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Managing Patient Identification in Uganda's Health Facilities: Examining Challenges and Defining Requirements for a National Client Registry

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Background and Purpose: Managing accuracy to identify any patient is very crucial in ensuring continuity, quality and coordination of their healthcare over time. Patient identification management (PIM) in healthcare is still a challenge in Uganda for both public and private healthcare institutions including insurance companies using different mechanisms to uniquely identify clients. This deters PIM and individual health data linkage across healthcare organizations. An integral part of individual health data linkage and health information exchange (HIE) process across healthcare organizations is verification and/or validation of a client's identity. This vital service can be provided by an administrative electronic health information system known as a client registry (CR). A *CR* is a central electronic database that holds patient identifying information such as unique identifiers within a given territory. Consequently, in preparation for the establishment of a National CR (NCR), we needed to first examine the current mechanisms used and the challenges faced in PIM in Uganda's health facilities. The NCR is envisaged to facilitate and harmonize PIM and HIE in Uganda's healthcare system.

Methods: A cross-sectional study was conducted to document the mechanisms used for and challenges facing PIM in Uganda and define NCR requirements. The Design Science Research (DSR) approach was employed to achieve the overall study aim with a much broader goal beyond this paper. Specific to this paper, the research question for which the methods and results presented was formulated under stage two of the DSR six-step process model.

35 key informant interviews with purposively selected representatives from select organizations and health facilities were conducted.

Results: Majority of health facilities use either paper-based or a combination of both paper-based and electronic tools to register clients, manage their identities and data. Key challenges reported facing PIM relate to data storage, retrieval, client identity verification, and tracking. These translated into four key NCR requirements that can facilitate PIM and HIE in Uganda's healthcare system.

Conclusions: The study proves that there is need to address the various PIM challenges; as such our next steps are to establish actual NCR requirements/services in order to harmonize PIM across Uganda's health facilities.

Keywords: Client Registry, Patient Identity Management, Health Information Exchange, Health Information Systems, Disease Management

1 Introduction

Managing accuracy in the identity of any patient is very crucial in ensuring quality, continuity and coordination of their healthcare over time. Being able to accurately and consistently identify a client who accesses healthcare services at any point of care helps to enhance provision of timely care, ease retrieval

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of individual medical records to aid informed treatment and forms a basis for developing a Shared Health Record (SHR) that can aid coordination of care between providers (1, 2). Managing accuracy in identities of clients who access healthcare services also has a big role to play in the quality of health data that is reported at health facility, regional and national levels (3). In low-and-middle-income countries (LMICs) scaling up of health services directed to combat endemic communicable diseases like HIV/AIDS, Tuberculosis and Malaria is more evident. This has however come with the need for increased data collection in order to create an individual longitudinal health record to aid monitoring and evaluating of the efficiency, effectiveness, equity and acceptability of healthcare at health facility, subnational and national levels; planning and coordination of healthcare service delivery; and accountability to donors and/or development partners (3).

Uganda currently lacks a standard mechanism to manage patient identities within and across its healthcare institutions, as such affecting the reliability of data, and realistic population denominators (4). Particularly, the healthcare facilities, institutes and vertical health programs use diverse identification schemes and patient number formats intended to identify each patient and manage internal patient identification (5). For instance, the current situation is characterized by the assignment of varying serial numbers to the same client who may access outpatient services from more than one unit (TB, HIV/ART, Diabetes, Malaria, Antenatal, Maternity, Postnatal, and so forth) within a health facility; assignment of varying vertical health program numbers (ART number, Unit TB Number, Antenatal Number, PMTCT Number, Child Number, and so forth) for a co-morbidity client or a client diagnosed with two or more conditions requiring careful monitoring to ensure timely intervention and subsequent better health outcomes.

