



Implementation and sustainability of Community-Directed Treatment of Onchocerciasis with ivermectin

Implementation and sustainability of Community-Directed Treatment of Onchocerciasis with ivermectin: A multicountry study

FINAL REPORT

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UNDP/World Bank/WHO
Special Programme for Research and Training in Tropical Diseases
(TDR)

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Cover photo: Community members distributing ivermectin - Ghana (WHO/TDR/Crump)
Concept and design: Andy Crump, Lisa Schwarb

Acronyms

APOC

African Programme for Onchocerciasis Control

CBO

Community-based organizations

CBTI

Community-based treatment with ivermectin

CDD

Community-directed distributor (a village-selected volunteer)

CDTI

Community-directed treatment (ComDT) with ivermectin

ComDT

Community-directed treatment

DHS

District health service

FGD

Focus group discussion

LGA

Local government area

NGO/NGDO

Non-governmental (development) organization

NOCP

National Onchocerciasis Control Programme

OCP

Onchocerciasis Control Programme in West Africa

PHC

Primary health care

REMO

Rapid epidemiological mapping of onchocerciasis

SHM

Stakeholders meeting

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EXECUTIVE SUMMARY

TDR pioneered the development of community-directed treatment with ivermectin (CDTI) for onchocerciasis control in 1995. This strategy was adopted by the African Programme for Onchocerciasis Control (APOC) in 1996. CDTI embodies the philosophy of primary health care in that communities are encouraged to take responsibility for organizing their own distribution of the drug ivermectin, which has been provided free of charge to APOC countries. CDTI was found to achieve significantly higher coverage than ivermectin distribution organized by professionals. Although CDTI has been accepted because of its positive effect on coverage in a short-term project, APOC was concerned about the long-term sustainability of the approach since onchocerciasis control using ivermectin needs to continue for at least 15 years in endemic communities. This multicountry project was, therefore, designed to identify factors that could predict sustainability and to develop an intervention that might enhance sustainability.

Six research teams completed: 1) a baseline study of issues that affect community involvement and health worker functioning in ivermectin distribution, 2) a quasi-experimental intervention to enhance the likelihood of sustainability, and 3) a follow-up evaluation. The teams were from Ghana, Mali, Togo, and three sites in Nigeria - Awka, Enugu, and Ibadan.

The baseline study was completed and analysed in June 1998 at a workshop where the results were used to design an intervention to enhance sustainability. A key baseline finding was that there was poor communication and interaction between community members and health workers. Each team chose four districts for study. In each district, four clusters of 4-12 villages were selected, most of which surrounded a district health facility. Two districts in each site were randomly allocated to an arm of the study with regular CDTI, and two to an arm with enhanced CDTI. The main enhancement was the inclusion of stakeholders meetings (SHMs) which were developed as a result of baseline findings. SHMs brought together community representatives, health workers and members of community-based organizations to plan CDTI in village clusters.

Two rounds of ivermectin distribution were undertaken in order to ensure that precursor factors that might improve the likelihood of sustainability could be identified, and that enough time would be given for the enhanced intervention to show an effect. At the end of the second round, a combination of quantitative and qualitative methods was used to document the following factors: coverage, community participation, willingness to continue CDTI, health worker performance, health worker attitudes towards CDTI.

Coverage was not found to be different between the two arms of the study, and averaged 74% of the total population (84% of eligibles). This was higher, though not significantly, than that achieved in TDR's first CDTI study. The researchers considered that a coverage ceiling might have been obtained using the CDTI strategy. The main question therefore, was whether communities and health workers could sustain this coverage.

The results indicated that communities are generally capable of implementing and sustaining CDTI. Resources were provided for procurement, side-effect management, support of community directed distributors (CDDs), and other basic programme management needs. CDDs are capable of distribution and record keeping, and are willing to continue. Many are motivated, not by cash incentives, but by gains in recognition, self-esteem and knowl-

edge. Community-based organizations (CBOs) have a potential role to play, but this role will not become fully evident until CDTI is implemented on a larger scale, at district level.

Health staff are also capable. They are able to facilitate meetings and interact with the community as partners. They can manage training, drug supplies, recording and reporting. They have expressed positive attitudes toward CDTI. Policy makers say they are committed to CDTI, but health authorities indicate that full support (financial, logistical) has not yet been forthcoming. Factors that will enhance political commitment are not yet known and were not within the scope of this study. They need to be addressed in the future.

The specific conclusion concerning the SHMs was that these offered a valuable forum for planning and solving problems. As noted, the enhancement process did not affect coverage - both groups had good coverage, i.e., the minimum desired population coverage of 65% was surpassed. On the other hand, it is important to note that a main reason for not receiving tablets - i.e. not being eligible - occurred significantly more in the enhanced arm of the study. Factors such as being absent and not being informed, were significantly more likely to happen in the regular arm of the study, implying a lower level of communication about the programme in that arm.

In communities in the enhanced arm of the study there were greater degrees of participation, definitive reporting, willingness to continue the programme, and actual meetings to plan the implementation. These communities perceived more benefits from the programme and were more satisfied. The enhanced study group of CDDs received greater community support to do the job, perceived more respect from community, and were more committed to future service. The enhanced study group of health workers had more favourable attitudes toward CDTI, were reported as having better community interaction, and engaged in more CDTI activities.

Has the question of sustainability been answered? The first CDTI study showed community capacity. This, the second study, has demonstrated both community and health worker commitment, and a strategy for enhancing commitment. The remaining question at district level is: will policy makers and planners also commit themselves to sustaining CDTI?

The researchers offered two main recommendations from their findings. First, APOC should promote SHMs in the context of developing a feedback mechanism among CDTI partners. This can be done on a pilot basis and can be used to test the hypothesis that sustainability can be influenced by such factors as health worker attitudes, community participation reports, and CDD self-esteem, among others detailed in this report. This process should be monitored over a longer period than in the present study. Secondly, the multicountry advocacy study, which is currently under way, should examine factors among policy makers that can enhance sustainability.

I

BACKGROUND

The history of onchocerciasis control using the drug ivermectin spans nearly 20 years. Figure 1 shows that efforts began in 1982 with efficacy trials in West Africa. In 1987, ivermectin was registered for human use. Large-scale community trials started the same year in OCP countries. By 1991, NGDOs teamed up with national, state and district governments to organize mass and community-based distribution of ivermectin in endemic areas, using REMO, a tool developed through TDR studies in 1993, to help target communities for treatment. An experimental multicountry study by TDR in 1994-95 documented that, when communities are responsible for organizing their own distribution of ivermectin, higher coverage is achieved than when the health system plans and delivers the drug.

Figure 1: History and timeline for CDTI

YEAR	ACTIVITY
1982	Ivermectin efficacy trials begin
1987	Ivermectin is registered as a safe drug for human use
1987	Large-scale community trials of ivermectin begin in OCP countries
1991	NGDO-assisted mass and community-based ivermectin distribution programmes begin
1995	TDR multicountry study concludes that ComDT achieves higher coverage than programme designed intervention
1995	APOC is formed in December
1996	APOC adopts CDTI as its major intervention strategy
1999	TDR multicountry study on ComDT sustainability indicators is completed
2000	TDR plans new study on advocacy to generate political will to sustain CDTI
2007	All endemic countries will have assumed full responsibility for CDTI

Not long after its formation in December 1995, APOC adopted CDTI as its official intervention strategy. As APOC grants were being implemented in 16 endemic countries, the question of sustainability of the CDTI approach arose. TDR commissioned a second multicountry study during 1998-99 to answer that question, and the results are reported below. The sustainability issues being addressed in this report focus on the community and health services levels. The role of advocacy in encouraging local, state/provincial and national government commitment to sustaining CDTI is being addressed in an upcoming TDR multicountry study. It is hoped that the lessons learned in these various studies will have been implemented by health ministries and departments in all endemic countries by 2008, when APOC grants will have been phased out and responsibility for onchocerciasis control will have been assumed by governments of these countries.

The principal challenge for onchocerciasis control is to deliver single-dose treatment to the populations of high risk communities, and to sustain the delivery for a sufficiently long period to bring about the control of the disease as a public health problem. Sustained drug delivery to all high risk communities is difficult to achieve by the regular health services alone, which are already overburdened with other responsibilities and short of resources. However, recent operational research on drug delivery for onchocerciasis control in Africa indicates a solution for this problem, namely, greater involvement of the endemic communities themselves in the delivery process.

In helping to prepare the technical basis for the new African Programme for Onchocerciasis Control (APOC), TDR has developed the concept of community-directed treatment with ivermectin (CDTI, also referred to as CDTI), in which the community itself has the responsibility for organizing and executing treatment of its members. A large, multicountry study by TDR had earlier shown that community-directed treatment is feasible and effective¹, and APOC accepted community-directed treatment as the basis of its control strategy. In the OCP, where ivermectin treatment now supplements vector control, ivermectin delivery by mobile teams has been transformed into community-directed treatment. The standard guidelines for CDTI developed by APOC contain 12 basic steps (see Appendix A). These steps distinguish CDTI from the former mass distribution process otherwise known as community-based distribution of ivermectin (CBTI) (see Appendix A).

Although the multicountry study demonstrated the effectiveness of CDTI, still many questions remained on the support mechanisms necessary for community-directed treatment to function well and on the optimal relationship with, and integration of, community-directed treatment in the health system, especially at the district level. The study also showed that it was difficult for health personnel to give communities the freedom to design their own delivery system. Furthermore, although the sustainability of CDTI can only be proven over time, there is an urgent need for operational predictors of sustainability which can be used in the evaluation of CDTI.

Thus, there remains a need for further operational research on the implementation of community-directed treatment and for generating ideas on improved approaches and optimal interaction with the health care system. APOC and OCP have requested TDR to help answer these questions.

CDTI is based on the principle of community participation (or involvement). A key element is the selection by villagers, and training by local health staff, of community directed distributors (CDDs), a version of the common village-based health worker. In a recent review on the current status of community participation in health programming, Zakus and Lysack² observed that "participation has proven difficult not only to define but to practically initiate and sustain," and it is just that issue of sustainability that is the challenge to the present study. One of the reasons they document as causing the problem is that the health system, in choosing what programmes require participation and thereby setting the health agenda for villagers, places an additional burden on an already disadvantaged population, since participation does require time and resources. Another problem is the lack of genuine support and understanding of the participatory process by health workers and managers. Part of the reason health professionals have difficulty promoting full involvement of citizens in programming is that they are wedded to cause-effect paradigm that focuses on individual behaviours to the exclusion of more complex social factors that are, in fact, the basis of how and why the community participates in health and development activities.³

The honing in on individual behaviours as the cause of specific diseases that are the main reasons for child morbidity and mortality in a region was given strong credence with the onset of Selective Primary Health Care.⁴ Out of this grew social marketing to promote isolated health behaviours, supplanting a more developmental approach that involved the community in identifying and solving its own priority health problems through their own efforts.⁵ In the area of tropical disease control, the same shift away from community involvement and toward individual behaviours has been seen in the area of guinea worm eradication, where an initial focus on community water supply development has been replaced by promotion of individual use of cloth water filters.⁶ Recent reports have emphasized that the transition from community-based programmes controlled by health staff, to CDTI, is a major challenge to health systems, as middle level health staff often lack the management skills needed to foster community participation.⁷ The benefits of changing from community-based distribution to CDTI have been expounded as sustainability, ownership and empowerment on the community side as well as cost-savings by the health departments.⁸

The reality is that communities are already participating in their own health and development, but their agenda and approach may differ from that of the health professionals. The achievement of community participation in priority programmes selected by the health planners will require greater change on the part of the health worker than the community. The health worker must achieve a shift in paradigm,³ suspend belief in the "universal" epidemiological model, and understand and accept "local truths" as a necessary basis for partnership with the community to solve such problems as onchocerciasis. It is hoped that the present study on factors that may promote the sustainability of CDTI will identify some of the health workers concerns and reservations, as well as some of those "local truths," and thus pave the way for sustained community participation in ivermectin distribution as an integral part of ongoing community-directed efforts to improve their own lives.

2

OBJECTIVES

The study took place in two phases. Phase I provided a situational analysis concerning onchocerciasis control at the community and district levels. This was followed by a planning workshop where the intervention strategy and design for Phase 2 was developed. Phase 2, therefore, consisted of the implementation of that strategy. The general and specific objectives that guided the whole study are outlined below.

2.1 General Objective

- To develop and test novel approaches to the introduction and implementation of CDTI which will facilitate its integration in the health system, encourage effective partnership between endemic communities and the health services, and improve monitoring and reporting; and to develop predictors of the sustainability of CDTI for routine operational use in evaluation.

2.2 Phase I: Specific Objectives

- Describe the community structures and traditional/non-traditional organizations and associations in the study communities, and determine their roles and functions with respect to ivermectin distribution.
- Describe the availability and functioning of health services in the study area, the drug supply system and previous experiences with onchocerciasis control.
- Assess the capacity of the existing district health system (DHS) to support CDTI and identify weak points that need strengthening.
- Determine the perceptions and attitudes of (i) health personnel at different levels towards CDTI and (ii) the population towards CDTI and the health system.
- Identify and assess the channels, nature and potential influence of communication between the community and the DHS.
- Identify the potential partners for CDTI, and study their attitudes and practices in order to facilitate the introduction of CDTI.
- Develop, implement and test an advocacy strategy for CDTI aimed at the health services at different levels.
- Determine how to introduce CDTI into a minimum health care package.

2.3 Phase 2: Specific Objectives

To develop and pre-test an enhanced approach to CDTI which includes the following components:

- Mechanisms for active involvement and re-orientation of the health system at the district level, for the inclusion of onchocerciasis control in the basic health package and for generation of commitment of health service staff to CDTI.

- Re-enforced introduction of CDTI in endemic communities to ensure optimal decision making by the community in the implementation of CDTI.
- Mechanisms for: sharing of information on the concept of CDTI (CDTI), including the findings of phase I, among first-line health workers, community representatives and community-based organizations (CBOs); exchange of ideas; joint decisions as to partner roles and tasks and appropriate intervention strategies.
- To test the effectiveness of an enhanced package of CDTI on levels of participation and satisfaction with CDTI by the principal actors.
- To compare ivermectin coverage between communities with the enhanced CDTI package and those with "normal" CDTI.

3

METHODOLOGY

3.1 Design

The study was both quasi-experimental and case study in nature. The main intervention tested was an enhanced effort to improve integration of CDTI with the DHS by addressing factors that may make health workers resistant to community control. This is outlined in Figure 2.

Figure 2: Design of enhancement intervention at each site

Integration mode (group)	Time 1	Intervention	Time 2
Standard CDTI in 2 districts	pre-intervention data collection	standard CDTI as outlined in Appendix A	post-evaluation evaluation
Enhanced CDTI in 2 districts	pre-intervention data collection	standard CDTI plus an enhancement	post-evaluation evaluation
Variables to be tested	willingness feasibility acceptability effectiveness	(process monitoring)	willingness feasibility acceptability effectiveness

At each site, four districts/local governments were chosen for study. After Phase I results were analysed and the intervention designed, two districts in each site were randomly allocated to receive standard CDTI and two to receive the enhanced intervention. Within each district, four clusters were identified. A cluster was usually based on an available health facility that served a group of surrounding villages. If there were more than four health facilities in a district, four were chosen randomly. If there were less than four, other central points were identified for forming clusters, e.g. a rural farm market. Each cluster thus contained, ideally, at least four villages/communities and one health facility and its staff.

3.2 Baseline Procedures

Phase I consisted of the collection of baseline and planning data. Five broad data collection procedures were used: observation, focus group discussions, in-depth interviews, review of documents, and structured interviews.

Observation: Participant observation and structured observation were used to describe existing health services (including the traditional health system) in the area with respect to facilities, personnel, equipment, and buildings. Observation, including mapping, was undertaken to delineate patterns of settlement, including roads and transportation facilities, and the physical features of the community, such as rivers and relevant ecological conditions. Observable features of traditional associations and the social and cultural features and activities of the communities, such as festivals and markets, were documented. The political system of the district and community was described.

Focus Group Discussions: Focus groups with adult members of the community determined perceptions and attitudes towards the general health system and CDTI, with particular attention to any past experience with health and development programmes and local distribution systems, especially ivermectin distribution programmes. FGDs were used to identify channels of communication between the community and the DHS, to consider the possibilities for using the political system (both local traditional and governmental) and other potential channels of communication, and to identify potential partners for enhancing health system capabilities in promoting CDTI.

