

Health Systems Strengthening Opportunities and Challenges for NTD Integration with the National Health Information System

Session Date: Friday, October 26

Session Time: 1:00pm – 4:00pm

Session Location: Frontenac, 3rd Floor

Session Description: Integration of NTD data into the national health information system is an important component of ensuring long-term government ownership of data systems and the data they contain. However, integration would require coordination with departments outside of NTDs and the concept of data systems and database integration is often foreign to the implementation focus staff of most NTD programs, making these discussions difficult. But, data system integration will allow national programs to move beyond data exchanges through email and data stored in parallel, partner owned, isolated databases, which will challenge national data governance policy. Integration will likely have sustainable cost benefits in developing and sustaining a trained labor force and maintaining reliable and secure software that will be necessary as donor funding is reduced during the period of post-MDA surveillance, a requirement of elimination dossiers. This breakout will provide policy makers with insight into what is happening on other disease programs already and provide the background on the national health information system needed to understand the opportunity, challenge, and provide an example way forward.

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KEY DISCUSSION POINTS

- Other disease programs are moving away from the vertical model and provide a roadmap for neglected tropical diseases (NTDs).
- New digital silos are developing as new mobile data collection tools are introduced.
- NTD data elements may or may not be part of the national health information system. However, even if NTD data are in the national health information system, the NTD donor vertical reporting system means that those national health information system data are not used by partners or the national NTD program.
- Health system strengthening is something that WHO, partners, and national programs are moving toward, particularly in the areas of MDA and morbidity management. See <http://apps.who.int/iris/bitstream/10665/255011/1/9789241565448-eng.pdf>.
- Effective programs need to implement nationally owned processes that lead to the intentional use of data to ensure high quality, identify gaps, and adapt.

- DHIS2, the leading platform for national health information systems, is an ideal platform to build interoperable systems. This is already being done in a number of areas, the Bill & Melinda Gates Foundation is supporting the development of an NTD system based on DHIS2 that models all the elements and indicators in the JAP and TEMF and could be interoperable with electronic data collection tools and other databases.
- Interoperability and open access to data are difficult and can only be achieved through policies that lead to well-defined indicators and data sources, SOPs for data collection, analysis, and use, and appropriate technology.

KNOWLEDGE GAPS IDENTIFIED

- Data-sharing and use policies that lead to well-defined indicators and data sources
- SOPs for data collection, analysis, and use
- Data reflection sessions at national and sub-national level that guide data for decision making and iterate programmatic activities based on data
- Appropriate technology to storing data that facilitates data sharing
- Data are collected at sub-national level for the sole purpose of reporting up (vertical flow). There is no use for the data at the level from which it is reported (horizontal flow) and there is no feedback from the national level with regards to the quality of the data or putting the data into context in the form of a report or analysis.

RECOMMENDED NEXT STEPS

- **Standardized data elements, coding, and structures:** NTD participation in OpenHIE to codify global standard for open data structures
- **Appropriate technology:** Supporting the principles of digital development (e.g., <https://digitalprinciples.org/principles/>), strengthening health systems through interoperability, and avoiding parallel systems and digital silos
- **Embrace national health information systems:** NTD partners and national NTD programs need to ensure high-quality, standardized NTD indicators are part of the national health information system. If they are not, then there needs to be support to get them added. Once added, national programs and implementing partners and donors need to rely on those data to build demand for quality.
- **Data for decision making:** If there were feedback (e.g., reports, meetings, other) from the national level to the sub-national (at which it is being reported), the data would be more meaningful and quality would likely be impacted positively.

Notes

Introduction

Part 1: high-level concepts from HSS, MERLA, and research

Part 2: examples of data system integration with HMIS and the challenges of integration

Problem:

- NTD programs are vertical programs that rely heavily on paper forms, generated at community level and reported up to national level. There are limited feedback loops or use for reported data at sub-national level.
- New digital solutions are creating new digital silos.
- Data are not freely shared between national programs and implementing partners and donors.
- Challenges that are common to all health programs are not solved with common solutions.
- Digital systems are not integrated. Data are exchanged as email attachments.
- Often the national health information system, which contains key health indicators, either do not contain NTD data, or they do contain NTD data but those are not used or reviewed by the NTD program, calling into question their quality.

Objective:

- Recognition of the digital transformation that is happening in countries and how the NTD global community can and will play a role
- Recognition that support for digital transformation will not only require technology solutions but all of the tools of health systems strengthening
- Recognition that reducing fragmentation, inefficiencies, and lack of interoperability will optimize data flow but there needs to be a focus on use to adapt program implementation to new challenges and opportunities driven by data

Digital Health/Health Information Systems Context

Challenges/issues with digital health:

- siloed, disease-specific data systems and solutions
 - Getting better – focusing on integration
- Donor ownership of systems and solutions
 - Getting better – government ownership
- Fragmented funding landscape
 - Getting better – donors are cooperating
- “Pilotitis” – insufficient scale
 - Getting better – more commitment and interest in large-scale and long-term projects/implementation
- Overemphasis on data collection for donor reporting
 - Getting better – data use/ethics is a new sub-field
- Limited country capacity to own and maintain solutions
 - Getting better – increased use of regional networks and communities of practice

Health Systems Strengthening and the NTD community

Equity, quality, responsive, efficient, resilient results in improved and maintained health. This leads to universal healthcare coverage.

