e-Surveillance of Neglected Tropical Diseases

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Version 2015-11-23

Background

The morbidity of neglected tropical diseases (NTDs) approaches half the disease burden of malaria in sub-Saharan Africa, and about double of that caused by tuberculosis. NTDs tend to affect the lowest economic strata of people living in sub-Saharan Africa, with an estimated 500 million being affected.[1] As elsewhere in sub-Saharan Africa, there is a near-complete lack of information on prevalent NTDs in Kenya, despite abundant anecdotal evidence of visceral leishmaniasis and echinococcosis. Yet, there are little or no hard data to support an evidence-based approach to public health planning and related cost-effective and sustainable interventions. It is reasonable to assume that the prevalence, disease burden and adverse economic effects of visceral leishmaniasis and echinococcosis in Kenya are grossly underestimated. This shortage of information is sustained by the fact that neither of the above are notifiable diseases, and therefore not integrated into the prevalent integrated disease surveillance and response (IDSR) mechanisms implemented by the Kenyan Ministry of Health (MoH), with support by the World Health Organization (WHO) and development partners.

Consequently, there is an urgent need not only to establish evidence-based data on the prevalence, incidence, disease burden and economic effects of visceral leishmaniosis and echinococcosis in Kenya, but also to establish cost-efficient surveillance mechanisms that continue to monitor key disease parameters in a robust, cost-effective and sustainable way to support evidence-based decision-making and public health interventions.

It is anticipated that with appropriate evidence, both visceral leishmainasis and ecinococcosus may become notifiable diseases, and hence become part of the established ISDR system to hasten regular reporting, appropriate intervention and feedback on established responses.

Introduction

Surveillance is the systematic collection, analysis, and interpretation of health data. It includes the timely dissemination of the resulting information to those who need them for action. Surveillance is therefore essential for informed decision-making in the domains of planning, implementation, and evaluation of public health practice.

Recent events have shown that the existing public health surveillance system is in a less than ideal position to provide comprehensive, accurate information in a timely manner. This holds especially true for paper-based reporting systems, but continues to affect electronic reporting systems that commonly necessitate the routine or event-based analysis of existing medical data created by the interaction between patient and health care provider. Ideally, surveillance data should be created automatically as embedded metadata of the clinical record established during initial and follow-up health care encounters, be this within the community and the peripheral health unit or referral levels.

The near-complete lack of surveillance data related to NTDs, especially leishmaniasis and ecinococcosis, may be regarded as an opportunity to drive the above embedded approach, where simple, robust medical record systems can, in tandem with point-of-care (PoC) diagnostic instrumentation, automatically effect the required data analysis, aggregation and reporting to the central level. Consequently, there is an urgent need for routines to swiftly identify, analyse and act upon bottlenecks to universal coverage[2]. With these in place, it is hoped that the performance of the surveillance and emergency preparedness and response systems can be extended to relevant NTDs,

1 Hotez PJ, Kamath A, Cappello M. *Neglected Tropical Diseases in Sub-Saharan Africa: Review of their Prevalence, Distribution, and Disease Burden.* PLoS Negl Trop Dis. 2009 Aug; 3(8): e412. [PubMed]

2 *Reaching Universal Health Coverage through District Health System Strengthening: Using a modified Tanahashi model sub-nationally to attain equitable and effective coverage.* United Nations Children's Fund (UNICEF), New York; 2013

whilst creating a point in case for near real-time disease monitoring without added user intervention. For the purposes of proper quality management, it follows that the monitoring of disease surveillance should be an integral part of the latter.

Definitions

There are several types of surveillance, each of which is defined by the purpose of the surveillance action required:

Passive surveillance is usually done on a regular basis by all institutions that see patients or test specimens, and are part of an established reporting network. Passive surveillance will typically only identify those who display signs and symptoms, and is therefore of limited value in pathologies that include healthy carriers or long incubation periods.

Active surveillance implies clinical outreach and active case finding, commonly through door-to-door surveys. It is an approach commonly deployed during outbreaks, and includes the gathering of information from all affected segments of the health care environment.

