Integrating a gender, equity and human rights focus into national programming on preventive chemotherapy and transmission control for NTDs: A focus on Kwara State, Nigeria

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Key messages

The burden of NTDs is unequally distributed within Nigeria; increased vulnerability and exposure often mean that the poorest individuals and households are the most affected, particularly in rural settings.[1] *Although the distribution of preventive medicines through mass distribution mechanisms is free; social, cultural and economic factors interact to impact the effectiveness and equity of medicine coverage. Using qualitative methods with state and district health providers, community drug distributors (CDDs) and community members to explore their perceptions of the barriers and facilitators to effective treatment coverage and analysed these in terms of accessibility, availability, acceptability and contact coverage. These methods were applied in areas where there were particular challenges to the effective treatment coverage of mass distribution of medicines (based on programmatic treatment data), to support programme decision makers in improving equity in access to mass administration of medicines.*

Availability: Shortages in medicines were reported in Patigi while a surplus was reported in Irepodun. However, clear channels of communication and record keeping facilitate redistribution of medicines at the State and LGA level. Many CDDs incur financial and opportunity costs in their role, this can lead to staff attrition and poorly motivated CDDs. Renumeration, assistance with transport, rain gear and training opportunities are highlighted as ways to support and motivate CDDs to ensure effective distribution.

Accessibility: The timing of MAM meant that some men and women were missed due to their occupation as they were absent from communities during distribution periods. Geographical barriers such as rainy seasons, difficult terrains, and long distances also meant that some populations were missed. House to house distribution methods also resulted in homeless groups not being accessed.

Acceptability: Acceptability is shaped by generation and health belief systems. Youths who perceived themselves as healthy did not see a need to accept medicines. Beliefs such as witchcraft as the cause of illness, and misconceptions of medicines leading to impotency, resulted in rejection of MAM by some religious and nomadic groups. Fear of side effects were a main barrier to acceptability. Adequate counselling, availability of antidotes for side, access to food and liquid formulations of medicines promote acceptability. CDDs who are well known and selected by community members strengthens both the acceptance and trust of the NTD program.

Contact Coverage: Gender shapes access and the level of coverage through interactions at the household; some women require the consent of their husbands to accept MAM, particularly when the CDD is male. This affects equity as many women may be left untreated if CDDs cannot access them.

Focus group discussion with females

Key messages continued…

Effective Coverage: People living with disability people are not addressed by the program and therefore are often further marginalised and excluded from MAM. Distribution strategies mean that women who are frequently pregnant or lactating also miss out of MAM. Children who are not enrolled in schools are also missed where school-based deworming is the only distribution method.

Other Developmental Priorities: Some community members did not consider NTDs as a priority health issue, instead they expressed their need for physical infrastructure; access to clean water was identified as a main priority.

Focus group discussion with male youth

Background :

Over the last 12 months, the Kwara State Ministry of Health in partnership with the World Health Organisation (WHO), Sightsavers, and the Liverpool School of Tropical Medicine (through the COUNTDOWN programme) have been supporting the piloting of WHO's new guidance document entitled: *Towards universal coverage for preventive chemotherapy for Neglected Tropical Diseases: guidance for assessing "who is being left behind and why".*[2] The guidance focuses on supporting programme managers within the Ministry of Health, Neglected Tropical Disease programme to understand who is being left out of current mass administration of medicines (MAM) and why. The aim of the project is to strengthen in-country capacity, as part of ongoing monitoring and evaluation of MAM to identify equity challenges in access to and impact of MAM according to a person's gender, age, disability and other socio-economic factors. The guidance is divided into 4 modules. This policy brief presents findings from module 2 and 3 to support programme implementers at the State, LGA and community level to be able to make recommendations to improve the equity of MAM in future implementation rounds.

