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From Paper Files to Web-Based Application for Data-Driven Monitoring of HIV Programs: Nigeria's Journey to a National Data Repository for Decision-Making and Patient Care

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Abstract

Background Timely and reliable data are crucial for clinical, epidemiologic, and program management decision making. Electronic health information systems provide platforms for managing large longitudinal patient records. Nigeria implemented the National Data Repository (NDR) to create a central data warehouse of all people living with human immunodeficiency virus (PLHIV) while providing useful functionalities to aid decision making at different levels of program implementation.

Objective We describe the Nigeria NDR and its development process, including its use for surveillance, research, and national HIV program monitoring toward achieving HIV epidemic control.

Methods Stakeholder engagement meetings were held in 2013 to gather information on data elements and vocabulary standards for reporting patient-level information, technical infrastructure, human capacity requirements, and information flow. Findings

Keywords
- data warehouse
- electronic health records
- global health
- health information exchange
- shared health records

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from these meetings guided the development of the NDR. An implementation guide provided common terminologies and data reporting structures for data exchange between the NDR and the electronic medical record (EMR) systems. Data from the EMR were encoded in extensible markup language and sent to the NDR over secure hypertext transfer protocol after going through a series of validation processes.

Results By June 30, 2021, the NDR had up-to-date records of 1,477,064 (94.4%) patients receiving HIV treatment across 1,985 health facilities, of which 1,266,512 (85.7%) patient records had fingerprint template data to support unique patient identification and record linkage to prevent registration of the same patient under different identities. Data from the NDR was used to support HIV program monitoring, case-based surveillance and production of products like the monthly lists of patients who have treatment interruptions and dashboards for monitoring HIV test and start.

Conclusion The NDR enabled the availability of reliable and timely data for surveillance, research, and HIV program monitoring to guide program improvements to accelerate progress toward epidemic control.

Introduction

Reliable and timely availability of data are crucial for clinical decision-making, program management, surveillance, and program evaluation activities for global human immunodeficiency virus (HIV) programs, which the Joint United Nations Program on HIV/acquired immunodeficiency syndrome (AIDS) (UNAIDS) estimates served 38 million people living with HIV (PLHIV) globally in 2020.[1] It is a key factor in the achievement of the UNAIDS 95–95–95 target, which aims to diagnose 95% of PLHIV, have 95% on antiretroviral therapy (ART) among diagnosed, and 95% virally suppressed among treated.[2,3] To attain the UNAIDS target, different levels of data-dependent monitoring are performed, including patient care monitoring at service delivery points by caregivers, program monitoring and evaluation by program managers at state and national levels, and surveillance and epidemic control monitoring by government at the national level.

Nigeria, the most populous country in sub-Saharan Africa, with a very fragile health system, has the fourth highest burden of HIV in the world with an estimated 1.9 million PLHIV.[4] In 2019, Nigeria had 107,112 new HIV infections and 45,000 AIDS-related deaths.[5]

Compared with paper-based record systems, electronic health information systems provide a more useful platform for capturing and analyzing longitudinal patient data.[6] Patient-level data captured in health care facility electronic medical record (EMR) systems can be combined in health data warehouses.[7] Patient level data warehouses are typically made up of four distinct components—source systems, data staging, presentation, and access component.[8–10] Source systems are the EMR systems which captures the daily patient interactions with the clinic and are thought of to be outside of the data warehouse. The staging component is responsible for a set of processes commonly known as extract-transform-load, presentation component is where data are organized and made available for use by the users and other analytical applications while the data access component provides ad hoc query for a small group of users like the data administrators.[8] Data warehouses support epidemiologic surveillance and public health response,[7,11] and can serve as publicly available data sources for further analysis when data security and patient confidentiality standards are maintained.

Since 2010, paper-based data systems in Nigeria have been replaced with facility-level EMR systems. Between 2010 and 2012, the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) supported the roll out of health care facility EMR systems.[12] While the roll out of health care facility EMR systems continued to expand gradually, there was no national central system in place to collate data at the national level for program management, epidemiology, and surveillance. PEPFAR's implementing partners (IPs) only began developing health data repositories to house data from these EMRs and support their use for program reporting and research. However, these health data repositories were largely proprietary and IP specific, limiting the ability to utilize data for national program management, epidemiology, surveillance, and research. A Nigeria National Data Repository (NDR) could overcome this hurdle by creating a central HIV data warehouse, merging patient-level data across all HIV health care facilities in the country. This article describes the NDR, including the development process and potential for surveillance, program evaluation, and program monitoring toward achieving HIV epidemic control in Nigeria.

