South Sudan ARISE - END Fund

Results from the Gender Equity and Social Inclusion (GESI) Assessment in Awerial County

Photo credit : South Sudan Ministry of Health

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Introduction

South Sudan ARISE

The END Fund's Accelerate Resilient, Innovative, and Sustainable Elimination of Neglected Tropical Diseases (NTDs) Fund, known as the ARISE Fund, is the second phase of a direct philanthropic response to the UK FCDO funding cuts to Neglected Tropical Diseases (NTDs) in 2021. The ARISE Fund, running from 2022 to 2025, invests in Burkina Faso, Ethiopia, Kenya, South Sudan, and Senegal. It emphasizes sustainability and focuses on country leadership to accelerate progress towards eliminating NTDs.

South Sudan is affected by a high burden of NTDs, most of which are preventable and/or treatable but pose severe health, economic, and social challenges. The country continues to experience persistent disease transmission of trachoma, onchocerciasis, lymphatic filariasis (LF), schistosomiasis and soil transmitted helminthiasis, despite ongoing Mass Drug Administration (MDA) efforts. Further information on NTDs in the country can be found in the South Sudan NTD Master Plan 2023-2027 and on the ESPEN portal: [South Sudan | ESPEN (who.int)]

The intersection of gender equity and social inclusion (GESI) factors has emerged as a critical area influencing MDA uptake, adherence, and overall program success. In South Sudan, the ARISE team is investigating GESI related barriers which can inhibit equitable access to MDA in order to enhance its delivery and eliminate NTDs nationwide. The END Fund has partnered with WI-HER, a woman-owned small business dedicated to co-creating holistic, integrated solutions grounded in data and experience through a blend of behavior change, human-centered design, and organizational improvement science,

as well as the Christian Blind Mission and The Carter Center. These organizations, in close collaboration with the South Sudan Ministry of Health (MOH), are conducting root cause analyses (RCA) and GESI assessments in two counties of South Sudan - Kapoeta North and Awerial. Both counties are endemic for trachoma, with Awerial also highly endemic for LF and onchocerciasis.

This report presents an overview of the findings from the RCA and GESI assessment conducted in Awerial County between October 2 and October 14, 2024, along with thematic analysis of the results, challenges and key recommendations.

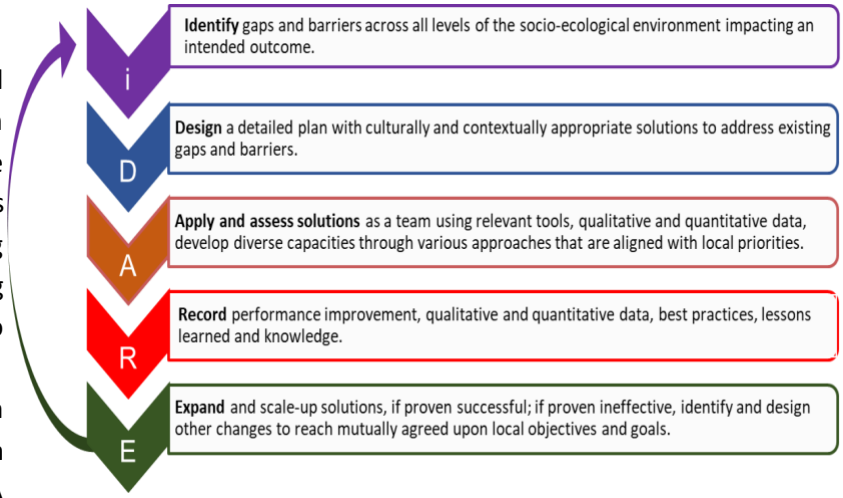
Root Cause Analysis & GESI Assessment

In October 2024, a core GESI Team comprising the MOH GESI Focal Person and a WI-HER Consultant traveled to Awerial to conduct an RCA and GESI assessment. Our approach looked at the intersection of gender with other social inclusion factors for a nuanced and contextualized understanding of GESI challenges, barriers, and opportunities, as they relate to and influence or shape provision, access to and use of/uptake of medicine during MDA for onchocerciasis and LF. By defining GESI related factors, the assessment's objective was to help answer a series of key programmatic questions around MDA absenteeism and systematic non-compliance, the supply- and demand-side factors and necessary strategies around MDA, and critically, the persistence of onchocerciasis and LF prevalence despite numerous rounds of MDA.