Sentinel surveillance is usually performed by strategically placed health care providers that regularly provide standardised reports on specific diseases.

Disease-specific surveillance defines any surveillance activities that capture a set of identified data related to a specific disease or condition.

Surveillance may be based on signs and symptoms, or common events, such as seen in health **facility-based** and **community-based** surveillance, respectively, while **laboratory-based** surveillance uses laboratory data to describe events or trends.

Requirements

Appropriate surveillance data have to be representative, statistically valid and issued in such a way that they can be readily shared among key agencies. Cost-efficiency is sustained by integrating surveillance procedures directly into routine health care and laboratory procedures, whilst capturing relevant data, only. Consequently, effective surveillance reflects both the scope of existing primary health care efforts or anticipated challenges, such as in the case of NTDs, and should inlcude vulnerable people and migratory populations. Although real-time reporting is not normally required, aggregate data should become available in a timely manner, to allow informed decision-making, typically at weekly intervals, or more often in emergencies. e-reporting has the potential to facilitate data processing, while providing near-real time access to analytical data.

Syndromic Surveillance

The usability of surveillance data is determined by what is captured and how it is reported. Disease-centric reporting has been shown to create a bias towards commonly encountered diagnoses, such as malaria and typhoid fever. This type of bias towards the common and usual may blunt the response to evolving emergencies, as seen in the 2014 Ebola outbreak. In response to this shortcoming, other regions have successfully implemented a syndromic approach into their surveillance activities.

The underlying principle of the syndromic approach is to identify patterns of disease as early as possible, well before specific diagnoses are confirmed, and to effect a swift response in an effort to reduce morbidity and mortality.[3]

3 CDC. *Overview of Syndromic Surveillance. What is Syndromic Surveillance?* MMWR 2004;53(Suppl):5-11

Integrated Disease Surveillance and Response

IDSR is a strategy developed by WHO AFRO region and AFRO member states designed to increase the responsiveness and effectiveness of existing public health surveillance systems in the African region. The IDSR strategy promotes rational use of resources by aligning common surveillance functions, such as case detection, reporting, analysis, feedback and action, as well as structures, processes and personnel for different priority diseases. IDSR takes into account the One World – One Health perspective as a strategy that addresses events at the intersection of human, domestic animal, wildlife, and ecosystem health: 75% of recently emerging and re-emerging diseases, and a great number of NTDs, are of animal origin or transmitted via animals.[4]

Community-Based Surveillance

Capturing NTD data from health facilities, only, is prone to limit the population covered by the envisaged surveillance systems. In order to eliminate this bias, community-based and household-level reporting should be strengthened, with mobile teams or canvassers situated inside the community to capture events and incidents. The nature of eccinococcus transmission calls for additional monitoring animal husbandry, slaughtering and meat processing, and therefore offers an opportunity to integrate with the screening for other cattle parasites. As before, embedded processing of surveillance data as metadata of the actual animal screening procedure offer near-effortless handling of summary data for surveillance and monitoring purposes, with transmission to the higher level. There are free and open-source mobile software tools available that conveniently capture data both offline and online, with built-in workflow tools to maximize data integrity, although they require a degree of (computer) literacy and daily charging of smart mobile devices.

International Health Regulations

International Health Regulations (IHR) 2005 have practical implications for IDSR, because all public health conditions and events of international concern (PHEIC) should be detected, assessed and responded to swiftly. IHR include the control of borders and containment at source of public health events. Because of the major role PHEIC nowadays play with regards to international public health security, travel and trade, IDSR provides a comprehensive platform for IHR 2005. This includes the safety of meat products, which is directly linked to NTDs prevalent in Kenya. Consequently, the inclusion of relevant NTDs into the public health surveillance system provides a favourable opportunity to improve IHR 2005 implementation in Kenya and the region.

