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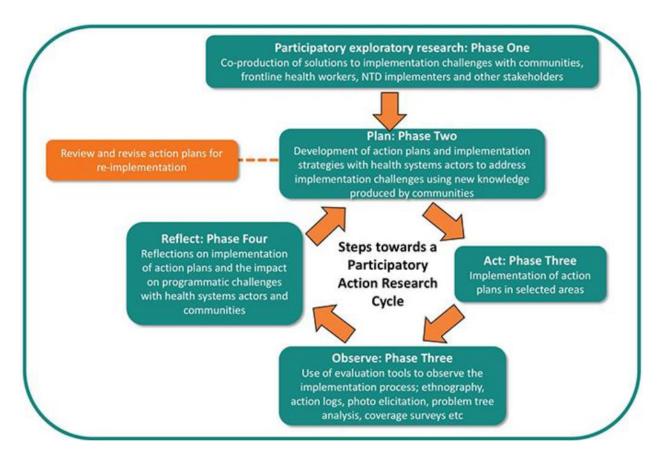
Calling time on Neglected Tropical Diseases

# Case study: Developing sustainable tools to improve community engagement and enhance Neglected Tropical Diseases programme equity

COUNTDOWN Nigeria has applied a Participatory Action Research (PAR) approach to improve equity of Mass Administration of Medicines (MAM) and inform Neglected Tropical Disease (NTD) policy through an enhanced community engagement strategy. A situational analysis conducted in 2016 identified community engagement as a bottleneck to achieving equitable coverage of MAM within different and emerging contexts (border, migrant, rural and urban) of Nigeria, related to programmatic, social, political and environmental changes over time See: (Dean et al., 2019), (Oluwole et al., 2019) and (Adekeye et al., 2019)

# The Participatory Action Research Approach

The PAR approach was utilised to promote a new bottom-up approach to policy and planning that would ensure voices from the community were captured and represented and that local level implementers were able to add context specific changes to MAM implementation (Ozano, 2018). To support this process, co-researchers from the Nigerian Federal and State Ministries of Health, and local level NTD implementers have been partners throughout the PAR process. Over a two-year timeframe, NTD implementers and communities have identified challenges and proposed solutions to implementation challenges. As a result, the team have co-created a new bottom up, context specific approach to planning and implementing MAM. The PAR approach is detailed in Figure 1.



During the exploratory phase, participatory methods enabled different community members and frontline health workers to analyse NTD challenges within their context and propose solutions. These findings informed the development of action plans for urban and rural contexts which were implemented and observed. A reflection process with NTD implementers at all levels of the health system resulted in revised and adapted action plans. Throughout the process joint research outputs, including implementation tools and guides, were co-created and are detailed below. The next phase of research is to support State ministries of health to scale up the new approach using the evidence-based implementation tools. Here we detail the PAR process and the resulting implementation tools.

# Phases of research and outputs

### Explore



During the exploratory phase, stakeholders were brought together to discuss the challenges of community and school-based mass distribution of medicines for 4 preventable NTDs (Onchocerciasis, Schistosomiasis, Lymphatic Filariasis, and Soil-Transmitted Helminths) (Dixon and Lar, 2018).

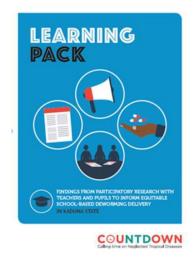
# This included:

- Participatory workshops with teachers and CDDs were held across the two states. Challenges and solutions were identified by stakeholders related to technical support, social support and incentives for frontline implementers including CDDs and teachers (Oluwole et al., 2019). This also included the identification of motivating/demotivating factors that would support implementers to continue working with the NTD programme.
- Stakeholder reviews of Information Education and Communication (IEC) materials on NTDs approved by the Federal Ministry of Health. The content and messages of IEC materials were reviewed by NTD implementers, non-health actors, civil society groups and religious bodies as well as community members (adult and youth) using the Envision toolkit where stakeholders recommended to adapt, scrap or keep the IEC materials. Recommendations around IEC materials were centred around being more gender or culturally sensitive and improving understanding using appropriate local languages.
- Participatory drawing exercise with secondary school aged children who depicted, in a drawing, their views on an NTD related story about transmission of each of the four NTD diseases to understand what messages would resonate with this group and identify gaps in knowledge.
- Transect walks and Social Mapping techniques were used with different groups of community members (segregated based on age and gender) to identify important structures and stakeholders within communities who could be engaged in MAM.