Setting: Kwara State, Nigeria

Fig.1 Map of Kwara, within Nigeria[3]

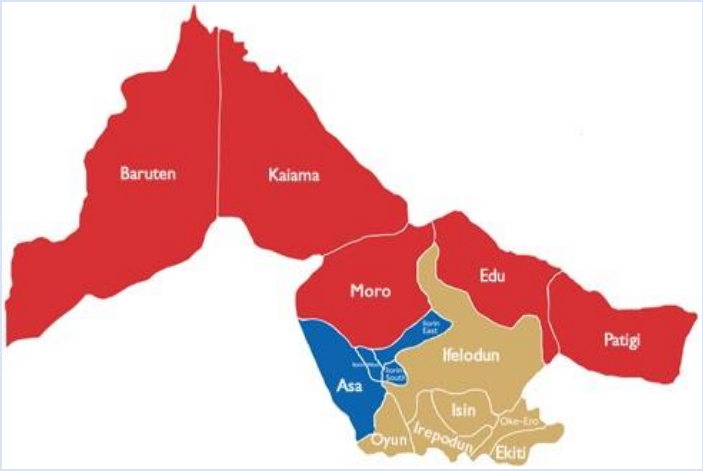

Fig.2 Map of Irepodun and Patigi, located within Kwara state[4]

LGAs that reported relatively low therapeutic coverage were identified through analysis of existing programmatic data in collaboration with the State Ministry of Health. The selected LGAs for the study were: Irepodun and Patigi.

Quantitative Findings:

We first analysed routine programmatic data to identify areas that were experiencing relatively low therapeutic coverage or from more in-depth analysis, showed possible equity challenges in treatment outcomes. From the quantitative analysis, Patigi and Irepodun were selected as qualitative study sites as they both showed relatively low therapeutic coverage (78% and 79% respectively) during onchocerciasis/LF MAM and variation in therapeutic coverage (94% and 91% respectively) during school-based deworming. These LGAs allowed for inclusion of the two main ethnic groups in Kwara (Nupe and Yoruba) within the qualitative study sample. Programmatic data was taken from the year 2017 in Kwara State.

Quantitative analysis across all LGAs, reveals very limited inequity across treatment coverage. However, across all data sets, establishing hotspots of inequity in coverage data was possible when analysing data at sub-LGA level (ideally school and community level). For example, when considering equity of medicine distribution at lower levels, in relation to onchocerciasis/LF treatment, some 40% of communities fall outside of a programmatically relevant equity threshold (m:f treatment coverage ratio is smaller than 0.85 and bigger than 1.15).

School-based deworming data showed the same trend with 31% of schools falling outside of a programmatically relevant equity threshold (m:f treatment coverage ratio of school enrolled children is smaller than 0.85 and bigger than 1.15); this did not include single sex schools. Across all LGAs, in 22% of health facilities there were no female CDDs. Conversely, only 4.5% of health facilities had 100% female CDDs and only 22% of facilities had an even split of CDDs (45%-55%). Where there was an uneven CDD split, this was in favour of men 80% of the time. CDD workload also varied at the health facility level, with some CDDs expected to treat approximately 100 people and some expected to treat approximately 9000 people. Teachers workload also varied dependent on location, with treatment per teacher a minimum of 4 and maximum approximately 10,000. This reflects a similar trend in the % of teachers who were trained which ranges from 27% to 100% i.e. where it is 100%, one teacher has been trained and had to administer all treatments, indicating a weakness in the training cascade system. This is the case 94% of the time.

Qualitative Methods:

A total of 52 interviews consisting of 23 Focus Group Discussions (with CDDs, teachers, and community members disaggregated by age and gender; see fig.1), and 29 Key Informant Interviews (KIIs) at State and LGA levels were conducted. Interviews were recorded, labelled and transcribed. Data was thematically analysed using a framework approach.[5] The five dimensions of the Tanahashi framework for effective coverage: availability, accessibility, acceptability and contact and effective coverage informed analysis.[6]

Qualitative Findings

Availability: *The ratio between availability of resources – such as medicine supply, human resources, facilities – and the size of the target population gives the measurement of availability coverage*[6]

Effective redistribution of medicines ensures availability when there are shortages in supply. Although Patigi reported underestimates in drug supplies, clear protocols and channels of communication facilitate distribution when more medicine is required. CDDs, Local Government NTD coordinators (LNTDs) and the storekeeper communicate between each other to obtain the required amount of medication. Clear records document the total amount of medication collected and the total amount that is returned to the store. When more medication is requested, this is taken from the supplies that have been returned and then re-distributed to areas where there are shortages. The records are also used to review estimates for the following year, to improve estimations of supplies. LGA staff and CDDs reported that this process is working well in both Patigi and Irepodun and should continue to ensure availability of medicines in these areas.

