COUNTDOWN
Calling time on Neglected Tropical Diseases
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Alternate and Enhanced Community Engagement for the Liberian Neglected Tropical Disease Programme : Community Perspectives on Mass Drug Administration

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Key Messages

- Limited awareness of diseases and associated interventions shaped the demand for and acceptance of MDA in communities. For example, strong traditional belief systems shaped perceptions about the origin of disease and guided community members demand towards traditional medicine treatment seeking pathways. For parents, not understanding why their child should take a specific medicine often led to refusal. Furthermore, in some cases poor awareness mechanisms led to children swallowing medicines without parental consent.

- Multiple methods of communication will be essential in increasing the awareness of community members about NTDs and associated programmes. Messaging should be simple, respond to traditional beliefs and communicated in local languages to ensure it is understandable to everyone, especially women, who have lower literacy levels. Engagement of health facility staff and the county health team in message dissemination would support CDDs and enable more consistent messaging

- To ensure maximum inclusion of all community members during MDA both house to house and fixed-point distribution methods are required. Preferences for fixed point distribution locations varied, although clinics were highly favoured. Due to variation by community and county, there is a need for CDDs to work with communities on a case by case basis to identify preferred distribution points.

- Timing of both awareness activities and medicine distribution was a key factor in shaping programme access. Community members were frequently outside of the community completing livelihood activities when distribution took place. Some men suggested that completing awareness and distribution over the weekend would mean more people would likely be present.

- Most community members accepted to swallow the medicines due to previous positive experiences and perceived benefit of curing sickness. In some instances, women particularly described accepting medicines due to the influence of community leaders. Where community members refused to swallow medicines, the main reason was due to observed or experienced side effects during previous MDA rounds. Strengthening awareness and referral around side effects would likely increase programme acceptance.

- Descriptions of how CDDs were selected emphasized varying levels of community involvement within the process. Community members did not describe an explicit link between who delivered the medicines and the likelihood of them accepting to take them, however, factors such as belonging to their community and having some prior knowledge of health or drug distribution methods was preferred.

Background

Liberia's health system is recovering following prolonged conflict and humanitarian crisis. Access to health care is frequently lacking, particularly in rural areas, and following the Ebola epidemic, trust between communities and the health systems broke down[1]. Strengthening the health system to promote trust and ownership of health interventions in Liberia is essential to ensure adequate health and social protection for all and support progress towards the Sustainable Development Goals. Liberia's Neglected Tropical Disease (NTD) programme targets four NTDs through preventive chemotherapy (onchocerciasis, lymphatic filariasis, soil transmitted helminths and schistosomiasis) using mass drug administration. These diseases disproportionately affect poor, rural and marginalised populations in Liberia and understanding how to reach these communities with existing NTD interventions is essential in ensuring health for all.

In 2012, the World Health Organization (WHO) released a roadmap for implementation aimed at 'accelerating work to overcome the global impact of NTDs', with specific targets and commitments from countries to strive toward control and elimination of many NTDs by 2020 [3, 4]. The focus of control and elimination efforts has predominantly been in relation to the Preventative Chemotherapy (PC) NTDs, namely; onchocerciasis, lymphatic filariasis, trachoma, schistosomiasis and soil transmitted helminths . Despite such focus, in many contexts there is a significant implementation gap between impending control and elimination targets and slow progress to date [3]. As such, it has become critical to understand what factors are hindering progression, and what can be done to scale-up and progress toward these goals.

In 2015, the COUNTDOWN consortium, funded through the UK Department for International Development, was established with an overall goal of reducing mortality, morbidity and poverty associated with NTDs[5]. The consortium is focused in four countries; Ghana, Cameroon, Liberia and Nigeria, and is conducting implementation research to address current NTD programme bottlenecks with a view to accelerate progress toward control and elimination of PC NTDs. This brief is one output of the work completed in Liberia. This research was designed to address and explore key challenges in ensuring equitable NTD programme delivery in Liberia. Implementation challenges to be explored were identified through a participatory stakeholder meeting during project inception.