FGDs provided information on the desires and expectations of the community concerning feedback from health and development programmes. Discussion items focused on communication between community members, district policy makers and health staff, on experiences with onchocerciasis and ivermectin, and willingness to be involved in CDTI.

In-depth Interviews: In-depth interviews were held with four main groups of people: village leaders, CDDs and other volunteers who had been involved in community work, CBO representatives, and health staff. Roles of each in community-based health programming were explored, as was their experience with ivermectin distribution. Questions were asked about the level of interaction and communication between the community and the DHS. These interviews were used to identify appropriate partners for promoting CDTI and the relevant experience of these partners.

Review Of Documents: A variety of documents were reviewed to learn about the functioning of the health system and potential collaborating partners. These included reports of the activities of the health system, maps, personnel lists, organigrams, financial reports, and budgets of the DHS and potential partners.

Structured Interviews: An attitude scale was administered to health workers who could potentially be involved in the implementation of CDTI to assess their willingness or resistance to the programme. Those interviewed provided information about their level of training, credentials, and years of experience.

3.3 Intervention design and monitoring

Baseline data collection took place between December 1997 and May 1998. In June 1998, seven teams assembled in Ouagadougou to analyse the findings and use these to design the enhanced intervention. At that time also, APOC reviewed with the teams the 12 steps comprising the standard CDTI intervention. As outlined in Section Five below, the key issues documented in Phase I included a low level of communication between community members and health workers, as well as a poor attitude by health workers toward community participation in health programming. The enhanced intervention of Stakeholders Meetings (SHMs) was therefore designed to address these issues.

3.3.1 Stakeholders meetings

The SHM was a mechanism for: sharing information on the concept of CDTI, including the findings of Phase I, among first-line health workers, community representatives and CBOs, exchanging ideas, and jointly deciding on partner roles and tasks and appropriate intervention strategies. Detailed Guidelines for the SHMs are found in Appendix B. Participants included representatives of the villages, community-based organizations and health workers.

The facilitators were DHS staff. At least one representative from the district level attended to facilitate the meeting. The research team oriented these representatives about how to conduct participatory meetings.⁹ Researchers attended the SHMs primarily as observers and took minutes of the meeting and special note of the processes and decisions as a way of documenting health worker performance, village concerns and villager-health worker interaction.

The venue of the meeting was an accessible, central place within a cluster of villages, e.g., a primary school or a meeting hall, but not a health facility. The initial SHMs were held in advance of the first distribution in the district. A second follow-up set of SHMs was held just before the second treatment after six months.

The process of the workshop was participatory. The agenda presented topics for consideration, but the participants were free to add items, give their own views and experiences and direct the course of discussion. Facilitators encouraged discussion, and did not impose ideas or solutions. The group was guided to debate alternative actions and make their own decisions. An important guiding principle was that each village takes the final decision about the approach to distribution, reporting, etc. Therefore, not all villages necessarily chose the same approach. Village representatives were told to carry the ideas from the SHM back to their communities for final approval and planning. The agenda in Appendix B guided the meetings.

Researchers and health staff followed up the village representatives to document what was shared with the community using a brief questionnaire asking both men and women what they heard about the decisions made at the meeting.

The agenda of the second SHM was, primarily, review of the first ivermectin distribution and planning for undertaking the second distribution. The SHM provided an opportunity for health workers to receive feedback from the communities and for the community representatives to share ideas among themselves on how to handle any problems they had encountered.

3.3.2 Monitoring the intervention process

It was necessary to monitor and document the intervention process so that the study teams could eventually attribute the findings to the enhancement process if it were successful. Monitoring was also used to gather valuable data on the general process of CDTI implementation that could provide lessons for APOC to share with its grantees.

Both qualitative and quantitative data were collected during the intervention. Monitoring addressed three broad issues: 1) whether any other interventions were taking place in the study districts that could have had an influence on the results (e.g. unexpected media coverage or the entry of a new NGO into the area); 2) whether the planned activities were executed in the intended manner; and 3) whether any events had taken place that could have influenced response to the intervention (e.g. major changes in district health staff or community conflicts).

Concerning quantitative data, records were kept of the ivermectin tablets received and distributed at each level within the study districts. Records were also kept of the actual numbers of meetings held and the attendance figures according to type of health worker present and hamlets represented. Qualitative data consisted of the minutes of the meetings, which were recorded by research team members who functioned as observers at: 1) meetings where CDTI was introduced to district health staff, 2) meetings where CDTI was first introduced to hamlet residents, and 3) workshops held with village clusters. As participant observers, the researchers also kept field notebooks for the purpose of recording events and responses of the key actors throughout the intervention period. Observations were recorded on such factors as storage and safety of ivermectin.

3.4 Follow-up Evaluation

Based on the objectives of Phase 2, the research teams developed a set of indicators that served as a foundation on which to build the final data collection instruments. Indicators at the community level included community members reports:

- of taking responsibility for all aspects of CDTI planning, implementation and provision of logistical support (gathered through *focus group discussions, in-depth interviews of CBOs, village leaders, and CDDs*).
- that persons responsible for ivermectin distribution in the community receive acceptable reinforcement for their efforts, e.g. that CDDs report compensation (gathered through *focus group discussions, in-depth interviews of CDDs*).
- of a correct understanding of the exclusion criteria, side-effects and side-effect management for ivermectin (gathered through *focus group discussions, in-depth interviews with CDDs, village leaders*).
- that CBOs have been considered, and if found potentially helpful, involved in the CDTI process (gathered through *in-depth interviews with association leaders*).
- that health workers interacted with villagers in a positive way to initiate and sustain CDTI at the village level (gathered through *focus group discussions, in-depth interviews of village leaders*).

Indicators at the health services level included health worker reports:

- of positive attitudes towards involvement of the community in onchocerciasis control (gathered through *structured interviews* with all health workers).
- that transportation was available as needed for CDTI related activities (gathered through *in-depth interviews with health workers, observations, primarily with district level staff*).
- that supplies of ivermectin were provided to sub-district and village levels in an adequate, safe and timely manner (gathered through *in-depth interviews of health workers and CDDs, focus group discussions, with district level staff - note the possibility of state/national levels not providing ivermectin in a timely manner and the need for district initiative to resolve the problem*).
- of being involved in the planning, monitoring and supervision for CDTI in the villages within their catchment areas (gathered through *in-depth interviews of health workers and village leaders, focus group discussions, CDDs*).
- that they have considered the potential role of CBOs and NGOs in CDTI, and, where found appropriate, have involved these groups as partners, not simply as providers of supplementary services (gathered through *in-depth interviews of health workers, potential partners*).

The same instruments used to collect baseline data were employed for follow-up study. Separate FGDs among male and female community members were held in each cluster. In-depth interviews took place with CDDs, village leaders, CBO representatives and health workers. The front-line health staff directly involved in the project were interviewed with the opinion/attitude survey instrument. Other quantitative data included household surveys to determine both satisfaction by the head of household and coverage for all household members.

4

STUDY SITES

The study took place at six sites (see map) in four countries. All sites were in West Africa. Two were based in francophone and four in anglophone countries. At all sites, ivermectin distribution had occurred previously, but to varying extents and with only a few districts having actually started CDTI. In Togo, distribution under the auspices of OCP had been under way since 1996. In contrast, The four districts outside Ibadan, Nigeria, had experienced only sporadic distributions either through research programmes or as outreach from the health service. The APOC grant to Oyo State did not take effect until after the project was over.

One project was based in the National Onchocerciasis Control Programme offices (Togo), one was based in a special unit of the Ministry of Health (Ghana), while the others were based at research institutions. As noted, the project took place in four clusters of villages in four districts in each of the six sites. The estimated population that was served by the project was 250 000. Now that APOC is under way in all sites, the CDTI activities initiated during the study will be continued in each district by the local government authorities.



TDRG/005

4.1 Awka, Anambra State, Nigeria

Awka itself is the capital of Anambra State, Nigeria. The town itself is fairly compact, but the surrounding local government areas (LGAs) where the study took place are rural in nature. Awka is the seat of various state ministries as well as Nnamdi Azikwe University, where the research team was based. The study was originally planned for four LGAs, Awka North, Awka South, Oyi and Ayamelum. Unfortunately, communal fighting in Ayamelum LGA made it unsafe to work there, and in fact much of the population had fled the area. It was therefore decided, since Oyi LGA was large, to divide it into two sections, Oyi 1 and Oyi 2, for research purposes. The three LGAs are contiguous and lie between 5.51° and 6.45° North. The population of Awka South is 130 666, of whom 72 614 are urban dwellers. Awka North has 60 728 inhabitants, while 109 921 people live in Oyi LGA.

The area has many rivers and streams running in a southwesterly direction, emptying into the Anambra River, which itself joins the Niger. Other important rivers include the Mamu, Ezu and Oyi, which are known breeding sites for *Simulium damnosum*. The pattern of onchocerciasis distribution is described as "diffuse" but hyperendemic by the State Ministry of Health, which has conducted rapid epidemiological assessments in the area.

Awka South LGA is densely populated and has a mixed vegetation of tropical rain forest interspersed with lightly wooded savannah. Awka North and Oyi are more sparsely populated with scattered communities. The inhabitants are almost entirely of Igbo origin, although there is a small Hausa settler community in Awka South.

There the vegetation is primarily wooded savannah with only patches of rain forest. Awka South and Oyi 1 were selected as enhanced LGAs, while Awka North and Oyi 2 received the regular CDTI intervention. The three LGAs are essentially rural and agricultural, with farming, fishing and palm wine tapping as their major occupations.

There are 85 health units within the three LGAs. Thirteen are located within the onchocerciasis endemic parts of these LGAs. These units are staffed by nurses, nurse-midwives and community health extension workers (CHEWs), with an average of 4-5 staff per unit. They have space to store ivermectin, but lack transport. A total of 86 655 people reside in the study area, or 29% of the overall population of the study LGAs. Although the NGDO Global 2000 River Blindness Foundation has operated community-based distribution programmes in the past, CDTI had not started in the area.

4.2 Enugu State, Nigeria

The study was carried out in four LGAs in Udi, Ezeagu, Igbo-Etiti and Nsukka, all in Enugu State of South-Eastern Nigeria.

Enugu State is bounded to the north by Benue and Kogi States, to the south by Imo and Abia, to the east by Cross-river and to the west by Anambra State. All the selected LGAs are culturally and geographically identical but each is located at least 30 kilometres away from the other. The estimated populations are 108 000 for Ezeagu, 131 000 for Igbo-Etiti, 218 000 for Nsukka, and 146 000 for Udi. All the study sites share similar seasons: rainy and wet between March and October, during which time most of the roads are inaccessible; dry and dusty between November and February, during which time the roads become accessible but dusty.

The inhabitants are all of the Igbo tribe and live in compact and stable settlements. They are predominantly peasant farmers. Their religion is mainly Christianity and African Traditional. Literacy levels are relatively high. Each village has a leader (village head or councillor), but a collection of villages that constitute a 'community' has one traditional ruler called 'Igwe'. The ruler is appointed or elected by the people and he administers the affairs of the community through the village leaders and elders.

Udi, Ezeagu, Igbo-Etiti and Ezeagu LGAs have 24, 11, 14 and 22 health facilities respectively. These are located in some of the villages. A number of these health facilities have not been functioning adequately. Community-based distribution of ivermectin, sponsored by NGDOs (Global 2000 formerly known as River Blindness Foundation/Lions Club), has been going on in these villages for the past two years. Although there was no formal CDTI in these areas, as learned from observation and interviews with the village leaders, distributors and some members of the community, the method used in the planning and execution of the distribution is almost similar to CDTI. The communities selected their distributors who are indigenous to the area. They also decided how and where the distribution would take place some of the time. Usually this was at a central location for everybody or house to house for those who were absent or too ill to come to the central place. The only two differences are: a) the responsibility for the programme has not been handed over to the community; b) the NGDO pay the distributors during training workshops.

4.3 Ghana

The study communities were drawn from the Western Region of Ghana, one of ten major administrative regions of the country. A region is divided into administrative districts and sub-districts. A regional minister, who is responsible for the administration of the region, heads each region.

The Western Region, with a population of 1.7 million, has eleven districts, each of which is headed by a chief executive appointed by the government and approved by the district assembly. The district assembly is made up of individuals elected from village committees and some government appointees; it oversees the functions of the departmental heads of the various sectors represented in the district. The Western Region is situated in the south-western part of Ghana and is 23 921 sq. km in area. It stretches from the Gulf of Guinea in the south to about 192 kilometres north. To the west of the region is the Republic of Cote-d'Ivoire.

The Western Region has a high annual rainfall relative to the rest of Ghana. It has a double rainy season with peaks in May-June and September-October. The region is drained by a number of large rivers and their tributaries. These include the Tano, the Pra, the Ankobra and the Bia, all fast flowing rivers, ideal breeding sites for the *Simulium* fly, the vector for onchocerciasis.

Much of the region is covered with tropical rain forest, which stretches almost down to the coast where mangrove swamps can be found. About 77% of the population is rural and about 51.1% of the population is engaged in agriculture. The crops cultivated range from cash crops like cocoa, coffee, rubber, oil palm and coconut, to food crops like rice, plantain, maize, cassava and vegetables. Fishing is important along the coast while further inland logging and mineral mining and exploration are important industries undertaken by companies with concessions and individuals.

The main ethnic groups represented traditionally include the Ahanta and Nzema who live in the southern parts, the Wassas, Brussas and Aowins, and the Sefwis who occupy portions further inland. There are a number of immigrant groups, living in their own villages. The immigrants have come from Ashanti, the Volta and Brong Ahafo Regions and are engaged in cash crop farming and other industries. Languages spoken include the Akan dialects of Fante and Wassaw, and the related languages of Nzema, Ahanta, Brussa, or Anyi and Sefwi. Most people understand the Akan dialects which serve as lingua franca.

It is estimated that there are 21 traditional councils throughout the region, each of which is headed by a paramount chief. Each paramountcy has a hierarchy of chiefs from the paramount chief to the village head or dikro. The four Western Region districts of Mphor Wassa East (96 153 population), Jomoro (101 398), Nzema East (131 118) and Wassa West (218 530) were selected for this study. The total population of these four districts was 647 209. These are districts with endemic communities that have onchocercal nodule prevalence ranging from 10–76%.

4.4 Ibadan, Oyo State, Nigeria

The study based at the University of Ibadan took place in the south western corner of Oyo State, which itself is in the south west of Nigeria. Four LGAs were chosen in Phase 1 and served as the focal districts for Phase 2: Ibarapa East, Ibarapa Central, Ibarapa North and Iwajowa. The area has an approximate population of 250 000, of whom 20-30% live in small farm hamlets (*abule*) in which onchocerciasis is most prevalent. Specifically, 31 570 people live

in the hamlets that participated in the project. Previous studies in the area have found a nodule prevalence rate among persons 20 years and older of 59%. Four major rivers flow through the area in a north to south direction, the Ogun, Oyan, Ofiki and Opeki, and these have been documented as *Simulium* breeding sites.¹⁰ Smaller Rivers include the Ayinsha in Ibarapa North, and the Oha, Opara and Ooko in Iwajowa. Focus of the study was on those persons living in the farm hamlets and thus most exposed to onchocerciasis.¹¹ The landscape of the area is noted for large granite outcrops known as inselbergs. All of the major towns in the four LGAs, except for Igangan, are nestled against inselbergs, many reaching over 300 metres above sea level. During the rainy season, these huge rocks, and the flow of water over them, could constitute ideal *Simulium* breeding sites.

Each LGA has a primary health care (PHC) department. The Federal Ministry of Health (FMOH) has recommended five major divisions for a PHC department: disease control, maternal and child health, monitoring and evaluation, essential drugs, Expanded Programme on Immunization (EPI), and health education. None has a health education section. All had onchocerciasis control programmes prior to the start of this project, but not had yet implemented CDTI. Although the LGAs have experimented with the training of village health workers (VHWs) and appointed village-based guinea worm scouts, the bulk of health service is delivered in static facilities which are concentrated in the main towns ranging in population from 5000-50 000. Each town has an LGA dispensary/maternity unit. A few of these units have been constructed among the outlying hamlets, but most have never functioned, as staff refuse to be posted to these locations that have no amenities and erratic transportation.