Objective

To identify GESI-related constraints and opportunities in Awerial County that affect the provision, uptake and adherence to MDA for onchocerciasis and lymphatic filariasis, and to develop actionable recommendations for future MDA rounds.

Methodology



The approach for the RCA and GESI assessment was based on WI-HER's iDARE methodology (see graphic to the right). WI-HER has previous experience of applying iDARE through a rapid RCA using KoboToolbox for USAID's Act to End Neglected Tropical Diseases | East (Act East), as well as through the RCA previously conducted in Kapoeta North. The RCA questionnaire used for Act East was used as a template and, through stakeholder meetings and review by the MOH, Christian Blind Mission, The Carter Center, and WI-HER in early July 2024, a newly updated version of the questionnaire was developed on the KoboToolbox platform for deployment in Awerial County. The questionnaire includes a request for consent and description of the project; questions in the tool could not be filled if participants chose "no" when asked for consent. Furthermore, in order to address barriers for MDA and ensure that future treatment campaigns for onchocerciasis and LF are community-informed and driven, WI-HER engaged and trained community influencers and conducted stakeholder meetings.

The RCA and GESI assessment in Awerial county employed a mixed-methods approach, including a Root Cause Analysis (RCA), Focus Group Discussions (FGDs) and Key Informant Interviews (KIIs). The quantitative component involved the collection and analysis of both

primary and secondary data through the RCA to provide measurable insights. This was complemented by qualitative methods, including FGDs, KIIs, observation, and the minutes from stakeholder meeting(s), which offered deeper, contextualized and evidence-based understanding. This combination ensured a holistic examination of GESI factors influencing MDA initiatives, allowing for a thorough exploration of both statistical trends and lived experiences.

Study Area

The assessment was meant to be conducted in the selected payams of Alel I, Bun-Agok, and Puluk within Awerial County, South Sudan. These payams were selected based on criteria including low MDA coverage, high rates of absenteeism and refusal to participate in MDA, significant prevalence of onchocerciasis and LF, accessibility, and potential for future MDA rounds. However, many of these villages were ultimately excluded because they were inaccessible—either by vehicle, due to flooding, or on foot, due to the long distances involved. These logistical constraints necessitated changes to the village selection process to ensure that the assessment could be effectively carried out in accessible areas. Replacement villages were chosen based on accessibility and low MDA coverage.

Sampling Design

Inclusion Criteria:

- Community members of diverse ages (with a minimum age threshold of 15 years), genders, and disability statuses.
- Individuals who did not participate in the most recent MDA round
- MDA implementers and health workers involved in conducting MDA.
- Local leaders, including religious and community leaders, who influence health-related decision-making in the community.

Exclusion Criteria:

- Persons unwilling or unable to provide consent
- Persons who were treated during the last MDA in Awerial county
- Persons under the age of 15

Sampling Strategy:

- Simple random sampling was used to ensure a diverse range of participants, with a focus on capturing variations in gender, age, and disability status and ensuring that individuals who did not receive MDA had an equal chance of selection

- Approximately 244 participants (one person per household) were included, divided across FGDs and KIIs. Participants for the FGDs were chosen randomly from those who missed the last MDA.

To calculate the sample size of 244 participants out of a total of 661, we used the sample size formula for a finite population. The most common formula is:

$$n = \frac{N \times Z^2 \times p \times (1-p)}{(E^2 \times (N-1)) + (Z^2 \times p \times (1-p))}$$

Where:

n is the sample size.
N is the population size (661 refusals).
Z is the Z-value (the number of standard deviations corresponding to the desired confidence level, e.g., 1.96 for 95% confidence).
p is the estimated proportion of the population with the characteristic of interest (often assumed to be 0.5 if unknown, as this maximizes the sample size).
E is the margin of error (e.g., 0.05 for 5% margin of error).
The calculation confirms that a sample size of 244 individuals is appropriate for a population of 661 refusals, with a 95% confidence level and a 5% margin of error.

