

## Digital Tools for Morbidity Management and Disability Prevention

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| <b>Session Date &amp; Time:</b> | Tuesday, November 19; 9:00 AM to 12 PM   |
| <b>Session Location:</b>        | Mandalay Meeting Room  |
| <b>Session Description:</b>     | On the road to the 2030 SDG goals, digital tools will be of great help for the evaluation, monitoring and treatment of NTDs. We will present different digital tools that are already used for MMDP and discuss the expansion of the existing tools to other NTDs as well as the development of new tools. |
| <b>Session Chairs:</b>          | Achim Hoerauf and Louise Kelly-Hope  |
| <b>Session Rapporteur:</b>      | Andie Tucker, Global Partnership for Zero Leprosy  |

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### KEY DISCUSSION POINTS

#### *Introduction:*

- Without digital tools it's clear that we won't fulfill the ambitious goal of reaching everyone with universal health coverage.
- They built into the Sustainable Development Goals (SDGs) the mandate that everyone should receive the care they need. All governments that have signed on to the SDGs have committed to meet these needs.
- Important diseases are highly underreported. Governments should be made aware of this, and we should work toward ideas for improving data bases to help them move toward better morbidity control.

#### *Patients estimation using digital/mobile platforms in Tanzania (Dr. Upendo Mwingira)*

- Tanzania is endemic for all the five neglected tropical diseases addressed through preventive chemotherapy (PCT NTDs)
- Two focuses in elimination of lymphatic filariasis (LF):
  - o 100% geographic coverage
- Tanzania is doing a good job in mass drug administration (MDA) but is lagging in morbidity prevention
- They have used various tools for mapping patients, including short message service (SMS) mapping, and regional and district level estimations of high case prevalence

## 1. SMS study in Dar es Salaam:

- Mapped patients through a census method, moving from one house to another
- Community health workers were collecting data by paper report and transmitting that data via SMS
  - Used normal phones for this exercise, not smart phones
- At the end of the exercise, many people with hydrocele and lymphoedema were identified
- The study created maps of where these patients are, so the health system can provide care in areas where there are more patients
- This study was costly and needed verification

## 2. Kilwa SMS patient mapping:

- Part of a LeDoxy trial as part of a larger, multi-country study
- Was administered by community drug distributors
  - Community drug distributors used a menu of questions on their phones to transmit information via SMS
- Used this data to identify patients for the trial
- This study faced verification delays and was costly

## 3. Mtwara Geopoll:

- Patients reported themselves or their friends and relatives using a mobile phone-based survey
- Conducted in one district
- Patient self-reported, therefore, over or under reporting could be high, this study will need verification

## 4. Regional coordination of district estimates

- Estimates lead to better planning, and districts can self-manage these estimates
- Data sent to health facility via a form, which is transposed into a data base recording cases in each district
- Reports from 181 of 185 districts; this covers almost the whole country
- May not be very accurate, but high coverage
- These data have been used to plan with partners
- Needs verification

- All methods presented benefits and challenges

## Q&amp;A:

- The verification that's needed for all these methods— what would that look like?
  - Community drug distributors are people that know how to read and write, but do not have extensive training. They can identify symptoms, that's about it. You need a clinician to come and identify the subtleties of the disease. To provide care you need to have a good estimate, so before providing care, you need to

verify estimates. The goal of these estimates is to avoid requiring a physician to come to each house, so we had a clinician visit about 10% of surveyed patients to see whether the initial estimate was close or not. Estimates were more correct in the late stages of the disease, and least accurate in the early stages of the disease.

- What hardware are you using? Why are you using SMS instead of a word doc?
  - o We are using SMS because we were not providing the hardware for the community drug distributors. They were using their own phones.
- Is the SMS system costly because of the software, or because it used a survey methodology with a lot of people on the ground?
  - o It was costly because it was a stand-alone exercise conducted in a capital city. It was the rainy season, which made the study more difficult to undertake. It was essentially census mapping, so getting community health workers to go to every single house was costly. The software cost was very minimal, but the human resources were most costly. However, evaluated per person, the survey was actually not that costly because it reached so many people.

*Morbidity Management and surveillance of lymphatic filariasis pathology and acute dermatolymphangioadenitis (ADLA) attacks using a mobile phone-based tool by community health volunteers in Ghana (Dr. Linda Batsa Debrah)*

- The second goal for the elimination of LF is to alleviate suffering among affected patients through morbidity management and disability prevention
- Health surveillance using mobile phone technology is an increasing area of interest
- Conducted a study on the use of mobile phone-based voice messaging system in health reporting in Ghana because of low literacy rates
- Software from a local company was used that was able to send and receive voice SMS to exchange information between users and the server
- Normal mobile phones were distributed to CHVs that did not have phones; for those that had phones, they used their own technology
  - o They used the phones to record cases of lymphoedema, hydrocele and ADLA
- The study trained community health volunteers (CHVs) to use the system with a voice SMS script
  - o The script was available in English and the most predominate local language
- CHVs first used a paper-based report to record their data before calling into the system
- The data that was called in was inputted into a mHealth System database
- This study was conducted between May 2018-April 2019
- Reports filed through the call system were more complete than paper reports filed in the study

- A correlation was drawn between CHVs' education level and reporting completeness
- This study identified a lot more cases reported through the call system than through paper reporting
- Multiple acute attacks were reported with the call system
- Data reached its final destination in the health system much more quickly than with paper recording
- The study offered lymphedema management training for patients and supplies for self-care
- The study conducted focus group discussions and interviews with patients about their perception of their condition and their perception of CHVs
  - Non-favorable perceptions of their condition, favorable perceptions of CHVs