Methods

Needs Assessment and Requirements Gathering

As a precursor to the NDR implementation plan, a stakeholder engagement meeting was conducted in 2013, which included representatives of the Federal Ministry of Health, United Stated Centers for Disease Control and Prevention

(CDC) Nigeria, United States Agency for International Development (USAID) Nigeria, seven PEPFAR-funded IPs, and 15 health care facilities across the country. The meeting focused on gathering information on current state of eHealth implementation among the partners to understand the effort needed to implement a system such as the NDR. Information gathered was centered on understanding (1) the data elements available in the EMR systems and if any vocabulary standards such as Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT), Logical Observation Identifiers Names and Codes (LOINC) or RxNorm were used for documenting and reporting patient-level information, (2) availability of necessary technical infrastructure, including Internet services and computer hardware of the source EMR systems, (3) human capacity requirements, including skillsets and number of personnel at the health facilities supporting EMR implementation and at the IP offices supporting development and implementation of their IP-specific data warehouses, and (4) pathways for data flow. The outcome of the meeting showed wide variation in implementation across the different health care facilities and IPs. While some partner EMR systems utilized vocabulary standards following the Columbia International eHealth Laboratory (CIEL) concept dictionary,[13] other EMR systems did not follow any form of vocabulary standards. Approaches to data flow also varied across IPs. Some partners routed data from health care facilities through regional locations to a central location, others sent data directly to a central location and provided access to regional offices. There were also varying levels of maturity of information systems across the different EMR systems and central repositories. These findings led to the decision to develop a data governance framework to enable common data definitions, data quality, and data security. Elements of this governance framework are described in the rest of this section.

Data Governance

The NDR was designed to satisfy key considerations for successful informatics projects which include building consensus, addressing program information needs, adhering to applicable standards, using technology safely, and adequate infrastructure.[14] Key guiding documents for the NDR's implementation provide guidance for standards and consistency across implementation locations for health information exchange, reporting, patient privacy, and data security and quality.[15,16] The Nigeria Federal Ministry of Health coordinates and oversees the management of the NDR, working closely with the CDC and the University of Maryland, Baltimore, the IP responsible for developing and managing the NDR from October 2017 to September 2021. All HIV service delivery partners provided technical assistance to health care facilities for EMR implementation and data exchange between the EMR systems and the NDR. The data elements sent to the NDR from the EMR systems include patients' demographic information, including date of birth and sex, fingerprint, HIV testing details, laboratory test information, treatment regimen information, and other clinical encounter details (►**Supplementary Table S1**, **Supplementary Material S1**, [available in the online version]). Data are sent weekly to the NDR from the health care facilities and the NDR dashboard and analytics are refreshed daily to meet near real-time data use needs. The NDR holds a single record per patient. Each patient's records, including visits to clinics, are updated as data are received weekly from health care facilities.

NDR Technology Architecture

The NDR is built on a three-tier architecture: the client layer, the application layer, and the data management layer (►**Fig. 1**).[17,18] The client layer allows users to upload data to the NDR via a Web interface; it features functionality for querying across both individual client records, aggregate data, as well as viewing indicators of interest. The application layer is made up of the queue manager, data validation engine, and an analytic engine. The queue manager is a message broker that provides message queueing services and ensures reliability and performance during data transfer. The data validation engine is responsible for both schema validation and data validation of all messages sent to the NDR. The analytic engine processes the data into aggregates and populates the reports and dashboards on the Web interface with the necessary data. Breaking the application layer into these three components (queue manager, data validation engine, and data analytic engine) allows for stratified management of data ingestion processes, load management, and scalability.[18,19] The data management layer houses all reported data, including patient demographic and fingerprint template data, HIV testing data, and clinical encounter, drug dispensing, and laboratory data. To ensure security of the data in the NDR, access to the NDR is limited via a role-based user authentication process with each session timing out after 10 minutes of inactivity. An audit log is also maintained across the different layers. Additionally, all users have access to only aggregate data; access to patient-level data is granted through a special permission process.

Standards and Guiding Policies

The NDR Implementation Guide provides detailed standards and guiding policies for effective data exchange when reporting individual-level messages from different EMR systems, including common terminologies, data reporting structures, and data organization.[20] This document is maintained through the governance structure and is updated at least annually or as deemed necessary by the governance team. The NDR data dictionary defines value sets and codes for all data elements and is aligned with the Nigeria national HIV program patient management and monitoring tools.[22] Individual messages from EMR systems are encoded in extensible markup language (XML) for exchange with the NDR. An XML schema definition (XSD) document governs XML message file encoding, structure, and content.

Data Exchange Mechanism

XML messages are extracted in any of three states: initial, update, or redacted (►**Table 1**). Extracted XML files are passed through an XML parser to authenticate the XML schema. Only XML messages that pass the schema validation