However, it is challenging to use the aforementioned facility-, unit-, and program-specific numbers outside the respective precincts and thus cannot be used to track a client and the healthcare services they use across healthcare facilities they visit. This is true regardless of whether eHealth applications (like UgandaEMR and Clinic Master) or paper-based systems (HMIS tools) are used for data collection and management, yet several conditions fought against in Uganda are longitudinal in nature (6). A disease or condition is longitudinal in nature if it requires careful monitoring or follow-up of a patient to ensure better treatment adherence and outcomes (3). Additionally, in some MoH technical working group meetings, a proposal to use the National Identification Number (NIN) to uniquely identify individuals at the point of care has been made. The NIN is however challenged with various gaps including; not all people who live in Uganda have NINs such as the children from zero months to 17 years of age, alien (non-citizens), and refugees. The NIN is serially generated without accounting for the fields / attributes' combination (what they mean or represent). Worse still, capturing of the NIN differs in varying institutions depending on the space / length of values in a given Information System; for example the Immigrations and International Interpol institutions do capture only the nine numeric values which are the "card number", while embassies do capture the NIN itself, so to say the NIN actually constitutes of fourteen alpha-numeric values; and its use for patient identification may minimize and/or compromise privacy and confidentiality of patients' health information. These gaps have negative implications on patient identification and matching efforts across healthcare organizations in Uganda directed to improve quality, continuity and coordination of patient care.

Based on the above situation, it is clear that Uganda's healthcare system lacks a standard mechanism to uniquely identify patients for ease of healthcare management and service provision. In other words, there is absence of a universal, ubiquitous and unique way of identifying patients and managing their identity across healthcare organizations in Uganda (3, 5, 7). Without proper identification of clients, it is difficult to manage client/patient identities within and across healthcare facilities; a vital aspect or backbone of a Share Health Record; proposed to facilitate consolidation of individual patient data collected during various encounters within and across different health service points to aid quality, continuity and coordination of healthcare (3, 8). To this end, this study aimed at examining the challenges facing mechanisms used for patient identification management; from which these could be used to inform requirements that a National Client Registry (NCR) should have in order to aid HIE in Uganda's healthcare system. A *NCR* is a central electronic database that holds patient or client identifying information such as unique identifiers within a country or nation.

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2 Materials and Methods

A cross-sectional study was designed to be conducted between April and November 2018 in seven regions across Uganda including Northern, West Nile, Karamoja, Eastern, Central, Western and South Western regions; particularly, within the Districts of Gulu, Adjumani, Moroto, Mbale, Kampala, Kabarole and Kabale Districts, respectively. The select study sites included Ministry of Health, National Information Technology Authority - Uganda, National Identification and Registration Authoriy, two development and/or implementing partner organizations; and 30 health facilities across the seven select regions. Study participants comprised mainly those from Ministry of Health, Partners and health facilities including health informaticians, monitoring and evaluation specialists, clinicians, data managers, nurses, midwives, among others. The Design Science Research (DSR) approach was employed to achieve the overall study aim with a much broader goal beyond this paper. The basis for using DSR approach stemmed from its ability to provide a rigorous process leading to elicitation and specification of essential NCR requirements and development of design models. Under stage one of the DSR six-step process model, the problem driving the much bigger study was identified. Specific to this paper, the research question for which the methods and results presented was formulated under stage two of the DSR six-step process model.

The purposive sampling technique was employed to select the study sites and key informants. This was because subject matter experts on key aspects such as patient data management, patient identity management and health information exchange were required at both national and sub-national levels to answer the research questions. Thus, the key informants that were purposively selected possessed enormous experience in healthcare, health information systems and health data management. Purposive sampling is a non-probabilistic sampling technique used when there is need to concentrate on people with certain characteristics who are better placed to contribute to a given research study (9, 10). The purposive sampling criteria included the organizational mandate, knowledge and experience, region, level of health facility, information system tool or mechanism type, end-user type and technical area.

Qualitative data collection methods were employed to document mechanisms used for and challenges facing patient identification management in Uganda's healthcare system. A semi-structured interview protocol and an interview guide were designed to collect data from select study participants at subnational and national levels, respectively. This study obtained ethical approval from Makerere University School of Public Health Institutional Review Board (IRB). Additionally, permission was sought from the stakeholder organizations that were selected as study sites for this research before any data collection was done. Thirty-five key informant interviews with purposively selected representatives from select organizations and health facilities were conducted. That is, nine at national level and twenty-six at subnational level). An inductive approach was used to analyse the collected data. The data collected was transcribed verbatim, manually analysed and coded by two coders (researchers) independently. The coding was compared and discussed before deriving themes from the data and categorizing results into final themes by the two independent researchers. The coded data were categorized into three key themes namely, process / workflow, technology and organizational (people) challenges.