Recommendations from the above methods were collated into state specific tools which have been called 'Learning packs' and covered both School based deworming and community-based distribution.

# Kaduna and Ogun Evidence Based Learning Packs





# **Participatory Planning**

The participatory planning approach used within the research challenged the existing top-down planning approaches that were previously dominated by national and state Implementers. The participatory planning approach brought together multiple level stakeholders to produce micro plans that responded to local contexts. Examples of the stakeholders that took part in the micro-planning process are listed in Figure 2. In addition, community solutions were also presented.



Figure 2 Stakeholders involved in participatory planning approaches

Through stakeholder planning meetings, context-specific action plans were developed (initially by state level implementers and later on by local level implementers) based on the evidence, to address inequities in coverage due to intersecting issues of gender, religion, age, and marginalisation (people with disabilities and migrants) as well as the changing dynamics of urbanisation (Lar et al., 2018).

Context specific action plans (see Figure 3) formed the basis for enhanced community engagement processes.

Activities	Month	Start Date	End Date	Persons Responsible	Expected Outcome	Budget	Note
Training of teachers							
Training of	June	19/6/2018	20/6/2018	The SMO	To have a	#4000 per	Some may
teachers should				through the	conducive venue	participant	have large
be held in three				Education	that is suitable	covering	number of
classes within a				Secretary (ES)	for learning. The	transportation	teachers to be

# TRAINING AND TRAINING MATERIALS

#### Figure 3 Stakeholders involved in participatory planning approaches

# **Act- Implementing Action Plans**

During MAM 2018, action plans were implemented in four rural and urban Local Government Areas (LGAs) across two states (Kaduna and Ogun). Actions included new or adapted activities related to training, community sensitisation and mobilisation, supervision, reporting and the supply chain. For example, for community sensitisation and the use of IEC materials, community members suggested where they be placed so different groups of people were reached, such as entertainment centres, sporting facilities, women's organisations and moto parks, to increase awareness of the program. In addition, a radio phone-in program helped increase sensitisation (Nuphi and Lebrun, 2019).

Another example was related to additional days for training as suggested by community volunteers (CDDs) and the use of role plays to increase understanding and engagement with training content. MAM 2018 in Kaduna saw the establishment of a new LGA NTD team which helped in the area of supervision and monitoring during MAM. In addition, the LGA head of health who is also the disease control officer, was on hand to provide his expertise.

#### Observations

The entire implementation process was observed and captured through a number of different methodologies to allow for triangulation and differing viewpoints. Through photo elicitation and action logs collected by NTD implementers, the research team were able to document any changes and new strategies used during implementation alongside opinions and reflections on implementing the changes in reality.

Ethnography of the MAM process allowed for detailed observations and discussions in communities which were documented by the research team. This included observing CDD selection, the training cascade, medicine acquisitions and logistics, sensitisation and community mobilisation, medicine delivery to the community and supervision and reporting.



#### **Reflection process**

Following MAM 2018, LGA and State review meetings with stakeholders took place to identify challenges and successes of implementing the enhanced community engagement strategies. Interviews and Focus Group Discussions also took place with a diverse (gender/ age, history of participation in MAM) population of community members in the selected LGAs, and with NTD implementers, to understand what worked and didn't work when implementing the action plans.

Following completion of the first PAR cycle, all evidence produced during the process was analysed and synthesised to create evidence-based implementation tools. The evidence and recommendations from stakeholders at all levels of the health system including communities, frontline health facilities, LGAs, States, and Federal were brought together to produce the *Participatory Guide for Planning Mass Administration* of Medicines to tackle NTDs.

This draws on multi-stakeholder voices with the aim to:

- Support collaborative, participatory bottom-up planning for MAM
- Provide guidance for more equitable community engagement
- Enable implementers to develop context-specific actions

# Participatory Guide for Planning MAM

The Participatory Guide for Planning MAM (PGP) is divided into four colour-coded modules, with two parts to module 2. It is practical, geared to the Nigerian context and designed to inspire action.



# PARTICIPATORY GUIDE FOR PLANNING MASS ADMINISTRATION OF MEDICINES

TO TACKLE NEGLECTED TROPICAL DISEASES



COUNTDOWN

<u>Module one</u> introduces how to use the guide and the roles and responsibilities of different stakeholders involved in MAM. <u>Module two A</u> and <u>Module two B</u> support implementers on how to engage communities and stakeholders in participatory planning, as well as providing examples of agendas which could be used to support planning meetings. <u>Module three</u> supports the development of context-specific (rural and urban) action planning, which is done at State and LGA level, providing examples from evidence of what activities worked and some of the challenges highlighted throughout the research. <u>Module four</u> outlines the need for continual review of MAM to improve equity in treatment coverage and learn from previous challenges.