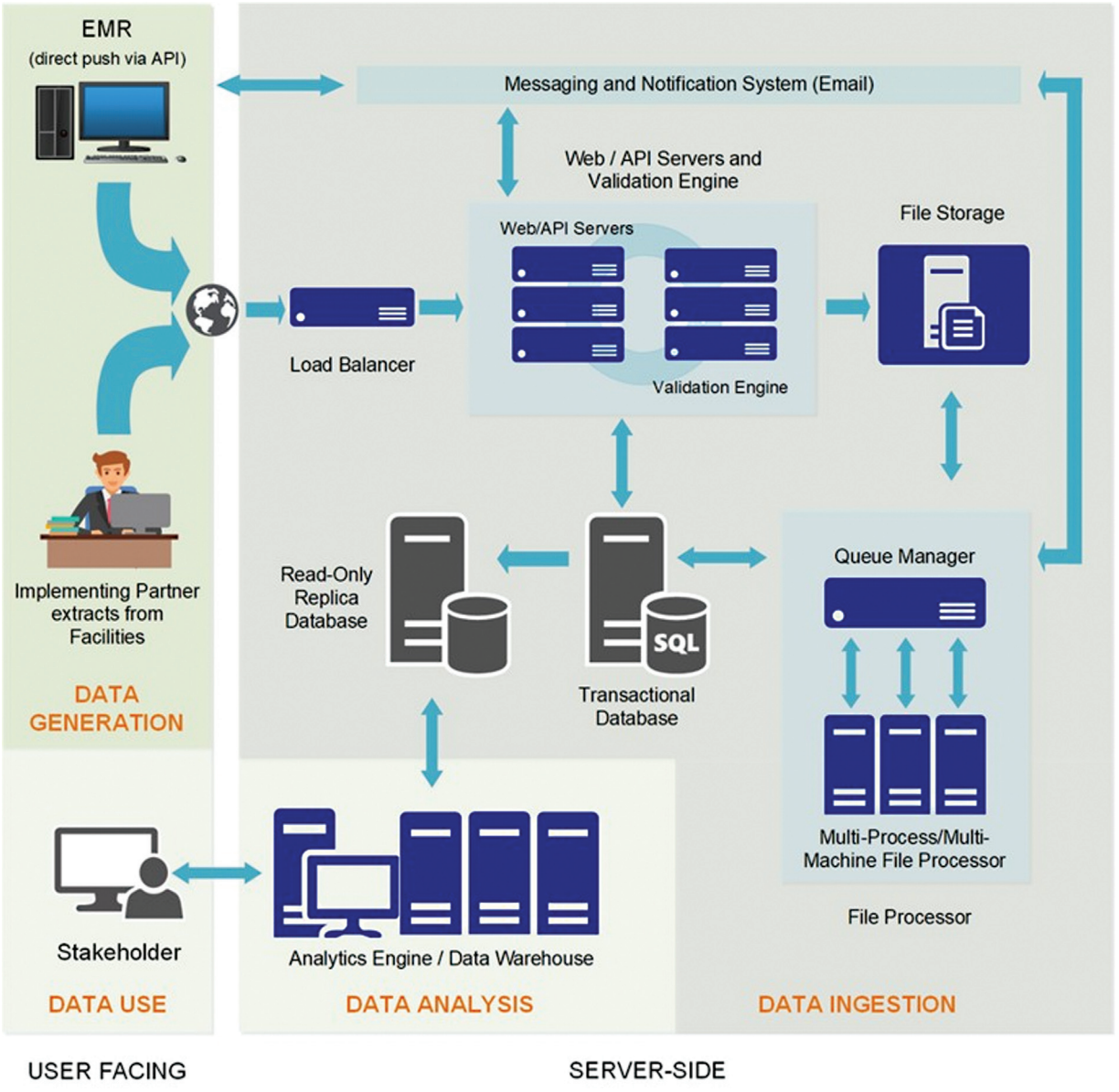

Fig. 1 Architectural framework of the National Data Repository (NDR). API, Application Programming Interface; EMR, electronic medical record; SQL, Structured Query Language.

are compressed into zip folders to manage file size and named following a structured convention to prevent file conflict. Files that do not pass the schema validation are listed in the EMR at the health care facility where they are reviewed by data managers to identify errors (usually incomplete data in the EMR) and make the necessary corrections. Compressed folders are uploaded to the NDR Web portal over a Hypertext Transfer Protocol Secure (HTTPS) with applied credential authentication to ensure data security. Files are matched to health care facilities using the

Table 1 Description of the different XML message states

Message state	Description
Initial	The patient record was newly created in the EMR and has never existed in the NDR
Updated	The patient record exists in the NDR but needs to be updated given changes in the EMR system (e.g., a new clinical encounter, update to the patient's medical record)
Redacted	The patient record has been deleted from the EMR and should be deleted from the NDR

Abbreviations: EMR, electronic medical record; NDR, National Data Repository; XML, extensible markup language.

facility's name and identifier provided in the XML files and matched to patients using an algorithm that combines the facility name, facility identifier, and patient identifier.

As part of the multilevel authentication and authorization of the NDR, all users uploading files have unique login credentials and access rights. Uploaded files are also checked to ensure the IP has been preconfigured to submit data for each facility. An audit trail logs all actions a user takes on the platform, including all data submitted and retrieved.

Data Processing and Analysis

A message broker sits at the beginning of the NDR data processing where the XML files reside until assigned to the correct validation engine (►Fig. 2). Load balancing is implemented to fulfill all requests efficiently and prevent server overload. For continuous data quality improvement, XML files are passed through a validation process to authenticate schema versions, file structure in accordance with the XSD, and data quality requirements including accuracy and completeness. Only files that pass both schema and data validation are processed and stored in the NDR. XML files that fail to meet the validation criteria on the NDR are listed as invalid files and are available on the NDR for the health care facilities to download, investigate, and correct. The list usually contains pointers to what part(s) of the XML files contained errors. Health care facilities download these files from the NDR and use that to investigate and make the necessary corrections on the affected records. This continuous data quality improvement function initiates the process to guide data improvements. A probabilistic algorithm that uses patient demographic information (date of birth, sex, fingerprint templates), patient identifiers, and treatment information such as the providing health care facility and HIV treatment start date is used to match and deduplicate records routinely.