Global Health Security

Global Health Security (GHS) constitutes an effort between the United States Government (USG), other nations, international organisations as well as public and private stakeholders to accelerate, and translate into practical terms the spirit of IHR 2005. It is anticipated that GHS will fast-track and prioritise e-surveillance and disease monitoring, as the latter provides the empirical base for swift response and follow-up.[5]

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4 *One Health Initiative will unite human and veterinarian medicine* [Internet]. [cited 2015 Nov 23] Available from: http://onehealthinitiative.com/index.php

5 *Global Health Security Agenda: Concepts and Objectives* [Internet]. [cited 2015 Nov 23]. Available from: http://www.globalhealth.gov/global-health-topics/global-health-security/ghsconceptsandobj.html

Proposed Tools and Workflows

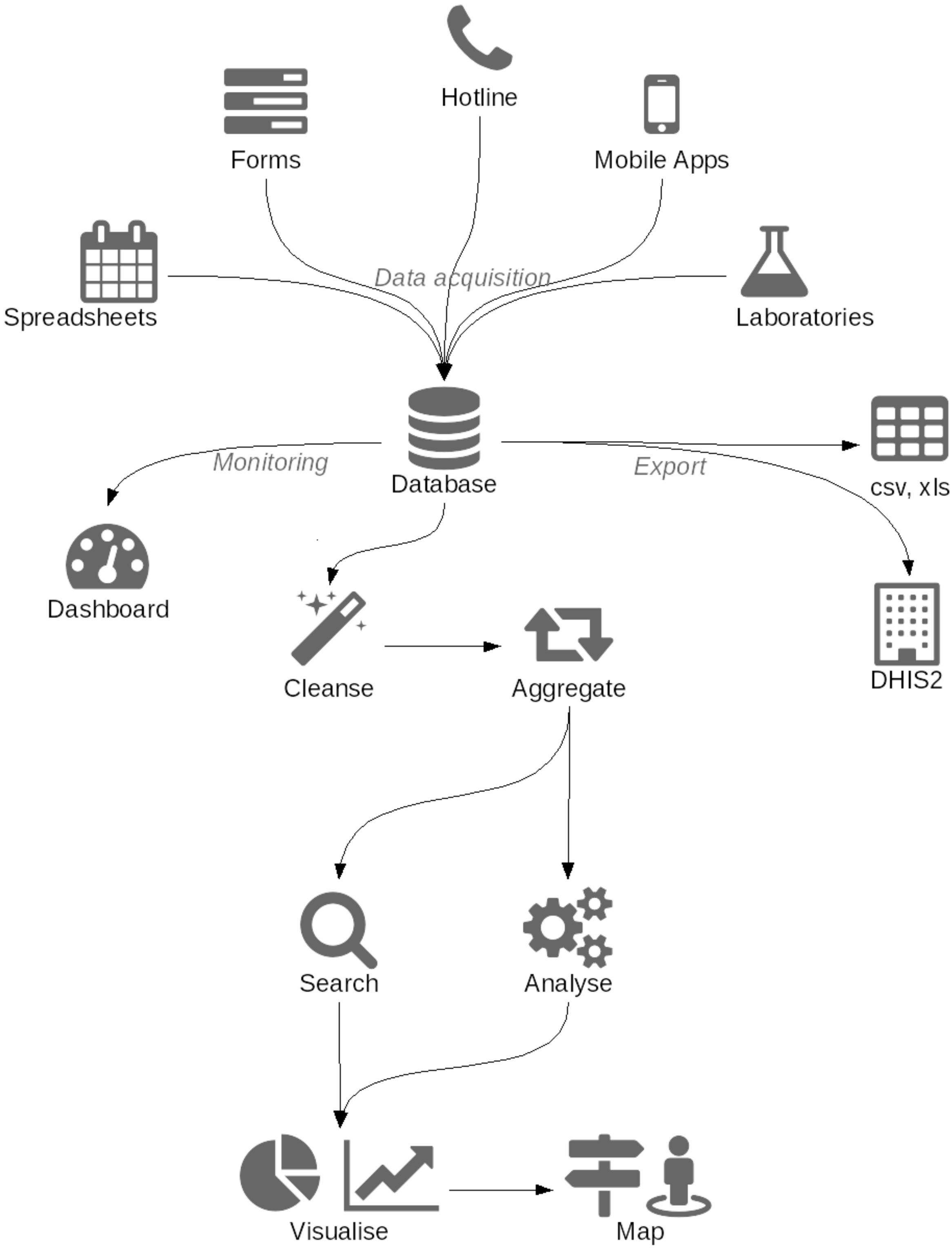

Illustration 1: Proposed functional layout of e-surveillance infrastructure

Data Capture

The suggested system aims to accommodate a multitude of reporting tools, including the manual entry of conventional paper-based forms.

However, for facilitated capture and processing, patient-related data will be captured as much as possible electronically, as this allows to embed data validation as well as metadata capture and processing without any extra effort. For instance, patient core data can be captured during interactions with health care providers, and include patient name, contact details, address, age or date of birth, and admitting diagnosis and, if possible, discharge diagnosis. These core data alone will greatly enhance the ability of the health care facility to report key epidemiological data to the higher level, both as event-based or routine surveillance data. Likewise, any such data are crucial for future health system planning, ranging from regional disease patterns and drug requirements in, for instance, coastal areas, to health system accounting. Depending on the size, infrastructural support, power and connectivity of the health care facility, notebook, netbook or mobile devices will be deployed to maximise robustness and sustainability of data handling.

Electronic data capture is also anticipated during community outreach and case-finding missions, where mobile devices from tablets to smartphones will be the preferred option to canvas field data. Ideally, the canvassing process will be able to link into existing medical records, provided the user has adequate access rights.