Each LGA is divided into health districts for the purpose of PHC management. These districts are usually based around static facilities, the maternity centre/dispensary complex. The health district team is comprised of the staff based at the static facility as well as those serving the surrounding area. These typically consist of nurses/midwives, community health extension workers (CHEWs), pharmacy technicians (formerly known as dispensers) and environmental health officers (formerly known as health inspectors). All main towns have such facilities, but only in Ibarapa East and Iwajowa LGAs are functioning facilities located among the outlying farm hamlets. The vast expanses of farmlands/hamlets in Ibarapa North and Central LGAs have been designated as health districts even though no functioning facilities are present.

Each LGA has appointed an ivermectin/onchocerciasis control coordinator. When mass ivermectin distribution started in the early 1990s, the National Onchocerciasis Control Programme (NOCP) in the FMOH had previously designated Oyo State as an area where ivermectin distribution would be the responsibility of the State Ministry of Health and the LGA PHC departments. This contrasts to other states where NGOs, such as the River Blindness Programme (Carter Center) and Sight Savers, assisted with ivermectin distribution. When Oyo State submitted its CDTI proposal to APOC, UNICEF assisted the state in developing the programme and thus served as a proxy NGO, although UNICEF itself is actually an international (and inter-governmental) agency, not a NGO.

In three of the four LGAs, recent TDR studies on onchocerciasis had been completed. These have yielded a nodule prevalence rate of 59% in the three Ibarapa LGAs.¹² Among 21 villages in the TDR onchocerciasis economic study conducted in Ibarapa East LGA, 20 had nodule prevalence of at least 40% (1996). All 17 hamlets in Ibarapa central LGA that were used in the TDR onchocercal skin disease study had nodule rates of over 40% (1995-96).¹³ Among 24 hamlets or hamlet clusters in Ibarapa North LGA, also part of the skin study, 20 had nodule prevalence of 40% or greater; none had below 20% prevalence.

REMO was conducted in 1998, in 20 hamlets/hamlet clusters that border the Ofiki and Oyan Rivers in Iwajowa LGA, to determine the epidemiological conditions there following the procedures of Ngoumou and Walsh.¹⁴ Of the 20 hamlets (hamlet clusters) studied, three had a nodule prevalence of 40%, eight had prevalence between 20-29%, while in nine, less than 20% of adults examined had nodules. The same staff were used for examinations in all cases.

4.5 Mali

Kolokani cercle (district) is located north of Bamako. The Baoulé river flows across its western portion from north to south, forming a natural border between Kolokani, Kita and Kati districts. The areas most affected by onchocerciasis are those located along the river. However, the district has an extensive drainage system made up of seasonal streams, and a large lake. In the district, the population lives in scattered clusters of settlements. The search for fertile land has led to the establishment of farm settlements. The population is settled, and lives mainly from crop farming, with livestock-raising as the second most important activity. In addition, seasonal fishing is practised in the streams and all year round in lake Wegnan. The district has a population of 85 049. Prevalence of onchocerciasis may be as high as 20% in certain villages along the Baoulé river.

Kati district is noteworthy for having Bamako within it, and a number of the district's villages were incorporated into Bamako district some twenty years ago. Kati district borders on Kolokani to the north and west. The district is watered by the Niger river and crossed by a multitude of streams. Onchocerciasis prevalence varies from one village to another, although it is everywhere below 20%. The habitat is the same as in Kolokani district. Almost all the villages have at least one farm settlement. There are more farm settlements than villages in the district. The main economic activity is agriculture, followed by stock-raising and fishing, with arboriculture as another common occupation. Mechanized farming is practised on numerous farms, especially in the vicinity of Bamako district. The district's population is 260 987.

Koulikoro district is situated to the east of Bamako district. Like Kati district, it too is crossed by the Niger river, and watered by large streams. Koulikoro has the highest prevalence among the four districts studied, and it may exceed 20% in some villages, with 5% blindness. The population lives from agriculture, stock-raising and fishing; market gardening and arboriculture are also highly developed in the district. The presence of a number of industrial firms and of the shipping company have led to the development of a salaried labour force. However, agriculture is often an important sideline for wage earners. The district has a population of 60 987. Its habitat has the same characteristics as the other districts studied. Some of the villages in Koulikoro district are located within the urban periphery of Bamako.

Bougouni district is located south of Bamako. It is the wettest of the four districts, both in terms of rainfall and of its drainage system. Two rivers, the Baoulé and the Bani, an affluent of the Niger, flow through the district, which is criss-crossed by a multitude of streams. Prevalence is below 20%. It was in this district that the first ivermectin treatment involving community participation was initiated. The main economic activity is agriculture, which benefits from the technical assistance of a development operation, the Compagnie Malienne du Développement du Textile, which has set up cotton-processing plants in the district. The habitat is made up of scattered clusters, with a large number of settlements. The district has a population of 282 813.

4.6 Togo

The study took place in the region of Kara Region in Togo, one of the five administrative regions in the country. Kara is situated 400 km north of Lome, the capital. Kara is bounded on the north by Savannah Region, on the south by Central Region, on the west by Ghana and on the East by Benin. It covers 11 490 sq km. with a population (1998) estimated at 702 000.

The administrative headquarters is Kara itself. Four prefectures were chosen for the study. Bassar has 293 villages and an estimated population of 110 000. Dankpen has 328 villages, and Doufelgou has 207. Kozah has 302 villages and a population of 200 000. Villages selected for the study were typical of those within the region.

The prefecture of Doufelgou has a tight settlement pattern, and Kozah is densely populated. Bassar and Dankpen have scattered settlements. The roads serving the prefectures and villages are mostly beaten earth and are impassable during the rainy season. At other times, access is difficult because of the mountains. Many different ethnic groups are found in the Region, of which the main ones are the Kabaye in Kozah, the Nawda and Lamba in Doufelgrou, the Bassar in Bassar, and the KomKonba in Dankpen. At the village level, the decision-making process involves a chief and a council of village leaders.

Kozah has 21 dispensaries and two hospitals. Bassar has 12 dispensaries and one hospital. Dankpen has very poor health coverage with only eight dispensaries and one hospital. Doufelgou has 12 dispensaries and one hospital. Each prefecture also has a chief medical officer. At the dispensary level, there is one nurse/assistant, and this is the staff person on whom all the villages depend for coordinating onchocerciasis control activities.

The savannah form of onchocerciasis is endemic in the Kara Region. At the beginning of the OCP (1977), the rate of onchocerciasis was 75-80% in the population. Blindness rates ranged from 0.3 to 0.6%. After more than 20 years of OCP vector control, coupled with distribution of ivermectin, a reduction in Kozah, Bassar and Doufelgou of 10-15% was seen, but the prevalence is still high in Dankpen, at around 60% in certain villages.

5

PHASE I FINDINGS

A summary of Phase I findings is presented here. They focus on the experiences and concerns of the CDDs, the CBOs, the community members and leaders and the health workers. What is important to note is that, in early 1998, CDTI had not been fully implemented at any of the study sites although community-based distribution and mass distribution may have been going on for up to five or six years in some places. Therefore, the findings from Phase I were largely based on respondents' experiences with the community based version of ivermectin distribution.

5.1 Community Directed Distributor's views and experiences

Most CDDs reported that they were selected by community/village members during assembly or general meetings. Some of them noted procedures that were not in line with CDTI guidelines, including selection by the village chief/head and his cabinet, by village chief/head alone, or by health worker and village chief together.

Various problems in carrying out activities were identified. Several problems focused on the process of preparing for and implementing the distribution. Transportation was a major concern, as many complained they received no provision to cover transportation costs to collect ivermectin - some even complaining that they spent their own money to cover transportation costs, which can exceed US\$ 2.50. Occasional shortages of ivermectin were noted, and these had sometimes been a source of tension between CDDs and community members. The issue of fear of side effects and their impact on compliance concerned several CDDs. They noted that the issue is complicated by lack of drugs to give relief from side effects such as itching.

On a personal basis, CDDs often complained that, "I have no time of my own. People can come to me any time of the day". There was low morale caused by lack of incentives to compensate for time spent on distribution. CDDs also observed that people were often absent during distribution, and this required the CDD to make additional home visits.

In relation to reporting, several CDDs said they faced difficulties: "I can't always cope with it," was one view. The problems were said to be caused by the short time for training, and by community members not contributing towards buying recording supplies, e.g. notebooks and pens. Those who had few problems reported that, "We continue to practise the work", "I get assistance from my supervisor", and "There is re-training with help from more experienced workers". In relation to the census, some CDDs observed that, "It is difficult to conduct census because it is difficult to meet community members at home".

The overwhelming majority of CDDs reported that they received no assistance from the health facility. The few who reported receiving assistance said it took the form of help in mobilization of community members and making announcements about the availability of drugs, provision of health education and initial training on reporting, management of side effects, storage of drugs, and monitoring of CDD activities.

In like manner, CDDs reported overwhelmingly that other community members did not play any active role in the distribution of ivermectin. One response that summed up the common reason for low community involvement was, "Nobody assisted me. They didn't know about it (the procedures). They didn't receive any training about it". Minor roles of some individual community members included: helping to make announcements, mobilizing others to participate, fetching water for people to take the drug with, staying in the village on the day of distribution, and, when they had taken ivermectin themselves, explaining the benefits of the drug to others.

5.2 Potential partners at the community level

Several local NGOs or CBOs were identified as being capable and willing to support CDTI. These included farmers cooperatives, women's organizations, youth clubs and organizations, age grades, and community development unions. In the past, these groups had provided assistance for community health programmes including sensitization/mobilization activities, collection of ivermectin from health facilities, helping distributors on their farms, construction of distribution centres, educating the community, selection and training of distributors, and provision of funds for certain activities. These groups also noted factors that inhibited their full participation, including inadequate transportation facilities, financial constraints, poor community commitment, demand for incentives, poor community mobilization, and misconceptions about the project.

CBO representatives shared their experiences with overcoming problems in the community and offered the following lessons. It is essential to mobilize the communities adequately before embarking on any programme, including making sure that transportation is ready. One must involve community and other associations through their leaders in planning and execution of projects. It is always necessary to educate community members on the activities of the programme. One must organize meetings to reflect on community activities in the programme. Community leaders must be fully informed. There must be liaison with all sections of the town. All CBOs indicated that they were willing to assist in future CDTI efforts.

5.3 Health worker experiences and views

Ivermectin shortage was seen as "no problem" most of the time, but under certain circumstances, it occurs. Poor estimation may result from poor record keeping/updating and poor head count. No problem was reported from state level to district level, nor from district level to facility.

Delivery of ivermectin to the CDDs was seen as no problem in several places because the health staff give out stock at meetings and training sessions where CDDs assemble. When problems occurred they were usually due to transportation, either for collection of ivermectin from the state level, or for taking it to facility level. As one health worker observed, "Staff at the health facilities are not mobile. We were given a motorcycle, but it was taken over by one of the councillors". Others complained about lack of funds and other logistics.

Training of CDDs presented a few problems. Selection is an issue where staff cannot find literate candidates; even semi-literate CDDs find it difficult to cope. CDDs and health staff also face transportation problems in getting to the training venue. Finance for training materials was also thought to be inadequate. Health workers also noted "non-response" by health authorities: "We have written a proposal to train CDDs, but we have not received any response yet".

Questions were asked about supervision. Most front-line health workers were not involved in CDDor programme supervision. This was usually left to the onchocerciasis coordinator of the DHS. Those who participated said it was "During the days of mass distribution, we were given a vehicle to go around". Another complained that "Transportation is our problem - we are not mobile/motorcycle is old".

The need for supervision is recognized: "Some CBDs may not get exactly the training system, but we keep explaining to them. We have not been supervising them. The community leader must assist them in the distribution".

Management of side effects was another important task discussed by health workers. They first noted that "Some people fear the side effects, so they don't want to take the drug. They complain of itching, swelling of body, dizziness, and stomach ache". They reported on the use of analgesics and antihistamines. Sometimes health workers provided these at the village level; sometimes villagers were advised to buy their own. Usually villagers were told to come to the dispensary, but "Some people out of ignorance go to the hospital or private clinic". Some community members were said to doubt the effectiveness of treatment of side effects.

Health workers reported standard means for getting information out, e.g. through local leaders - chiefs, council members, religious leaders, through various committees and meetings, the public address system throughout the town, markets, town criers, extension workers of other agencies, schools, and when people attend health facilities. Where churches were common, health workers reported that important meetings, events and programmes are usually announced in the church. For people who don't go to church, information was passed to them by churchgoers. Home visits, attending town meetings and taking part in local festivals were other ways by which health workers in communities with health facilities can interact with the people.

In villages where there were no health facilities nearby, health workers said that information came via sick people who do reach health facilities, who bring information back to other members of their community. Immunization outreach and the radio were other means of reaching far away communities.

The major complaint of communities with no health facility was that they do not have an opportunity to discuss their health needs with health workers - communities with health facilities have better means of interaction with health workers. Irrespective of whether or not communities have health facilities, a need was seen to improve interaction through information, education and communication.

Health workers were asked about their awareness of NGOs and CBOs. There was a high level of awareness of the following groups: boy scouts, girl guides, legion, civil defense, the Red Cross, religious groups, community development associations in the various towns, market traders associations, transport workers union. Comments were made on the past contributions of these CBOs - for immunization days, campaigns, and environmental sanitation exercises, they provided mobilization, health education, and logistic support. Health workers saw the future roles of CBOs in CDTI as basically more of the same. Additional ideas included help in recording. There was a little skepticism about CBO contributions: "They won't help for free," and "They won't keep promises".

Health staff also responded to the structured opinion survey found in Appendix C. More details on the attitude scales are provided in the Phase 2 results section, but, in basic terms, it was found that at baseline, health staff felt that they could cope with the workload of CDTI. They were only slightly positive about the community having roles in CDTI, and they believed strongly that health workers should have a leading role in running CDTI.

5.4 Community experiences with ivermectin and health workers

A major issue raised in interviews and FGDs with community members was that of ownership of the programme. The majority of respondents reported that CDTI belongs to the community. On why they thought that the programme belongs to the community, they gave responses such as: "We are the beneficiaries", "We plan the distribution", "We do the distribution", "We select the distributor", "The distributor is ours", and "Because we are told so!".

Those who thought that the programme does not belong to the community stated that it belongs to the government or the ministry of health. "It is the government that brought this programme to us but we have been told that in the near future, it will be our own." Some of these people believed that ownership would eventually be transferred to them.

Most community members saw their role in CDTI as a passive one. Perceived roles are classified as passive or active. These roles included - accepted to swallow ivermectin, allowed everybody to swallow, attendance at health education meetings, and passing on information about distribution.

Active roles were mentioned by a few and focussed primarily on the day of distribution. These included: providing a house as venue; measuring height; giving drugs to people; keeping records; organizing people for distribution; providing clean water for taking ivermectin; providing chairs for people to sit on; and ensuring compliance by informing friends, neighbours and youths about distribution.

The perceived roles of the health worker are captured in the following statement: "Delivery has been regular for the past three years. The health workers spend about one hour to discuss health issues but they rarely talk about onchocerciasis". This statement indicates that health workers have been involved in drug delivery (not necessarily ivermectin) as well as in advising communities on health needs. Other perceived roles of the health worker include collection of reports, management of side effects and supervision of distributors.

Community members identified some problems with the programme to date. These include: non-involvement of certain segments of the population (especially men) in the programme. On the subject of absenteeism, one women said "Our men are sometimes not present when distribution takes place". Others observed poor compliance, including both low turnout and refusal to take the drug. Others noted that there was lack of awareness of the importance of the drug. This problem is compounded by wrong messages which are sometimes passed to community members. For instance, in one of the sites, members complained that, "At first, pregnant women were not allowed to take ivermectin; now the message has changed". In some localities, a fee was levied to help defray costs incurred by the CDD. This discouraged some people who explained that "When you do not have (the amount for the levy), you do not get the drug". Finally, migration in some areas made the population unstable.

Community members also pointed out organizational problems. They complained that there were not enough CDDs. It was said that there are no incentives (money, lunch, raincoats etc) for the distributors. Hence, they were not motivated. The drug itself presented a few problems also. There was the fear of side effects - swelling, itching and death - in some communities: "Initially people got worried about the side effects and discouraged their friends from taking the drug". Occasional shortages were noted, and villagers complained that there was no provision for drugs to treat the minor side effects. The problem of contraindications or

eligibility criteria was noted in that people who were not eligible at the beginning of the distribution may have been forgotten if they eventually became eligible. Finally, community members observed that lack of mobility for the health staff was a problem. Lack of transport, especially for the distributors and supervisor was a common occurrence. Some of the roads were bad, thus making it difficult to move from one place to another.