Results

By June 2021, the NDR had received up-to-date patient-level data for 1,477,064 (94.4%) PLHIV on current on treatment across 1,985 health care facilities, of which 1,792 (90.3%) were supported by PEPFAR. The NDR additionally contains historical records of all individuals ever treated for HIV in Nigeria. The earliest patient record available in the NDR is from 1990. Of the patients records in the NDR, 1,266,512 (85.7%) have fingerprint template data stored as Base64-encoded alphanumeric strings. Since October 2020 when the NDR was expanded to store patient-level information for clients that had HIV tests, 1,729,390 (23%) of approximately 7,500,000 HIV tests conducted between October 2020 and June 2021 were recorded on the NDR.

Data Quality

Each XML message contains 160 data elements, of which 45 are required data elements that are validated. The remaining 115 data elements are not required as they may not be relevant for all clients during each clinic visit. The proportion of rejected patient files resulting from the validation process decreased from 12.3% in November 2020 (when the NDR began tracking these data) to 4% as of June 2021. This shows improved quality of the data uploaded to the NDR over time as well as indicates improvements in the quality of the data available in the EMR systems. Additionally, fingerprint template data in the NDR has allowed for deduplication of records among PLHIV who receive HIV treatment at multiple health care facilities. Our preliminary assessment as of June 2021 showed less than 3% of patients records are duplicated across all supported sites regardless of the IP. Identification of duplicates was not possible before the introduction of fingerprint captures due to the unavailability of an alternative unique identifier system such as a national identification number. In the longer term, the ability to track patients across facilities will help support patient self-determination for where they wish to receive care as well as support continuity of services as they transfer between facilities.

Data Use for Program Management

The NDR's user-friendly dashboards are used to support program management data use needs and include automated analytics, which disaggregate data by subpopulation (sex and age group) and various programmatic levels (health care facility, state, IP, and national) (►Fig. 3). Quality of care indicators are analyzed along the entire clinical cascade (i.e., HIV testing to death) (►Fig. 4) using the NDR. Viral load monitoring data on the NDR informed weekly viral load monitoring discussions between health care facilities, IPs, and CDC that led to sustaining high viral load coverage of 93% in October 2020 and 94% in January 2021 and at the end of June 2021 despite an increasing number of clients on treatment. The NDR dashboard facilitates monitoring of programmatic priorities such as "Test and Treat" and progress on UNAIDS targets toward achieving epidemic control.[2,21] Feedback provided to the facility by NDR reports, such as monthly lists of patients who have treatment interruptions and data quality issues found in uploaded data, helps to close the loop on the data value chain to impact individual patient care and progress toward epidemic control. In 2021, two of CDC's client-centered program goals were to prevent an increase in interruption in treatment (IIT) and to optimize continuity of treatment. This effort was driven by the availability of NDR data that allowed weekly tracking of patient who had IIT. Ultimately, the low IIT levels of 3% in January 2021 and 2% by June 2021 were sustained.

Surveillance

The NDR facilitates the availability of data for patient-level tracking and monitoring across systems through the integrated HIV case-based surveillance system (►Fig. 5). The NDR contains built-in longitudinal analyses, like case-based surveillance; data can also be exported to other tools for additional analysis not included in the NDR analytics. Case-based surveillance utilizes longitudinal data from the point of diagnosis to death to monitor key sentinel events, including HIV diagnosis, ART start date, CD4 count, World Health Organization staging, and death.

