

2009 Global NGO Deworming Inventory

Report to the WHO Working Group on Access to Quality-Assured Essential Medicines for NTDs

April 7, 2011

Background

The year 2010 was set by the World Health Assembly (WHA) Resolution 54.19 as the target year to achieve treatment of 75% to 100% of school-age children at risk of soil-transmitted helminthes (STH) and schistosomiasis morbidity. According to WHO's Preventive Chemotherapy and Treatment (PCT) databank, which compiles annual deworming treatment data from Ministries of Health (MOHs), only 99 million of the 884.5 million (11%) estimated at-risk population were treated with an anthelmintic drug in 2008.¹

Because non-governmental organizations (NGOs) provide deworming treatment to at-risk populations as a secondary activity or component of broader child/community health campaigns, deworming treatments go unreported to MOHs. Recognizing the need to complement the PCT databank with deworming reports from NGOs, the WHO Working Group on Access to Assured-Quality Essential Medicines for Neglected Tropical Diseases (WGA) mandated Children Without Worms (CWW) to survey and compile deworming data from NGOs worldwide.

The Global NGO Deworming Inventory (hereafter referred to as the Inventory) was therefore created with the purpose of collating data on NGO deworming activities into a centralized, reliable database for use by the STH community. Specifically, the Inventory was designed to:

- Enumerate the extent and scope of NGO deworming activities worldwide
- Provide an informed estimation of treatment doses allocated to assess the unmet need for deworming
- Provide a platform for information sharing amongst deworming programs

This report provides a brief overview of the Inventory data collection process, summarizes results of the Inventory, and concludes with lessons learned and recommendations for the 2010 NGO Deworming Inventory. It is submitted to the WGA for their review and comments.

¹ <http://www.who.int/wer/2010/wer8516/en/index.html>

Process

Developing Partnerships

A critical component of this project was garnering support and collaboration among targeted organizations. As such, communication materials, including a website (www.deworminginventory.org), an informational flier, a Frequently Asked Questions page, and a Data Use and Sharing Policy, were developed to clearly communicate the purpose of the Inventory and how data would be utilized.

Recognizing the organizational sensitivities and potential challenges in collecting program data, CWW developed partnerships with key organizations such as USAID, RTI, Deworm the World, the Schistosomiasis Control Initiative (SCI), and NGO consortiums such as CORE and InterAction. These partners helped disseminate key communication messages to NGOs and were instrumental in encouraging participation in the Inventory.

Identifying Deworming Programs

An online search was conducted using key words and phrases such as deworming, mass drug administration, antiparasitic treatment for children, helminth control, etc, to identify NGOs to participate in the Inventory. Once organizations were identified, they were contacted to obtain complete contact information for the person(s) responsible for the deworming program. In addition to the online search, key partners were also asked to help identify deworming programs in the countries in which they work.

Establishing Data Elements to be Included in the Inventory

The information requested was carefully aligned with the information captured in the PCT databank. Table 1 specifies the data elements requested in the treatment reporting form.

Table 1. Data elements requested in the treatment reporting form

Deworming Program Information
<ul style="list-style-type: none">• Organization name and contact information• Target countries/districts• Target populations per district (school-age, preschool age, pregnant women)• Number of treatment rounds per year• Number people treated per district at last treatment round (segmented by target population)• Drugs provided (albendazole; mebendazole; other)• Level of deworming in 2008 and anticipated for 2010

Lymphatic filariasis (LF) treatments were included in the Inventory because albendazole, which is used to treat this disease, is also an effective treatment of STH. Information on past and future deworming activities was also included to help assess the longevity of the program.

Following discussions with the PCT databank administrator, an excel-based treatment reporting form (Annex A) was developed to capture critical pieces of information about deworming programs. A Data Reporting Guide was developed to define required data elements and provide instructions for completing the form.