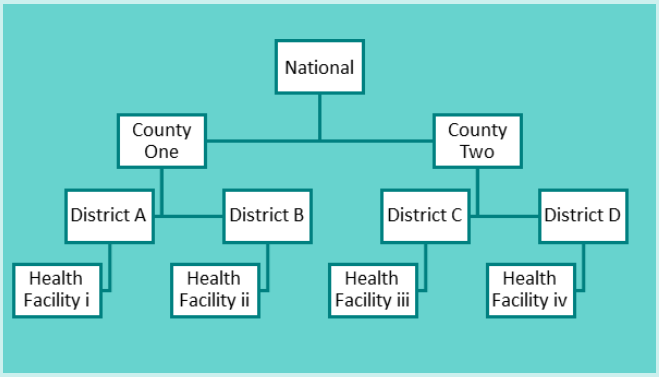
This brief responds to challenges identified by stakeholders in relation to ensuring and sustaining community ownership of the NTD programme to improve disease and programme awareness, as well as medicine availability, accessibility and acceptability.

Methods

This study was completed between January 2017 and January 2018 in Maryland and Bong County, Liberia. The study used a variety of qualitative methods to elicit the views of stakeholders engaged with the NTD programme at all levels of the health system, including; the community, health facility, district, county, and national level. The findings from methods used at different levels were triangulated and synthesised into key outcomes.

Study Sites: Figure one shows the cascade of purposive study site selection to achieve maximum variation in disease endemicity and prevalence, programme impact (measured by geographic and therapeutic coverage), literacy, wealth and geography.

Figure 1 Study Site Selection



Data Collection and Analysis

Key Informant Interviews: Thirteen key informants were conducted with purposively selected stakeholders at the national, county, district and facility level. Only staff directly involved in NTD programme delivery (specifically MDA) were involved. This method was used to explore the realities of MDA implementation from a health systems perspective and focused on what helps and hinders the programme with specific reference to financing, leadership and governance, health workforce and service delivery.

Life and Job Histories with Community Drug Distributors (CDDs): Forty-two life histories were conducted with purposively selected CDDs across both counties. Thirty were male and twelve were female. Maximum variation was also aimed for in terms of length of time engaged with the NTD programme and age. Life histories were used to explore CDDs' life and career history and elucidate their motivations for the work they do, training they have received, and the ways in which they are supported to fulfil their role. The purpose of these interviews was to understand current levels of job satisfaction and level of engagement with the NTD programme to be able to assess what strategies could be utilised to better support CDDs.

Community Members

Focus Group Discussions and Social Mapping: Twenty-one FGDs were completed with purposively selected groups of community members to explore general perceptions of Mass Drug Administration (MDA) as well as health communication preferences. FGDs incorporated the use of participatory social mapping to explore community structures (physical and social) that are currently used or could be better used in NTD programme delivery. Separate groups were completed with men, women and youth and influential community members (also separated by gender).

In-depth Interviews with acceptors, refusers and absentees linked to LF, Onchocerciasis and STH MDA: Forty-one in-depth interviews were completed with purposively selected community members to understand their knowledge, perceptions and experiences of existing MDA strategies. Table 1 below shows the variation in participants spoken too:

***Table* 1 – In-depth interview study participants (LF, onchocerciasis, STH)**

	Men			Women			Total
	18-25	25-49	Over 49	18-25	25-49	Over 49	
Those who take MDA	2	3	4	2	9	1	21
Those who refuse to take/absent during MDA	1	5	4	2	6	1	19
Total	3	8	8	4	15	2	40
	19			21			

In-depth Interviews with parents of school aged children linked to schistosomiasis MDA: Nineteen in-depth interviews were completed with purposively selected parents of school aged children to understand their knowledge, perceptions and experiences of existing MDA strategies for Schistosomiasis. Mothers and fathers were interviewed separately but analysed as 'sets' to try and understand variation in view points and decision making within one household. Table 2 below shows the variation in participants spoken too:

Table 2- In-depth interview participants (schistosomiasis)

	Parents of School Aged Children (number of sets- 1 mother and 1 father per set)	
Those whose children take MDA	5 (full sets) 1 (no father)	11
Those who children refuse to take/absent during MDA	2 (full sets) 2 (no father) 2 (no mother)	8
Total	12 (19 participants)	

Data was conducted for all methods until saturation was reached. Data was analysed using a thematic framework approach.