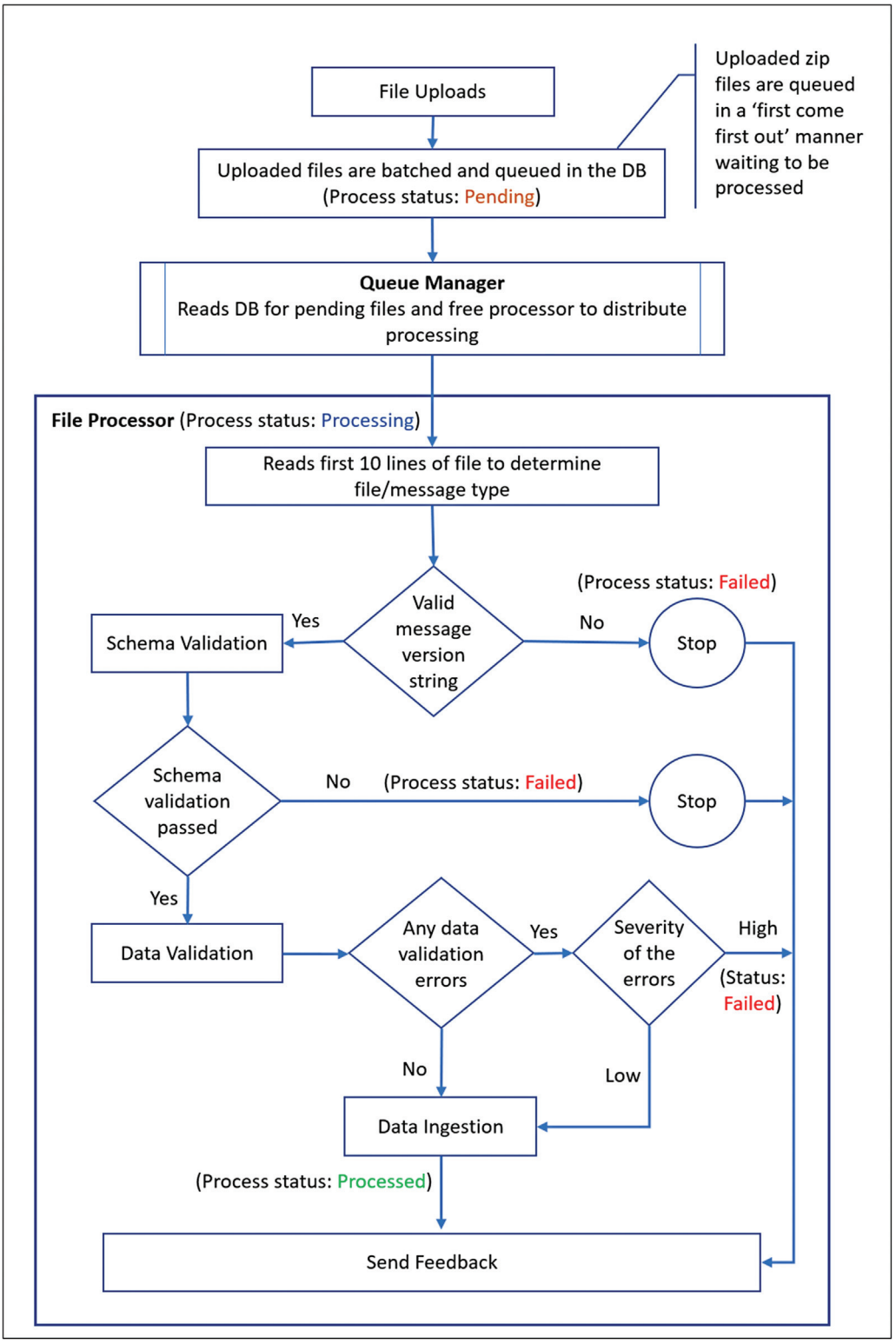

Fig. 2 Schematic description of the National Data Repository's (NDR's) data processing workflow.

The NDR also includes HIV recent infection surveillance data that supports the monitoring of preliminary recent and confirmed recent infection using the Recent Infection Testing Algorithm. The NDR patient-level data provides information for detection and characterization of new HIV infections to inform targeted public health interventions, including monitoring by geographical locations, identification, and tracking of sentinel events (►**Fig. 6**). Data can also be exported to other tools for additional analysis not included in the NDR's analytics.