Community suggestions to address these problems included more health education to be provided by health staff, which implies greater contact between health workers in the communities. Many suggested incentives for the CDDs. They thought that villagers who had successfully taken ivermectin and tolerated the side effects should educate others in the community on compliance. Villagers requested that drugs be made available in the community to treat side effects since health facilities are often quite distant, and they made a plea that ivermectin always be made available on a regular, adequate and timely basis.

5.5 Feedback for enhanced districts

The above findings pointed to a need to improve communications between health workers and community members. Using these findings, the researchers developed a set of basic messages about health worker and community experiences, and roles in CDTI were developed and subsequently shared at meetings with health workers and community members in the enhanced districts. Formal meetings were held with the health staff as an initial step in Phase 2, as seen in the next section. More specifically, the findings led to the development of stakeholders meetings in the enhanced study districts, and the following messages, plus site-specific detailed findings, were among the first items on the agenda:

- Health workers have a lot of work and responsibilities, and have trouble obtaining transport for CDTI activities, so communities have to be self-reliant.
- Communities can direct CDTI.
- Communities would like to have more interaction with health workers.
- Record keeping can be a burden on distributors - it has to be kept simple.
- Potential partners exist and are willing to participate.
- Remuneration of CDD's is an issue: People doing the distribution have been discouraged because of lack of transport to get the drug, the fact that they can be disturbed at any time, and don't feel adequately compensated or encouraged. CDD's would like more recognition.
- Side-effects are to be expected.

6

INTERVENTION PROCESS

There were eleven basic steps in the intervention process that included steps necessary to establish CDTI as well as to implement the enhanced intervention. Most steps were repeated twice since it was planned to hold two ivermectin distributions within the study period. The need for two distributions was justified because, at most sites, actual CDTI had not been undertaken by the local DHS. Therefore, it was felt that one distribution would not provide adequate time and experience for determining possible factors that could promote sustainability. Also, with the SHM intervention, it was envisioned that the value of this intervention would become more pronounced by the second meeting where community representatives and health staff would have actual experience to discuss and problems to solve. The 10 steps are outlined below:

- Defining the study area and population.
- Collaborating with DHS staff/building capacity/giving feedback.
- Village Meetings as part of the introduction of standard CDTI.
- Obtaining and managing ivermectin following normal channels: NOCP to district.
- Stakeholders meetings: feedback, planning, enhancing communication.
- Preparation: training CDDs, census.
- The distribution process in the villages.
- Management of side-effects: simple at the village, severe on referral.
- Recording, reporting and coverage calculation.
- Feedback and DHS, capacity building.

Table 1 summarizes three of the main steps, SHMs, CDD training, and distribution for both rounds. This is done in order to document that intervention took place and ensure that Type III errors are not committed when interpreting the data. Five sites were able to complete all activities in two rounds of ivermectin distribution as required for the project. Togo completed only one round. Togo followed the protocol for their one distribution. They used CDDs who had been trained previously under their onchocerciasis control programme.

Table 1: Summary of Major Activities in Phase 2

ACTIVITY	SITE AND DATE					
	Awka	Enugu	Ghana	Ibadan	Mali	Togo
1st SHM	1/99	8/98	11-12/98	11/98-2/99	11/98	9/99
1st CDD Training	3/99	8/98	11-12/98	3/99	11/98	1997
1st Distribution	5-6/99	11-12/98	5/99	3-4/99	12/98-1/99	10/99
2nd SHM	10-11/99	8/99	10-11/99	8/99	6/99	x
2nd CDD Training	11/99	9-11/99	10-11/99	8-9/99	5-6/99	x
2nd Distribution	12/99	9-12/99	11-12/99	9-10/99	6-7/99	x

7

PHASE 2: RESULTS

7.1 Coverage

A standard household coverage survey was used to determine the impact of the interventions. A minimum of four villages in each district were randomly sampled. Within each village, a 10% sample of households was chosen for interview. All residents of the household were enumerated, and information was sought on each person including age, sex, whether they took the tablets, how many tablets were received, side effects experienced, and reasons for not taking the drug as appropriate.

Coverage was calculated in two ways. The standard APOC coverage rate, consisting of total number treated divided by the total population, was used. The second rate involved dividing the number treated by those who were eligible for treatment, i.e. those who were at least five years of age, not pregnant, not nursing an infant less than eight days old, and not having a serious illness. A combination of questions on age and reasons for not taking the drug were used to determine this denominator.

A total of 23 842 people were accounted for in the survey at the six sites that followed the protocol, of whom 20 832 (87.4%) were eligible to receive ivermectin at the time the drug was distributed. Figure 3 shows the overall population-based coverage by study arm. The enhanced group achieved 72.7% coverage of 11 878 people, while the regular districts reached 76.1% coverage or 11 028 (Odds Ratio [OR] = 0.84; 95% confidence interval [CI]: 0.19 - 0.89). The difference was significant. The difference between study arms was similar when the eligible population was used as denominator (Figure 3). In the enhanced study districts, 83.6% coverage among 10 176 people was achieved, while 85.0% of 9808 was the coverage rate for regular districts (OR = 0.90; 95% CI: 0.84 - 0.98).

Coverage using the village as the unit of analysis yielded similar results. Data for village level population-based coverage were available from five sites, and coverage was calculated for 130 enhanced and 140 regular villages. The mean coverage for enhanced study villages was 69.4% (s.d. = 14.9) and that for regular was 71.5% (s.d. = 14.6). The difference was not significant (t = 1.22, p = 0.22), as seen in Figure 3.

The same trend for population-based coverage rates was seen across all sites (Figure 4), at Awka, Ghana and Mali, the higher coverage among regular communities was significant. Using eligibility to deter-

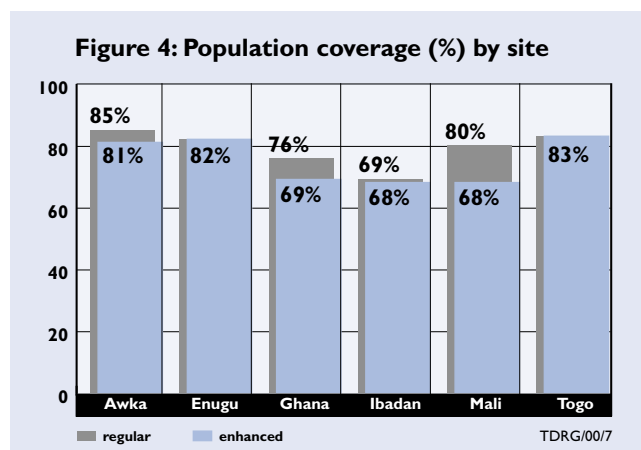
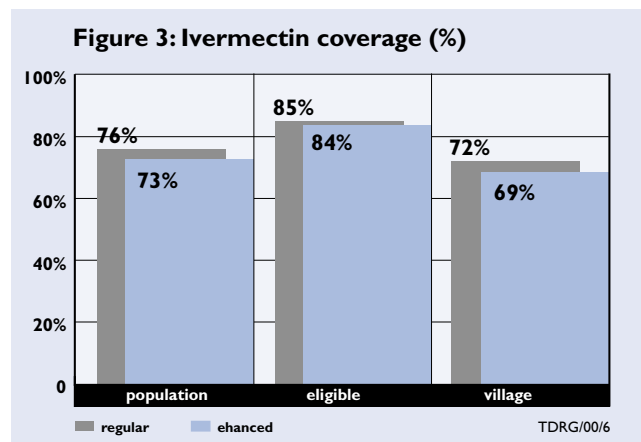
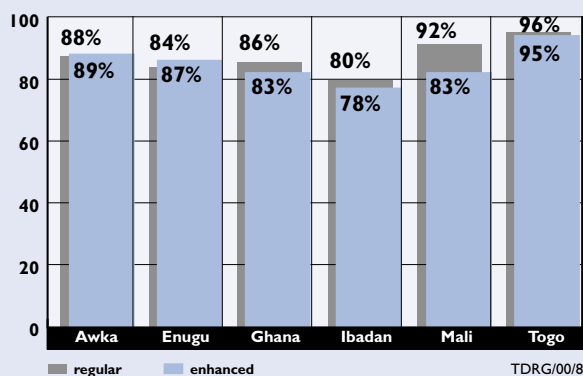


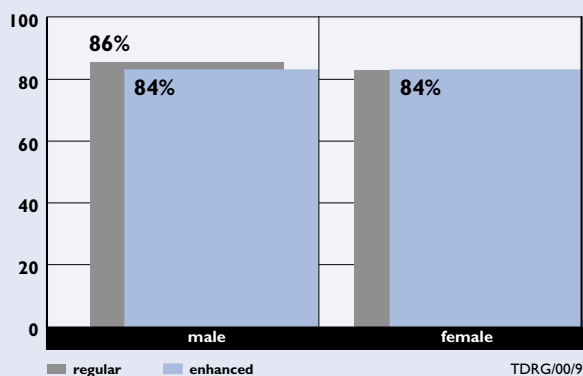
Figure 5: Eligibility based coverage (%) by site



mine the denominator resulted in mixed results across sites, but the case where the regular arm achieved significantly higher coverage occurred only in Mali (Figure 5).

Analysis for age and sex was calculated only among eligible persons since this would automatically exclude children under 5 years and pregnant women. The 17 440 people who received tablets were 29.0 years of age on average (s.d. = 19.29). Those 3181 who did not get tablets averaged 25.7 years (s.d. = 18.54), and were found to be significantly younger. Both student's t test (8.929) and the non-parametric H test (95.481) were significant, but the latter was recommended because of significant differences in the variance of the two groups. Male and female coverage was nearly equal overall, and no significant differences were observed by study arm (Figure 6).

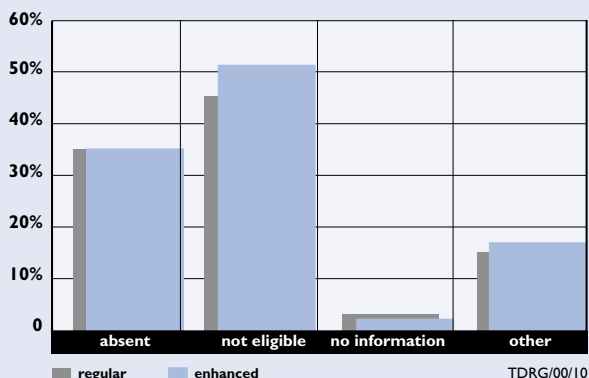
Figure 6: Comparison of coverage (%) by sex



It was intended that the survey make note of whether each household member was present during the interview, or absent, in which case another household member could provide information on his/her behalf. The need to add this information to the household coverage survey form did not reach two sites. Although a significantly smaller proportion of those absent (61% of 4575) than those who were present (75% of 11 534) (OR = 1.95; 95% CI: 1.81 - 2.10) were reported to have received ivermectin, the same pattern between enhanced and regular arms was seen within both the present and absent groups.

Coverage was 74% among the 5786 persons present in the enhanced arm compared to 76% among those 5748 in the regular arm (OR = 0.91; 95% CI: 0.83 - 0.99). Also, among those absent, 57% of 2483 in the enhanced arm were reported to have taken the drug compared to 65% of 2091 people in the regular arm (OR = 0.72; 95% CI: 0.64 - 0.81). Since the pattern was the same at the sites where there was information on presence at the time of the interview, as in the overall data, the combined data set was used.

Figure 7: Reasons for not receiving tablets



Further analysis looked at the reasons given by people who did not receive ivermectin. Among the 3358 in the enhanced study arm, the main reasons were not eligible (50.3%), i.e. pregnant, under age or sick, absent at time of distribution (30.9%), not informed (2.5%) and other reasons (16.3%) including refusals, too short even though of correct age, and tablet shortage. Among the 2713 in the regular study arm who did not receive tablets, significantly more (33.5%) were absent or had not been informed (5.5%), while significantly fewer (45.9%) did not take it due to ineligibility. A similar proportion gave other reasons (Figure 7.)

It was possible to compare the results obtained in this study with those of the first multi-country study where the CDTI strategy was first developed. In that first study, the 153 CDTI villages achieved a significantly higher mean coverage of 68.6% compared to 62.2% where programme staff designed the intervention. In the present study, it was possible to obtain village level coverage based on population surveys from 264 villages in five study sites. The mean coverage was 70.3%, which was not significantly different from the achievements of previous CDTI efforts, but as before, was higher than the programme-directed approach (see Table 2).

Table 2: Comparison of village level coverage between two TDR CDTI studies

Statistics	STUDY 1 -1995		STUDY 2-1999
	A-ComDT Arm	B-Programme directed Arm	C-all ComDT Arms
Number of villages	153	119	270
Mean coverage	68.6	62.2	70.5
Standard error	10	1.9	0.88
Comparisons	Mean difference	t value	p value
A vs B	6.4	3.281	0.0012
A vs C	1.9	1.364	0.17
C vs B	8.3	4.532	0.0001

In conclusion, high treatment coverage was achieved in all sites: 69%-84% of total population and 79%-95% of eligibles. No difference was found between enhanced and regular CDTI intervention groups, and no difference by age and sex. It would appear that the CDTI strategy itself is still able to produce high coverage results at this point in time. On the other hand, since the main reason for not taking tablets was ineligibility, the lower coverage in the enhanced arm may be an artifact of the composition of the respondents of the survey. What is more interesting is that people in the regular arm gave the reasons of being absent and not being informed, implying less communication about the programme in the regular arm. The question still exists concerning what is needed to sustain these results. It is therefore the role of the other data collected in this study to determine what may be appropriate indicators for sustainability and whether the process of enhancement of CDTI through SHMs had any influence on these indicators.

7.2 Community level indicators of sustainability

7.2.1 Community participation and decision making

In both study arms the responses concerning community participation by community members (FGDs, village leaders) and others (health workers, CDDs) were quite positive. Various community roles in CDTI were identified, including selecting CDDs, rendering help to the CDD, procuring ivermectin, sensitizing and mobilizing the community, and following up on absentees. Examples of positive comments concerning community participation and commitment to CDTI in the enhanced study arm follow:

- "The community tried a lot. They selected us as their CDDs without any problem. They sponsored us to the meetings and trained us and they bought piriton and paracetamol for the treatment of the side effects" (CDD, Ibadan).
- "We [villagers] contributed money to buy biros, a notebook, drugs for side effects and a drug box" (FGD, Ibadan).
- "Le jour de distribution, nous balayons la cour, puisons de l'eau. Les chefs de ménage se cotisent (100 CFA par ménage) pour les ATC [CDD]. Les femmes s'organisent pour leur faire à manger. Il arrive que, après les dépenses faites pour le repas des ATC, il reste de l'argent que nous leur remettons" (FGD, Togo).
- "Our community has paid all the CDDs except in one ward. However they will pay her in due course. The community was also responsible for mobilizing the villagers through the use of town crier and announcements in churches" (FGD, Akwa).
- "The community showed interest in the programme because they provide transport means for me whenever I am going to the meeting, and they used to help me on the farm" (CDD, Ibadan).
- "We bought things like notebooks, pens and a drug box. The village was to mobilize the people during the census and the drug distribution. They were told to determine the method of distribution to be adopted as well as the compensation to be given to the CDDs" (FGD, Enugu).
- "L'avis que nous avons, si nous voulons que le traitement se fasse bien ici, si vous vous aidez nos distributeurs, cela nous fera plaisir!" (FGD, Mali).

Many respondents in the regular study arm were equally positive as seen below:

- "We came out to do the census. We count ourselves house to house" (FGD, Ibadan).
- "The community only supported the CDDs during the actual distribution period by helping to mobilize the people as well as making sure that nobody molested them while carrying out their duties" (FGD, Awka).
- "Those that wanted to reject the drug, we called them and we explained the importance of the programme and the drug to them" (FGD, Ibadan).
- "The village bought paracetamol and Piriton, census materials, drug container and they fetched water when we were using the drug" (FGD, Ibadan).
- "La communauté est participative dans la diffusion de l'information. Par exemple, après la messe, les fidèles des Eglises Chrétiennes partagent l'information entre eux" (FGD, Togo).
- "There is no doubt that our people are committed to this programme because we always hold meetings to take decisions on how to succeed in the programme for the benefit of our people. We selected the CDDs and provided them with working materials. We supported the CDDs during distribution by employing the services of the town crier to make announcements about the distribution throughout the period of the distribution" (FGD, Awka).
- "The household heads assist in the sense that they ensure that members of their households who are unwilling to take the drugs do take the drugs" (village leader, Ghana).
- "In this place, we use the town crier to announce the arrival of any good thing in the community. The community members are very good at information dissemination" (FGD, Enugu).

