



December 2018

DEVELOPING A NATIONAL HEALTH SECTOR CLIENT REGISTRY IN TANZANIA

BACKGROUND

Despite making good progress, the Government of United Republic of Tanzania is still working to meet the latest global guidelines for HIV/AIDS programs.¹ One major reason is that the country's data collection and health information systems (HIS) do not efficiently deliver the quality information required for monitoring, decision making, and planning. The Joint United Nations Programme on HIV/AIDS (UNAIDS) has recently implemented a surveillance-based approach to define the success of its 95-95-95 by 2030 HIV care and treatment framework—that is, 95% of people living with HIV knowing their HIV status, 95% of people who know their status on treatment, and 95% of people on treatment with suppressed viral loads. These approaches require consistent and accurate identification of the consumers of these health care services.

As in many developing countries, health service delivery data in Tanzania have tended to be disease- and health program-centric rather than patient-centric. Patient information is stored in many independent system systems and each program has its own patient identification system, making it hard to ensure continuity of care.

Meanwhile, according to The 2016-2017 Tanzania HIV/AIDS Impact Survey, adult HIV prevalence in Tanzania is estimated at 5%²; 1.4 million people are living with HIV out of a total population of some 52,000,000 people. An estimated 65,000 new infections and 32,000 AIDS-related deaths occur in Tanzania annually.³

The U.S. President's Emergency Plan for AIDS Relief (PEPFAR) in Tanzania supports the Government of Tanzania in implementing its national HIV policies and health sector strategic plan to meet the UNAIDS 95-95-95 goals.⁴ Measuring progress toward these benchmarks requires comprehensive surveillance and data capture.

The Government has also committed to the Sustainable Development Goals (SDGs). Globally, Target 16.9 of the SDGs aims to achieve “legal identity for all, including birth registration” by 2030. In response, the Government has made various efforts, some ongoing, to establish a countrywide legal identification system, including a national ID, birth and death registration, tax identification number, and driver's license registration.

The Tanzania Technical Support Services Project (TSSP), led by Management Sciences for Health and funded by PEPFAR through the Centers for Disease Control and Prevention (CDC), supports and strengthens Tanzania's Ministry of Health, Community Development, Gender, Elderly and Children (MOHCDGEC) and key public health institutions to achieve HIV epidemic control and sustain HIV-related health systems and services.

SDG 3, “Ensure healthy lives and promote well-being at all ages”, implies that there is universal health coverage (UHC), which in practice means ensuring that everyone can access affordable, essential, quality health services. UHC makes it necessary for patients to be uniquely identified each time they receive health services for a more complete picture of their health and how they access the health system. Further, to provide efficient and quality health services, a provider should have a reliable way of identifying a patient at each encounter to provide them with appropriate care based on their clinical history.

DIGITAL HEALTH SYSTEMS IN TANZANIA

Africa is increasingly adopting digital health solutions, particularly electronic medical records. Primary, secondary, and tertiary health care facilities that traditionally recorded patient records manually have embraced digital health solutions for patient management and data. The Tanzania Ministry of Health, Community Development, Gender, Elderly and Children (MOHCDGEC) recognizes the potential of information technology to transform health service delivery, including health care operations, management, and decision making. The country laid out a Digital Investment Roadmap for 2017-2023 that details priority activities to improve health system performance.⁵ Its digital health investments align with the National eHealth Strategy (2013–2018), including the Tanzania Health Enterprise Architecture (THEA), of which the Client Registry (CR) is a foundational digital health solution.

The Government has rolled out several digital health systems. DHIS2—digital software used to implement the national Health Management Information System—was rolled out nationally in incremental stages from 2013 to 2015. A rollout of a Unified System, which is a combination of Government of Tanzania Hospital Management Information System (GoTHOMIS) and electronic Facility Management System (eFMS), started this year. Tanzania has developed a Health Facility Registry (HFR) that is integrated with DHIS2. Private-sector health facility data, including that of faith-based organizations and NGOs, are included within THEA and the national DHIS2 and HFR digital health solutions. A birth registration system and national identification system have also been established recently.⁶ However, none of these systems provide a single, unified patient registry for the health sector, which is the main roadblock to achieving the UNAIDS goals.

Under the current plans, the country is implementing a Health Information Mediator (HIM) as an interoperability layer that facilitates easier, standard-based information exchange among disparate HIS. DHIS2 will connect to the HIM. Data can be exchanged among DHIS2 and other HIS that connect either to the HIM or directly to DHIS2.

Figure 1 shows how data could connect to the HIM from various registries, including the civil registration and vital statistics systems.