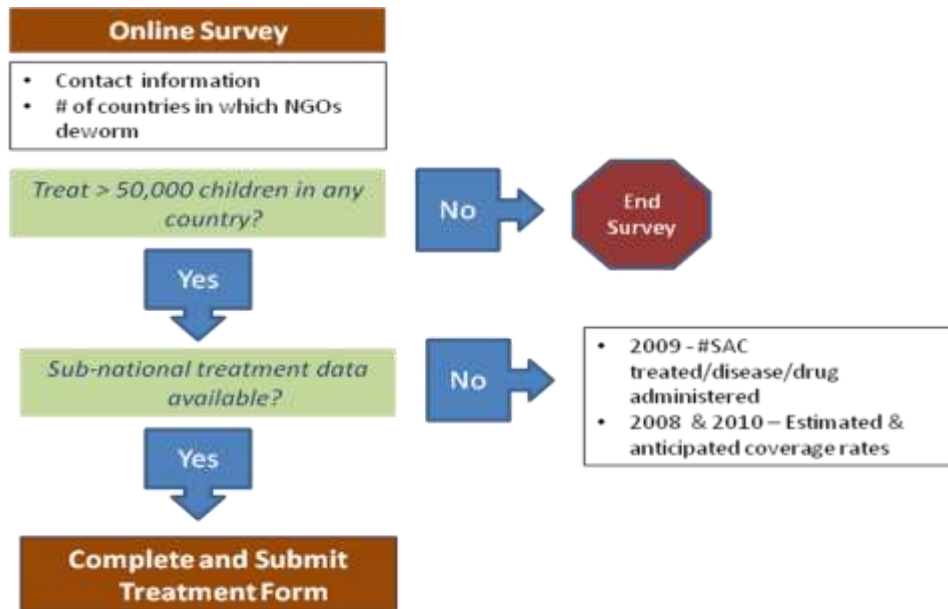
Pilot Testing

Three non-governmental organizations (NGOs) were selected to pilot test the data collection tools and communication materials: Helen Keller International (HKI), the Schistosomiasis Control Initiative (SCI), and the Carter Center. These organizations were selected based on their diverse deworming portfolio in multiple countries, as well as CWW's existing relationship with the NTD program managers in each organization, which facilitated response to the request for participation. Additionally, input was sought from two large NGO consortiums, CORE and InterAction, on the objectives of the Inventory and proposed data collection methods.

The treatment reporting form was revised to reflect input received from pilot NGOs and consortiums. In efforts to make the data collection more efficient, it was suggested that the treatment reporting form include a screening question to ensure that only programs that distribute over 50,000 doses per year are included in the Inventory. The 50,000 threshold level was selected based on the assumption that organizations treating below this level may not collect treatment data.

Based on results of the pilot test, the following data collection process, as depicted in Figure 1, was established. All organizations were asked to complete an online survey. If programs provided treatment to more than 50,000 children in one country and had only country-level treatment data, they were asked to provide national-level treatment data via the online survey. Programs that treated fewer than 50,000 children were not asked to provide further information. If programs provided treatment to more than 50,000 children and had sub-national level treatment data, they were asked to download the excel-based treatment reporting form and provide district level treatment data.

Figure 1. Data collection strategy



Where programs had already produced their deworming treatment reports that specified the data elements requested, they were encouraged to submit these program reports instead of the treatment reporting form. The data was then entered transferred to the reporting form for analysis.

Data Collection

Once the data collection tools and processes were finalized and approved by the WGA, email invitations to participate in the survey were sent out to all identified NGOs and partners on June 7, 2010. Links to the online survey and the Treatment Reporting Form were posted on the Inventory web site. Announcements of the launch of the Inventory were also sent to key partners such as USAID, RTI, Global Network for Neglected Tropical Diseases (GNNTD), CORE, and InterAction, who then disseminated the announcement to their members and posted it on their web sites. Follow-up emails were sent to the list of organizations to remind them of the Inventory and encourage participation.