Closer reading of the positive comments revealed that a fair number of respondents used phrases like "we should ..." "we are supposed to ..." and "we are expected to ..." This implied that they were aware of a community role in CDTI, but that their community had not fulfilled it completely. Such comments, as seen below, were much more common in the regular study arm than in the enhanced.

- "I can't say precisely, but the villagers should be ready to assisting and support the CDDs and health worker. They (CDDs) should be encouraged".
- "We are supposed to be having meeting regularly."
- "The villagers supposed to be buying paracetamol that would be used for side effects through contribution."
- "Our community is expected to support the programme by selecting our CDDs, mobilizing the people for the programme, buying materials and paying incentives to the CDDs."

In addition, while people in both arms talked about villagers having a role in mobilizing each other on the day of distribution, this role was often the only one mentioned during FGDs in regular groups. Furthermore, while people in both arms talked about the passive role of simply showing up to take the ivermectin, this comment featured in the regular arm interviews.

Negative comments about community roles and participation were made in both arms, but these were twice as common in the regular arm. Examples of comments showing lack of involvement and complaints by CDDs follow:

- "They (community members) have only been promising but they haven't done anything" (CDD, enhanced study, Ibadan).
- "There was no meaningful role played by the community in planning the time of distribution" (FGD, enhanced study, Ghana).
- "We are not aware of community involvement in supporting the CDD during collection of ivermectin but believes that it is about time they did something about supporting the distributor when the time comes for him to do the next collection" (FGD, enhanced study, Ghana).
- "The villagers need to be told what they are to do in this programme. They believed that everything is free" (CDD, regular study, Ibadan).
- "The programme is a community programme. Because the health workers usually come and visit the villagers, but not a single person did anything" (CDD, regular study, Ibadan).
- "Nous ne leur donnons rien. Ils font ce travail de plein gré et ne sont pas inquiets" (FGD, regular study, Togo).
- "Nous ne recevons aucune assistance de la communauté puisque nous visitons chaque ménage pour donner les comprimés" (CDD, regular study, Togo).
- "They have not been of any help. I do it alone" (CDD, regular study, Enugu).
- "The community at large does nothing specific to assist in drug distribution" (CDD, regular study, Ghana).
- "Non cela n'a pas été ma décision, mais nous avons aimé cela et c'est un honneur pour nous, n'est pas? c'est un honneur pour nous! depuis que nous avons commencé à prendre ce médicament beaucoup de maladie ont disparu, c'est un bon médicament" (FGD, Regular, Mali).

7.2.2 Community management of logistics

Concerning procurement of the ivermectin, few problems were reported in either arm. Most villages aided CDDs with transport (e.g. lending him a bicycle) or money for transport to the nearest health centre. In some cases ivermectin was made available at the training/re-training of CDDs so that they would not have an additional visit to the health centre. Even then, villagers provided transport support to their CDDs to attend the training.

CDDs were the primary persons to collect the drugs in most villages, although an occasional village leader or CBO also helped. Where support was not provided, the CDDs exhibited patience or simply endured. They then either trekked, used their own money for transport or used their own bike. It should be noted that distance to facility/collection point influenced whether the village provided transport support. Also, rural transportation is not regular, which necessitated trekking in those cases.

Most of the problems associated with procurement were not a function of enhancement or no enhancement. Weather, poor roads, extra people turning up in the village at the last minute to request ivermectin were factors that could not be influenced by enhanced interventions.

Storage problems at the village level were not reported. Many communities already had drug boxes in the village. Some constructed their own boxes. Others had a box from other programmes such as PHC and guinea worm eradication. A few said storage was not a problem because they arranged distribution as soon as the drug arrived.

7.2.3 Community response to, and management of, side effects

The system adopted to manage side effects at each site was dependent on ivermectin distribution history. For example, in Togo there was a 4-5-year history of ivermectin distribution. This meant that there were few side effects after each distribution. Community support was low for side effects management across all sites except Ibadan.

At Ibadan, CDTI was new. Therefore, all CDDs were trained to manage minor side effects and villages were encouraged to buy paracetamol and chlorpheniramine: 82% of villages (equal in both study arms) bought side effect drugs for CDDs to use, and 42% of villagers who had minor side effects went to the CDD for help. At Enugu, some differences were observed according to arm of the study: health workers treated side effects in the enhanced arm, while villagers were left to manage their own side effects in the regular arm.

During FGDs, respondents made note of many common minor side effects emanating from the ivermectin, including swelling, itching, hunger, insomnia and headache. There were various responses of community members to the side effects. Some people simply bore the swelling or itching until it went away. Some said they intentionally did not seek treatment for these side effects because they wanted the ivermectin to "work properly". Some did nothing because they said there was no provision made to help people with side effects. In many villages people had contributed money to obtain paracetamol and antihistamines, which were kept in a village drug box. When they had side effects, they used drugs out of this box. In other settings, people went to a nearby health facility or a chemist to seek treatment. In a few cases, people who experienced side effects promised never to use ivermectin again. Finally, in some villages it was observed that, by the second round of treatment, there were fewer or no side effects.

In most villages in both arms of the study, people either accepted the occurrence of the side effects as a normal part of ivermectin administration or sought treatment for the side effects.

Most of those who sought treatment expressed satisfaction with the arrangements that were made for managing minor side effects, either through the CDD using a village drug box or through a local government health facility.

There were some complaints, and these were twice as common in the regular arm of the study at Ibadan, but about equal in both study arms at other sites. For example, community members in the regular arm complained that:

- "The selection of CDD and training of CDD were good enough but they were not told what to do for side effects or the CDD was not informed on what to do" (Ibadan).
- "The villagers are not helping in the treatment of side effect" (Enugu).
- "We didn't plan for it because our CDD didn't tell us that we should buy the paracetamol. Until when people started to complain about side effects that he told us that we should go and buy paracetamol and piriton to use. Then we gave him money to go and get it for us. We didn't plan for any side effects" (Ibadan).
- "The WHO should have provided the side-effect drugs" (Awka).
- "[Because of the side effects] there are people who, in spite of our efforts, still do not accept the treatment. What can I do!" (Ghana).
- "They [the health workers] are supposed to be providing us the drug when due because we don't know when to use it" (Ibadan).
- "The community members did nothing to help any one that reacted to this drug" (Enugu).
- "We have no medicine to give to those who have side effects" (Ghana).
- "The health workers should have provided the drug for the side effects" (Awka).

Examples of complaints in the enhanced study arm included:

- "Our CDD bought it [the drugs for side effects], we didn't contribute money" (Ibadan).
- "Provide free drugs that people will take to prevent side effects" (Enugu).
- "We have even decided not to use it [ivermectin] any more [because of side effects]" (Ibadan).
- "People refuse to take the drug because of the side effects and the cost involved in treating the side effects" (Ghana).
- "We didn't buy the drug for side effects because we forgot the name of those drugs" (Ibadan).
- "Some people are afraid to take ivermectin because of side effects" (Enugu).
- "When people develop side effects, they became angry with the distributor. A distributor was beaten" (Ghana).

7.2.4 Perceptions on interaction with health workers

Interaction between the health workers and communities was reported to be cordial in most sites in the enhanced arm of the study. Evidence of this was provided in the SHMs which brought together CDDs, health workers, village leaders and CBOs. During SHM follow-up, interview respondents described the atmosphere at the SHMs variously as open, free and cordial.

Some feedback on the performance of the health workers was received during the second SHMs and was reflected in the minutes. At one meeting, a village representative noted that "It was not until the health workers came to their village that some people started coming to take their own ivermectin". Representatives from several villages said that they really appreciated the efforts of the health workers. At another meeting, villagers explained that they were pleased with what the health workers were doing for them - "They are checking on us regularly and ask for our health". In another SHM set of minutes it was stated that a CDD commended the efforts of the health workers, "They have performed wonderfully. They usually address our village problems whenever they come".

Many SHM participants commended the efforts of the health workers for making regular visits, guiding them on the census and so on. One woman observed that the interest of the villagers had risen after the last village meeting health workers had had with them. Those with health facilities in their clusters expressed satisfaction with their access to the facility to collect drugs. Examples of comments in the follow-up interviews are below:

- "The relations before was not all that cordial because we go to them, but now they come to us."
- "We have never had any such interaction before, although they use to come here. We have never sat face to face and discussed on important issues like that."
- "Such a meeting that involves both the villagers and the LGA health workers has never happened before. That was the first one. The interaction was fine and can establish an endless friendship between us."
- "People now have confidence in health workers. Formerly many didn't believe in them because we thought health workers used tricks to get information from us without any useful result."

Interaction between health workers and communities was better at most of the enhanced study sites than at the regular arm sites. FGDs and in-depth interviews also offered an opportunity for community members to provide feedback on health workers. Comments such as the following were common from both arms of the study:

- "I think it is more good now than before because I can see health workers at least once in every month; they don't come regularly like that before."
- "Before there was a wider gap in the communication between the health workers and the villagers."
- "I was able to know that I can go directly to [the Onchocerciasis Coordinator] to ask for the drug any time. We all discuss freely at the meeting, there was no head or tail [leader or follower]."
- "People now have confidence in health workers. Formerly many didn't believe in them because we thought health workers used trick to get information from us without any useful result."
- "I don't think that there was a good relationship between the villagers and the health workers before the meeting, but immediately after the meeting there is a positive reaction."

Some skepticism persisted with negative comments coming primarily from the regular arm of the study:

- "Health workers only came for immunization."
- "There was no interaction. We never see them."

- "Health workers unlikely to come after research team concludes work."
- "We rely on you [researchers]. We don't see the effect of the HWs [health workers]."
- "We don't see them any more."
- "We didn't see HWs from the LGA. It was you [the researchers] that usually came and took care of us."
- "We don't see their effort except your own [researchers'] effort on us."

7.2.5 Satisfaction and willingness to continue community-directed treatment with ivermectin

A basic assumption was that if people are satisfied with ivermectin and the organization of the programme, they will want to sustain it. At all sites and in both study arms comments made by community members show considerable satisfaction with the drug. For example:

- "We like the tablets and we are happy the tablets are sent to us. We hope that the distribution will continue for many more years because a lot of us are now healthier and we are able to work better" (Ghana, village leader).
- "Initially they do not come for the drug but when they noticed efficacy of the drug on others they all come" (Enugu, village leader).
- "Definitely yes. The drug helped improve the sights condition of a lot of people, it took care of the skin problem of many of people, as well as helped others to pass out worms. The nodule on a lot of people had been dissolved" (FGD, Awka).

So satisfied are the communities that they would recommend that the drug be distributed several times in a year and it should be distributed more regularly. Awka and the enhanced Ghanaian site suggest twice, while the regular Ghanaian site would not mind having the drug distributed six times a year.

Community members recommend the drug for a number of reasons including its perceived ability to cure or ameliorate onchocerciasis-related problems as well as other health issues not usually connected with onchocerciasis such as guinea worm (Ibadan), joint pains (Awka), poor appetite (Ghana). Those in the enhanced arm at Ibadan mentioned these other benefits more often than did respondents in the regular arm, for example, "It was good for farmers. Eye dizziness has reduced".

Dissatisfaction was rare and not associated with study arm. It was centred mainly on side effects at sites where these were common. For example in Ghana, "A woman who fell sick after taking the drug went round saying that it was the drug which caused her sickness." In contrast, some villagers at the Ibadan site refused to buy drugs for treating minor side effects. "We did not buy paracetamol because people said that if they used panadol it will lessen the work of the onchocerciasis drug." Such people willingly endured the side effects. Another element of dissatisfaction that occurred, but very seldom, was inadequate or untimely supply of the drug. For example, in Mali it was noted that, "Quelques plaintes pour des cas de rupture d'ivermectine ou pour des cas de visites fréquentes sans avoir l'ivermectine."

Overall satisfaction with CDTI as a programme was high in both arms. The fact that the drug is given free, the concept of community ownership of the programme, and the supervisory role of the health workers, were factors that people mentioned as reasons for their satisfaction. Comments at SHMs testify to this as exemplified by this statement from the Ibadan site: "It is very convenient for us to treat in the village because we farmers cannot be able to come to town for the drug".

Another key sustainability indicator at the community level was expressed interest by the communities' willingness to continue their own responsibilities in CDTI. Focus group respondents commented on their community's willingness to continue CDTI. Below are several comments across study sites and both study arms that indicate a positive attitude toward continuing the programme:

- "We are ready and very willing to continue taking this drug; this we will do through mobilizing our community members" (Enugu).
- "Yes, because we benefit a lot from the programme. We always play our own part as has been spelt out in the programme. The drug is good for us. Please let there be a continuation of last year" (Awka).
- "This community members are very much willing to continue taking the drug, the quantity of drug distributed by the CDD attests to this" (Enugu).
- "We were told that taking this drug should be for at least ten years. We are willing to continue to take if the drugs are supplied" (Enugu).
- "You will agree with us that we have done all that is required of us in this programme and we are willing to continue doing so as long as this programme continues" (Awka).
- "We are capable to continue using the drug because we benefitted from the programme and we want it on a regular basis. Many people used it" (Ibadan).

Women in particular showed interest in making things better for future distributions:

- "We will persuade those who failed to take the drug because we consider ivermectin a blessing" (Ghana).
- "I will ensure that the village selects a women CDD next time" (woman leader in Ghana).
- "We are capable to continue with the programme. We women will hold a separate meeting. Whenever you come you are going to meet us" (Ibadan).

In addition to finding out whether communities were willing, questions were also asked about perceptions of community capability. In all FGDs, respondents expressed feelings that their village was capable of continuing the programme in both arms. But in Ibadan, when asked specifically whether the village had held a meeting to plan for the future, half of those interviewed in the enhanced group said they had already held a meeting, while two-thirds of the responses in the regular group interviews said no meeting had been held.

In conclusion, communities are generally enthusiastic about the standard CDTI programme and are satisfied with the results. Reports of participation in the enhanced communities are stated more positively, while conditional responses are more common in the regular arm. More complaints about non-participation were leveled by CDDs in the regular arm. Enhanced communities have more positive comments to make about their interactions with health workers and may also be more likely to have started planning to continue efforts since the last distribution.

7.3 Sustainability From The Community-directed Distributors' Perspective

Annual distribution of the drug ivermectin (Mectizan®) is based on the concept of village volunteers supported by co-villagers. The villagers select their own CDD, who is then trained by the health services in the following: the disease onchocerciasis, the drug ivermectin, how

to mobilize villagers, how to calculate dosage using a simple stick to measure height, how to recognize and manage simple side effects, and how to record and report. Community members are expected to support their CDD so that he/she can attend training, go to the nearest health facility to collect the drug and submit records, and spend the day(s) needed to make sure every eligible person in the village receives the drug.

Several main issues were explored with the CDDs. One concerned their ability to keep records and make reports. Another concern was their willingness to continue the volunteer work. Their perceptions of their status within the village were also examined, while another concern was the role of support or incentives in motivating the CDD and sustaining his/her interest. A brief outline of the issues follows.

7.3.1 Recording and reporting

In most cases, CDDs said they had no problems with recording information. A few recording problems were reported in the regular study arm. In Togo there were problems said to be related to low levels of literacy and perceived inadequacy of training.

In contrast to the generally positive perspective of the CDDs, comparisons between reported and surveyed coverage indicate that problems exist. These possibly arose from census mistakes. Census problems that could result in over and underestimates of coverage included: difficulty in updating village registers with newborns, counting relatives living elsewhere, taboos about counting small children, and "invisibility" of ethnic minorities. Overestimates of census lead to high levels of 3mg tablet wastage.

Most CDDs said they had no problem in submitting their reports. The problems of distance/travel were similar to that expressed during procurement. At some sites, CDDs were reluctant to submit reports unless given an allowance. The problem of frequent visits to facility without finding a health worker was observed by some CDDs. This was linked to an LGA staff strike in Ibadan, Oyo State, which was beyond the scope of the intervention/enhancement.

7.3.2 Evidence of support provided to the community-directed distributor

In addition to personal willingness to continue the programme, another aspect of sustainability that could influence continuation of the work by CDDs would be the level of support CDDs receive from the community to carry out their work.