Health programs in Tanzania include the National AIDS Control Program (NACP), National Tuberculosis and Leprosy Program, and Reproductive and Child Health

Services. A single client will usually receive health services from multiple programs. Each vertical health program in the MOHCDGEC issues and manages its own program-wide identifiers, and some vertical programs that comprise multiple services issue unique identifiers for each service. For example, a pregnant woman co-infected with HIV and TB will have at least three unique program identifiers, one for each point of service. She will also have other identifiers, such as the national ID.

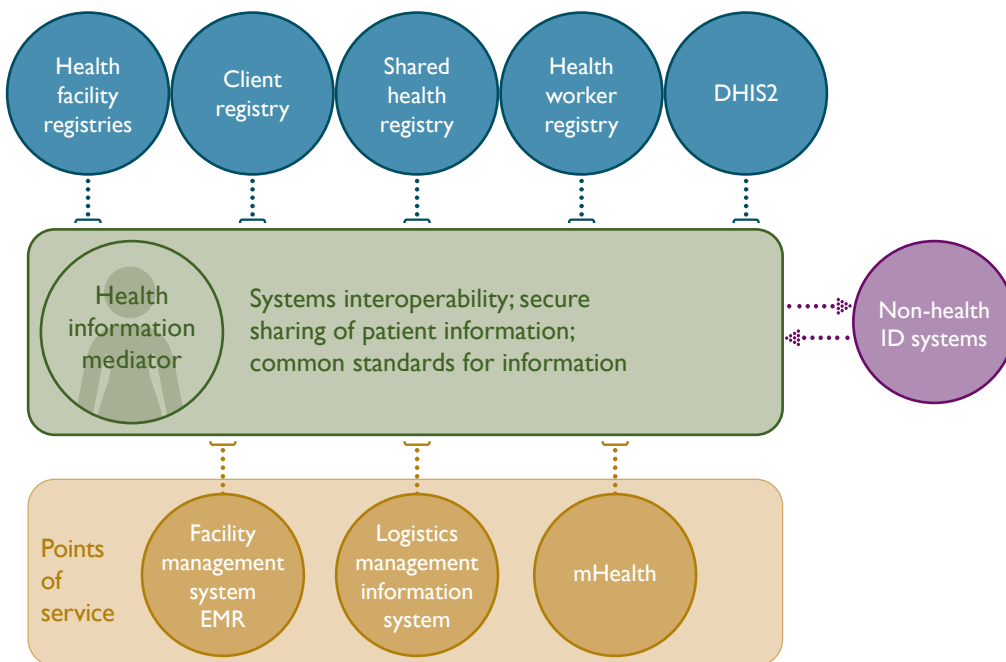


Figure 1. Tanzania health information exchange

Unique identification is essential to progress toward meeting **PEPFAR's 95-95-95** goal. For people living with HIV, better program management means more timely testing and promotes continuity of service for lifesaving sustained ART. Providers can assess treatment regimens and their effectiveness toward achieving viral suppression. Finally, with population data from the system, the Government and donors can accurately assess the effectiveness of health facility, national, and global HIV/AIDS strategies and investments.

STRATEGIC APPROACH: A NATIONAL HEALTH SECTOR CLIENT REGISTRY

A national health sector CR will help make sure that individuals in Tanzania receiving health services, including for HIV/AIDS, receive unique IDs. Utilized fully, key benefits of a registry for Tanzania include:

- **Continuity of care:** Tanzania will be able to connect and transfer individual identification details, such as age, gender, address, and case history, among various digital health solutions. Each patient will have a unique ID to help ensure consistency of service or care across time and service provision points, thereby improving health outcomes. Access to medical histories helps providers adhere to established standards for diagnosis and case management.
- **Cost management:** Client services verification is important for claims reimbursement and to justify funding. The CR also reduces time for client registration and identification, which will improve service efficiency.
- **Quality of data for decision making:** With integrated records, deduplication, internal consistency, and a complete record of all health encounters, the MOHCDGEC and other public health institutions can better understand disease epidemiology and programmatic constraints. They will have data for evidence-based decisions to strengthen program monitoring, standards-based case management, epidemic prevention and control measures, policy, and resource allocation.
- **Targeted health communication:** Basic details, such as geographic location, age, and family members, support targeted information campaigns between the health sector and the client to educate, inform, and remind.