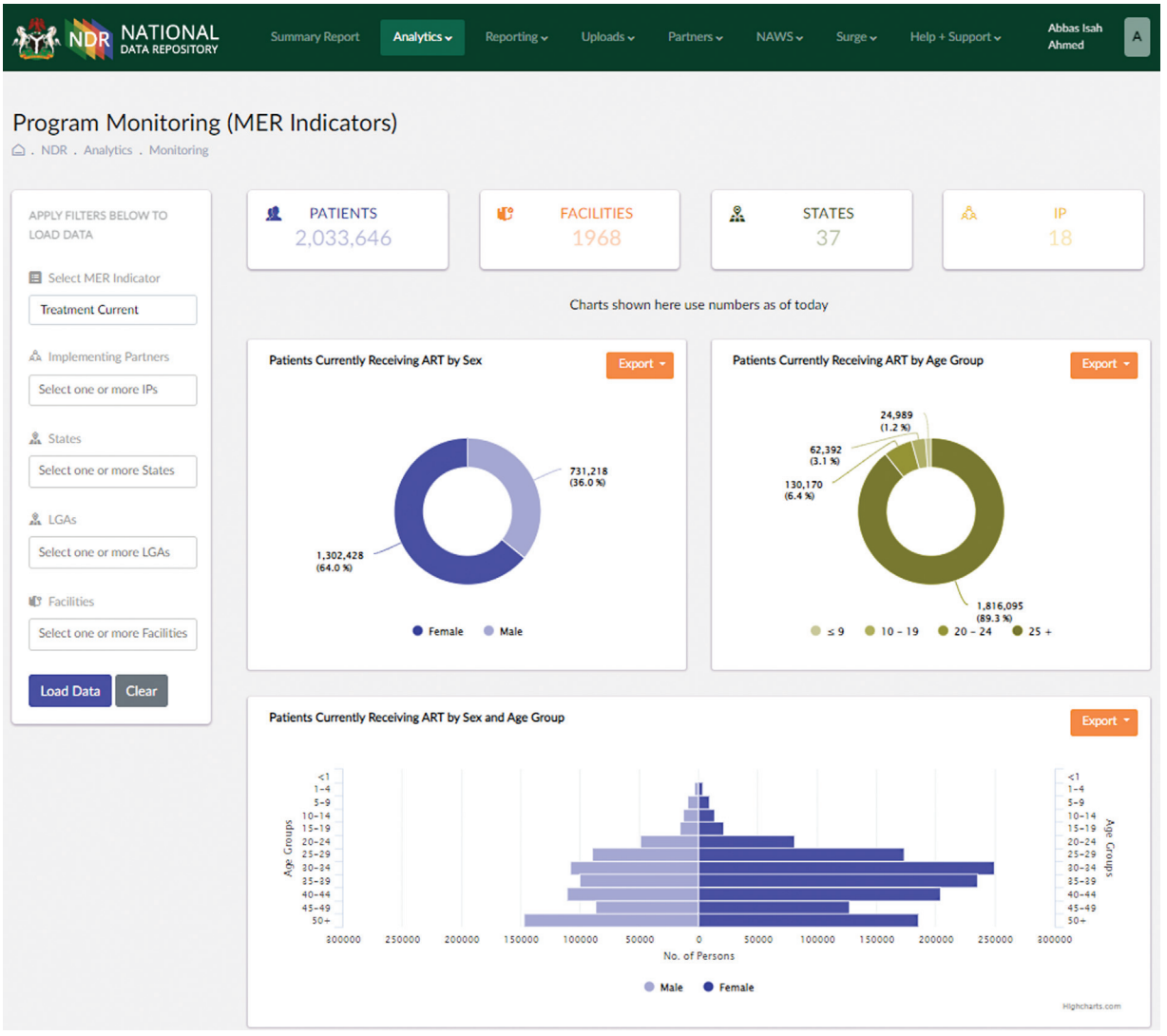

Fig. 3 Screenshot of the National Data Repository (NDR) analytic dashboard showing the number of clients on treatment disaggregated by age and sex with options on the left to filter by different levels (state, implementing partner, Local Government Area, and health facilities).

Support for Studies and Program Evaluations

An annual data freeze allows for the creation of deidentified analytic data sets stored in a separate analytic database and provides a platform where researchers can access specific data sets for special studies. Access to patient-level data follows the Federal Ministry of Health approved data use agreement policy. The accessibility of deidentified longitudinal data has the potential to support locally driven research to contribute to the international knowledge base.

Discussion

The NDR has helped improve the quality of data used to guide program implementation. We found the NDR provided near real-time availability of patient-level data, which facilitated data-driven programming. Weekly data supported real-time monitoring of efforts to scale-up of the number of PLHIV on ART.[22] The NDR also supported prompt identification of service delivery gaps and helped target interventions to accelerate Nigeria's progress toward epidemic control. Large data sets available in the NDR offer opportunities for detailed investigations to explore the interplay between patient characteristics and clinical outcomes as well as support predictive modeling and analytics that drive prevention-focused strategies.[6,7] Additionally, the data available in the NDR provides opportunities for researchers who want to conduct longitudinal studies of patient and program outcomes. These benefits align with studies that have shown how central repositories like the NDR can improve efficiency, productivity, and data access for research.[23]

To truly assess HIV treatment coverage and progress toward epidemic control, there is a need for a reliable and accurate method to deduplicate patients' records within and across health care facilities.[7] The NDR collects patients' fingerprint templates and uses this for matching, unique identification, and deduplication using probabilistic algorithms. This function is currently supporting client tracking efforts within the program while ensuring that accurate and deduplicated aggregate numbers are used for program decision making. The three-tier architecture of the NDR allows