Laboratories will be able to feed confirmatory tests into the existing system either via simple paper-based records or, ideally, via electronic data transmission. This provides an attractive data handling avenue, because the majority of modern PoC diagnostics offer electronic data handling and transmission capabilities.

Moreover, a proposed hotline that could be used for public health alerts nationwide, which could, of course, also capture alerts from the community pertaining to relevant NTDs.

It is understood that there is a significant body of historical patient data are expected to play a key role in the long-term follow-up of affected patients. Therefore, spreadsheet-style import of bulk data is required to cater for existing records.

Data Storage

Patient data are ideally stored in the electronic medical record set hosted by the respective health facility, with a copy of the core data mirrored to the central level to ensure indexing and uniqueness of patient records nationwide. Facility-based data are backed up locally to a different location on-site and remotely to maximise data security.

Aggregated data are stored in a centralised database which replicates across several hardware server instances for added data security and redundancy.

Given the amount of storage found in various locations across the country, the concept of client-sdie encrypted distributed filesystems[6] for file and database backup becomes an attractive option, as it ensures full ownership by the Government of Kenya (GoK), without the involvement of commercial hosting providers, and related privacy and cost concerns.

6 Example: *Tahoe-LAFS* [Internet]. [Accessed 2015 Nov 23]. Available from: https://en.wikipedia.org/wiki/Tahoe-LAFS

Data Export, Aggregation, Analysis and Presentation

It is envisaged that the proposed system feeds directly into Kenya's de-facto standard data warehouse, DHIS2[7].

Additional data export is possible via common spreadsheet data formats.

For monitoring purposes, a dashboard is intended to provide an at-a-glance overview of key data handling features, while optional internal analytical capabilities may serve specific research purposes, such as statistical data analysis, data mining r anything else that may go beyond the public health-oriented capabilities of DHIS2.

General Features

Choice of Software

In order to maximise ownership, cost efficiency and long-term sustainability, it is strongly suggested that all software deployed is free/libre and open-source (FLOSS)[8], with a proven track record of commitment to the latter, as, for instance, evidence by an appropriate license and a social contract.