Validation

Following submission, treatment data were carefully reviewed to ensure that data were reported in the requested format and included the critical data elements requested. Where necessary, organizations were contacted to clarify any questions and gaps in the data submitted. Due to the dearth of district data submitted, treatment data were aggregated at the country level. A detailed summary of the Inventory data was then shared with WHO headquarters as well as WHO's regional offices in Africa and the Americas to further review and validate the data received. The African and American WHO regional offices were contacted and involved in the validation process as the majority of data received through the Inventory were for these regions. Where there were outstanding questions with data, organizations were once again contacted to provide further clarification on the data they provided. This validation

process also allowed analysis of Inventory data to identify and eliminate any double counting of treatments that may have been reported both to the WHO and to the Inventory.

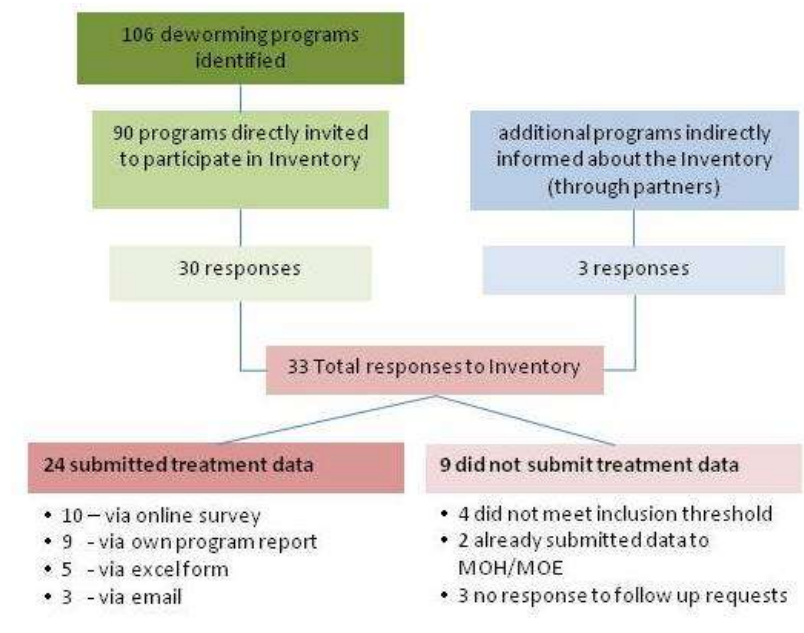
Findings

Response Rate

The online search identified 106 programs (including some bilateral and donor organizations) that were either currently or had at some point in the past conducted or supported a deworming program. Invitations to participate in the Inventory were sent to 90 of these organizations for which contact information was available. In addition, the invitation to participate in the Inventory was widely disseminated by key partners (CORE, InterAction, USAID, RTI, GNNTD, the School Health and Nutrition mailing list).

A total of 33 organizations responded to the Inventory, three of which were not on the initial list of deworming programs identified through the online search, but may have received the invitation from a partner or via the Inventory website. Of the 33 organizations, 24 submitted treatment data to the Inventory - 10 via the online survey, five via the Microsoft Excel form, nine through their own program reports, and three by email. Nine organizations that responded to the request for data did not provide actual treatment figures. Of these, 4 organizations did not meet the minimum inclusion threshold of treating more than 50,000 children, 2 noted that they work directly with the ministries of health/education in their respective countries signifying that their treatment numbers had already been reported to WHO via the ministries, and 3 did not respond to follow up requests for data submission.