'No, there are usually no remnants. It is just enough because we work towards achieving target population…Usually some communities have more medicines than others and I have all the records with me; should we run short of medicines in any community I know who to call to get more medicines for the communities in need of more medicines.' (LGA Health Staff, Male, KII, Irepodun)

Financial and opportunity costs of CDDs lead to staff attrition which can mean medicines are not available in some areas due to a lack of or poorly motivated CDDs. The financial and opportunity costs of being a CDD are a key factor that shape programme equity as dissatisfaction amongst CDDs can lead to attrition and some communities, particularly those that are geographically isolated not being reached as additional costs and travel expenses are required to access them. Lack of incentives and provisions, such as rain gear and bags also lead to staff attrition. Training is a key motivator for CDDs, as it is perceived to be an opportunity for increasing knowledge and strengthening social networks. Therefore, it is widely suggested that incentives such as higher renumeration and assistance with transport should be provided, in addition to training and career development opportunities, in order to support and motivate CDDs for effective distribution.

'The knowledge acquired during the training is one of the benefits. Apart from this their prestige in the community rises as they are viewed as important people in their community; this is because their community see them as people who have medical knowledge...It also increases their social network as they get to know more people during the course of their work.' (State Health Staff, male, KII, Irepodun)

Accessibility*: Even if services are available, they must be located within reasonable reach of the people who should benefit from it. The capacity of the service is limited by the number of people who can access it.* [6]

Timings of distribution, livelihoods and geographic isolation affect how people access medicines. Some women and men are missed during MAM due to their livelihood activities; working in the market and farms means that they may be absent from communities when distribution takes place. It is recommended that days for distribution are extended, including evenings so community members can be reached. Distribution at the market is also suggested in order to reach women who may have been missed. Difficult geographical terrains were described by CDDs and community leaders as negatively influencing access to medicines for communities across Patigi and Irepodun. Poor road networks, far distances and rainy seasons result in CDDs being unable to access people living in hard to reach areas.

'…during farming season, you will hardly meet people at home so if you go in the morning and don't meet them you need to revisit in the evening' (LGA Health Worker, male, KII, Irepodun)

Nomadic groups, such as the Fulani are less likely to have access to medicines during MAM due to language barriers and past conflicts resulting in negative perceptions of them by CDDs. However, State NTD staff and CDDs mentioned that by sensitising and recruiting CDDs from their own communities, nomadic groups are more likely to be accessed and to accept medicines as this will address language barriers and mistrust in the health system.

''We are scared of them because there are claims they usually kill people. But we can pick CDDs from among them that can help us bridge the gap and so allay our fears' (LGA Health Staff, male, KII, Irepodun)

Homeless people are excluded during MAM as they are also missed during house to house distribution due to having no fixed address. Therefore, it is suggested that fixed point distribution as well as house to house distribution of medicines may be a strategy of improving community access to medicines, especially for homeless and nomadic groups.

Acceptability: *Even if services are available and accessible, it still needs to be acceptable by the population. Acceptability coverage is influenced by people's perceptions, expectations for health services, and personal beliefs.* [6]

Acceptability is affected by cultural and religious beliefs, and also shaped by generation. Health belief systems as well as fear and misconceptions of possible side effects, such as medicines leading to impotency result in rejection of MAM by religious (Apostolic and Deeper Life churches and some Muslims) and some nomadic groups, such as the Fulani. Community members who believed the cause of illness to be witchcraft were less likely to accept the medicines as they perceived it as a condition that cannot be treated using conventional medicine; many therefore seek care from traditional healers. Religious beliefs were also expressed as a barrier for some groups in accepting the medicines as some stated their belief that prayer is all they need to heal from illness, not medicine. However, religious institutions can also positively influence groups to accept MAM as religious leaders often play a key part in announcing health messages and distributing medicines in places of worship.