The CR will provide unique health and social services client identification across varied health programs and service provision points and for different types of services, including diagnostics, consultation, pharmacy, and community support. It can improve management of health care costs and surveillance and monitoring of quality data, thereby contributing to better public health reporting, clinical research, and patient outcome management. It links individuals to family members, which supports a broader understanding of disease burden within the health sector.⁷

INTERVENTION

MSH is supporting the development and implementation of a CR for Tanzania. The work comprises developing an approach, setting a framework, and producing a set of digital tools in collaboration with the Government and other partners. The CR is a key component of THEA and of Tanzania's eHealth strategy.

The Tanzania CR will:

- Maintain a central registry of all clients, provided they have given informed consent, along with their identifying demographic information, and will assign a unique identifier to each
- Link client registration entries to support tracking even if the client moves or there are data entry errors during client registration or missing identifying information
- Enable health care workers to link client identifiers provided by different registration processes, such as vertical programs, and national person identifiers
- Enable health care workers to link client records, such as those of family members, to help case management and to help track patients
- Enable client matching and deduplication processes through a user interface that can determine whether two client records match and display possible mismatches or other errors so that a data integrity team can more easily spot and resolve them

A CR requires a shared health record (SHR) or electronic medical record (EMR)/hospital management information system that can link client health information using a unique client ID. It needs to be linked to the HIM to enable interaction with point-of-service systems and other disease-related or vital statistics registries. It will provide a user-friendly graphical interface. Pending resource availability, it may also interact with other point-of-service systems, such as human resources and finance.

The MOHCDGEC will have the mandate to create and handle a client's identifying information at any point of service and ultimately storing it in the CR. The agency will also govern how this process will be implemented, including delegating work to approved front-line health care workers.

THE CLIENT REGISTRATION PROCESS

Figure 2 explains the client registration process from a point of service. Data are collected only when a client has been informed of the process and has given full written consent.

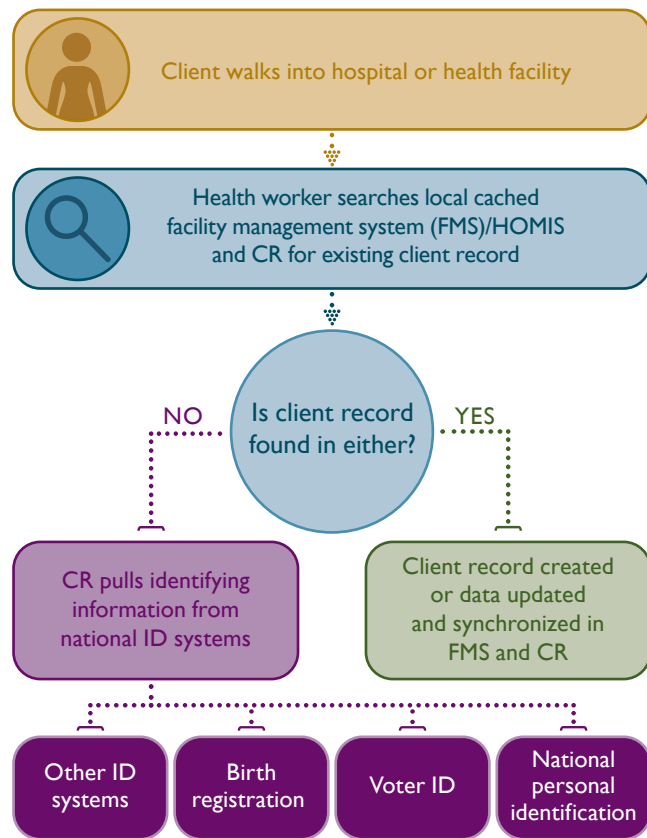


Figure 2. The client registration process

MEASURING PROJECT PROGRESS

The CR project's two main objectives are to:

- Implement an initial CR that demonstrates the use of linking client data horizontally across the health system for specific health services
- Evaluate the CR implementation and develop a five-year road map for health services in Tanzania to adopt and use it. This will include a detailed two-year plan and higher-level plan for years three through five.

Indicators for CR performance are under development and may include:

- Total number of new patients added to the CR in a given time period
- Total number of potential record matches presented by the CR algorithm in a given time period
- Total number of true matches missed by the algorithm and identified during normal operation processes
- Percentage of CR clients with updated demographics in a given time period
- Number of CR lookup requests per hour

Each health service program has specific indicators that demonstrate how the CR will improve program performance. Per the MOHCDGEC, for HIV/AIDS treatment these include:

- Number of clients who have tested positive for HIV who present for testing at another site but are not retested, thereby reducing unnecessary testing and double-counting
- A decrease in the percentage of HIV clients lost to follow up over time

Leaders of each health service program will work with MSH and the CR project team to further develop detailed performance measures on how the program improves service delivery and achieves strategy and outcome goals.