3 Results

In summary, 78% (22/28) of the health facilities visited were Government-owned, while 11% (3/28) and 11% (3/28 were PNFP and PFP respectively. It was reported that about 50% (15/28) use both paper-based and electronic HIS while only 39% (11/28) and 2.8% (2/28) use paper-based and electronic HIS, respectively. In addition, close to 90% (25/28) health facilities use HMIS tools which have provision for recording client numbers like the ART number, Child number, TB number, ANC number, etc., assigned to clients during their first visit at health facilities for ease of identification on subsequent visits. Slightly over 30% (10/28) health facilities use both HMIS tools and UgandaEMR system, particularly for ART care clients, and only 3% are using any of; PARAS Healthcare MIS, Butabika Medical Records System, ICEA or Microsoft Dynamics Navision.

Region	Health Facilities								
	Clinic	НСП	HCIII	HCIV	GH	RRH	NRH	НМО	-
Northern	0	1	1	1	0	1	0	0	4
Eastern	0	1	1	1	0	1	0	0	4
Central	1	0	1	0	1	1	2	1	7
Western	0	0	1	1	2	1	0	0	5
South Western	0	1	1	1	1	1	0	0	5
West Nile	0	0	0	0	1	0	0	0	1
Karamoja	0	1	0	0	0	1	0	0	2
Total	1	4	5	4	5	6	2	1	28

*HC – Health Center; GH – General Hospital; RRH – Regional Referral Hospital; NRH – National Referral Hospital; HMO – Health Management Organization

Table 1. Health facilities that participated in the study by region and level

3.1 Overview of Mechanisms

	Mechanism	Description of Purpose & Functionality of Mechanism	How Patient Identity is		
			Managed		
1.	Health Management Information	HMIS is a paper-based routine health information system used to monitor and evaluate the health sector as well as provide warning signals of events like	Patients' identifying data are recorded in the paper-based registers and pre-primary tools		
	System (HMIS)	epidemics (surveillance), and health facility commodity stock-outs. It enables health workers offer better care and manage health facility supplies and resources; supporting health workers in their efforts to organize and supervise health development work in	such as client cards. Patient number formats are used to identify clients. However, these number formats do not effectively serve the purpose of managing		
		their communities; and provides data to the health sector and partners for decision making.	patient identities within and across health facilities.		
2.	UgandaEMR System	UgandaEMR is an electronic health information system (eHIS) built on an open source platform (OpenMRS). It is used to register HIV positive clients and their clinical information such as their vitals, viral load, CD4 count, regimens prescribed, drug allergies, among others, based on the paper based HMIS form called the HIV Care / ART Card, as well as scheduling appointments and report generation based on the national HMIS standard reports.	System-generated medical records numbers are used to identify patients. However, the system-generated medical records numbers are known only within the ART clinic of a given health facility. Thus, a medical records number assigned to a patient may be rendered useless when a patient say moves across other units within the same health facility and/or visits other health facilities for care (other than HIV care).		
3.	Integrated Clinic Enterprise Application (ICEA)	ICEA is a proprietary, modular ART/HIV centric system that supports patient registration, consultation, prescription, lab, counselling, TB management, referral data capture; Clinical Decision Support; Order Entry Prescribing; and report generation. It also tags each clinician to the patients they handle on a routine basis.	System-generated medical records numbers are used to identify patients. However, the system-generated medical records numbers are known only within the Infectious Disease Clinic. Thus, a medical records number		

