 | 47.3 | 58.3 | 70.6 | 75.0 | 73.0 | 98.0 | 74.5                                             |
| Coverage of antiretroviral therapy in line with National Clinical Guidelines.                      | ≥95  | 85 - 94.9  | <85  | 98.4                  | 99.9 | 95.5 | 95.8 | 94.2 | 94.7 | 84.0 | 86.0 | -12.4                                            |
| Proportion of PLWHA, not on antiretroviral therapy, with a CD4 count done in the reporting period. | ≥95  | 85 - 94.9  | <85  | 67.8                  | 84.4 | 55.7 | 54.1 | 53.1 | 44.7 | 58.0 | 50.0 | -17.8                                            |
| Proportion of PLWHA on antiretroviral therapy with a viral load done in the reporting period.      | ≥95  | 85 - 94.9  | <85  | *                     | 86.7 | 63.6 | 79.3 | 86.7 | 85.9 | 88.0 | 95.0 | 8.3                                              |
| Proportion of PLWHA with antiretroviral therapy and undetectable viral load.                       | >90  | 70 - 89.9  | <70  | *                     | *    | *    | 51.4 | 57.5 | 66.8 | 68.0 | 70.0 | 18.6                                             |
| Proportion of PLWHA with early diagnosis among incident cases.                                     | ≥95  | 85 - 94.9  | <85  | *                     | *    | *    | 57.4 | 60.0 | 59.0 | 59.0 | 58.0 | 0.6                                              |
| Proportion of PLWHA receiving expert medical assistance.                                           | ≥95  | ≥90 - <95  | <90  | *                     | *    | 93.3 | 94.0 | 92.9 | 93.3 | 92.9 | 94.3 | 0.3                                              |
| Proportion of PLWHA with CD4 + T lymphocyte count at diagnosis.                                    | ≥95  | ≥90 - <95  | <90  | *                     | *    | 63.4 | 65.7 | 75.0 | 78.1 | 86.9 | 91.4 | 25.7                                             |
| Proportion of PLWHA with a viral load result at diagnosis.                                         | ≥95  | ≥90 - <95  | <90  | *                     | *    | *    | *    | *    | *    | *    | 87.8 | **                                               |
| Proportion of PLWHA with a total lymphocyte count at diagnosis.                                    | ≥95  | ≥90 - <95  | <90  | *                     | *    | 52.5 | 52.2 | 66.5 | 64.0 | 76.0 | *    | *                                                |
| Proportion of PLWHA with annual Tuberculin Skin Test (TST).                                        | ≥80  | ≥50 - <80  | <50  | *                     | *    | 14.6 | 22.5 | 33.9 | 38.8 | 46.8 | 48.7 | 34.1                                             |
| Proportion of PLWHA with follow-up of CD4 + T lymphocytes and viral load in the last 6 months.     | ≥95  | ≥90 - <95  | <90  | *                     | *    | 69.5 | 72.8 | 74.0 | 73.1 | 73.9 | 70.0 | 0.5                                              |
| Proportion of PLWHA with annual syphilis screening.                                                | ≥95  | ≥90 - <95  | <90  | *                     | *    | *    | *    | *    | *    | *    | 79.5 | **                                               |
| Proportion of PLWHA with annual cardiovascular risk assessment.                                    | ≥80  | ≥60 - <80  | <60  | *                     | *    | *    | *    | *    | *    | *    | 61.6 | **                                               |
| Proportion of ART in pregnant women living with HIV.                                               | 100  | ≥95 - <100 | <95  | *                     | *    | 82.6 | 93.7 | 95.1 | 96.8 | 82.3 | 89.0 | 6.4                                              |
| Proportion of PLWHA with adequate prescription of antiretroviral therapy.                          | ≥95  | ≥90 - <95  | <90  | *                     | *    | 68.8 | 67.0 | 57.7 | 69.1 | 72.0 | 75.0 | 6.2                                              |
| Proportion of PLWHA with active tuberculosis on simultaneous treatment for tuberculosis and HIV.   | ≥80  | ≥60 - <80  | <60  | *                     | *    | 54.4 | 80.6 | 87.3 | 76.2 | 70.2 | 75.8 | 21.4                                             |
| Proportion of PLWHA with undetectable viral load after 48 weeks or more of antiretroviral therapy. | ≥80  | ≥70 - <80  | <70  | *                     | *    | 50.1 | 55.0 | 61.2 | 63.1 | 64.4 | 79.0 | 28.9                                             |
| Proportion of PLWHA on virological failure with a genotype study.                                  | ≥90  | ≥70 - <90  | <70  | *                     | *    | *    | *    | *    | *    | *    | 28.1 | **                                               |
| Proportion of PLWHA with antiretroviral therapy switch.                                            | <30  | ≥30 - <40  | ≥40  | *                     | *    | 8.1  | 9.7  | 7.2  | 7.4  | 5.8  | 6.0  | 2.1                                              |
| Proportion of PLWHA in latent tuberculosis therapy.                                                | ≥95  | ≥90 - <95  | <90  | *                     | *    | 12.8 | 18.0 | 27.8 | 28.6 | 28.7 | 61.4 | 48.6                                             |
| Proportion of PLWHA with prophylaxis for <i>Pneumocystis jirovecii</i> pneumonia.                  | ≥95  | ≥90 - <95  | <90  | *                     | *    | 43.2 | 50.0 | 56.4 | 61.7 | 66.8 | 68.8 | 25.6                                             |
| Proportion of PLWHA with full hepatitis B vaccine schedule (if indicated).                         | ≥95  | ≥90 - <95  | <90  | *                     | *    | 31.5 | 39.3 | 45.1 | 46.1 | 54.9 | 47.1 | 15.6                                             |

Abbreviations: PLWHA: Persons living with HIV/AIDS. \* The indicator was not measured. \*\* It is not possible to calculate the difference. Management risk indicators measured in Colombia from 2012.

decreased by about 31%<sup>32</sup>, Colombia has seen an increase reported cases, probably due to the differences in these estimates<sup>33</sup> a better capture of cases by the health information system or major access the PLWHA to care services.