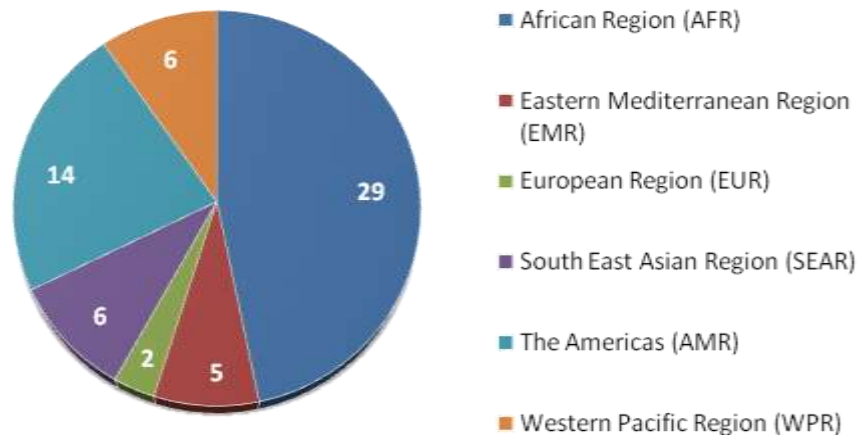
Figure 2. Response Summary



Treatment Data

Data were received for a total of 62 countries, with a majority of treatment data reported for African countries. Figure 3 displays the regional distribution of countries for which data were received.

Figure 3. Regional Distribution of Countries

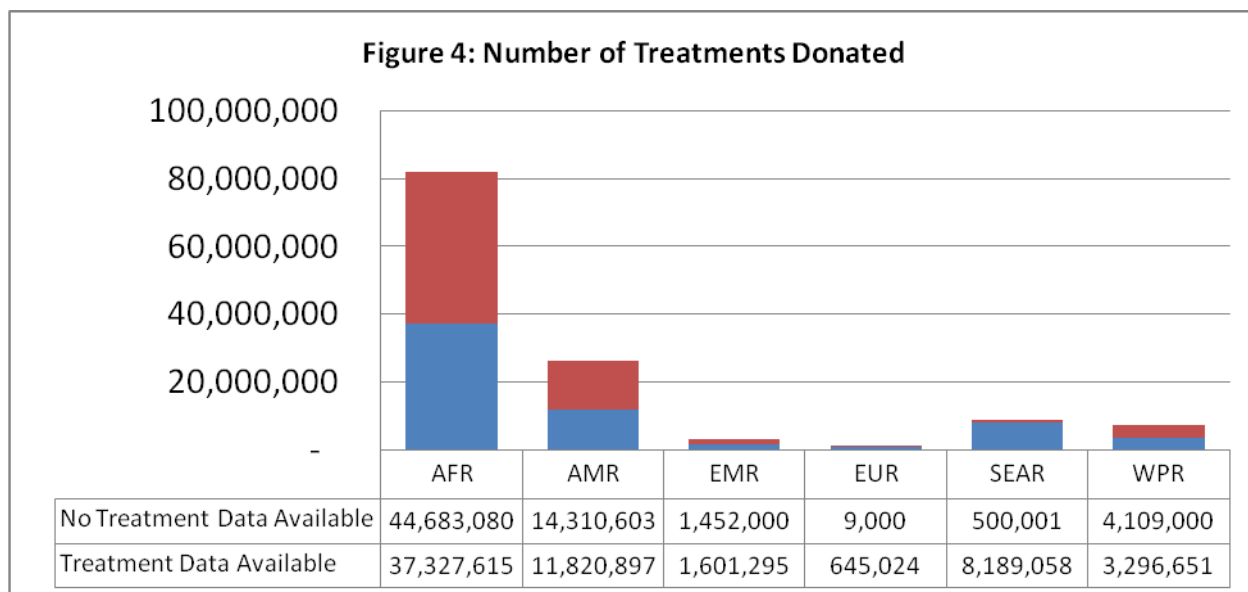


A total of 62,880,540 school-age children (SAC) were reported to have been treated by organizations participating in the Inventory. According to data submitted, an additional 65,063,684 tablets of mebendazole or albendazole were provided to countries. However, corresponding treatment numbers were not provided for these drugs. Therefore, it is implied that there were more than 62.8 million school-age children treated in 2009 by participating organizations, however the exact figure cannot be determined.