- The sampling approach was carefully crafted to ensure a broad and diverse range of participants, with particular attention to variations in gender, age, and disability status, to promote inclusivity.
- A representative sample was selected from the entire population of Awerial County. This will be achieved using an online sample size calculator to determine an adequate and statistically significant number of participants.
- The sampling was further enriched by incorporating targeted Focus Group Discussions (FGDs) and Key Informant Interviews (KIIs).
- This combined strategy not only facilitated the triangulation of data but also enhanced the accuracy, reliability, validity, and depth of the analysis, ultimately leading to well-founded conclusions, actionable recommendations, and valuable lessons learned.

Data Collection

Focus Group Discussions (FGDs):

- Nine FGDs were conducted with different community groups, such as women, men, youth, and herders.
- Each FGD consisted of 6-10 participants and lasted between 1 to 1.5 hours. This number was deemed adequate to reach thematic saturation.

- Key Informant Interviews (KIIs):
    - Five KIIs were conducted with health workers, MDA implementers, and local leaders.
    - Each KII lasted approximately one hour.
- Observation:
    - Observation research methods were used to systematically record behaviors and interactions within a specific context, utilizing tools like checklists, field notes, and recording devices.
    - This method gathered qualitative data, offering insights into behaviors and social dynamics not captured by surveys or interviews.
- Data Collection Instruments:
    - Semi-structured interview guides were used for both FGDs and KIIs, developed to explore GESI-related issues in the context of MDA.
    - Data was collected digitally using tablets via the KoboToolbox software, ensuring efficient and accurate data capture in the field. The data, including non-anonymous information, is securely stored on encrypted servers within KoboToolbox and a locked WI-HER Google Drive, with access restricted to authorized personnel only.
    - Personal identifying information (PII) will never be shared in reports or any other public documents. Instead, all reports will utilize anonymized data, ensuring the privacy of respondents is protected throughout the analysis and reporting process.

Data Triangulation

Meetings with stakeholders, including local authorities such as the Commissioner, County Health Director, and Executive Director were conducted to discuss current challenges, possible findings during the RCA and better understand the local context. Then, through meetings with the Ministry of Health, The Carter Center, Christian Blind Mission, and WI-HER, the RCA and GESI assessment data findings and analysis was discussed and validated.

Data Analysis

- Quantitative Data:
    - Descriptive statistics were used to analyze quantitative data from existing MDA records, focusing on coverage rates, absenteeism, and non-compliance.
    - Descriptive statistics were used to analyze quantitative data from the RCA questionnaire (see “Findings & Thematic Analysis).
- Qualitative Data:

- Thematic analysis using NVivo software was conducted on qualitative data from FGDs and KIIs, identifying key themes related to GESI factors that impact MDA.

Stakeholder Meetings

Logistical planning for the RCA and GESI assessment in Awerial involved selecting and training data collectors and securing approval from local health authorities. This was facilitated through collaboration with the County Health Director (CHD) from the Awerial County Health Department and the State NTD Coordinator in Lakes State. These officials played a key role in identifying and mobilizing county stakeholders and ensuring buy-in. These meetings provided the assessment team with valuable insights into the previous MDA rounds and helped frame the requirements for ensuring the success of future MDA campaigns.

Training of Data Collectors

Facilitated by the MOH, in partnership with WI-HER, The Carter Center and Christian Blind Mission, the training of data collectors focused on data collection approaches, techniques, and the use of the KoboToolbox and the FGD and KII templates. It emphasized the importance of interpreting the questions effectively, maintaining data quality and confidentiality, and properly handling the digital tablets used for data collection. Participants were encouraged to acquire new knowledge and skills.

Training of Community Influencers

Community influencers, such as local leaders and respected figures, are essential advocates for a successful MDA campaign. They can enhance trust and credibility, effectively communicate the benefits of MDA, and reach underserved areas. They facilitate better community engagement, promote behavior change, and ensure culturally sensitive approaches. Their involvement is crucial for increasing participation, inclusivity and ownership of MDA interventions, improving program effectiveness, and achieving better health outcomes.

A comprehensive training session was held on the 13th of October at the County Health Department (CHD) office, bringing together 15 Community Influencers, 5 of whom were females. Participants were carefully selected based on preliminary findings from stakeholder meetings and interviews with data collectors. The session focused on equipping participants with essential knowledge and skills for onchocerciasis and LF prevention, control, and elimination. Through the training, significant gaps in onchocerciasis and LF efforts were addressed, and the critical roles of the Community Influencers in driving behavior change were emphasized. The training concluded with the understanding that a county GESI team will be formed after a planned behavioral change training which will be conducted in the first quarter of 2025. Boma Chiefs underscored the importance of involving local authorities in grassroots initiatives. Key objectives included understanding disease transmission, defining iDARE, the importance of behavior change techniques, and addressing barriers to MDA access and acceptance.