Generally support took several forms: providing transport money and feeding allowances, helping CDDs with their regular work and, in some cases (e.g. Enugu), giving cash, which may have been mandated by some CDDs. Some CDDs in Enugu's regular study arm stopped because of lack of payment of "incentives".

In Ibadan, in the more enhanced study villages, the community provided some form of support to the CDD and helped the CDD with his/her regular work.

While only one CDD in the enhanced arm in Togo complained that "I have never received any assistance at all because they think I am being remunerated", several in the regular arm raised concerns about lack of support:

- "The chiefs don't give us anything. I have complained to the nurse."
- "Certain ones believe I am being paid by the government. I told them that this is volunteer work, and I do it freely."
- "We are working without motivation. We made this known to the nurse who responded that we are working for our community."

As to support received during distribution - CDTI is not a one-person affair - all members of the village have potential roles including the following that were reported in interviews:

- "Villagers collected water."
- "Some helped hold the measuring stick. Others helped do recording."
- "In many villages they mobilized each other to attend."

Many villagers still believe, "Ours is only to cooperate and swallow the tablets".

Some CDDs contrasted their own experience under CDTI with that of their own or other peoples' service under other community-based programmes. It was noted in Nigeria that the guinea worm programme provided some of their village-based workers with bicycles, drug kits and T-shirts. Some CDDs were philosophical about this and said that they would continue their service in CDTI because maybe in the future they would benefit from such incentives. Others were not happy with the contrast.

CDD Support must be viewed in a cultural context - not all communities gave material support, and not all CDDs expected it. The idea of community service and volunteerism exists in many villages and cultures. In some communities, everyone is expected to contribute to community welfare and CDTI is an opportunity for the CDD to make his/her contribution. Poverty is a factor that may inhibit cash contributions. Other donor programmes set "bad" precedent by giving cash and materials to their village-based workers.

There were some ambiguities in the regular study arm. Women, especially in regular arm interviews, were more likely to say "don't know" what was done or "only the men know." Respondents in the regular arm were more likely to state support in terms of what they were "supposed" to do, not what they did.

7.3.3 Respect, knowledge and willingness of the community-directed distributor to continue the work

In Ibadan, Nigeria, 32 of 33 CDDs interviewed from both study arms said they wished to continue as seen from the following comments:

- "I am ready to continue with the work because it is for the glory and benefit of my village."
- "I am willing to continue serving as a CDD because those who are free from oncho shall be praying for me."
- "People recognize me as their doctor. I too was suffering from onchocerciasis before, but now, I am feeling fine".

Status enhancement or high self-esteem was a non-monetary incentive to continue. CDDs were asked whether they perceived that their status in the village had changed since the programme started. Responses included higher levels of recognition and appreciation. CDDs reported that people prayed for them and called them the village doctor.

At Awka, Nigeria, 17 of 19 CDDs in the enhanced study wanted to continue, while 8 of 13 CDDs in the regular study wanted to continue. In both Awka and Ibadan, 53% CDDs in the enhanced study reported that their status had been raised, but only 26% of CDDs said so in regular arm.

In Ghana, CDDs from the enhanced study arm reported positive feelings about their status:

- "You can ask anyone in town. People see me as one who is helping the village. When individuals have a personal problem, I am invited to come and assist in solving the problem."

- "The chief respects me more now than before."
- "I am being perceived as a community health worker because of my concern and involvement in health issues. This has enhanced my status. I am consulted over matters in the village."
- The community respects me more. They appreciate what I am doing."
- "The chief and elders listen to me and support me in my work. I have been treated as one of the elders to be consulted and brought into discussions concerning the development of the town."

While a few of the regular arm CDDs from Ghana saw a change, for example, "My work as a committee member and CDD has ensured me some respect", most did not observe any change in status.

Most CDDs from the enhanced study arm in Togo talked about examples of the respect and recognition they received. People were observing the CDD in one village, "But when they realized that I had done a good job, everyone in the community started to respect me". Other comments included:

- "All members of the community thanked me, believed in me and encouraged me."
- "I will always be a teacher in their eyes."

One noted that respect was possibly coupled with uncertainty: "I was given consideration. The people respected me, but some feared that if they did not show respect, they would not be given the drug the next time."

Togolese CDDs in the regular study arm also saw evidence of community respect:

- "I know people are happy with me because the majority of families came for the medicine."
- "They respected me before, but now I receive much more consideration from the people because I work for them."
- "Some have bought me drinks and others gave me food; [one community leader] loaned me a bicycle."
- "I receive thanks from the community. People appreciate my work and say that without me, they would never have received the medicine in this village."

An equal number expressed doubts:

- "We are working without motivation."
- "Certain people in the village mistrusted me and went to tell the nurse that I was selling the drugs."

After listing support received from some quarters, one CDD complained that:

- "Nevertheless, certain ones of them believe that I am paid for this work by the programme, and expect that the programme will give all the support needed. I don't understand why the chiefs of this village don't give us anything."

Overall, it was thought that greater interaction with health workers provided through the enhanced intervention could be one factor that contributed to improved perceptions of status by CDDs. Also, one can say that an enhanced sense of respect is an important non-monetary incentive for CDDs to continue their work.

Another non-monetary incentive is the self-actualizing experience of gaining and using new knowledge. As noted by several CDDs:

- "I have learnt a lot. Initially, I didn't know what they called Piriton before, but since I have started the programme, I even know more than I expected. I know how to treat minor problems like itching, fever and body swelling with the help of Piriton and paracetamol."
- "I am willing to continue as a CDD because no knowledge is a waste."
- "I am willing to continue because of the more knowledge I am receiving from the health workers."
- "I will like to continue because ... I have learnt how to treat minor sicknesses."

Willingness to continue was also expressed at Enugu, Nigeria. CDDs in both arms were positive, as seen in these statements:

- "Yes, because of its usefulness to my village."
- "Yes, I like to do humanitarian work and to help my people."
- "Yes, I will like to continue as a CDD because it is my contribution towards the development of my village."
- "Yes, any worthwhile venture I can handle for my community, I do not hesitate to do it."

Some were conditional or less than positive, and these were primarily from the regular arm:

- "Yes, if we are paid incentives."
- "I would like to continue if it does not disturb my work."
- "Yes, since I have seen no disadvantages since I started."

7.3.4 Conclusions on sustaining community-directed distributor commitment

- Most CDDs have found the experience rewarding and want to continue.
- The issue of "incentives" may interfere with continued service.
- Natural mechanisms and expectations for volunteerism as a contribution to community development exists in many places and should serve as the basis for community support rather than artificial, externally produced incentives.
- Enhanced study arm CDDs appear more willing to continue because they perceive that their status in the community is heightened.
- Communities in the enhanced study appear more supportive of their CDDs.

7.4 Health Service Level Indicators Of Sustainability

Health worker interviews consisted of two parts, an in-depth component that sought information about their experiences within the programme, and a structured part that elicited their opinions on community participation and their own role within CDTI. The 30 opinion items were the same as used during health worker interviews at baseline.

7.4.1 Health worker attitudes

At baseline, three attitude scales were developed to reflect different aspects of health worker perceptions and experiences with CDTI. Each item was scored on a five-point scale ranging from strongly agree, through uncertain, to strongly disagree. Reverse scoring was done for

items that were negative in their orientation toward the variable in question. Analysis used a wider range (e.g. -15 to +15 points), so that the positive or negative nature of the opinion scale would be clearly visible. Interviews from 114 health workers at baseline and 98 at follow-up were analysed.

Two levels of analysis were performed with these scales, a comparison between Phase 1 scores, and those at follow-up to Phase 2. Since districts had not been allocated to study arm (regular or enhanced) prior to the baseline interview, appropriate identifiers were not attached to baseline respondents so that their study arm could be determined. Therefore, comparison by arm of health worker opinions was possible only at follow-up.

Scale 1: The role of the community in CDTI and health programmes was reflected in the following five items:

- Distribution of drugs like ivermectin is best done by health workers.
- Communities are quite capable of managing the distribution of ivermectin.
- Community involvement in ivermectin distribution saves the time of the health worker for doing other things.
- Village health workers and community-based distributors should not handle ivermectin because they are not trained health workers.
- Only professional health workers should distribute ivermectin.

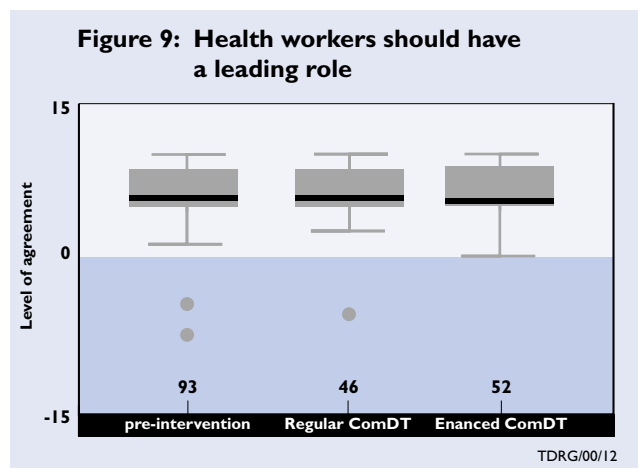
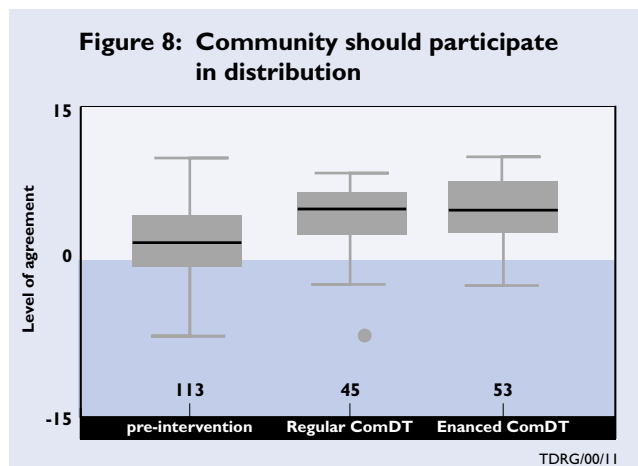
Figure 8 shows that the mean attitude score increased significantly between the baseline and the post-intervention period ($Z = -5.769$, $p = 0.000$). This indicates that, after participating in CDTI in any form, health workers developed a more favourable opinion of the community taking responsibility in CDTI. The difference in scores between enhanced and regular groups at follow-up was not significantly different ($Z = -0.891$, $p = 0.373$).

Scale 2: A second set of four opinion items considered the health worker's role in CDTI as seen below:

- Health workers would like to participate in the training of community members to take responsibility for ivermectin distribution.
- Health workers should take part in all decision-making processes concerning the distribution of ivermectin at the community level.
- Health workers favour involving communities in ivermectin distribution.
- There must be avenues through which health workers and the community should share information on health issues.

Figure 9 shows that, although health workers had a positive view of the different roles they were expected to perform in CDTI, their opinion stayed high at the end of the study ($Z = -0.238$, $p = 0.812$). Again there was no difference between health workers in the enhanced and regular arms of the study ($Z = -1.094$, $p = 0.274$).

Scale 3: Finally, there were two items that raised the issue of whether health workers need community input to run onchocerciasis control programmes:



- Health workers in this community cannot cope with ivermectin distribution because their number is too small.
- Health workers in this community cannot handle ivermectin distribution because they are over-worked.

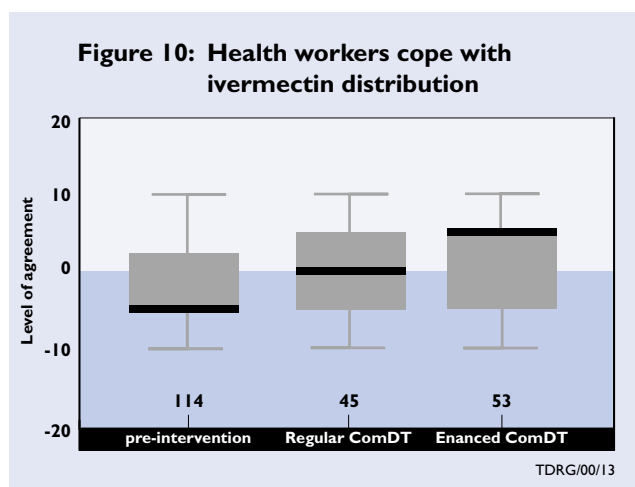


Figure 10 shows that, at baseline, health workers did not perceive any difficulties in organising an onchocerciasis control programme. The significant increase in this scale by the follow-up period reflects a greater sense of reality about the demands of CDTI, especially at the initial set-up phase ($Z = -3.125, p = 0.002$). At follow-up, the health workers in the enhanced group had a significantly greater sense that health workers could not cope alone with CDTI than did their counterparts in the regular arm ($Z = -2.107, p = 0.035$).

Discriminant analysis was performed to see which, among the total 30 opinion statements, actually

changed over time, and of those, which held together conceptually to form what could be termed a Health Worker Attitude toward CDTI Scale. The following five items were selected through this process:

- Communities are quite capable of managing the distribution of ivermectin.
- Onchocerciasis control should be best run by the district (as opposed to state or national levels).
- Community involvement in ivermectin distribution saves the time of the health worker for doing other things.
- Health workers in this community cannot handle ivermectin distribution because they are over-worked.
- Health workers do not believe that community-directed distribution of ivermectin is the best way to make ivermectin available to the people.

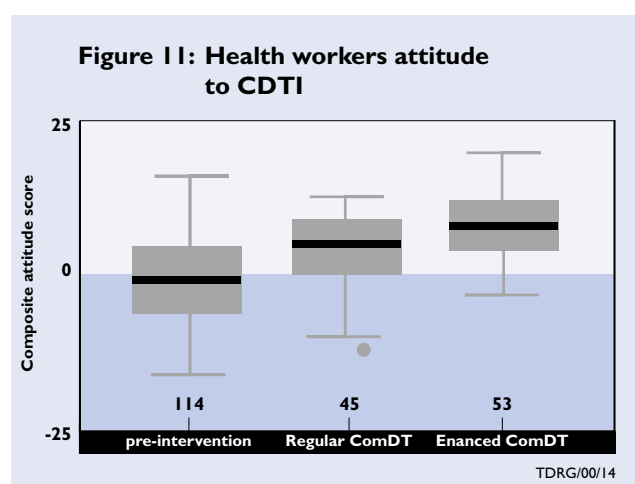


Figure 11 shows that, by using these five items that changed most over time, health staff in the enhanced arm of the study finished the programme with a significantly more positive attitude toward key components of running CDTI than did those in the regular arm ($Z = -2.866, p = 0.004$).

7.4.2 Health worker performance

Observations at village meetings, training sessions and SHMs allowed the researchers an opportunity to see whether local health staff could implement CDTI in a facilitative manner and work together with the communities as partners. Below is an

example from SHM minutes of how the Assistant Onchocerciasis Coordinator (AOC) from Iwajowa Local Government in Oyo State, Nigeria, performed during a typical SHM:

"At the first Joloko SHM, The AOC greeted the gathering and asked them to select their chairman who will be directing the affairs of the meeting. Prior to the meeting, he had gone into the market to remind village representatives that the meeting was about to start. The AOC expressed that the meeting would be like a family discussion. He continued that the purpose

of the meeting was to discuss about oncho, the causes, signs, and symptoms, its control, and appealed for everybody's contribution. The AOC encouraged the women to comment. The AOC and the chairman encouraged passive village representatives to talk. The AOC asked if those people from other states (e.g. the farm labourers present) could tell the whole gathering their local names for onchocerciasis. The AOC expressed that he himself had learnt a lot from the village representatives."

Observations were also made of the SHMs conducted in the Ibarapa Central Local Government of Oyo State. The meetings were facilitated by the two women AOCs who alternated the duties of facilitator. The minutes of the SHMs recorded that the facilitators often asked questions to get discussion moving. "Have you seen or used ivermectin before?" "What can communities do to show commitment to their CDDs?" "What are some of the local remedies for onchocerciasis?" "What can we do to make sure that everybody gets ivermectin?"

Such questions at the second round of SHMs included, "Why did some residents take the drug while others refused it?", "How did the CDDs perform?", "What kind of support was given by the community to the CDDs", "Was the collection centre, time and amount of ivermectin all right?", "Were there any problems with census or recording?". Although most of such questions in both rounds of the SHMs were programmed into the agenda, it is still important to note that the facilitators were able to handle the questions and discussion with minimal intervention by project staff.