Mapping

Smartphones and tablets offer the ability to capture global positioning system (GPS) data on-the-fly, which greatly enhances the proposed geographical information system (GIS) capabilities of the system. Therefore, essentially each and every event will be geocoded and can thus be allocated to a map. OpenStreetMap[9] is the preferred mapping option given its high versatility and openness to community input, as experienced during the 2014 Ebola crisis.

QR Codes

Smartphones, tablets and even many notebook computers offer the ability to read Quick Response (QR) codes[10], which are FLOSS two-diensional high-density barcodes that allow the capture of relatively complex data via a small area barcode. This feature is ideal for sample and document tracking, and does not need any extra hardware other than a mobile application.

Access Rights

Finely grained user and group access rights guarantee that only those with the right authority and the “need to know” are permitted to access surveillance data. This is of critical importance for data sets that carry patient identifiable characteristics, where privacy and confidentiality are of utmost concern.

Likewise, district and counties should have write access to their epidemiological data sets during data entry, review and verification, while other district and counties can only view the data of other localities.

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7 *DHIS* [Internet]. [Accessed 2015 Nov 23]. Available from: https://en.wikipedia.org/wiki/DHIS

8 *Free/libre and open-source software* [Internet]. [Accessed 2015 Nov 23]. Available from: https://en.wikipedia.org/wiki/Free_and_open-source_software

9 *OpenStreetMap* [Internet]. [Accessed 2015 Nov 23]. Available from: https://www.openstreetmap.org/about

10 *QR code* [Internet]. [Accessed 2015 Nov 23]. Available from: https://en.wikipedia.org/wiki/QR_code

Connectivity, SMS and USSD

Modern internet standards, such as HTML5, permit the capture of data without active internet connection, and their transmission, as soon as connectivity has been (re-)established. This feature has become commonplace in mobile applications, yet is evolving also in desktop software. Therefore, surveillance does not require real-time internet connectivity, yet provides near real-time data processing capabilities, as the canvassed data will be automatically transmitted, whenever internet access becomes available.

In areas, where internet access is persistently unavailable, SMS and Unstructured Supplementary Service Data (USSD)[11] support offer less user-friendly, but proven avenues to remote data capture.

Universally Unique Identifiers

A feature that find increasing use is the concept of universally unique identifiers (UUIDs)[12]. They can be created with commonly available free and open-source, as well as proprietary software tools across all common operating system. Although there is, in theory, a highly remote chance that two individual UUIDs may happen to be identical, UUIDs are generally considered unique in practical terms. Subsets of UUIDs can be created with concatenated fixed prefixes or suffixes to accommodate categorisation.

Useful examples[13] include:

`CNTRL_58b2410a-5c3d-439b-a6ec-8750529cdf94` for control tracking and management,

`SMPLE_51f87a83-d3c0-47d4-9413-9356cd2a4048` for sample management, and

`INSTR_13830574-b5a3-4bf2-8a86-4e790d2464e4` for instrument management.

Challenges

One of the most significant challenges to long-term case follow-up is the prevalent lack of a unique patient identifier system in Kenya. This gap obviously affects all e-health applications, and is anticipated to require additional legal and policy support, ensuring patient privacy as well as feasibility.

A possible avenue into leveraging a health care card with a unique patient identifier may be the time when national ID cards are made available to those reaching legal age; the said health care card could be prepared and distributed at the same time. It may be unavoidable that it will take several years to penetrate the whole nation with both national ID as well as health care cards.

Otherwise, anticipated challenges will be greatly influenced by the degree of policy support, technical robustness, user-friendliness and community acceptance.

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11 *Unstructured Supplementary Service Data* [Internet]. [Accessed 2015 Nov 23]. Available from: https://en.wikipedia.org/wiki/Unstructured_Supplementary_Service_Data

12 *Universal Unique Identifier.* [cited 2013-10-18]. Available from: http://en.wikipedia.org/wiki/Universally_unique_identifier

13 The barcodes shown here have been created with Code 128, a freely available, high-density one-dimensional barcode font compliant with ISO/IEC 15417:2007, and extensively used in logistics. Further details are available from: https://en.wikipedia.org/wiki/Code_128