Challenges

There were a few major challenges faced by the assessment team during administration of the RCA and FGDs/KIIs:

1. **Logistical issues in Awerial County (e.g., transportation, security, etc.):** The data collection process in Awerial County faced several significant challenges that impacted the effectiveness and efficiency of the assessment. One of the primary logistical issues was related to transportation and security concerns. The vehicle hired for the assessment could not accommodate the entire team at once, necessitating two separate trips for deployment in the field. This logistical limitation resulted in delays that adversely affected the overall timeline of data collection.
2. **Difficulties in getting representative voices, especially from marginalized groups:** Additionally, difficulties arose in capturing representative voices, particularly from marginalized groups like nomadic pastoralists, within the community. Mobilization efforts were often complicated by personal interests and heightened expectations from local authorities, who were required to support the assessment team. This mixed motivation created challenges in engaging the target populations effectively and gathering diverse perspectives that accurately reflect the community's needs.
3. **Language or cultural barriers in conducting the FGDs/KIIs:** Language and cultural barriers further complicated the data collection process during FGDs and KIIs. Most discussions were conducted in the Dinka language without immediate interpretation for WI-HER's consultant to review and ask further questions. This linguistic challenge made it difficult for the consultant to extract key insights and significant information essential for identifying critical issues and developing appropriate solutions.
4. **Community resistance:** While community resistance was generally minimal, there were isolated instances in Kackuot village where resistance was noted; many households were found unoccupied, as residents had left for their daily activities by the time the assessment team arrived in the afternoon. Among those present in their homes, there was initial hesitance to participate in the discussions. However, with the help of community elders and interpreters, who played a crucial role in encouraging participation, the community members gradually became more receptive and engaged. The attitude of the participants noticeably shifted once they were reassured and persuaded to take part in the discussions, showing that effective communication and understanding of local dynamics were key to enhancing community engagement. However, this resistance did not extend to other areas within Awerial County, allowing the majority of data collection efforts to proceed with relative acceptance from the community. Overall, addressing these challenges is vital for improving future assessments and ensuring more robust and representative data collection processes.

Solutions Applied & Lessons Learned

As the assessment team navigated the above dynamics and challenges, they made changes to their approach in order to successfully complete the GESI assessment in Awerial county. Here are some lessons learned and solutions which were applied:

1. To resolve challenges related to community resistance, the team **engaged local community members**, which facilitated a deeper understanding of the cultural and social dynamics within the areas assessed. The involvement of community leaders in mobilization efforts helped to foster trust and encourage participation in the data collection process.
2. In response to logistical issues, the team was highly **flexible** in adapting to on-the-ground realities, such as adjusting timelines and strategies, which was beneficial in navigating the complexities of the local context.
3. One significant lesson learned is the **need for better logistical planning, particularly regarding transportation and security measures**. Ensuring that adequate vehicles are available to accommodate the entire team at once could help mitigate delays and enhance the efficiency of the data collection process. Additionally, establishing contingency plans for transportation and security challenges would be prudent to maintain the assessment timeline.
4. A key lesson learned involved the need to **refine strategies for capturing representative voices, particularly from marginalized groups**. Future assessments should focus on **establishing strong partnerships with local authorities and community organizations** to foster meaningful engagement with diverse populations. **Clear communication of expectations** with local authorities, alongside emphasizing the necessity of inclusive participation through the application of strict selection criteria, can help mitigate the conflicting motivations observed during the recent assessment.
5. Addressing language and cultural barriers is also essential for future assessments. Although interpreters/translators were identified and trained, **further training** for these individuals in the assessment methods could help bridge communication gaps and ensure that key insights are accurately captured. Additionally, offering training on cultural sensitivity for the assessment team can enhance the quality of interactions with community members, leading to richer and more nuanced data collection.
6. Lastly, while community resistance was minimal overall, **understanding the underlying reasons for resistance** in specific areas, such as Kackuot village, is vital. Engaging with communities to address concerns and enhance transparency around the assessment's purpose can help mitigate any potential resistance in future assessments.