Figure 2. Life and job history interview

Figure 3. Research Sensitisation Meeting

Lack of awareness of diseases and the programme can shape medicine uptake and preferences

Most of the community members interviewed had limited awareness of the drug distribution programme or the neglected tropical diseases asked about (lymphatic filariasis, onchocerciasis, schistosomiasis or soil transmitted helminths) in this study. Traditional belief systems were prominent in the interpretation of disease, with most men and women believing they were caused by 'African signs' and therefore needed treatments linked to 'country medicine' such as the 'boiling of leaves'. Many men and women did however describe links between the environment and disease, particularly when talking about schistosomiasis. A few women also emphasised the link between dirty food and disease. A few men and women were able to name the medicines that had been distributed e.g. Mectizan or Albendazole, but no one was able to describe exactly what these medicines were for. Parents in Maryland county who were asked about MDA for schistosomiasis, described that they did not know about the distribution before it took place and were fearful to let their children take the medicines as a result. Fathers described being confused as to why their wives had let their child take the medicine and, in some instances, parents described their children taking medicines without their consent.

Thinking about causes of disease

'……that is [my] first time to hear about that sickness; that snail worm. So now [I] don't have any question to ask you people how it is going on. But now you people can inform [me] what happen, how they discovered it, how it can got, how it can manifest' (**Maryland, Female)** in relation to schistosomiasis).

'This is why I am saying that I don't even know it before, I have not come across it to even know the signs and symptoms, at least if I have seen it on someone I can describe it, say yes, I saw it so so place' **(Maryland, Male).**

Preferences for Awareness Messaging

Despite a lack of disease and programme awareness amongst community members, CDDs described having delivered awareness messaging in advance of the LF and onchocerciasis distribution using multiple methods such as interpersonal communication, mass meetings, and the engagement of town chiefs or elders. CDDs did however describe challenges in reaching all community members as many were absent from the community during the short time they had to complete sensitisation activities. Some CDDs described that involving their supervisors in awareness would support them in better engaging communities as it would increase respect for the messages shared.

'when it comes to the distribution of the tablets, the first thing I do is to go in the community and call mass meeting to tell them the important of the tablets, have them inform that so so tablets is coming and we will start distributing from so so date to so so date, because before the distribution start they need to be aware, so when the distribution start I go from house to house. If they are not aware when you go to them they will tell you why you did not inform us on time because most of them are doing farming so at the end result you will not get some people. So it is always good to have them inform before the distribution start' **(CDD Maryland, Male).**

Community members views aligned with CDDs with many expressing a desire to receive more awareness about the diseases and the programme. Most men described that they would like to receive awareness messages through face to face dialogue and that engaging the town chief and county health team would be beneficial in sharing the messages. However, most women preferred to receive information through fliers and posters in the market place and clinic and emphasised that messaging should be shared in local languages or very simple English. This suggests that in enhancing awareness of the NTD programme and associated diseases at community level a variety of different communication platforms should be utilised.

'I will like for you to come and visit me to tell me what you have done. I think that will be the best way to get better information to come and send agent on the field to give me advice' ***(Bong, Female).***

'She can get it clearly from the Clinic….They understand about the sicknesses from the health talks at the clinic more than radio because some of them don't understand English' ***(Maryland, Male).***

Making Medicines Accessible

The need for a variety of distribution strategies: Most men and women interviewed in Bong county described preferring house to house medicine distribution as it was easier for CDDs to track refusals. They also described that house to house distribution would need to be coupled with improved awareness messaging so that people remained at home to receive medicines. Alternatively, some men and women in Bong county preferred distribution to take place at a fixed-point, ideally the clinic, as it was clean, and people were knowledgeable about medicines there. Other fixed points recommended were the palava hut (normally an area with a thatched or tin roof in the centre of the community) and town hall. Group distribution was described as having the potential to increase medicine acceptability by several participants.