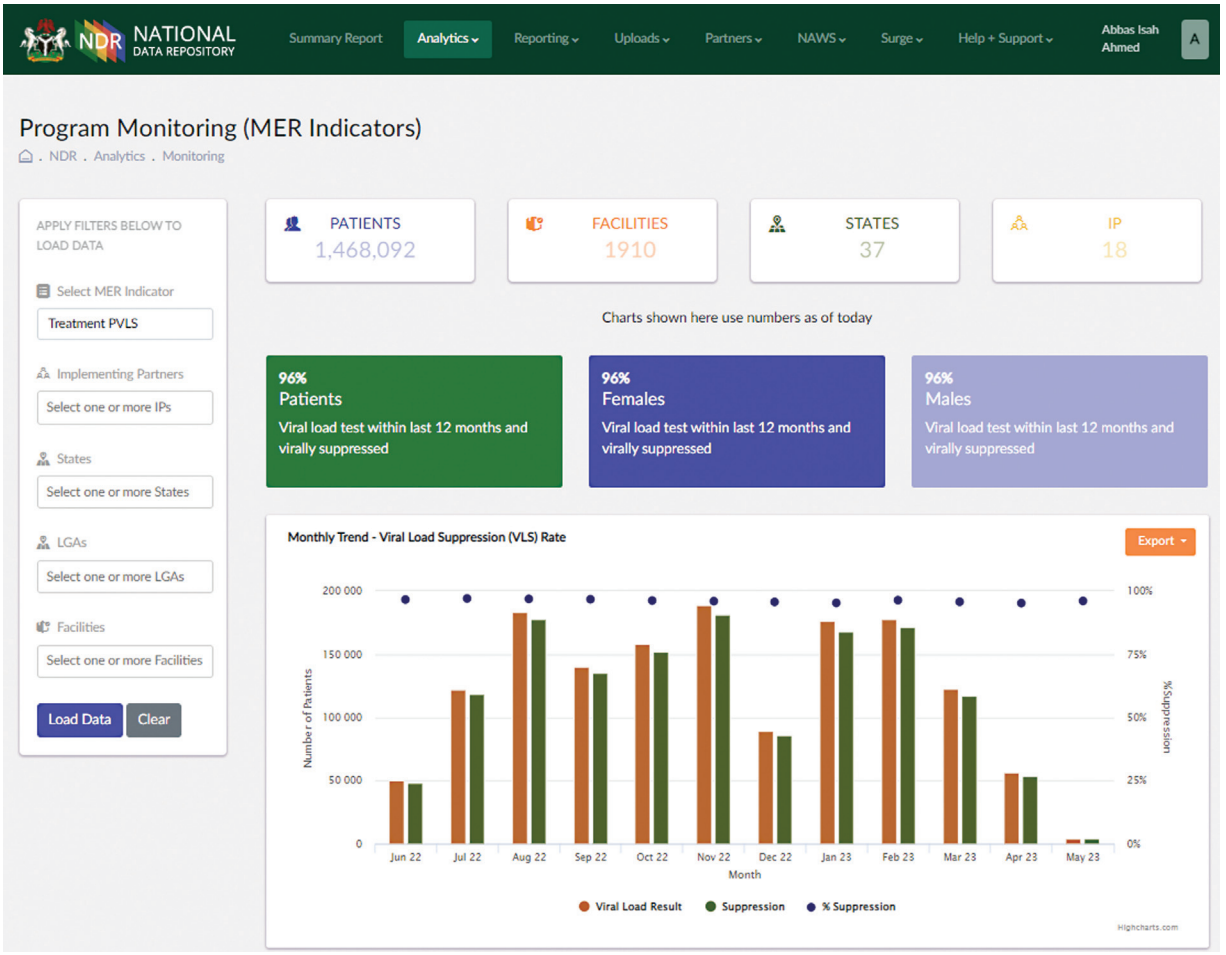

Fig. 4 Screenshot of the National Data Repository (NDR) analytic dashboard showing its use in monitoring viral suppression.

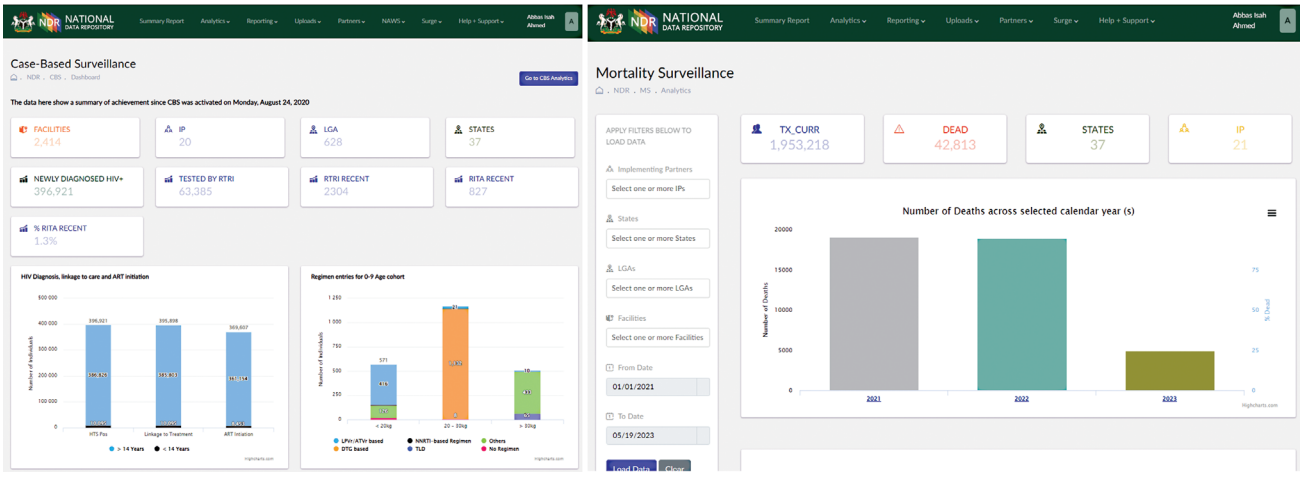

Fig. 5 Screenshot of the National Data Repository (NDR) analytics dashboard showing case-based surveillance and mortality surveillance use cases.

for scalability, while established data privacy and security standards have fostered acceptability.