IMPLEMENTATION

MSH developed and will lead the CR Implementation Plan, which includes eight phases over five years (2017–2022).

PROJECT CONCEPTION PHASE

In year one of the project, the team developed a CR concept note in collaboration with Government and health care stakeholders. Owner stakeholders, including the MOHCDGEC, the President's Office-Regional Administration and Local Government, The Registration Insolvency and Trusteeship Agency (RITA), and the National Identification Authority (NIDA), ensured that the CR will meet government standards, align with government priorities, and be implemented effectively.

In addition to MSH and the CDC, partners include PATH; Public Sector Systems Strengthening International; D-Tree; FHI 360; the Institute for Health Improvement; Jhpiego; AEHS; Elizabeth Glaser Pediatric AIDS Foundation; The Christian Social Services Commission; Gates Foundation; JSI; the Tanzania mHealth Public-Private Partnership; RTI International; Pathfinder; WorldVision; Intellisoft; Jembi; The University of California, San Francisco; and the Tanzania OpenHIE CR community.

The CR concept note describes the project and its objectives and guiding principles and proposes the CR implementation plan. It references existing health program IDs and possible health program indicators that can use the CR and proposes a landscape analysis framework to be used in subsequent phases.

Developing the concept note was a highly collaborative, detailed process. TSSP led a number of meetings for stakeholders to delineate roles and responsibilities, ensure synergy, and figuring out how to surmount many and varied technical obstacles to merging the various data systems. A timeline was set for project completion. MSH will lead the process and oversee task completion.

REQUIREMENTS

The CR project management team, which MSH leads, developed the CR Systems Requirements Specification (SRS) through iterative discussions, meetings and workshops with stakeholders, and formal endorsement by the eHealth Project Management Office.

The Care Delivery Technical Working Group (TWG) was instrumental in the CR SRS. The MOHCDGEC led the effort to form the TWG in early 2016 as part of the Tanzanian eHealth governance model. It reports to the National eHealth Steering Committee and is responsible for developing and implementing a facility management system that includes EMR software, a master CR, and an SHR. It sets standards and guidelines, including performance, data quality, and privacy.

PROJECT PLANNING

MSH led the project group in developing a detailed CR implementation roadmap that includes initial implementation and rollout for selected health service locations and a time line for including additional health services and sites and remaining health and other sector services.

CR guiding principles include lessons learned from MSH's work in Rwanda, a leader in eHealth in the region.⁸ These include using comprehensive practical use cases and integrating the CR with a scaled up facility management system. With technical assistance from MSH, the team developed a quality assurance (QA) framework and will update it based on CR stakeholder review during implementation. The team also wrote a CR Project Charter that describes the project, its stakeholders, project governance, scope and high-level objectives, risk management, project communication, change management, and project management.

VENDOR SELECTION

The project management team developed a landscape analysis questionnaire built on lessons learned from implementing health information data systems in Rwanda and following the Tanzania eHealth strategy. The CR landscape analysis will inform the final request for proposals from potential vendors. A selection team will review responses and choose a vendor. Once a CR implementer (whether vendor or consortium of partners) has been selected, MSH will lend technical assistance to the MOHCDGEC to finalize a work contract, including deliverables and performance monitoring.

INITIAL IMPLEMENTATION

The project management team will work with the selected vendor to develop a comprehensive technical design that supports the first two priority digital health solutions that will use the CR—facility management systems and HIV/AIDS digital health solutions. This implementation will be the foundation for additional HIS integration and additional health services.

Table I. Major Requirements for the Client Registry

CR Functional Requirement	Description
Software Interface	Interfaces allow authorized personnel to review for possible duplicates, ensure quality and consistency of data, and make changes as necessary
Software Interface	Able to both operate independently and interface with and use services through the HIM when they become available, with defined use case for exchanging information
Software Interface	Able to send and receive data with legal identification databases, such as RITA and NIDA
Software Interface	Ability to operate in centralized and distributed modes with predefined mechanism for providing updates and synchronizing with cached versions of the CR content or subset of content
Workflow	Allows for creation of a new client record only when none exists. Allows authorized users to assign an internal system-generated identifier (Enterprise Client Identifier) that will be specified on the client's clinical document and to which other client IDs will be linked to create and consolidate a client's identifying information.
Workflow	Allows (per relevant security policies) querying of existing client records, including viewing the update history
Configurable Entity Matching	Default implementation is flexible and configurable so that nonprogrammers can adjust it to meet their needs
Patient Linking and Deduplication	Implements industry recognized, verified, and validated accurate and efficient client linking and deduplication methods. Voids but does not delete clients who are certified as dead.
SHR Synchronization	Allows synchronization of client IDs with SHR (supports patient-level clinical data workflow)
User Interface	Supports searching clients and manual edits (e.g., create, update, merge) with configurable search and browsing rules (e.g., optional and required search fields); capability to view historic client information
Configurable Attributes	Allows configuration of attributes of client records, including those used for matching. Metadata allows for indicating/marketing level of field activity.
Privacy and Security	User management and access controls are configurable for authentication, authorization, privacy, integrity, and nonrepudiation
Data Transfer	Uses secure sockets in all transactions that include any confidential user or client information; confirms all transactions with the authorized user's web browser; no cookies on a user's computer containing the user's password or confidential user or client information