4.	Butabika Medical Records System (MRS)	Butabika MRS is a proprietary EMR system built on Microsoft Access to enable registration of mental health clients, coding of client illnesses based on ICD-10, capturing of their history, storage of mental health client data, capturing clinical data including drugs being administered to client, allergies and	assigned to a patient may be rendered useless when a patient say, visits other health facilities for care (both HIV and other care). System-generated medical records numbers are used to identify patients. However, the system-generated medical record number is known only within a given unit of the National Beformel Hagmith and has no
		report generation.	Referral Hospital and has no meaning attributed to it. Thus, a medical records number assigned to a patient may be rendered useless when a patient say moves across other units within the referral hospital and/or visits other health facilities for care (other than mental care).
5.	Microsoft Dynamics Navision	This is a proprietary integrated hospital Management Information System customized to enable registration of clients, prescribing drugs, patient billing and inventory information management. It is generally an Enterprise Resource Planning tool that several private healthcare facilities in Uganda have customized to enable client registration and related clinical and administrative patient data, such as clinical notes capturing, drug prescription, patient billing, and drug inventory information management.	System-generated medical records numbers are used to identify patients. However, the system-generated medical record number is known only within a given unit of the Hospital and has no meaning attributed to it. Thus, a medical records number assigned to a patient may be rendered useless when a patient say moves across other units within the referral hospital and/or visits other health facilities for care.
6.	PARAS Healthcare Management Information System	PARAS Healthcare Management Information System is a proprietary patient-centric comprehensive and integrated healthcare delivery application that covers a complete spectrum of patient care designed to suit the needs of all kinds of health care providers such as hospitals, clinics, laboratories, day care centers, diagnostics, etc. Its key functionalities include client registration, appointment scheduling, dashboards, e- prescription, alerts and notifications, inventory and stock management, and system administration.	System-generated medical records numbers are used to identify patients. However, the system-generated medical record number is known only within a given unit of the Hospital and has no meaning attributed to it. Thus, a medical records number assigned to a patient may be rendered useless when a patient say moves across other units within the referral hospital and/or visits other health facilities for care.

3.2 Challenges Facing Mechanisms Used for Patient Identification Management

This section presents the general challenges faced by the mechanisms used for patient identification management described above. They are categorized as process (workflow), technology, organization and other challenges.

Process / Workflow Challenges.

Data Entry: Regarding data entry, it was reported that some of the HMIS tools did not have all the required data elements to enable capturing of client identifying information and other important data as may deem necessary. For instance, some respondents reported that these tools often lacked provision for entry of new data elements due to the time it took to request for effecting these changes by the mandated Division, and transition from the old to new tools. Also, some health programs (not mentioned here) lacked unique identifiers for clients.

Data Storage: Health facilities especially those that use mainly paper-based information systems and/or both electronic and paper-based systems lacked proper ways to store client's health information. A respondent from one of the National Referral Hospitals said this regarding storage, '...the issue is about storage where the shelves get full and some records are kept on the floor. You sort them today, tomorrow as you retrieve, they get mixed up. You have to again re-sort'.

Data Retrieval: Majority of the participants attributed the challenge of retrieving client records to lack of EHIS and the tedious nature the paper-based tools pause to health workers when trying to access past medical records. A respondent at a regional referral hospital said, "...you know this thing of opening, opening... it takes a lot of time looking for something. If at all it was electronic it would be easier. Because sometimes patients are many and you must look for them individually, and update such that we isolate those people who missed appointments yet have to adhere to treatment prescriptions."

Client Identity Verification: Difficulty to validate and/or verify client identity were reported by health facilities that have ART clinics, TB clinics and those that handle clients with health insurance. For example, for ART clinics, there was difficulty in accounting for the incentives given to HIV clients due to lack of verification means. A respondent said, "Seriously every insurance company and hospital has a different identifier they assign to a client, this brings lots of confusion for us. I mean ... now for us with several ART care clinics, the clients test for HIV and access ART care. When they hear of another clinic dispensing porridge as an incentive, they seek care from that clinic and abandon the previous one where they were first initiated on treatment, do not tell the truth regards their medical history and there is no referral form for reference. So, we always register the client afresh and miss all the medical history that might have been collected before and don't get to know the last regimen received".

Client Tracking: Lack of ability to track clients was also mostly reported especially by health facilities that deal with clients who have chronic illnesses like TB, HIV and services that require continuity of care like immunization and antenatal care. At health facility level, a respondent from one of the refugee hosting Districts in West Nile said, "...the current HMIS tools do not allow us to capture the identity of infants who present for immunization. So, there is no way of telling the true identity of an infant, where they live or come from and whether they are a refugee or not, for us to follow up if they got immunized or not". A national level respondent said, "In TB care, the biggest problem we have is during TB client follow-up periods where accountability of cohorts in terms of whether a client got cured or died or was lost to follow-up is very much required. Overtime we have realized that loss-to-follow-up is meaningless especially because a client may be accounted for as lost-to-follow-up, yet they continue receiving services from another facility with no way of telling that due to lack of streamlined client identity management across healthcare facilities in the country".