'it will be good to walk from house to house. because when they say this building let everybody come na [not] everybody will leave their area to go there some people will be running away but when they move to your house they say house many person here you bring them outside person who will refuse your will really know' ***(Bong, Female).***

In Maryland, most women described a sole preference for fixed point distribution because they felt comfortable there and liked to take medicines with friends, whilst men preferred the house to house method. Men in Maryland also described a need for enhanced awareness when using the house to house method which they felt was essential in ensuring that everyone was reached including people living with disability. Due to the wide variation in distribution preferences amongst the study participants, to prioritise equity in programme delivery, it will be necessary to work with communities on a case by case basis to identify preferred distribution points. The impact of multiple distribution approaches on CDDs and other programme staff should also be considered.

'it is good because other person in the house can't walk to the place where they schedule their medicine, so house to house is good' ***(Maryland, Male).***

'They get two places here; we get the peace hall and the town hall…We can use the peace hall….It is big for everybody to go there and most of the time people can be happy there' ***(Maryland, Female).***

In specific relation to schistosomiasis programme delivery, there was a strong preference amongst all community members for MDA to take place both in and out of school to ensure absentees and out of school children were captured.

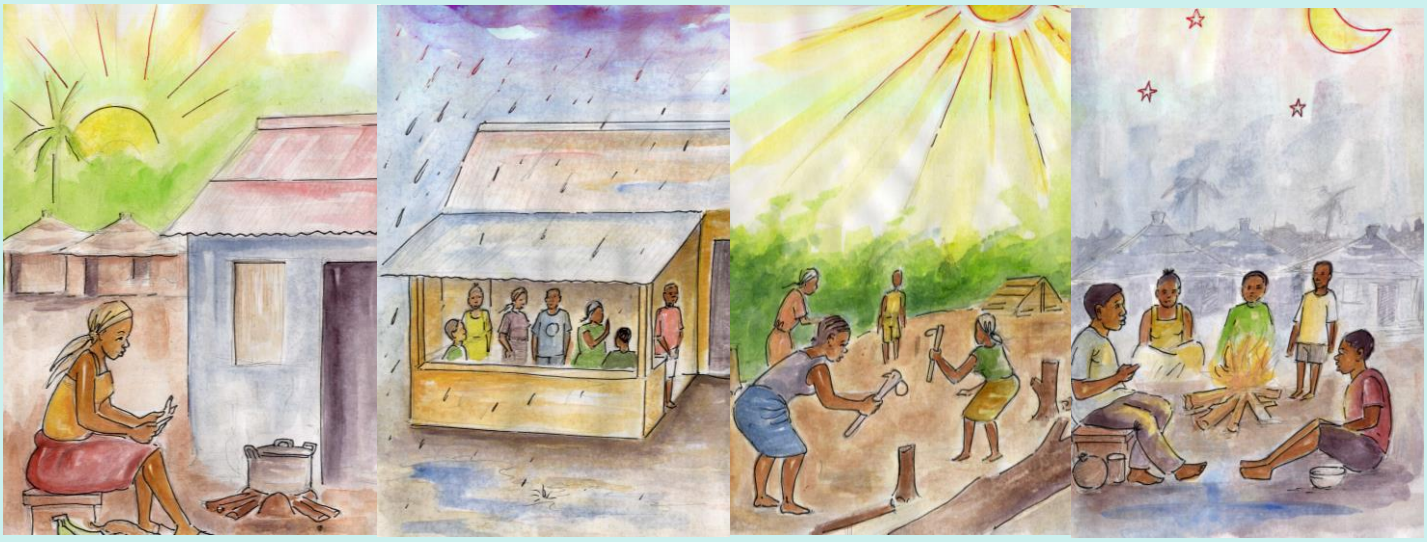
'*Well, what I want to recommend it was given in school, and sometimes the child might not be in good health to go to school that day and I believe absentee did not take it that day. So, I want to suggest or recommend that drugs should be given in school and in the community as well. Then off course it will cover the entire……instead of just limiting it or the administering of it in school'* ***(Maryland, Father).***