'If you could recall, sometimes ago, there was this news that immunization that was given in the northern part affected children, others became impotent and some became HIV positive so all these makes people afraid of just taking medicines given to them.' (LGA Health Staff, female, KII, Irepodun)

'You know there are people that do not believe in taking medicines. They believe all they require is prayers and that will be enough' (LGA WASH Staff, KII, Irepodun)

Many youths perceive themselves as healthy and do not see a need to accept medicines. Older people, on the other hand, were more likely to accept medication due to positive experiences of taking the medication and having seen the long-term benefit in communities. Services and sensitisation, which are age-appropriate may encourage young people on the uptake of MAM.

'Some youths do not like it; for instance if my mother should collect the medicine for me I will tell her that there is nothing wrong with me and I will not use it. Some will pretend they have taken the medicine but do not really use it as they usually claim there is nothing wrong with them.' (Youth Female, FGD, Irepodun)

Community leaders are often gatekeepers in not only granting access for CDDs to enter communities, but also in encouraging acceptability and uptake of MAM. Lack of sensitisation leads to rejection of MAM and therefore inequities in coverage. When community members are found to be unwilling to accept the medicines, community leaders are often involved to encourage and inform groups on the benefits of the medicine. In some cases, community leaders warn members that they will be expelled from the community if they refuse the medication. While this raises ethical concerns, it highlights the strong influence of community leaders in shaping medicine acceptance.

'We normally report them to the village heads or the head of clans that is close to them. I once witnessed a case where the head of the clan warned that those who refused the medicine will be expelled from the community so they don't become a problem to those who have taken the medicine.' (LGA NTD Staff, male, Patigi).

Sensitisation is critical in building awareness and therefore acceptability of MAM. Adequate counselling is critical in informing community on the benefits of medication and to clear misconceptions.

There may be inequities in accessing health messages as people who live and work in far distances may miss announcements by the town crier. Therefore, various modes of sensitisation are recommended, such as radio, health talks at festivals, social media and ICE materials. However, this needs to be communicated in different languages as many tribes, who do not speak Yoruba or English miss out on sensitisation.

'…places where legs cannot reach, radio can reach…when the town crier announces, it is not everybody that will possibly hear it so it will be better if awareness can be done through posters, social media, television and radio because a lot of people listen to news.' (Men, FGD, Irepodun)

Community selection of CDDs promotes trust within the community and was a facilitator to acceptability. CDDs, who are well known, and respected members of the community are trusted and therefore, people are more willing to accept medication from them. Health staff, community leaders and youth groups in Patigi and Irepodun mentioned that they will be more responsive to people they are familiar with. Medicine is most likely to be rejected if they are delivered by CDDs who are unknown to the community.

'you see the CDDs are crucial in acceptance of the medicine. For instance if one of the people present here who is my friend happen to be among the CDDs even if I do not want to collect the medicine before I can be encouraged to take it. If you just go and pick one old woman that I am not familiar with, I will not even respond to her' (Male youth, FGD, Irepodun)

Lack of trust and fear of 'fake doctors' was mentioned as a barrier to acceptability by community leaders in Patigi and Irepodun. Therefore, CDDs who are well known and selected by the community can foster trust in the health system. Uniforms are also suggested so that CDDs can be identified and recognised.

'When people see them with their uniform they easily identify them as distributors and this motivates the people to participate.' (LGA Health Staff, male, KII, Irepodun)

Fear of side effects are a main barrier to acceptability. Many community members refuse to take the medicine, citing adverse reactions such as rashes and dizziness for Meticzan and Albendazole; vomiting and weakness were particular side effects described for school aged children after taking Praziquantel. However, adequate counselling and the provision of antidotes for side effects, such as glucose, vitamin C and Piriton are facilitators for medicine acceptance; although shortages of these supplies were reported in schools. Access to food is also described as an enabler as children are encouraged to take Praziquantel on full stomachs. Liquid formulations are preferred, as elderly people and children struggle with swallowing the tablets therefore syrups or injections could increase the acceptability of medicines.