Duplicate Client Records: Majority of the respondents also reported duplication of client records, particularly due to lack of a unique identifier that could consistently and uniquely identify a client. In other health facilities, respondents mentioned that they were not able to determine duplicate client records and that such aspects are never discussed or prioritized.

Technology Challenges

Lack of effective data validation rules: Health facilities that use both electronic and paper-based information systems especially in the HIV clinics, were concerned about the data validation rules

customized by developers; these sometimes were overridden by data entrants who simply appended punctuation marks e.g. full-stops or commas to clients' names if the systems rejected the entries.

Lack of better effective ways to identify and control duplicates: Respondents were greatly concerned about information inaccuracy in EHIS, e.g. during client searching, there are no means of differentiating between two clients who may have similar data elements; worse still the EHIS do not indicate data wrongly entered by health data clerks or managers to prompt correction through edits and updates. A respondent from one of the urban hospitals in Kampala said this about data entry challenges faced using electronic information systems: *"Electronic system has information accuracy issues. For example, before registration I search a client by name and when I finds two or more people with the exact names am never sure of who this person is, first or second entry. I normally use the phone number to differentiate the two although sometimes there is no phone number recorded. Also, there are data entrants who are never kin and therefore end up appending details to a wrong client record which may result into one client's medical history falling under another's client's demographics which may not be easy to change because the system is not intelligent enough to flag it for resolution."*

Absence of well-configured EHIS to generate national-level HMIS reports: Respondents also reported that the electronic health information systems deployed and used at the health facility are not configured to generate standard national-level HMIS reports, and yet manual report compilation is one of the major pain points in health data management. A respondent from a Health Center IV in Western region where the Case-Based Surveillance Project has been implemented said, "We still cannot generate the quarterly report perfectly...the Form 106a. The figures or data are often overlapping or incorrectly placed in the provided spaces whenever we try to generate it electronically. So, we still have to manually compile this report."

Organizational Challenges

The national-level respondents majorly reported the organizational challenges including;

Lack of governance and coordination of the mechanisms used to collect patient data; as a result, several uncoordinated mechanisms have mushroomed across the country, worse still unknown to the Government.

Lack of defined needs for health data management in health facilities. Health workers, data entrants and records assistants simply do not know why they collect this data apart from reporting it to the higher levels, thus do not attach importance to the aspect of data management.

Low usability of the PIM mechanisms. Some of the tools/mechanisms used for PIM are somewhat complex or seem a burden for the health workers to use; as such they refrain from using them for patient data collection. This leads to missed opportunities to collect important health data. For example, some end-users mentioned that they found it hard to construct logical commands to generate reports using cohort builder. The majority mentioned that it was a burden to record data in both paper based HMIS forms and the electronic systems and so they always ended up recording in only one of them.

Difficulty interpreting data elements that constitute the tools/mechanisms; health workers nationwide lack uniformity in interpretation of the data elements that constitute the HMIS tools. This impacts negatively on the quality of data that is collected.

Lack of inclusiveness of frontline health workers during the development of some of these EHIS tools/mechanisms, as well as Standard Operating Procedures.

Other Findings and Challenges

Data Analysis: Majority of the respondents at the health facility level mentioned that the paper based HMIS tools made it so difficult for them to analyse data; this required one to first enter the data into an

EHIS leading to somewhat double work or burden. Additionally, a data analysis skills gap and definition of the bare minimum for health workers to analyse was reported.

Reporting: Reporting gaps were also reported at health facilities that use mainly paper-based and both systems. Particularly, it was tedious to sift through all registers to ably count all clients who visited the health facility at all entry care points during the reporting period (monthly or quarterly). Worse still, there were no means of generating standard HMIS periodic reports for those facilities that use electronic mechanisms.

Target Population Estimation: The issue of population denominators was raised by respondents mainly working on the Immunization program in refugee-hosting, borderline districts and Kampala where the population is always fluctuating. It was reported that it was difficult to generate accurate denominator estimations for health facility catchment areas, yet these estimates guide ordering for vaccines and other injectable materials. Specifically, the figures provided to health facilities are centrally based and generated from occasional surveys, thus they do not give a true reflection of the actual children numbers that come to outreaches or health facilities for immunization. Quoting verbatim from Adjumani District respondent *"For us here, these target population estimates from the District do not help because any time we receive refugees from South Sudan. We have no way of knowing when it will happen and so the number of vaccines sometimes is not enough..."*.