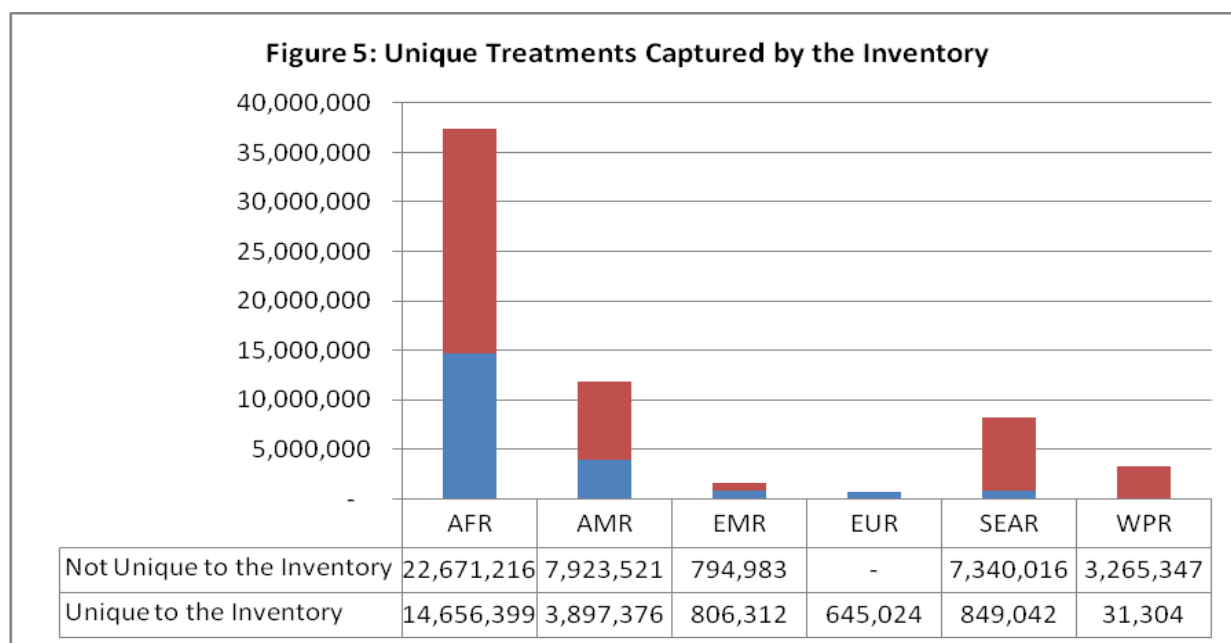
The majority of treatments were reported for the African and American regions. Considering the relatively lower infection prevalence rates in the European and Eastern Mediterranean regions, it was to be expected that the treatment numbers from this region would be low. However, the treatment numbers reported from the Southeast Asia and Western Pacific regions are lower than was expected.

Additionality to WHO PCT Databank

Of the 62.8 million treatments reported, about one third (20.8 million; 33.2%) were treatments uniquely reported to the Inventory and not captured in the WHO PCT databank. The remaining treatments were reported either directly to WHO headquarters or to the regional WHO offices in addition to being reported to the Inventory.



Though a small number, the total number of treatments reported for the European region was entirely unique to the Inventory. Similarly, half of all the treatments reported for the Eastern Mediterranean region were not previously captured in the PCT databank. The proportion of treatments uniquely reported through the Inventory for the Southeast Asian and Western Pacific regions was notably low.



Treatment data for 2009 will be published in the *Weekly Epidemiological Record* in June 2011. It is estimated that a total of 182,179,416 school-age children were treated with deworming drugs in 2009².

² Data to be published in June 2011 in the *Weekly Epidemiological Record* (Data from the WHO PCT Databank)

This number includes treatments that were reported directly to WHO or its regional offices by Ministries of Health, as well as treatment figures uniquely reported to the Inventory. Treatments uniquely reported to the Inventory contributed about 11.5% of the total number STH treatments.

The PCT databank figure includes only treatments with mebendazole or albendazole. Treatments for lymphatic filariasis that used a combination of albendazole and ivermectin were also included in the PCT report for STH. Although the Inventory collected some data on treatments using praziquantel, these treatments were not included in the PCT report for STH, but were instead included in the schistosomiasis report.