'if they can reform the praziquantel, so that it can come in different form, such as in liquid, or injection form, so that they student will make their choice whether liquid, tablet or injection. When comes to that tablet if they can sugarcoated it so that it will be sweet.' (State NTD Staff, female, KII, Kwara)

Contact Coverage: *This includes the people who use the service; the actual contact between the service provider and the user.* [6]

Gender shapes access and the level of coverage through interactions at the household - although this varies between Patigi and Irepodun. State NTD staff and CDDs mentioned cases where some women amongst the Hausa, Islamic and nomadic communities have refused medicines because their husbands or male relatives were not present. The gender of CDDs also impacts coverage as male CDDs described requiring permission of husbands before they can enter households or talk to females; male CDDs often have to re-visit when their husbands are present. This affects equity as many women may be left untreated if CDDs cannot access them. Therefore, considering a balance in gender when selecting CDDs can promote equity and increase effective coverage.

…if you come here now, and just enter straight to meet the women, the women will not swallow the drugs in the absence of their husbands, because if they take it without the husband's consent, if any side effect occurs, the husband will say, who told you to take the drugs? But if it is with the man's permission, they will know how to settle it. (Adult Male, Patigi)

However, there were some cases in Irepodun where women are said to not need the permission of their husbands after attending awareness campaigns. A female LGA NTD staff explained that it is often women who collect the medicines on behalf of their husbands. However, she explained that perceived gendered roles of women as nurturers often mean women do not take the medication themselves, instead they distribute it to others.

CDD selection processes are linked to gender norms. There are more male than female CDDs in Patigi due to perceptions of women as the weaker sex and unable to walk long distances, compounded by their lack of transport (e.g. a motorbike) ownership. Some women mentioned lack of knowledge of MAM and the roles available to them as well as requiring consent from male household heads to participate in MAM as a CDD. This highlights a need for the inclusion of women by the program and community leaders to increase female participation and selection.

'The CDDs should be encouraged and more females should be accepted though they are seen as the weaker sex and may not be able to do the work for long but with encouragement they can do the work.' (LGA NTD Staff, Patigi)

Conversely, it was reported that there are more female CDDs than male in Irepodun. This was attributed to a higher population of females in the community, perceptions that women work harder, and that females complain less about poor pay than men. Gendered roles are also a factor as men are perceived to be providers of the family and seek more profitable opportunities, while women's perceived role as nurturers enable them to fulfil roles as CDDs.

Therefore, selection strategies to promote gender equity amongst CDDs may need to be context specific and support in place to ensure the role is appropriately supported and remunerated.

'They work even better than their male counterpart; I told you earlier that the male usually look down on the stipend claiming the one thousand five hundred naira…it is easier to persuade the women than men. Moreover the men bear the brunt of providing for their family so it is easier for them to look for more profitable opportunities.' (LNTD, KII, Irepodun)

Effective Coverage: *a stage in service provision where a service performance that is appraised as satisfactory by specific criteria is achieved. The number of people who have received satisfactory service is thus another measurement of service output.*[6]

Pregnant women and breastfeeding women, children under 5 years old and those that are sick are exempt from MAM. However, this can result in inequities in coverage for women, who are frequently pregnant/breastfeeding and are therefore vulnerable to protracted NTD infection as they miss multiple NTD rounds during their reproductive years. The importance of establishing registers and a clear process for follow ups on people who were previously excluded due to the criteria (pregnant and breastfeeding women and children under 5) but are now eligible for MAM was highlighted by state health workers. Children who are not enrolled in school also miss out on MAM when school distribution activities do not actively prioritise their engagement, the programme therefore needs to consider ways in which to reach them.

'We have such cases; it is everywhere. We need to sensitize them by telling them about family planning and the need to space their children.' (LGA NTD Staff, female, Irepodun)

People living with disabilities are not specifically addressed in training, therefore many are missed out during MAM.