The facilitative abilities of the onchocerciasis staff in Ibarapa East Local Government in the regular study arm were observed while they conducted training and village meetings. The facilitator (Onchocerciasis Coordinator) encouraged passive women to make contributions. The facilitator used an onchocerciasis poster to explain the details of the disease. The facilitator asked questions intermittently to evaluate the participants' level of understanding and also encouraged CDDs to ask questions for clarifications. He used encouraging words like, "I am very happy about the contributions of all CDDs." He conducted practical demonstrations for determining drug dosage and recording.

At one site, a quantitative analysis was done concerning health worker tasks in CDTI. Interviews with 16 health workers who were at the front line of the CDTI programme focussed on four sets of roles and 17 possible activities. These roles included: 1) planning with the community, 2) managing ivermectin supplies, 3) delivering ivermectin and 4) supervising distribution. Enhanced health staff (8) averaged 11.0 activities each. Regular health staff (8) averaged 6.6 activities each.

A Female health worker reflects on her role in CDTI:

"During the introduction stage I followed the researchers to hold meetings in the village that fell under my cluster. After that, I was going from one village to the other to mobilize them in readiness for the drug distribution. Then we organized for the training of the selected CDDs, but we were not involved in the selection of the CDDs. We left that to be done in the village during their various village meetings. Once we heard that the programme is community-directed programme, we gave the village free hand to select their CDD of their own choice, who must be generally accepted among them. Then drugs were distributed to the CDDs who distributed it in the various villages and later returned the remnant and the recording form to me in the health facility at Joloko, and I too submitted those forms and the remnant drugs to the officials."

From the foregoing, it appears that under the guidance of the research teams, local health staff were quite capable of planning and managing CDTI. They were able to master the skills and attitudes needed to implement CDTI. While both groups of health workers improved their attitudes toward CDTI, those in the enhanced arm were more favourably inclined toward the programme. There is some evidence that those in the enhanced study arm may have been involved in more activities, which may have given them a better perspective on what is needed to organize CDTI, and thereby could have influenced their attitudes.

7.5 Role Of Community-based Organizations

CBOs were mentioned specifically as participants to be invited to SHMs. The option of involving them in regular CDTI always existed, but this decision was left to the health staff and

community members in the regular arm of the study. Contributions to sustaining CDTI at the village level were documented. In the enhanced arm of the study, CBOs were reported to have provided transportation and feeding allowance to CDDs, supervised CDDs, mobilized the community, and participated in community planning.

In the regular study arm, CBOs were reported, in addition to mobilization, to have provided cash support to CDDs and been involved in CDD selection.

CBOs were not universally located in all clusters and villages. In Ghana, there are smaller villages and it was said that, "Everyone is a CBO". Only two CBOs attended SHMs there. At Ibadan, there are very small hamlets where onchocerciasis is endemic and CBOs are located mainly in the larger central towns. Due to the nature of the intervention, CBOs were specifically invited to SHMs. Some attended SHMs, and later helped in only ten enhanced study villages. It was observed that CBOs will be more relevant when CDTI is implemented throughout the LGAs in the Ibadan area.

At Awka, CBOs are formed at the town and village level, not umunna or kindred level, where CDDs were selected. Community-wide CBOs were reluctant to be involved in a programme that affected only a few umunna. It was proposed that the CBOs will be more relevant and willing to take a role when CDTI is implemented throughout a larger community.

7.6 Health System Concerns

The scope of this multicountry project focused on community and health worker factors that could influence the sustainability of CDTI. Another important level of commitment, that of policy makers, needs to be addressed in future research. In order to identify issues for research at the district policy making level, follow-up interviews were held with district administrative staff and policy makers in Enugu and Ibadan.

A Male Health Worker's CDTI Experiences

"My role in planning CDTI at the village level is to pay a visit to the community leader, secure appointment date for a meeting between CDTI facilitation team and community leaders. Then we held the meeting of community chief and the facilitation team. After that we set a date for meeting with entire community. After the meeting with community, selection of CDDs may take place before the ending of the meeting. But we should allow them to select for themselves. My role is to train selected CDDs on how to distribute the drug and how to record on the recording form."

At Enugu, discussions were held with local government (LG - district) and primary health care (PHC) department officials. In one discussion with the LG chairman and the PHC coordinator in the enhanced study area, it was learned that CDTI had been incorporated into the schedule of work for the department so that front-line health staff could legitimately e.g. undertake CDD training and treatment of side effects as part of their regular work responsibilities. The chairman pledged that, "The Local Government is ever ready and willing to support all programmes aimed at improving the health of the community, including CDTI". He went further to discuss plans to provide more transport, personnel, and finance to the PHC Department, including the possibility of a small remuneration for CDDs. The PHC Coordinator herself explained that lack of finance to date had been a result of the recent change in LG Chairman. She stressed again the commitment to incorporate CDTI duties into the job of front-line health staff.

LG authorities in a regular study area noted that any support for onchocerciasis control activities would be the same as for any other health programme in the LG. In both study arms, the authorities expressed thanks to WHO and requested continued help for their communities.

At the four LGs in Oyo State, the Ibadan site, each LG supervisory councillor for health was interviewed to determine LG commitment to sustaining the programme. In the LGs in the regular study, the councillors noted that:

- "We are preparing next year's budget and would contact our people in charge of this programme for further scrutiny so that at the end of the day, we would have no problem."
- "We are maintaining the already covered villages and we will cover some other ones."
- "The LG lacks vehicles but we were given two motorcycles by the Petroleum Trust Fund (PTF). I know my C/M will support and finance the programme."

Comments from councillors in the enhanced study LGAs were as follows:

- "We are going to plan on it. Once we've seen the proposal, we will make sure that the disease is eradicated in a short time."
- "We maintain our workers' cycles and we give them imprest. The LG is ready to support the programme."
- "If the condition warrants them to travel out of the LG, we will provide transport."

Views of the PHC department coordinators (heads) were also elicited. The PHC coordinator is the principal officer in charge of health for the LGA. He or she supervizes the onchocerciasis coordinator on the one hand, and on the other, seeks resources from the LG to carry out all health activities. Comments by the coordinators in the regular study arm LGs show that, in not all cases is there reason to be as optimistic as the supervisory councillors:

- "Nothing is given to the coordinator if there is urgent need for him to go to Ibadan for collection of drug or any other things."
- "No amount is voted or spent on the programme."
- "There is plan to train 100 people. The proposal is there on C/M's table."

Comments from PHC coordinators in enhanced study arm LGs were similar:

- "This LG is ready to finance any health programmes at hand."
- "Whenever they go to Ibadan for collection of the drug, they normally claim their transport and inconvenience allowance."

- "LGA didn't cater for the collection of ivermectin from HQ."
- "Their imprest has stopped now."
- "We are going to increase the number of clusters."

Finally the LG onchocerciasis coordinators were interviewed. They were even more realistic about the hardships faced:

- At Ibarapa Central (enhanced study), the coordinator explained that, "The LG gave monthly imprest for the fuelling and maintenance of the oncho machines to conduct Oncho activities like village meetings, mobilization and health education".
- At Ibarapa North (regular study), the coordinator noted that, "We were given some amount of money sometimes ago when we organized a workshop, but we've not received anything concerning the field work".
- At Ibarapa East (regular study), the coordinator said that, "At LG level there has never been specific amount of money released for the programme. I bear the cost of transporting drugs from the state capital to the LG".
- At Iwajowa (enhanced study), he observed that, "We trained the LG staffs. The LG provided books, biro, table, rule and others. They provided imprest for me. But now one circular came that put an end to it".

8

CONCLUSIONS

8.1 Sustainability indicators for community-directed treatment with ivermectin

Communities are capable of implementing and sustaining CDTI. Resources were provided for procurement, side-effect management, CDD support, and other basic programme management needs.

CDDs are capable of distribution, and record keeping, and are willing to continue. Many are motivated, not by cash incentives, but by gains in recognition, self-esteem and knowledge.

CBOs have a potential role to play, but this role will not become fully evident until CDTI is implemented at a larger, district level.

Health staff are also capable. They are able to facilitate meetings and interact with the community as partners. They can manage training, drug supplies, recording and reporting. They have expressed positive attitudes toward CDTI.

Policy makers say they are committed to CDTI, but health authorities indicate that full support (financial, logistical) has not yet been forthcoming. Factors that will enhance political commitment are not yet known and were not within the scope of this study.

8.2 Enhancing community-directed treatment with ivermectin through stakeholders meetings

Coverage was not seen to be affected by the enhancement process. Both study groups had good population-based coverage, i.e., the minimum desired 65% was more than achieved at the village level. Coverage was slightly but not significantly higher than achieved by CDTI in the first study (1995). Possibly a ceiling has been reached on coverage. Therefore, it may be necessary to consider other indicators for enhancement effect and sustainability.

On the other hand, it is important to note that a main reason for not receiving tablets, not being eligible, occurred significantly more in the enhanced arm of the study. Factors such as being absent and not being informed were significantly more likely to have happened in the regular study arm, implying a lower level of communication about the programme in that arm.

Enhanced study communities showed greater levels of participation, reported definitively, showed willingness to continue the programme, and have actually met to plan for CDTI. They perceived more benefits from the programme, and were thus more satisfied

The enhanced study group of CDDs received greater community support to do the job, perceived more respect from community, and are more committed to future service.

The enhanced study group of health workers had more favourable attitudes toward CDTI, were reported as having better community interaction, and engaged in more CDTI activities.

Has the question of sustainability been answered? The first CDTI study showed community capacity. This, the second study, has demonstrated both community and health worker commitment, and a strategy for enhancing commitment. The remaining question at district level is: will policy makers and planners also commit themselves to sustaining CDTI?

8.3 Recommendations

- A. APOC should promote SHMs in the context of its desire to have feedback mechanisms among CDTI partners. This can be done on a pilot basis and can test hypotheses that sustainability may be influenced by such factors as i) health worker attitudes, ii) community participation reports, and iii) CDD self-esteem, among others detailed in this report. This process should be monitored over a longer period than was available to undertake this present research.
- B. The multicountry advocacy study should examine factors among policy makers at District level that would enhance sustainability.

9

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APPENDIX A:

Steps in Community-Directed Treatment with Ivermectin (CDTI)

- Step 1:** Health worker pays a visit to community chief; secures appointment date for a meeting between CDTI facilitation team and community leaders. (It is advisable for the health worker to obtain an estimate from the district office of the population likely to be covered by the CDTI project, so that the required number of tablets will be available when the community decides to implement CDTI).
- Step 2:** Meeting of community chief/leaders and the facilitation team. Set date for meeting with entire community.
- Step 3:** Meeting of facilitation team and entire community. CDTI explained. Selection of CDDs may take place at this meeting.
- Step 4:** Allow community time to select distributors (CDDs) from their own ranks based on their own criteria. Community informs health worker and trainer (facilitation team) about community's preferred date for training CDDs.
- Step 4a:* If the facilitation team has information on the total population figure of the community, it should take an estimated number of tablets likely to be required for distribution to the community on the day of training.
- Step 5:** Training of CDDs.
- Step 5a:* In cases where the facilitation team does deliver tablets during the training session, CDDs should begin distributing ivermectin as soon as possible after completing their training.
- Step 6:** CDDs conduct census, record in notebook, and keep a copy in home of village/community leader.
- Step 7:** Community decides on month and dates of ivermectin distribution.
- Step 8:** CDD informs health worker/facilitation team about chosen date of distribution. If possible, CDD should collect ivermectin during the same meeting.
- Step 9:** If the ivermectin has not already been collected, CDDs should collect ivermectin tablets from the health post on a date previously agreed with health workers.
- Step 10:** Distribution of ivermectin by CDDs.
- Step 11:** CDDs monitor adverse reactions, treat cases of minor reactions where possible, and refer cases of severe adverse reactions to the nearest health facility.
- Step 12:** Complete the treatment record notebooks/forms and return a copy to the post from which the ivermectin is collected.
- Step 12a:* CDDs keep ivermectin tablets and treat, at a later date, those community members who did not receive treatment due to absenteeism, sickness, etc., making careful note of any such treatment.
- Step 12b:* Health worker during any future visit to the village monitors the CDDs' treatment record notebooks and updates the health post record accordingly.

Differences between Community-based Treatment (CBTI) and Community-Directed Treatment (CDTI) with Ivermectin for Onchocerciasis Control - APOC/WHO

While both CBTI and CDTI ensure that commodities (in this case the drug ivermectin) are available right in the community, the approach is quite different:

CBTI <i>Community-based Treatment</i>	CDTI <i>Community-directed Treatment</i>
<p>CBTI is a procedure wherein health providers determine the steps and the schedule to be followed. Activities are based in the community but not owned by the community.</p> <p>Community does not exercise authority over decisions on project design and implementation. Project activities, such as treatment dates and procedures, are designed outside the community without any, or with limited, contribution by the community.</p> <p>Community is told who should distribute, when to distribute, whether or not to pay distributors and how much to pay.</p> <p>The community is a recipient of services within limits and rules set by the provider. There is no sense of ownership; the project is seen as foreign.</p> <p>The educational role of the health worker is to communicate the benefits of the programme to the community and instructions on how to comply with procedures.</p> <p>The health worker's workload remains constant and high since year after year he/she must handle all training, logistics and outreach to every village.</p>	<p>CDTI is a process built on the experience of community members and thus enhances decision making and problem solving capacity. Activities are both in and of the community.</p> <p>Community exercises authority over decisions. Therefore, the community plans the distribution, decides on the method of distribution acceptable to them (e.g. central place, house-to-house), and when to distribute. Ensures sensitivity to community decision-making structures and social life.</p> <p>Community is informed about the detailed tasks of distribution, but they decide who should distribute and whether or such persons are strictly volunteers or should receive some compensation.</p> <p>The community is the lead stakeholder in the provision of services, creating a sense of ownership, and thus enhancing the likelihood that the activities will be integrated into the community's health agenda. There is room for innovation by the community.</p> <p>The educational role of the health worker is to communicate the benefits of the programme to the community and then pass on programme management skills to community members.</p> <p>While start-up field work may increase the immediate workload of the health worker, in the long term, an empowered community takes more responsibility for programme implementation, thus reducing the health worker's workload.</p>

APPENDIX B: Meeting of potential stakeholders in CDTI

This meeting is a mechanism for 1) sharing information on the concept of CDTI (also known as CDTI), including the findings of Phase I, among first-line health workers, community representatives and community based organizations (CBOs), 2) exchanging ideas, 3) jointly deciding partner roles and tasks, and 4) designing appropriate intervention strategies.

1. Participants include representatives of:

Villages: These will come from a natural cluster of 6-10 villages. During the process of introducing CDTI to the villages, facilitators would encourage the village to select 2-3 representatives to attend the workshop. Ideally those selected should be respected persons and also be representative of various interests in the village. Villagers might take into consideration the village political structure, persons concerned with village development, and various factions and sub-groups within the village.

CBOs: These include local groups such as age grades, trade associations, cooperatives, social clubs, among others. During the introduction of CDTI to the village, the issue of CBO involvement will be raised. Communities will be requested to invite representatives of 1-2 CBOs whom they believe have made substantial contributions to community development and might play a role in CDTI.

Health Services: First-line health workers include those who normally provide services to the cluster of villages. These include both community and facility-based workers (e.g. health inspectors, nurses, medical assistants, dispensers).

2. Facilitators

At least one representative from the district level will attend to facilitate the meeting. These representatives will have been previously sensitized about how to conduct participatory meetings. Researchers will attend as observers and take minutes of the meeting and special note of the processes and decisions.

3. Venue

The venue of the meeting should be accessible, central, adequate and comfortable. It should also be neutral, for example, a primary school or a meeting hall, but not a health facility. It is hoped that the focus on small clusters of villages will make it possible for participants to travel from and return to home the same day. If this is not possible, consideration for accommodation will be necessary when choosing a venue.

4. Timing and frequency

The initial workshops will be held in advance of the first distribution in the district. A second follow-up meeting will be held just before the second treatment after six months. The need for further meetings as part of the enhanced intervention package will be decided on the basis of the results of the final evaluation.

5. Duration

The first time a cluster meets, it is estimated that the workshop will take two days based on the agenda below. Subsequent meetings should not last longer than one day. The meeting on any particular day should start at a time when people would have been able to walk to the venue and close in time to allow people to walk home before it is too late.

