#### A conversation with Yolisa Nalule, October 14, 2014

#### **Participants**

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**Note**: These notes were compiled by GiveWell and give an overview of the major points made by Yolisa Nalule.

### Summary

GiveWell spoke with Yolisa Nalule of the Schistosomiasis Control Initiative (SCI) as part of its process to update its review of SCI. The conversation was intended to better understand SCI's work in Uganda, as a case study to better understand SCI's role, impact, and need for additional funding.

### Background on Uganda program

SCI's program in Uganda is fully funded by DFID (other than one use of unrestricted funding, discussed below).

SCI had previously worked in Uganda with funding from the Bill & Melinda Gates Foundation. After this funding ended, USAID funded work by RTI International in Uganda. Around 2006, Uganda started an integrated NTD program in districts endemic with more than one NTD. Districts with only schistosomiasis (SCH) were not treated.

When SCI re-entered Uganda, it started SCH programs in the districts not receiving treatment. Also, in about 30 districts, USAID stopped treating SCH because prevalence dropped below 20%, so SCI supported the continuation of these treatments with an aim towards elimination.

Ms. Nalule commented that NTDs are found almost exclusively in the poorest and most deprived regions of the world, where residents face unsafe water, poor sanitation and limited access to basic healthcare. The afflictions form part of a vicious cycle in which ill health resulting from NTDs helps to anchor millions of people in long-term destitution

# Overview of Uganda program

Ms. Nalule is responsible for coordinating with the local government and holding it accountable. Her activities vary depending on time of year. In Uganda, SCI is working in low prevalence districts so it treats every other year; the treatment year will have a schedule similar to this:

• April-May: program planning

- June-September: mass drug administration (MDA) preparation
- September-early October: impact measurement and evaluation (M&E) in sentinel sites
- Mid October-November: MDA
- December-March: Reporting and performance M&E

During program planning, Ms. Nalule works directly with the national government to develop budgets and plans for the year (e.g. scheduling treatments, training, advocacy, etc.). The SCI budget is more or less set in advance, and with this information, local health ministers decide the best uses of funds. SCI reviews the government's requests and, if necessary, may top up DFID funding with unrestricted funding.

Preparations for the MDA include making sure the drugs will arrive on time, training is prepared, and advocacy is in place. This work is done by the Ministry of Health. Ms. Nalule gets feedback from them on what they need help with. She can mostly follow along via emails, though it is usually necessary to visit the country just prior to the MDA to ensure monitoring data is collected correctly. The MDA is generally scheduled to coincide with child health days, which includes a full month of awareness and advocacy. Though the Ugandan teams are quite experienced, her supervision is still helpful.

After the MDA, Ms. Nalule handles follow ups with the government and begins to work on reporting and data analysis. DFID reports must be completed by March, and she works with the SCI statistician to prepare them.

Each year, Ms. Nalule visits Uganda 3-4 times:

- National planning meeting in June/July, which is usually about a week.
- Preparing for M&E requires a visit that is about 3 weeks long.
- For the MDA, she went for 2 weeks (she went since it was her first time being involved in Uganda but it is not always necessary).
- A particular meeting or event can justify an additional visit.

## **Budget decisions**

Government officials decide how many people to treat, and Ms. Nalule helps ensure the budget is appropriate and realistic. For example, DFID expects M&E costs to be no more than 20% of the program.

In deciding on the budget, there might be some disagreement around whether impact M&E (having sentinel sites) is worth the expense. The government might prefer to provide more treatments. Ms. Nalule and other researchers argue for the value of M&E.

Last year, M&E funding was augmented by £23,000 from SCI unrestricted funding. Without this, there likely would have been cuts in the number of sentinel schools. This M&E is enabling research to compare different treatment strategies in areas where prevalence is low. DFID was not interested in funding this research.

### Treatment strategy

Currently, because prevalence is low, SCI treats only school-aged children per WHO guidelines, though it is considering changing this. The children are about 5-15 years old. The treatments are delivered by teachers.