Treatment Coverage

Calculations of treatment coverage are based on WHO's estimated at-risk population of 889 million school-age children.³ The updated PCT data indicate that about 20% of these at-risk school age children were treated with deworming drugs in 2009.⁴ While this overall coverage level is well below the 75% treatment target set by the World Health Assembly, there are variances in treatment coverage by country. The PCT databank report available on the WHO website⁵ provides total treatment numbers and coverage rates for each country.

Limitations

The data captured through the Inventory provide a general overview of the landscape of NGO deworming activities. However, there are limitations that present a challenge when interpreting the data.

The biggest challenge is in the age disaggregation of treatment data. While the Inventory specifically requested treatment data for school-age children 5-14 years of age, not all organizations collect age-disaggregated data. Therefore, some of the numbers reported may include pre-school age children or less frequently, adults that may have received deworming drugs. Similarly, treatment figures may not have been disaggregated across different treatment rounds. Therefore, in some cases treatment numbers may be an overestimate as they sum up the total number of treatments across multiple treatment rounds instead of distinguishing the number of children treated by treatment round. Other limitations include possible double counting between organizations donating or procuring the drug and organizations distributing the drug to at-risk populations.

It is also important to note that there were additional deworming drugs (65 million treatments) provided to countries for which corresponding treatment data were not provided. Moreover, the

³ Data to be published in June 2011 in the Weekly Epidemiological Record (Data from the WHO PCT Databank)

⁴ Ibid.

⁵ http://www.who.int/neglected_diseases/preventive_chemotherapy/sth/en/index.html

information captured in the Inventory, while contributing new information to the PCT databank, does not reflect the entirety of deworming programs around the world.

Conclusions and Recommendations

The Inventory was successful in identifying 20.8 million new treatments that were not previously captured by the PCT databank. An additional 65 million deworming drugs were provided to countries, but the number of children treated with these drugs was not reported. These numbers are a good indication of the wide-spread deworming activities and accomplishments of NGOs around the world. CWW will disseminate the results of the Inventory widely to encourage recording of treatment data and increased participation.

Overall, organizations responded very positively to the Inventory request and noted the need for such a tool to help plan deworming activities. CWW was invited to the Gifts in Kind Summit in Fort Lauderdale, FL in November, 2010 to present on the Inventory and discuss the use for such a tool. In general, the Inventory was regarded as a useful tool to avoid overlapping and over treatment in some areas, while addressing treatment gaps in other areas.

The Inventory was also seen as a useful resource by WHO headquarters as well as WHO regional offices, particularly AMRO and AFRO. In the Americas region, AMRO had been actively collecting treatment data from NGOs for the past couple of years. Having seen that the Inventory was an effective way of capturing the same data, AMRO has commissioned the task of collecting NGO data to CWW moving forward. In the African region, the AFRO reporting mechanism, once established, may replace the Inventory efforts. However, while the AFRO reporting mechanism is being developed and refined, the Inventory will serve as way to cross reference and validate this new mechanism. As such, WHO headquarters has asked CWW to continue collecting deworming data from NGOs.

Using lessons learned from the 2009 round of data collection, the data collection form and process have been simplified for collection of 2010 data. To avoid exclusion of any deworming programs, the minimum treatment threshold of 50,000 will be lifted. This will eliminate the need for screening participants through the online survey. Instead, all organizations will now be asked to either complete the revised 2010 Treatment Reporting Form or submit their own program reports. The revised 2010 Treatment Reporting Form (Annex B) is very closely aligned with the WHO Joint Reporting form, but includes additional data elements such as a description of the reporting program's role in the deworming program, notation of any implementing partners, the source of drugs used, and the number of drugs provided. These additional data elements are intended to help avoid double counting between different organizations that may support the same deworming program in different capacities.

Moving forward, CWW will work with WHO and the Global Atlas of Helminth Infections⁶ to map treatment data and overlay it with disease prevalence data. This comparison of disease prevalence and

⁶ <http://www.thiswormyworld.org>

treatment coverage data will be tremendously useful to identify treatment gaps and help coordinate deworming activities worldwide.