Distribution Timing is Critical in Ensuring No One is Missed

Timing of distribution was described by community members as critical in ensuring they were able to access medicines. Many men described being missed by awareness and distribution activities because they were completing livelihood activities outside of the community such as farming or fishing. They suggested that completing awareness and distribution at the weekend would mean more people would be reached. Parents also described that their children who travelled out of the community with them while they completed livelihood activities also missed distribution. Several women also stated that awareness and distribution didn't reach their part of the community, but that they weren't concerned as they were unlikely to accept the medicines anyway due to a lack of programme understanding.

'Some of them can go on the farm soon in the morning and then they can just make announcement one time. This group things, some of them can go to work. But mainly when it is Sunday everyone will be in the town. So when you make that announcement Saturday evening, then Sunday the whole place will be park. Sunday is a resting day and nobody will be able to go on the farm' (**Bong, Male).**

'I am not permanently residing in the town, I most often spend my time in the village, so I can come when necessary…I have not experienced people coming here to talk about river blindness, what cause it, I have not experienced it. I have not seen people coming here to talk about elephantiasis and the causes agent of elephantiasis...' **(Maryland, Female).**



Timing of distribution and seasonality

To accept or not to accept?

Intrinsic and observed benefits vs side effects and perceptions of health and disease

In most cases men and women had accepted to swallow the medicines as they felt that the benefits outweighed the side effects and they had an intrinsic belief that the medicines had reduced the experience of sickness or itching overtime. In a few instances, some participants, particularly women described swallowing the medicines based on community leader instruction and a fear of disrespecting authority.

'I've got plenty sickness in me so I just took it maybe it will help you...I've been taking it from the time they been bringing it...But the past time, the first time never used to. But when I started taking the drugs this few time even when I reading in the night I can sometime see clear' ***(Maryland, Female).***

Across both counties however, side effects such as itching, swelling or vomiting experienced or observed during the previous MDA cycle were cited by community members as the main reason for medicine refusal. Key informants felt that information regarding side effects was a key programme weakness that needed to be addressed to improve acceptance.

'It is my policy and the reason why I was refusing to take it…Because the first one I took it make me to feel bad so I look at it I say I scare to take it again because when I take it just like to say my sickness is coming up...The medicines made me to be sick almost one week, when I took it my something [scrotum] and my foot swollen and I can go in the latrine fast....No I took it that's what I saying I took it but la [it was] the second time that I didn't took [take] it...It is my policy and the reason why I was refusing to take it' ***(Maryland, Male).***

Some men described other reasons for refusal as the fact that they did not feel sick and therefore there was no need for them to take the medicines. In Maryland, a few men also felt that the medicines had the potential to lead to death and stop women from getting pregnant and therefore should not be taken. Women in Maryland, described a preference for not being measured using a stick and suggested that a different way of measurement would increase medicine acceptance . Women were also told not to swallow medicines when pregnant and breastfeeding.

'In my belief I feel that I don't have filarial and I am not feeling scratch is what I feel to myself I did not take it' ***(Bong, Male).***

During MDA for schistosomiasis in Maryland county, some parents reported refusing to allow their child to participate due to fear of side-effects experienced during the previous distribution. In addition, during the Ebola outbreak, they described being told not to take medicines from anyone, so they refused these medicines due to a lack of additional awareness activities. In very few cases, some participants also described a perception that the medicines were bringing Ebola. Having said this, some mothers and fathers described an increased likelihood to accept medicines in future MDA rounds due to the follow up visits CDDs made to their children during this distribution period.