To support the utilisation of the PGP, an explanatory <u>video</u> for NTD implementers and an enhanced action planning template with context specific examples were developed to accompany this guide.

#### **Challenges of stakeholder engagement**

The PAR approach and methods allowed for the identification and engagement of multiple stakeholders along the spectrum of NTD implementation, recognising their importance and valuable contributions to both the research process and programme implementation, however it has not been without challenges. MAM is time-bound, and dates often change, sometimes at short notice, therefore training of co-researchers and other logistical responsibilities often coincided. The power dynamics of having stakeholders of varying cadres come together to proffer collaborative solution-based decisions was initially challenging. This was overcome by careful negotiation of existing power dynamics by research leads who took time to communicate the value of participatory planning and embedded good communication networks between the core-COUNTDOWN researchers and co-researchers.

For PAR to work well, co-researchers and communities need to have 'ownership' of the research, and although this took time, co-researchers are now leading the way in driving the agenda forward. Capacity strengthening on research skills, communication and facilitation skills has been paramount to the initial success of this new approach and will continue to have a key focus as this project is evaluated and scaled up. The use of participatory methods at community level also allowed for community solutions to ongoing challenges to be identified and shared with programme implementers for consideration. To date this has been rare in the design and delivery of vertical health interventions; yet our experience shows the value of this approach.

#### Sustainability of the new approach

Through heightened interest in this participatory approach to MAM, new stakeholders who wish to engage have continually been identified. A working group was developed after phase 4 of the research to support the development, scale up and sustainability of these tools. The working group is made up of co-researchers as well as other key policy makers and stakeholders in the Federal, State and Local Government health system. They met in Abuja, Nigeria on 24th July, where, in its draft form, the PGP and action planning templates were reviewed and suggestions for changes were made and incorporated. At this inaugural meeting it was decided that the working group would be State specific. Since then, State working groups have continued to meet to support scale up of these tools across Kaduna and Ogun.

The expertise across the team has enabled the development of these tools, which may have the potential to be used for different health issues and within different settings.

"I have tried to go through the PGP, and I quite appreciate that we are trying to use it for NTD. I see it as quite useful that we can even use beyond NTD programme...other programmes in the communities can benefit from this as before we tend to plan for the people without their input and keep wandering why it is not accepted"

Director of Primary Care, Working Group meeting

# **Gender and Equity**

These tools have been developed to increase equity of MAM for all community members including women, youth, migrant populations, children and people with disabilities. Mapping exercises with women, men, leaders in the community and youth helped identify where the different groups of people met, what activities have been, and could be, conducted at these places in relation to mobilisation, sensitisation or distribution of medicines.

Through the use of participatory methods different community groups were able to critically reflect on NTD implementation challenges and identify new social structures and distribution strategies that would reduce challenges faced when trying to access medicines. Women, youth, men, migrant populations and people with disabilities presented different views and how to improve accessibility, acceptability and availability of medicines in relation to their own experiences. Recommendations, such as diversifying CDD selection to include women, helped in some communities to improve access to households in Purdah, or where men are forbidden to enter the household.

"You know if it is a male, he may not be able to enter the house to talk with me but if it is a female, she can enter my house even to my room to talk to me or I can invite her inside myself."

Female community member, Kaduna

# Impact

#### Awareness and Understanding

Through community engagement and increased stakeholder involvement, community members and Heath Systems Actors at different levels within the state have increased awareness of the importance of a participatory approach to MAM. As these tools are now to be scaled up across the two states and evaluated, we anticipate that ongoing and sustained learning about different participatory approaches to planning for MAM will continue to develop. The PGP also provides guidance on how to engage with communities and conduct stakeholder analysis to ensure that all relevant stakeholders are engaged in action planning for MAM, and in reviewing the process, lessons can be learnt and implemented in subsequent distributions.

Through engaging with community members and NTD implementers, key challenges and recommendations for the MAM process have been documented. One of the main areas this research explored was challenges around sensitisation and mobilisation. Important recommendations for IEC material adaptations and use of different social structures have been published in the learning packs and PGP. We anticipate that if this guidance is followed, greater awareness of MAM through effective sensitisation and mobilisation will result in more equitable coverage of MAM in these communities.