Weak security, confidentiality and privacy measures: The way some of the electronic information systems deployed in health facilities are designed compromises the privacy and confidentiality of patient health information. For instance, for some mechanisms a health data clerk is able to see all of a client's data information (both identifying and clinical information). Furthermore, majority of the health facilities using electronic mechanisms had no defined standard procedures on use of login credentials like user passwords. For some electronic health information systems deployed at health facilities, respondents mentioned that there was no way of telling who and what a user did or changed in the system at any point in time. Lastly, several respondents especially those from facilities in central region (Kampala) mentioned client perceptions and organizational culture with regard to security, privacy and confidentiality of person health data in healthcare institutions as a challenge to technology advancement including PIM and HIE. A respondent from one of the major hospitals in Kampala said, '...even with two facilities (with different ownership) using an electronic health information system developed by the same vendor, it is not acceptable by both clients and the management teams (of both health facilities) have the two instances of that system be integrated in any way because they do not trust that their data will be safe or be kept private'.

4 Discussion

This paper documents several mechanisms used to register patients, manage their identities and data; and key direct and indirect challenges facing PIM including, data storage, retrieval, client identity verification, client tracking, duplicate client records, among others, in Uganda's healthcare system. Relatively, there was no explicit identifier(s) used to link all person health information to an individual who may access care across health facilities identified. The study also revealed other related key challenges pertaining to data management including data entry, analysis and reporting which were of key concern to the respondents. Technical and organizational challenges which may influence PIM mechanisms were also revealed by this study.

Data storage, retrieval, analysis and reporting were reported as some of the key challenges because majority of health facilities selected to participate in the study were public health facilities that either use only paper-based forms or both paper-based forms and digital health tools to register patients and manage their identities and data. The same challenges relating to paper-based health information tools are common in low resourced countries like Uganda with recommendations to consider adopting digital tools (10). Furthermore, like many African countries, Uganda has recently developed a National eHealth Policy and Strategy to direct eHealth adoption with so much left to do in terms of understanding the current situation and creating awareness of what and how digital health interventions can alleviate some of the

challenges faced in the healthcare system (7). Thus, the current situation characterized by low levels of proficiency on topics such as patient identification management and health information exchange among health workers, health system managers and policy makers may also have had an impact on the findings from this study. Organizational challenges, especially, the lack of active governance of data management mechanisms and absence of uniformity in data element definition are gaps that have an impact on the move towards the patient identity management and health information exchange. These are critical factors that that need immediate attention for successful implementation of the National Client Registry and Health Information Exchange (11). The main strength of this study is the Design Science Research (DSR) approach that allowed for a more rigorous process to achieve the major study objective beyond this paper. However, the study was limited by dominant participation of the public health facilities as compared to Private for Profit (PFP) and Private Not for Profit (PNFP) health facilities. It is possible that the latter could have demonstrated more post-eHIS gaps since majority have adopted digital health tools for patient registration and health data management (12).

In conclusion, the findings from this study reveal that several mechanisms are used to register and manage patient identities and their data. The study results also concretize the lack of a standard mechanism to manage patient identities within and across its health institutions in Uganda as a key challenge facing PIM in Uganda's healthcare system. Majority of health facilities use either paper-based or a combination of both paper-based and electronic information systems to register clients, manage their identities and data with data storage, retrieval, client identity verification, client tracking being common challenges across health facilities. Study findings disseminated in this paper focus on the problem and motivation identification; and study objective definition stages of the DSR process model. Processes within these two stages are what led to the documentation of mechanisms used for and challenges facing PIM in Uganda's healthcare system. NCR requirements elicitation and design of models based on the documented challenges will be done as the next steps under the third stage. Much as more needs to be done in terms of laying ground for the establishment of a national CR, we can recommend from this study that there is a clear need to embark on an all-inclusive journey to develop and implement NCR for PIM and HIE in Uganda. Most importantly, the government will need to examine and decide on whether Uganda will take up an existing identifier (NIN) to act as the individual identifier or a parallel health individual unique identifier for its health system. Therefore, our next steps are to establish possible CR requirements/services in order to harmonize patient identification management across Uganda's health facilities.

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Statement on conflicts of interest

The authors declare no conflict of interest.

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