OR questions that could help with health strengthening, enabling data use, improving data systems and data sharing:

1. What factors hinder integration of NTDs into national programming and coordination and HMIS?
2. Does NTD integration (of data) lead to better decision making? If so, which decisions?
3. How can donors/partners support better data integration?
4. What function of the health systems leads to national sustainable programming?

Comments:

- Pre-made and pre-cooked solutions to strengthen health systems do not actually train or strengthen the abilities of country partners long-term. We don't need immediate satisfaction and fulfillment when it comes to HSS, we need long-term solutions that build capacity in country. Training of data methods need to happen.
- Black box / one use solution is not always the best way.

Using MERLA to mainstream and sustain data systems

Problem and innovation: 2006, 25% malaria prevalence in Zanzibar

- Began implementing USAID-funded indoor residual spraying program for malaria control
- Hugely successful program: as malaria prevalence dropped, IRS strategy graduated from blanket spraying of households to targeted spraying of hotspots
- By 2011, prevalence dropped below 1%
- MEEDS – great surveillance story
 - Mobile phone data collection to report malaria cases
 - Data used to identify hot spots

MERLA – intentional application of results-focused **monitoring, evaluation, and research** to inform continuous **learning** and **adaptation** for improving program effectiveness and policy decision making.

Best practice 1: assessed government's needs, pain points

- Took time to understand government's needs, wants and pain points around malaria surveillance

Best practice 2: Made government equal stakeholder in success

- Made government part of program design, implementation and success: built trust
- Set up transition plans for government to run and refine the system

Best practice 3: ensured local ownership of learning and adapting

- Implemented MERLA tools and approaches to build government capacity
 - Data action and review guides
 - Pause and reflects sessions with gov
 - Learning platforms and communities of practice
 - Embedded data systems experts and analysts within the MOH
 - Peer to peer scientific capacity building workshop
- Components of MERLA are not new. What is new is a deliberate and holistic approach

Comments:

- Building capacity through training should get more funding

Strengthening MDA data systems: experiences from large scale operational research

TUMIKIA project – aimed to evaluate the impact and cost effectiveness of community-based versus school-based deworming on STH transmission in Kenya

For this project, we addressed many of the challenges around the use of paper registers for recording MDA treatment by developing electronic data entry and inventorying systems in SurveyCTO. Specifically, we:

- Created an individual-level census for Kwale County for the MOH
- Integrated study information using pre-labeled treatment registers to support county implementation of NPELF and facilitate subsequent data entry for reporting
- Developed data entry that allowed for linkage of paper-based individual records in order to measure coverage within and compliance between rounds of MDA

DeWorm3 – aims to demonstrate feasibility of interrupting STH transmission through MDA-based approaches in setting where LF programs have progressed to post-MDA surveillance
Evolving from the systems utilized by TUMIKIA, for the DeWorm3 project we developed an electronic MDA treatment reporting form in SurveyCTO that could be used to collect a population census (coverage denominator) and record individual treatment status between multiple visits and MDA rounds. By linking the data system with Google sheets, a simple dashboard was created to visualize coverage rates and facilitate treatment mop-up activities. This open-source data system eliminates many of the issues identified around the use of paper-based treatment registers.

Eliminating Data Silos with DHIS2

Data silos exist for reasons:

- Structural
- Political
- Growth
- Vendor/technology lock-in

Downstream effects of data silos:

- Inefficient use of project resources
 - Double data entry
 - Management overhead
- Missed data linking opportunities
- Reduced data quality

DHIS2 – District Health Information System

- Capture, management and analysis of information
- Flexible data platform, wide range of use-cases
- Open source software
- Extensible through Web APIs and app framework

Benefits of DHIS2

- Reduce data entry burden
- Improve data timeliness
- Improve data quality
- Support local governance

Obstacles to Integration – Experience from Implementing Digital Location Services

InSTEDD – non-profit in Silicon Valley

- Geospatial data is a mess – don't know where key infrastructure is located
 - Created digital services – facility registry
 - Obstacles to integration – integration is largely a business process
 - Non-technical reasons why integrations don't happen
1. A common goal
 - a. Clearly define the value to be derived from the integration.
 2. Incentives
 - a. Costs and benefits of integration must also be cross referenced with each organizations mission, mandate, policies, and capacity.
 3. Data sharing framework
 - a. Policy, regulatory, and contractual requirements for integration should be shared.

Last 2 obstacles

1. Semantic interoperability
 - a. Do key fields mean the same things? Metadata repositories and data dictionaries are important.
2. Technical

Decreasing data entry workloads for HCW – how do we add value to HCW, while reducing data entry related workloads?

- Start by designing solutions for the needs of all users including HCW's expected to enter data, and to be frugal in terms of the requests for what data they need to enter. Services that provide value to those entering data will result in higher utilization and better quality data. If it is a one-way value proposition; e.g., enter this because it's your job; the quality typically degrades over time.