#### **Capacity Strengthening**

Increased community and stakeholder engagement have created opportunities for local level 'ownership' of communitybased distribution. This has been observed through stakeholder meetings and captured in interviews with NTD implementers in MAM 2019, as well as demonstrated through working group members driving scale up of these tools across their geographical regions. Increased facilitation skills at meetings, especially with co-researchers, appears to have contributed to a more participatory approach to planning for MAM 2019. This will continue to be observed and formally evaluated as we scale up across the two states.



Capacity strengthening of co-researchers continues to develop as they lead the scale up of the implementation tools. The state co-researchers have been instrumental in strengthening capacity of other implementers who will now use the tools. They have co-designed and delivered a 2-day training workshop as part of the scale up process. Day 1 will be focused around strengthening capacity of skills such as power sharing, knowledge exchange, team building, conflict management, mutuality and respect.

These skills will help to ensure a paradigm shift from the current planning and implementation of the NTD programme through embedding evidence contained in the PGP and other adaptive tools. Participants at the training will be the Local Government NTD programme coordinators (LNTDs), Health Educators (HE) and Monitoring and Evaluation officers (M&E) in Ogun while in Kaduna it will invite LNTDs, assistant LNTDs and Social Mobilisation Officers (SMOs). The training adopts the existing political demarcation of states into three senatorial zones and cluster LGAs within each zone to a central location and delivers the training based on the four-structure modules of the PGP, the use of evidence from the learning packs and context- specific action planning templates.

Key in the agenda will be how to effectively engage communities to identify structures for MAM; how to plan and implement activities related to MAM through the collaborative use of action plan templates. Each participant will be given a copy of the PGP and learning pack as tools to support them in their programme planning and delivery. A training toolkit was co-developed and will utilised moving forward. We continue to evaluate the outcomes of these training workshops throughout the next phase of research.

Capacity strengthening of the core COUNTDOWN researchers has also taken place throughout the PAR cycle. New research methods were learnt, adapted and utilised. Researchers have developed presentation and leadership skills whilst presenting the results at international conferences including an Implementation Research conference held in Bangladesh earlier this year.

# **Policy and Practice**

The tools which have been developed have the potential to be used in a wide range of health programmes and for a range of contexts. We will continue to evaluate and share the impact of these tools on increasing equitable coverage of MAM, as well as the potential to be used in other campaigns, such as school-based deworming.

To influence policy and process within MAM we engage with the National Steering Committee meeting on NTDs which is a biannual event that provides strategic oversight to the implementation of the NTD programme activities in Nigeria. As such, it is a critical activity in shaping the content and implementation of NTD policies and programmatic guidelines. The PGP and intervention tools will be introduced at this meeting by a national co-researcher both in the National Steering Committee and research sub-committee for their buy-in, and potential future inclusion into the NTD Master plan. A <u>short video</u> has been developed to introduce these tools in a visual way. A <u>longer training video</u> has also been developed to support understanding of how to use these tools. The impact of this will continue to be evaluated, and interviews will be conducted to understand how these tools have impacted on policy and practice.

# **Key Recommendations**



- Methods such as transect walks, social mapping, in-depth interviews and focus group discussions with a range of community members can be used to understand barriers and facilitators to participating in MAM that arise from gender, age, disability, geographical location or occupation.
- ✓ To ensure effectiveness of participatory planning for health interventions, engagement with the right stakeholders is essential and will depend on the context in which you work. The stakeholders identified above are some of the ones involved here such as community leaders, Community-Based Organisations, associations and committees, as well as State, Federal, and local Government NTD implementers.
- ✓ Microplanning at LGA level can help ensure that action plans are context specific and support more effective macroplanning at state level. Bottom-up planning also facilitates accountability of health systems.
- Training, sensitisation and community mobilisation, medicine delivery, medicine logistics, supervision and reporting all need to be thought through in detail during the planning stages with local level implementers.

- ✓ Alternative methods of medicine distribution, community sensitisation and mobilisation should be considered to improve equity in MAM, especially within changing contexts such as urbanisation.
- ✓ Review meetings with stakeholders after MAM can help capture what worked well, what were the challenges and what could be improved next time.
- Motivation, incentives and enablers of frontline implementers are important to consider in the planning phase to ensure full cooperation.
- ✓ Tools to support enhanced NTD programme equity should be simple to use and promote ongoing learning for sustainability of new approaches.
- ✓ Co-researchers and stakeholders from all levels of the health system, are key in driving a 'bottom up' approach to policy development.

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