The program is intended to capture non-enrolled children as well; however, a recent coverage survey showed non-enrolled children are not being reached well. In the past, attempts to reach them have included communication via a megaphone for several days prior to the MDA as well as telling the school children to bring any of their siblings, friends, and relatives who do not go to school on the day of treatment. SCI is now trying to figure out an improved approach, and one possibility is adding a community-based treatment program.

Also, SCI is taking over treatment from RTI in 15 districts that have higher prevalence, and, in these districts, it will treat adults. Since prevalence is over 50% WHO guidelines say to treat children and high risk adults (e.g. fisherman), though usually programs will just try to treat all adults.

Pre-school children are not treated in the Uganda program.

In integrated programs, praziquantel is given 1 week later than other drugs because it cannot be taken with one of the other drugs.

### Coverage data and findings

A coverage survey was recently completed in Uganda, which has not yet been compiled into a report. Overall coverage was about 40% compared to the target of above 75%. SCI is analyzing why this happened. Factors that may have contributed:

- Since most districts have low prevalence, people don't see the effects of the disease in their communities, and it becomes difficult to get them to take the drug.
- Some districts were being treated for the first time, and teachers and communities were unfamiliar with the program.
- Districts with an integrated program (run in conjunction with RTI) had lower coverage than districts with just a SCH/STH program (run by SCI).

One lesson from the coverage survey was that coverage of non-enrolled children was very low. It was surprising and disappointing to learn about the issue but good to catch at this point because the MDA strategy can be adjusted.

Among enrolled children, coverage rates from the survey were lower than the coverage rates reported by the districts. In some places, the survey found rates below 10% compared to 80% reported by the districts.

Some coverage issues were known prior to the coverage survey. For example, in one sub-county, there was a miscommunication where only schools that were mapped were treated. Ms. Nalule helped uncover this issue through a set of conversations after she saw a suspicious reference to "selected schools" in an email she received.

Three months later, the other schools were treated, though the confusion likely lowered coverage.

## **Program reviews**

Ms. Nalule has attended a national stakeholder meeting, which serves as an annual review prior to planning for the next year. District level meetings are done separately and reported to others via this central meeting. She learned from this, though by that point most information was not new.

Activity reviews after each activity (MDA, M&E) are more informative. For example, she learned that coverage surveys required more preparation than previously expected and that some surveyors did not appreciate the rationale for selecting villages. The latter led to improving the explanation during training, so that surveyors appreciated the importance of random selection, for example.

### Ugandan government's access to SCI funding

The funds are delivered straight to an account where Ugandan officials have access. There are two signatories, and the account requires both signatories to sign off on purchases. SCI's finance manager can monitor this account. A government accountant reports to SCI monthly and provides receipts and other spending details. This setup provides SCI with good visibility on spending. It probably would be politically difficult to create an account like this today, but it has been allowed to persist in the form it was set up.

## Use of additional funding

If SCI allocated more funding to Uganda, Ms. Nalule would want additional funding to treat adults. Also, she would consider doing work on water, sanitation and hygiene (WASH) to help achieve SCH elimination. To start, work on WASH would probably focus on operational research.

Also, islands in Lake Victoria are in need of treatment. They are hard to reach but have a high burden of SCH (many of the residents are fisherman and move a lot). There are about 150 islands with 200,000 people.

With funding, the government would be willing to treat adults and the Ugandan islands.

Ms. Nalule thinks the SCI program could deliver an additional 2.4 million treatments. For comparison, currently about 1 million school-aged children receive treatment. Additionally, the Ugandan islands would require about 400,000 treatments per year because twice yearly treatments would be required due to the high prevalence.

# Ms. Nalule's experience

Ms. Nalule commented that as a Ugandan citizen, the work that she does with SCI has put her in a position where she can give back to her country. She appreciates the immediate effects of improving the health of children each year who would

otherwise not have been reached, and also important, the long run benefits of interrupting the vicious cycle of poverty that the effects of SCH have been associated with in these communities.

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