Although highly beneficial, the NDR does have limitations that need to be addressed for further growth and impact. The NDR is currently, by design and funding, an HIV-focused system, to introduce new program areas such as tuberculosis, coronavirus disease 2019, and other diseases of public health importance into the NDR, computing resource

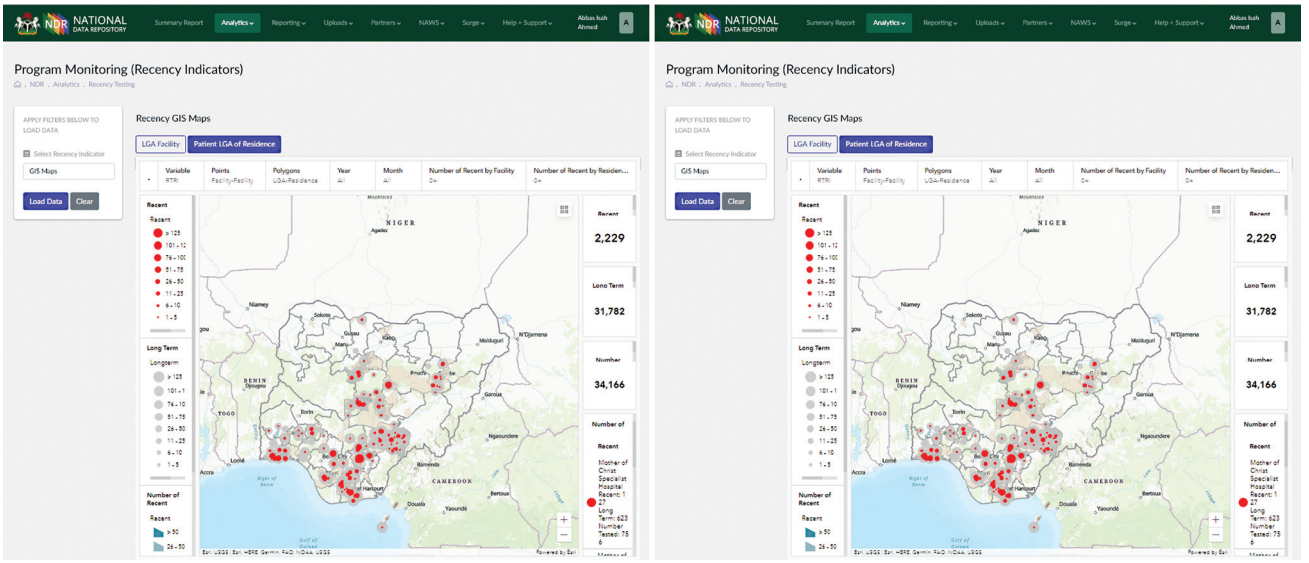

Fig. 6 Screenshot of the National Data Repository (NDR) analytics dashboard showing recency surveillance use cases.

requirements will increase, thus necessitating infrastructural upgrades to sustain system performance. For this reason, plans for sustained financing are essential. Second, introducing additional public health programs may require several steps to standardize data as the country currently does not have a national standard for eHealth data documentation. While we have tried to resolve this for the HIV program, other public health programs may require substantial effort for data standard harmonization. Finally, since the NDR does not contain personally identifiable information of clients, such as names, phone numbers, or addresses, and no national identifier is currently in use, patient identity management becomes difficult to implement. While fingerprint templates stored in the NDR present an opportunity for patient matching, other health care program areas would need to also capture fingerprint templates in the same format to enable moving the NDR toward a shared health record platform. Combining these data with other demographic information could improve data validity for managing patient identity and data exchange with other health programs.[23]

On the data exchange side, although XML is standard format for data interchange and can easily be made to conform to Health Level Seven specification, the files tend to be big, resulting in large uploads for high-volume facilities which can be time consuming. Also parsing XML files for validation against the XSD and data ingestion is central processing unit resource intensive.

There are several lessons learned which other countries may find useful to consider as they undertake development or expansion of an NDR. Bringing stakeholders from other health areas to enable planning for expansion from the start can save time by ensuring a common variable core and a master facility list that is not limited to one health condition. Leveraging government owned or managed cloud or server infrastructure to garner shared governance from the start is useful for sustainability planning. Lastly, countries considering implementing an NDR should prioritize establishing a national data standard for electronic Health Information System implementation as this is a crucial foundation to enable interoperability and data exchange between systems.

Recommendations and Future Plans

The NDR's functionality has the potential for expansion to accommodate other disease areas such as tuberculosis, malaria, and noncommunicable diseases to support monitoring and research of coinfections. The research potential of the NDR can be further harnessed by the establishment of a scholarly consortium from program implementers and academics within and outside of Nigeria to set and implement research priorities. The NDR needs to integrate seamlessly with other national aggregate reporting systems like the District Health Information System.

Conclusion

We have outlined how the NDR enabled data use for real-time program monitoring, service delivery, and implementation of strategies to promote program improvements for the Nigeria HIV program. We also discussed use of the NDR for HIV surveillance, including HIV recency surveillance, HIV case-based surveillance, and mortality surveillance. More work is needed to improve patient identifiers, record matching, and use of open standards for secure data exchange between other non-HIV specific EMRs and the NDR.

Ethical Approval Statement

This project was reviewed in accordance with CDC human research protection procedures and was determined to be nonresearch.

Authors' Contribution

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the funding agencies.

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Conflict of Interest

None declared.

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