Many CDDs mistakenly regard people living with disabilities as 'sick' and therefore ineligible for treatment; this results in inequities in coverage and poor treatment outcomes as they cannot access the medicine. The poles used for determining treatment dosage by height also do not make provision for measuring individuals with physical disabilities or wheelchair users, nor is there clear guidance to CDDs on how to address the issue. It is suggested that for MAM to be disability inclusive, community links should be strengthened to direct CDDs to people with disabilities. Clear training should also be implemented to differentiate between people who are excluded due to sickness and those living with disability but are eligible for MAM; this should also include guidelines for people who do not measure up to the dosage poles.

'The blind and deaf are treated, the only ones they don't treat are the 'dwarfs' and disabled.' (CDDs, FGD, Patigi)

Other Development Priorities:

Some community members did not consider NTDs as a priority health issue; structural barriers, such as access to clean water was identified as a main priority by community members. This was highlighted by women, particularly in the rural communities of Patigi and Irepodun, which raises equity issues as it is usually women who bear the burden of fetching water from wells and other water sources, increasing their exposure to many waterborne NTDs.

*'The needs are many. First is hospital and then eradication of those diseases. we also need clean water …The issue of water is really a challenge for us because sometimes we are so tired that going down to the stream will be a real problem for us…*We don't have good water here.' (Women, FGD, Patigi)

The importance of clean water in relation to health was widely recognised. Collaboration with WASH was recommended by NTD staff and community members to increase access to clean water and toilets, and in the integration of health messages. State staff believe that if WASH also incorporate NTD messages in their health promotion activities, it will give 'credibility' to the NTD campaign.

'It's not only chemotherapy alone you also need to take the environmental factor into consideration too. WASH can never be over emphasised on the issue of eliminating NTDs in Nigeria and in Africa.' (State Staff)

Recommendations:

- This research has highlighted equity challenges in the delivery of MAM; specific groups are often missed due to gender, age, disability, nomadic and socio-economic factors, including homeless groups and children who are not enrolled in schools. Possible recommendations are suggested in order to address these gaps in coverage.

- Renumeration, assistance with transport and providing raingear are highlighted as ways to support and motivate CDDs in their role, for effective distribution. Training and career development opportunities are also key motivators for CDDs.

- A balance in gender should be considered when selecting CDDs to promote equity and increase patient accessibility and acceptability. Increasing the inclusion of women by the program in participation and selection can aid in accessing more female community members and increasing their uptake of MAM.

- The community should be actively involved in CDD selection and selecting CDDs from nomadic groups should also be selected; this can address language barriers and increase acceptance of MAM.

- Training should be disability inclusive - clear guidelines to differentiate between those who are excluded due to sickness and those living with disability but eligible for MAM should be implemented; this should also include guidelines for people who do not measure up to the dosage poles.

- Extending days for distribution, including during the evenings can increase coverage, especially for community members who work away on farms and market days. Fixed point distribution as well as house to house distribution of medicines may be a strategy of improving community access to medicines, especially for homeless and nomadic groups.

Recommendations continued…

- Various modes of sensitisation and community engagement are recommended, including; radio, health talks at festivals, town gatherings and ICE materials. Messages should be communicated in local languages to be inclusive of people, who do not speak Yoruba or English. Community and religious leaders should be actively involved in sensitisation activities, through a people centred approach, by counselling community members and addressing any concerns regarding MAM. Consider age appropriateness of services and sensitisation should be age-appropriate to encourage young people on the uptake of MAM.

- The provision of medication to counteract the side effects, such glucose, vitamin C and Piriton can increase acceptability and coverage. Medication in liquid forms for children and elderly people are recommended.

- Establish clear process for follow ups on people who were excluded (pregnant and breastfeeding women and children under 5) but are now eligible for MAM, through the use of registers. The program should also address reaching children, who not enrolled in school, and miss MAM activities.

- Intersectoral collaboration: integration and collaboration with WASH is recommended. Provision of clean water and sanitation is key, as well as integrating health messages.

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Acknowledgements:
We would like to thank the data collection team who were essential in allowing this study to take place. We would also like to thank Karen Miller and Kelly Smyth for their support with the production of this brief. Our greatest thanks go to all the participants who gave their time and valuable contribution to this study.

COUNTDOWN
Calling time on Neglected Tropical Diseases

Sightsavers

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