## Q&amp;A:

- What if someone makes a mistake when they're recording through the phone system? Can they fix mistakes?
  - We couldn't correct specific data points, but if you input the wrong directive it bumps you back to the start of the process, or you can end early and begin the report again without the beginning being recorded.
- Why did reporting stop after 3 months?
  - In Ghana men are unwilling to share that they have hydrocele cases. It's easier to identify lymphoedema cases.
- Did you record locations of patients during this study?
  - Yes.
- From what you've seen, do you think this could be used to follow up with patients? Could patients use this system themselves?
  - I think this is feasible. We didn't do that in this study, but if this system gets absorbed it could be provided to everyone in the country. It could be extended beyond lymphedema to other diseases. It's an open system.
- Did you use a free number for the call system?
  - The system calls you back, so the cost is not borne by the person making the call.
- Where is the Ghana health service data available?
  - At the health directorate. The CHVs are tasked with the mass drug administration program. As they administer the MDA they are supposed to record cases on paper. This is separate data from the health directorate data.

*Leveraging the DHIS2 platform to standardize local and global NTD information (Dr. Knut Staring)*

- If you want to improve NTD data you need to put effort into several elements of the cycle of information gathering: standardization, strengthening the flow of information, ensuring quality, and the analysis skills required to do something with the data
- The World Health Organization (WHO) has been working on an integrated data platform (WIDP)
  - o They have chosen DHS2 software to form the infrastructure
    - This is because it has already seen uptake in a lot of countries
    - There is a network of supporting experts around the world that are able to support this software
    - There is an established series of training workshops and online training available
    - It is also being used by a number of NGOs
- DH2 supports aggregated data, events, and tracking
- DH2 data is being built through a combination of different kinds of input: SMS, tablets, laptops, with an increasing emphasis on supporting mobile platforms to make information system available to appropriate users
- WHO is already working with the University of Oslo to create standards for health facilities data: HIV, TB, malaria, etc.
  - o Trying to complement existing standards for data analysis, standardization of indicators, and to support counties in their own data collection
- NTDs have been leading DHIS2 use
- WHO is supposed to try to help countries with standardization, building capacity, and global reporting and program management. The start of this is aggregate data and reporting, but there's also other types of data that are being collected increasingly, for certain NTDs
- There is a lot of data that is not part of this WIDP platform, there are other sources from parts of WHO, the UN system, other international data systems
  - o The idea is to consolidate sources of information to get the full picture
- WIDP team in Geneva is small and is working to support data collection in-country
- University of Oslo led development of this platform and is working to build a community to support it
- This platform is meant to be configurable and tailored to address the needs of countries; it's a global public good

Q&A:

- What kind of health facility data do you have?

- Basically, activity reporting from a facility. We would love to try to support the ministry in collecting all data from facilities. For many countries in Africa that's not possible to do electronically. You have to use paper reports up to the district level. The focus is typically on the monthly reporting of whatever the facility is already reporting on paper. In most cases we are not recommending that each country digitize their books. We don't think most counties are ready for that yet, but it might be useful to do for a few things.
- Can data be entered offline?
  - There is often no connectivity. A lot of emphasis has been put on creating android apps, but those phones are costly. That is the main answer from our side, to develop apps that can store data locally, but then you need synchronization when you get connectivity. You're restricted in how much data you can transmit.
- What is the interaction with DHIS with WHO?
  - WHO has their own DHIS2, most of that info is entered by in country offices and ministries of health. Some data they try to capture at a subnational level. If the country has integrated the set up into their own database, they can do an export into the global platform. If they don't have anything beyond paper or excel, then they could choose to report directly into the global platform. NTDs for certain diseases are setting up a global data base for case-level data. They are trying to do that because there is no such system at a country level.
- Is there capacity to link country data systems and the WHO system to make data import automatic?
  - Yes, this is possible. Typically, countries want to have control over what is sent. There's an approval process. But technically, yes, this is possible. One of the benefits of standardizing indicators and definitions is that possibility.

## **KNOWLEDGE GAPS IDENTIFIED & RECOMMENDED NEXT STEPS**

- One thing that would be helpful apart from having a congruent data platform is considering the actual tools that are used— are the tools that are being used in the field similar or congruent?
- Morbidity is a big umbrella term. How are we measuring it?
- Underreporting is dependent on tools used to measure and the very type of disease.
- Is our data dynamic enough? Should we continue including people in our data that have received treatment?
- How do we capture sub-national level data?

- There is underreporting, when you go house to house and look for cases you find them, but that real data doesn't trickle up to the national government. How do we deal with unreliable information? How do we get more accurate primary information?
  - o Incentives could be a solution, using smaller studies to verify larger data could help
- Could we use mobile technology to help administer care for or information about these diseases, in addition to using it to finding cases?
- Leprosy tends to have better registration than other NTDs, but after treatment people stop engaging with the health system, so district level health personnel often don't know how many people impacted by leprosy disability may be in their catchment area.
- You don't need to do national burden estimates every year, probably every 5-10 years. In the interim you'd need a tracker to follow treatment for NTDs. How many people have had surgery to treat an NTD, or other kinds of treatment?
- The more cases the government finds, the more resources they are obligated to designate for morbidity management. There's a disincentive to find more cases. How do program managers deal with that conflict?
  - o Accurate numbers can help to compete for resources and demonstrate what priorities should be, based on burden of disease.
  - o If we look at this from a rights-based perspective it might be easier to align incentives. Everyone has a right to care.
- Where is information about the quality of facilities in addition to data about the availability of services? Could this be digitized?
  - o WHO has surveys that could be collected using standardized data systems, but then, how do we make that available? How do we embed it into the routine system? There's a lot of data available, but it's not put together.