

Data Use and Sharing Policy

for the Global NGO Deworming Inventory

This document describes the policy governing the use and sharing of data gathered by Children Without Worms (CWW) to develop an Inventory of non-governmental organization (NGO) deworming programs.

1. Data Ownership

No one organization, CWW included, will have ownership of the Inventory and the data contained therein. Organization-level deworming data will remain under the ownership of the respective NGO that submits the data. CWW will maintain the integrity of the data submitted. CWW will not change or in any way modify the organization-level data submitted by each individual NGO.

2. Use of Data

2.1. Primary Use of Data

CWW will collect district-level deworming data from NGOs to develop an Inventory of NGO deworming programs. The purpose of the Inventory is to collate data on NGO deworming activities into a single, reliable database for use by programs working on soil-transmitted helminthiasis (STH), schistosomiasis, and lymphatic filariasis (LF). This Inventory will include information on deworming against STH, LF, and schistosomiasis so that disease-specific initiatives are clearly captured and differentiated. Data from this Inventory will be merged with national-level data from Ministries of Health (MOHs) contained in the WHO Preventive Chemotherapy (PCT) databank to provide comprehensive country-level deworming data.

To facilitate use of data collected by the Inventory, CWW will produce the following reports and post them on the openly-accessible Inventory web site (www.ngodeworminginventory.org):

1. Treatment reports aggregated at the district, regional or provincial, and national level
2. List of NGOs that are supporting deworming activities at the district, regional, and national levels
3. List of countries in which each NGO has a deworming program
4. Analysis summary of geographic gaps in treatment coverage

2.2. Secondary Use of Data

The Inventory, as a repository of NGO deworming data, may serve as a data source for research on deworming coverage. Use of aggregate deworming data provided in the Inventory must be cited or referenced for use in publications or grant proposals.

3. Data Sharing

3.1. Sharing data with the WHO

Deworming data submitted by participating NGOs will be shared with the WHO PCT program to complement national-level deworming data submitted to the PCT by MOHs. The WHO PCT program will adhere to the terms of this Data Use and Sharing Policy in preserving the privacy of individual NGO deworming numbers.

3.2. Sharing data with national Ministries of Health

Organization-level deworming data submitted by participating NGOs will be shared with the respective national MOH of the countries in which the NGO operates. CWW does not have any jurisdiction over the use of data by MOHs.

4. Data Privacy

CWW will maintain the privacy of the organizational-level data submitted by each NGO. With the exception of sharing organizational-level data with the respective MOH and the WHO (see Section 3), CWW will not publish or otherwise disseminate NGO-level treatment data. Only aggregate-level data will be publicly shared, as described above. In the case where there is only one NGO deworming program operating in a district or a region, CWW will first request permission from the NGO to publish the data. If permission is not granted, such data will be aggregated at the next administrative level in which there is more than one NGO deworming program.

5. Access to Data

All Inventory reports, as described in Section 2.1., will be posted on the freely-accessible Inventory web site (www.ngodeworminginventory.org). Anyone who visits the project web site will have access to aggregate-level treatment reports posted on the site. Only CWW, the WHO PCT program, and the respective MOH of the countries in which each NGO operates will have access to organization-level data submitted by each NGO.

6. Data Validation

To verify and ensure the quality of the data submitted, CWW will employ data validation procedures. Data validation procedures will include:

- Reviewing the role of each NGO working in a district (where there are multiple NGOs deworming in one district) to ensure that the same deworming numbers are not reported multiple times by organizations that may be providing different types of support to a deworming program.
- Reviewing NGO deworming reports with respective MOHs to ensure country-level reports submitted to the PCT databank do not already include NGO data.

By submitting treatment data for the deworming Inventory, the NGO grants to CWW the right to use the submitted data for the purposes stated above and permits CWW to share organizational-level data with the WHO and the respective MOH.