'Well this world we living in everybody want good thing about themselves, even though this time we are skeptical in taking the tablet because the Ebola that broke out people said that people were doing bad things about it that even if you are healthy as soon as you take the tablet then you become weak from there you can't know the place they can carry you, so we are skeptical, so now if they say it will help to stop the disease or through taking the tablet you will not get it' ***(Maryland, Mother).***

Who is the distributor?

There is a set criterion for CDD selection; to be literate, dwell in the community, of good moral standing and recommended by the community. Community based selection of CDDs is one of the cornerstones of the community directed treatment approach with the rational that this will increase community ownership and support of the programme. Men and women often described the process of CDD selection slightly differently, with women perceiving the community to have been more involved in the process through community meetings. Both men and women also described community leaders, hospital and clinic staff as playing an influential role in selection processes. CDDs also described these different approaches to selection and often perceived that they were chosen as they were literate or because they had worked on other health programmes.

'what they can do they can put the community people together to give them one person they will get together and select the person from there and give it to town management committee…the community people can select the people then they carry them to the OIC' ***(Bong, Female)***

'That one they can do in the clinic; they can't do it outside here. That is the clinic people who knows can carry drugs around. They get outside before we can know them' ***(Maryland, Male).***

Although community members rarely explicitly stated that who the CDD was shaped whether they were likely to accept the medicine or not; most men and a few women, described preferring distributors who had some medical knowledge, were linked to the clinic, or those who are already knowledgeable on the drug giving procedures. Most women preferred the current CDDs because they understand the distribution process but described that they need more CDDs to cover the entire population. Key informants supported that more CDDs were required to reach the whole population, but that funding shortages had reduced the number of CDDs that the programme was able to engage. Male community members also described a preference for CDDs to be given a salary, so they are motivated to do the work and cover the distances needed to reach everyone in the community.

'I want them to go in each community and take one person from there…Each community they should choose people from there to be a part of it' ***(Maryland, Male).***

'Medication it needs somebody who has idea, medical idea, somebody must be attached from the health facility before that person can be given the chance to carry out medication around, so you can just go around and take any other person from there. People who are involved must have little medical idea, you can go to somebody like her to ask the person to carry medicine around…' ***(Maryland, female).***

Recommendations

This research has highlighted several challenges in ensuring that communities are aware of NTDs and associated programmes; that they can access medicines and information; and that when accessing medicines, they are encouraged to accept them. Strengthening programme delivery based on community perceptions and opinions is likely to contribute in promoting equitable and effective person-centred service delivery. The following recommendations are designed to inform the first step on the pathway to enhancing NTD programme delivery in Liberia:

1. To ensure maximum inclusion of all community members, both house to house and fixed- point distribution methods should be used during MDA. Proper awareness should also be completed in advance of distribution using these strategies.
2. Research should be completed that explores how CDDs could use simple tools to identify community level distribution preferences and how they could be given the flexibility to adapt service delivery strategies at the local level.
3. Health communication and awareness messaging should be guided by the newly developed NTDs communication strategy and should focus on the use of a variety of communication tools, including but not limited to; workshops, face to face discussions, radio campaigns and other social behaviour change communication techniques (SBCC) such as radio jingles and posters/flyers etc. Messaging should be delivered in local languages or simple English.
4. Explore with communities the most appropriate times of day, week, year and month that awareness and distribution should take place and how flexibility in drug delivery timelines can be achieved. This could include additional time be allocated for awareness activities prior to MDA campaigns coupled with ongoing disease awareness between campaign periods.
5. Investigate the best ways to improve information sharing regarding side effects as well as referral systems for people experiencing side effects.

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COUNTDOWN (grant ID PO 6407) is a multi-disciplinary research consortium dedicated to investigating cost-effective, scaled-up and sustainable solutions to control and eliminate the seven most common NTDs by 2020.

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