6. Process

The process of the workshop will be participatory. The agenda, as seen below, will present topics for consideration, but the participants will be free to add items, give their own views and experiences and direct the course of discussion. Facilitators will encourage discussion, but will not impose ideas or solutions. The group will be guided to debate alternative actions and make their own decisions. An important guiding principle is that each village takes the final decision about the approach to distribution, reporting, etc. Therefore, not all villages will necessarily choose the same approach. Also note that it will likely be the case that representatives will need to carry the ideas from the workshop back to their communities for final approval and planning. The workshop process consists of the following steps, details of which are appended:

Orientate: Explain the purpose and objectives of the meeting/workshop: people are coming together, both community members and health staff, in a partnership to come up with ideas on what to do about onchocerciasis in this area, and to take these ideas back to the community to plan action.

Learn: Find out what people do about onchocerciasis. Encourage group members to think about what other people in the community do in relation to their onchocerciasis and medication problems, and prioritize these problems. Ask questions to stimulate discussion. Do you know any people in this community who have suffered from onchocerciasis? What caused their illness? What problems did onchocerciasis cause these people? What have they tried to do about onchocerciasis? Have you ever heard of ivermectin? Have you ever heard of programmes to involve the community in the management and distribution of drugs to treat onchocerciasis? What do you think about the possibility of your communities becoming involved in the control of onchocerciasis using ivermectin?

Share: Brief presentation on results of first CDTI study. Brief presentation of findings from the baseline study. Brief presentation of the organization and objectives of CDTI. See attached sample list - each group must summarize its own key findings to make the session relevant to the local area!

Brainstorm: Make a list of the problems people in the community have in handling their onchocerciasis, getting the drugs they need, getting ivermectin in a timely fashion, handling side-effects, etc. All ideas are accepted, no one is criticized for making a contribution. Only after a list has been generated are the individual contributors asked to clarify or explain their ideas. At that point, similar ideas can be merged with the consent of the group.

Solve Problems: Based on the problem areas suggested above, participants will work in small groups to develop suggested solutions to these problems. Small groups can be given different tasks (see 7c below). Groups should clearly decide on practical issues such as the timing, financing, materials and people that are needed to make their suggestions possible. Small groups will eventually report back to the whole group so that a set of recommended actions can be taken back to the village.

I. Organization

Using the attached guidelines, the facilitator helps the group organize itself and ensures a climate where everyone feels free to contribute ideas and participate in discussion.

I. Agenda

- Orientation - Introduction to purpose, partnerships, goal of high coverage.
- Learning about how local people see onchocerciasis.
- Sharing - Feedback from Phase I.
- Brainstorming of problem issues suggested by the participants. Where not specifically mentioned, include:
 - determining roles for each partner.
 - ivermectin stock management, including estimation of need (census).
 - appropriate distribution mechanisms - discussion of alternative approaches.
 - management of side-effects.
 - funding and resources.
 - reinforcement, support and/or compensation of persons who distribute the ivermectin.
 - record keeping and reporting.
 - reporting back to the village - planning for action.
 - decision making processes - how to create ownership.
- Solving problems - small group activity.
- General session to agree on package of ideas to take back to villages.
- Planning follow-up timing in village and for whole group.

Refreshments: Appropriate refreshments will be offered at the meeting, ideally through participation of all partners.

II. Decisions:

Outcomes expected from the workshops include:

- I. Interpretations and implications of feedback from Phase I will be obtained.
- II. Roles of various partners will be defined.
- III. Recording system will be established.
- IV. Alternative procedures for distribution will be identified.
- V. Resources and sources of funds will be designated.
- VI. Management procedures for side effects will be resolved.
- VII. Ivermectin stock management, including safe storage will be decided.
- VIII. Plans for reporting back to the village and reaching decisions in an inclusive way will be made.
- IX. Other issues raised by participants will be resolved.
- X. Follow-up: Facilitators will take the lead, accompanied by the researchers, to visit the villages after the workshop and in advance of distribution to learn how the ideas raised at the workshop were turned into village action plans and help resolve any conflicts or problems that may have arisen therefrom.

FOLLOW-UP (or 2nd) STAKEHOLDERS MEETING

According to the protocol, there should be a second stakeholders meeting (SHM) prior to the second ivermectin distribution. The purposes of the second SHM are basically two: 1) share experiences in the implementation of the first distribution, and 2) plan how to improve the second distribution based on these experiences.

The same people who attended the first meeting attend the second, including community members, leaders and local CBO representatives. Any villages that did not participate in the first SHM should be asked to attend. Also CDDs can be invited in addition to the regular village representatives.

As before, the LGA/district onchocerciasis coordinator and related health staff should take the lead in facilitating the meeting, while the research team takes minutes and notes of the meeting and processes and of how well the health workers facilitate the meeting. Also as before, the team should guarantee appropriate refreshments.

The agenda for the meeting is as follows:

- Opening statements, purpose of the meeting, etc.
- Introduction of participants; selection of chairperson, secretary, etc. (from among villagers present - who should take an active role).
- Review of previous distribution:
 - Levels of coverage - did most people take the drug or not? Why or why not?
 - Performance of the CDD - what did they do well? How could they improve?
 - Community contributions - did people support the programme? How and why/why not?
 - Management of the ivermectin - did it arrive on time? Was it adequate in quantity?
 - What was the experience with side effects? Were they effectively managed?
 - Community ideas about ivermectin - how did it work? Was it beneficial? Why/why not?
 - Distribution pattern - were the dates, times and places appropriate/acceptable?
 - Records, census - how accurate and effective - what were the problems, solutions?
 - Health workers - what role did they play/ how satisfied was the community with this?
 - Any other concerns.
- Ideas to improve the next distribution (small group activities).
- *Group I:*
What to do to improve coverage, community interest, contributions, support, participation.
- *Group II:*
CDD performance - how to help them do their job better; health worker performance and support.
- *Group III:*
How to improve ivermectin supplies and management of side effects; integration with primary health care.
- Small group reports.
- Plenary session to develop group recommendations.
- Strategies to share recommendations with the village, and implement them.
- Closing statements.

GUIDELINES FOR CONDUCTING Stakeholders meeting-enhanced CDTI intervention PARTICIPATORY APPROACHES

Objectives

The stakeholders meeting is an opportunity for health staff and community members to come together and form a partnership to: explore what steps are needed in organizing CDTI, and plan effective and appropriate ways to ensure that the programme is a success.

NOTES FOR THE RESEARCHER

ORIENTATION: The researcher will orientate the facilitator, e.g. local onchocerciasis coordinator, on the participatory processes needed to conduct the stakeholders workshop, as well as any needed information about CDTI/CDTI which the facilitator may not already know. The researcher will model the idea on facilitating behaviour, but will ultimately expect the facilitator to run the meeting because it is really his/her duty to manage the onchocerciasis programme in that district/locality. In other words, the researcher(s) will take a back seat.

OBSERVATIONS: A primary role for the researcher(s) is to act as observer during the workshop. A broad checklist is attached to enable the researcher to take useful notes on the process of the workshop. These notes should be reviewed with the facilitator at the end of the meeting for both accuracy and as a learning experience for the facilitator. All notes should be neatly typed and preserved as "data."

ARRANGEMENTS: The place where the meeting is set should have plenty of room for people to move around and form small groups as needed. It should offer protection from sun and rain, and be far enough away from noise and distractions. Seats should be arranged so that people can face each other, NOT in classroom rows.

LEADERSHIP: The facilitator is there only to make sure that people get along together and that everyone plays an active role in the deliberations. The facilitator should ask the group to decide on its own leadership structure, e.g. a chairperson, co-chairs, alternating chairs. Members of the research team will be observers and take detailed notes of the process. The facilitator's role will be to encourage members to take an active part in the proceedings, but he/she will not serve as chairperson or leader.

PROBLEM SOLVING: The meeting will be very practical. People will work in small groups to address issues such as getting drug supplies to villages, mobilizing community members, finding local resources. This is not a time for political debates and posturing. Everyone must contribute to the welfare and development of the community.

NOTES FOR THE FACILITATOR (Local onchocerciasis staff member)

RELATIONSHIPS: This meeting will involve both health workers and community members. The facilitator should let everyone know that all participants are equal in stature. Health workers may be experts treating or preventing certain diseases, but community members are also experts in knowing how to get things done in their own communities. Everyone must therefore work together in partnership.

PURPOSE: The facilitator should introduce the purpose of the meeting clearly and allow people to ask questions until everyone is clear on what is to be accomplished as well as the list of "norms" as outlined for the participants. The procedures should be explained, especially brainstorming and small group work.

LEADERSHIP: The facilitator is there only to make sure that people get along together and that everyone plays an active role in the deliberations. The facilitator should ask the group to decide on its own leadership structure, e.g. a chairperson, co-chairs, alternating chairs. Members of the research team will be observers and take detailed notes of the process. The facilitator's role will be to encourage members to take an active part in the proceedings, but he/she will not serve as chairperson or leader.

PROBLEM SOLVING: The meeting will be very practical. People will work in small groups to address issues such as getting drug supplies to villages, mobilizing community members, finding local resources. This is not a time for political debates and posturing. Everyone must contribute to the welfare and development of the community.

CONSENSUS: The programme will last longer if people reach a common agreement on how to proceed. Everyone should feel free to express concerns and disagreements until such time that everyone is convinced that a suggestion is realistic. The facilitator should therefore work to make sure that all views are presented and that participants do not simply agree with someone because he/she is a community leader, is forceful or threatening.

NORMS TO SHARE WITH PARTICIPANTS

RELATIONSHIPS: This meeting will involve both health workers and community members. The facilitator should let everyone know that all participants are equal in stature. Health workers may be experts treating or preventing certain diseases, but community members are also experts in knowing how to get things done in their own communities. Everyone must therefore work together in partnership.

LEADERSHIP: The facilitator is there only to make sure that people get along together and that everyone plays an active role in the deliberations. The facilitator should ask the group to decide on its own leadership structure, e.g. a chairperson, co-chairs, alternating chairs. Members of the research team will be observers and take detailed notes of the process. The facilitator's role will be to encourage members to take an active part in the proceedings, but he/she will not serve as chairperson or leader.

SHARING IDEAS: Everyone at the meeting is important - everyone has important ideas to share. All must agree, not only to allow each to take a turn in speaking, but to actively encourage each other to share experiences and ideas. This is not a time for political debates and posturing. Everyone must contribute to the welfare and development of the community.

RESPECT: Members must respect each other. People should not talk and gossip when another is speaking. People should stay together as a group until the task is done. Conflicts and quarrels are normal in groups, but these should not be allowed to get to the point of abuse and disrespect.

TIME: Participants also need to respect each other's time. The group should be conscious that members have other commitments in business, family and farm, and should therefore not come late, take excessive breaks, or otherwise delay the proceedings.

CONSENSUS: The programme will last longer if people reach a common agreement on how to proceed. Everyone should feel free to express concerns and disagreements until such time that everyone is convinced that a suggestion is realistic.

OBSERVATION GUIDE FOR RESEARCHERS

The process of observation and note taking will not be dissimilar from the taking of minutes at a meeting, but the emphasis will be slightly different. Note taking in this case will focus especially on the process of how decisions are made, not just a listing of decisions. These process notes will become part of the data of our research about factors that promote sustainability. Some of these issues overlap. Special note should be made of the following concerns:

LEADERSHIP: Document what form of leadership is chosen by the main group and small groups. Describe how leaders are chosen. Do they propose candidates and vote; do they accede to allowing someone to lead because of his/her stature in the community; is there a consensus, etc.?

Once the leaders are chosen, how do they conduct the affairs of the meeting - democratic, authoritarian, free flow, etc.? Do people show respect to the leader? Do they challenge the leader or simply accept whatever the leader says?

ROLE OF FACILITATOR: Does the facilitator (onchocerciasis coordinator) encourage community members to take leadership and decide on the direction of their own discussions? Does he/she make direct suggestions and corrections or even give orders; or does the facilitator ask helpful questions to guide the group along productive lines?

DECISIONS: Document specific decisions (in addition to leadership) arrived at by the larger and the smaller groups. Describe how the decisions are made. Is there voting; do one or two people push an idea until others get tired and agree; is there reasonable discussion until consensus is reached; does the leader simply state that a certain way is desirable and others are afraid to disagree, etc.? Document roles of the different types of members - by gender, age, position.

LEVEL OF PARTICIPATION: Generally during discussions, who and how many people participate - i.e. contribute ideas, ask questions, make clarifications, etc? Are there certain people or types of people who are more active or less so? Are there age, gender and/or position differences in who participates? Do the leaders or facilitators try to bring everyone into discussions - seek opinions of those who seem reticent to talk?

COMMUNITY MEMBER-HEALTH WORKER INTERACTION: Describe how health workers and community members interacted during the workshop. Is there mutual respect? Do they seem comfortable or uncomfortable around each other - give specific examples of what was seen to make these conclusions. Do they respect each others contributions to discussion?

UNCONSTRUCTIVE BEHAVIOURS: Comment on behaviours that may show lack of commitment or may disrupt the meeting. Do some people read the newspaper, gossip, become argumentative, leave the room often, etc.? Are there any observable characteristics about such persons concerning gender, age, position, etc?

LEVEL OF UNDERSTANDING: Document, from listening to discussions, how well the participants understand the purpose of the workshop as well as that of CDTI. Give specific examples of comments that people make that demonstrate their understanding or lack thereof. Note the characteristics of people who understand more and those who seem to understand less. Do the leaders and facilitators appear to be aware of misunderstandings? If so, what do they do to help people get back on track?

CONFLICT MANAGEMENT: Do conflicts occur? What are the issues involved? Who takes which sides? When conflicts occur, do the persons involved take the matter personally (i.e. as attacks on their person), or do they take such differences in their stride and continue to discuss in search of a solution? How are conflicts resolved - taking flight (one party simply stops talking or leaves the room), abuse (one or more parties discredits the other using personal remarks), aggression (one party keeps arguing and pushing until the others acquiesce)? Do the leaders play any role in trying to get each side to focus on the real issues and not on personalities?

APPENDIX C (part 1/3)

Health worker opinion items

Attitude to ComDT	Strongly agree	Agree	Don't know	Disagree	Strongly disagree
Health workers believe that ivermectin distribution should be handed over to community-based volunteers					
Distribution of drugs like ivermectin is best done by health workers					
Communities are quite capable of managing the distribution of ivermectin					
Onchocerciasis control is really a federal (national) programme not our own					
Onchocerciasis control should best be run by the state/provincial government					
Onchocerciasis control should best be run by the district/LG					
Health workers favour involving communities in ivermectin distribution					
It is not the duty of voluntary associations and NGOs to run ComDT					
Health workers would like to participate in the training of community members to take responsibility for ivermectin distribution					
Community involvement in ivermectin distribution saves the time of the health worker to do other things					
Community involvement in ivermectin distribution amounts to a take-over of the duties of the health worker					
Village health workers and community-based distributors should not handle ivermectin because they are not trained health workers					

APPENDIX C (part 2/3)

Attitude to ComDT	Strongly agree	Agree	Don't know	Disagree	Strongly disagree
Only trained professional health workers should distribute ivermectin					
Members of the community should come to health facilities to receive ivermectin instead of health workers going to them					
Health workers in this community cannot handle ivermectin distribution because their number is too small					
Health workers in this community cannot handle ivermectin distribution because they are already over-worked					
Health workers involved in the distribution of ivermectin should be paid allowances for their involvement					
Health workers do not believe that community directed distribution of ivermectin is the best way to make ivermectin available to the people					
Some of my colleagues do not believe that the distribution of ivermectin by community members is not a solution to their oncho problem					
Community members believe that ivermectin has other benefits besides the treatment of onchocerciasis (e.g. improved vision)					
Side effects of ivermectin may discourage community members from taking the drug					
Community members believe that ivermectin does not give immediate relief					
Community members fear that ivermectin is harmful (e.g. can cause sterility, AIDS)					

APPENDIX C (part 3/3)

Attitude to ComDT	Strongly agree	Agree	Don't know	Disagree	Strongly disagree
Communities are suspicious of the purpose of distributing ivermectin free					
Community members have always expressed their concern about the high prevalence of onchocerciasis before the distribution of ivermectin started					
Symptoms of onchocerciasis were not known in this community before ivermectin distribution started					
Onchocerciasis is one of the major causes of blindness					
Many health workers do not feel comfortable working in the community					
Health workers should take part in all decision-making processes concerning the distribution of ivermectin at the community level					
There must be avenues through which health workers and the community should share information on health issues					