EVALUATION OF THE INITIAL CR IMPLEMENTATION

This includes a review of the M&E performance measures and documents lessons learned. Insights will contribute to the success of additional project iterations. It will be an ongoing activity as the CR is integrated with additional systems.

INTEGRATION OF CR WITH ADDITIONAL HIS

The project team will prioritize additional HIS to integrate with the CR and will incrementally implement these plans.

EVALUATION OF THE EXPANDED HIS-CR INTEGRATION

This will include monitoring and review of results to date, as well as documenting lessons learned. It will be an ongoing activity as the CR project integrates additional systems.

PRELIMINARY LESSONS LEARNED

The following principles, which will guide project completion, reflect initial CR project lessons learned and MSH's experience with similar projects in other countries. These include:

Government ownership: The MOHCDGEC owns the project, in collaboration with the President's Office-Regional Administration and Local Government, and other stakeholders. TSSP leads technical assistance to support implementation. The owners make key decisions at each step of the process to guide the implementation to support a CR that is sustainable and responsive to local needs.

Alignment with national strategies, including data privacy: The CR implementation is aligned with the National eHealth Strategy for 2013–2018 and is identified as one of the key recommendations in the digital health investment roadmap. It supports Tanzania's efforts to achieve UHC. Project alignment with these health priorities is key to government ownership and sustainability.

Having a common understanding of CR development: The CR is a complex digital health solution that will promote efficiency and desired health outcomes over the long term. MSH expanded on the digital technology progress already being made in Tanzania to build support for a CR system that provides a unique health sector ID. A key part of reaching consensus was the learning journey that took place among all stakeholders. Each had a voice and a role in the discussions on improving HIV/AIDS care in Tanzania and how the CR is expected to contribute to this outcome.

Integration of the CR with a scaled-up facility maintenance system/EMR: The use of a CR implies that there is some level of implementation of an SHR. To make sure that all medical record details reach the national CR

level, where all client medical information can be linked using an individual client ID, it is critical to have a robust, scaled, and sustainable facility management system. TSSP provided technical assistance in developing a facility management system that was piloted in select health facilities in August 2018.

Iterative CR development: Reflecting best practices based on prior experience with other digital initiatives such as DHIS2 (which was rolled out incrementally at a national scale) and given the large scope of this CR project, the team will incrementally integrate the CR with additional digital health solutions after reviewing comprehensive practical use cases. The team will conduct QA throughout the CR project on processes as well as software. Continued stakeholders involvement will ensure that all emerging needs and improvements in other national-level population registers are incorporated. When developing and implementing the registry, it is critical that stakeholders from the immunization register and health facility registry share their experiences to cue expectations and milestones for each iteration of development.

Training and risk management: When introducing a new HIS, project leaders must adequately train front line health workers to use the system effectively and efficiently. Introducing a CR raises privacy concerns, such as hacking or inadvertent sharing of information. Potential solutions for Tanzania include documented annual or regular privacy training for those with access to the registry data and the development of a formal incident management process.

CONCLUSION

- Many health system challenges in Tanzania are linked to poor client-level data systems. The CR is a foundational digital health initiative for Tanzania's eHealth architecture.
- The CR will significantly contribute to TSSP project achievements, such as improving health data availability, accuracy, and quality.
- The CR supports HIV programs in the country toward attainment of the 95-95-95 global target by ensuring that clients enrolled in care and treatment programs are appropriately identified, enrolled, and maintained.
- The project promotes sound HIV program management. It supports Tanzania's goal of UHC by tracking patient access to and use of health commodities and services.
- The CR can be adopted across other health service areas and health service delivery sites and MSH can adopt the model for similar interventions in other low- to middle-income countries.

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TANZANIANS AND AMERICANS
IN PARTNERSHIP TO FIGHT HIV/AIDS



This publication was supported by Cooperative Agreement Number, NU2GGH001929-01-00, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.