Our registry complies one of the key definitions set by the Agency for Healthcare Research and Quality (AHRQ)<sup>3</sup> as an organized system that uses observational methods to collect uniform data on a population defined by a particular disease (in this case HIV/AIDS), followed over time. The purpose of this registry is to describe the impact of the disease on pa-

tients' health, estimate the burden of the HIV/AIDS epidemic in the country and the trends over time. In a health care system with limited funds, AIDS care represents an important economic burden<sup>34</sup>. Therefore, HIV registries contribute to improving outcomes related to healthcare and managing resources efficiently<sup>35</sup>. This registry periodically publishes information available and accurate, avoiding expensive data collection to assess health system results, as indicated by Cylus J et al<sup>36</sup>. As data infrastructure grows and more suitable data becomes available, the necessity to transform the data into useful information emerges.

Mayer et al<sup>4</sup>, in a systematic review of the literature, identified 13 HIV registries, of which 61.5% are the product of a collaboration policy and 53.8% have a management process for requesting data collaboration, although there are shortcomings related to ethical support and research data<sup>5</sup>. In comparison, our registry contains all the key features for data collection like criteria for inclusion of participants (case definitions, data elements collected, etc.) and support for data interoperability between the MHSP, the CAC, health insurers and health care providers.

We have a legal commitment, supported by an epidemiological team, to produce an annual report of the HIV/AIDS situation in the country and to propose ideas for future research. In this way, the information generated allows the monitoring of HIV case management and follow-up of global goals aimed at elimination of the pandemic<sup>37</sup>, as demonstrated by Zheng et al<sup>33</sup>, who indicates that National HIV registries are the starting point for this follow up as the requested information is available on the national system and easily accessible from the clinical records. Although, it can contain incomplete data, it can also be strengthened by routine record practices.

Our registry, that started with 37,325 cases reported, captured information from 109,056 PLWHA in 2019. This has allowed us to characterize this population and to provide a useful tool for public health making decisions in Colombia. Other registries have a variable number of PLWHA, like the Singapore one<sup>33</sup> with up to 5,000 PLWHA per year; The Swedish National HIV Registry<sup>33</sup> with 7,000 cases; Australia in the Kirby institute<sup>38</sup> reported 28,000 cases and close to 1,000 new cases per year. These registries are usually part of a wider national health information system. Other registries consolidate information from several countries to have a larger volume of information and to analyze the behavior of the disease between regions. This is the case of leDEA registry<sup>39</sup>, which consolidates and analyzes data on almost 2 million PLWHA under care in routine settings from 46 countries around the world, or the Global AIDS Monitoring (GAM) report of UNAIDS<sup>40</sup> which is a worldwide HIV monitoring and evaluation system.

The Colombian HIV/AIDS registry works as a complement to other sources of national information like The Public Health Surveillance System (SIVIGILA in Spanish)<sup>41</sup>, which monitors case notification of diseases of public health interest like HIV, but doesn't do follow up of linking to care, ART initiation or retention on care. In this way, the CAC registry and the SIVIGILA help to show different faces of the epidemic in the country.

Registry's strengths include data collection of priority groups for screening like pregnant women, children born to HIV-positive mothers and TB patients, with disaggregated data by geographic regions and municipalities. Self-reporting of PLWHA within key populations is also important to identify disease burden among smaller groups like MSM, transgender women or people who inject drugs. Other strength of the data collection process is the inclusion of health services planning information

like affiliation, insurers, health care providers and costs, which have standardized definitions and labels for all elements of the dataset. This information also undergoes an auditing process and frequent feedback to the reporting entities.

Our estimates and analysis may be limited due to under-reporting and missing data (estimated on 5%) not found in the medical records. In fact, we only rely on data reported in the medical records of persons affiliated to public or private health insurance regimes, with a coverage of 97.8% in Colombia<sup>19</sup>. However, as it is a high-cost disease, a low percentage of Colombians would probably look for care with out-of-pocket money. The percentage of PLWHA who are not affiliated to the health system and, therefore, are not reported in this registry, is unknown. This is the case for PLWHA assisted by non-governmental organizations that look after illegal migrants or vulnerable populations. Although the health insurers report all their affiliates, it's possible that the cases lost to follow up (PLWHA without care in the last year) have outdated information, however this percentage is less than 2.0%. Other limitations are the heterogeneity in medical records among health providers (manual and/or digital) and practices of care in health programs. On the other hand, the process of auditing and analyzing the data highlight the need to continue strengthening the information system and move forward to reporting of HIV data in real time.

In conclusion, the Colombian HIV/AIDS registry has been useful not only for the clinical follow-up of patients but also to evaluate the quality of care provided by insurers and health institutions and for building public health policies based on evidence that aimed at PLWHA. Although different information sources in Colombia track HIV/AIDS at different points of care, the CAC registry consolidates the most significant number of variables that relate to the continuum of care. However, additional work is needed to integrate data from different sources and follow-up programs within the primary care to have a full comprehension of the HIV situation in the country. Finally, this exercise could be useful for other countries in the Latin American region that are interested in the development of specific disease follow-up registries.

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