In conclusion, by leveraging successful strategies while addressing logistical, engagement, language, and community concerns, future GESI assessments in South Sudan can be more effective and inclusive, ultimately leading to better-informed programming and interventions.

Data collectors and interpreters training, October 2024, Awerial County.
Photo credit: South Sudan Ministry of Health

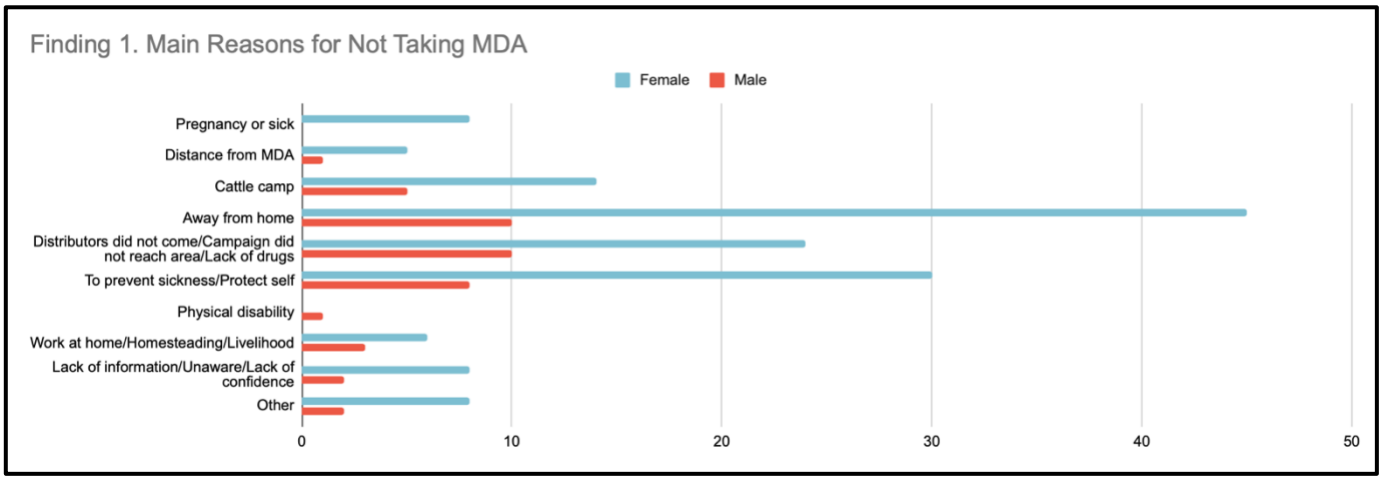
Findings from the RCA and Qualitative Interviews

General Findings

The RCA in Awerial county was conducted with a total of 190 respondents, including 148 female respondents and 42 male respondents. The imbalance between male and female respondents was mainly due to unavailability of male community members, who were invited to be included but generally stated that they did not have the time or were uninterested in participating. Respondents came from 4 payams (Alel I, Alel II, Bun Agok, and Puluk), 6 bomas (Duony-Gok, Kalthok, Ming-Kaman, Aguarkuoth, Jarweng, and Thanytoch), and 13 villages (Agreed, Aguarkuot, Alel, Bun Agok Centre, Hanten, Kackuot, Kamich, Mabil, Maguok, Mariik, Nhom-diang, Thanytoch, and Tong Liet).

Additionally, findings were supported by 9 FGDs and 5 KIIs. FGDs were conducted with internally displaced persons (IDPs), elderly persons, youth, persons with disabilities (PWDs), nomadic pastoralists (separately with females and males), male community members, and female community members. FGDs were conducted in Kamich, Aguarkouth, Magok, Dor Village (Rearmonydan cattle camp, Mingkaman, Kackout Village, and Bun Agok Payam. KIIs were conducted with the County NTD Focal Point, County Health Department Director, Boma Health Workers (one female and one male), and the County NTD Surveillance Officer. KIIs were all conducted in Mingkaman. In total, there were 62 participants in FGDs and 5 participants in KIIs.

This report includes high level findings from the RCA and qualitative interviews, as well as a thematic analysis, challenges, and recommendations for future MDA campaigns.

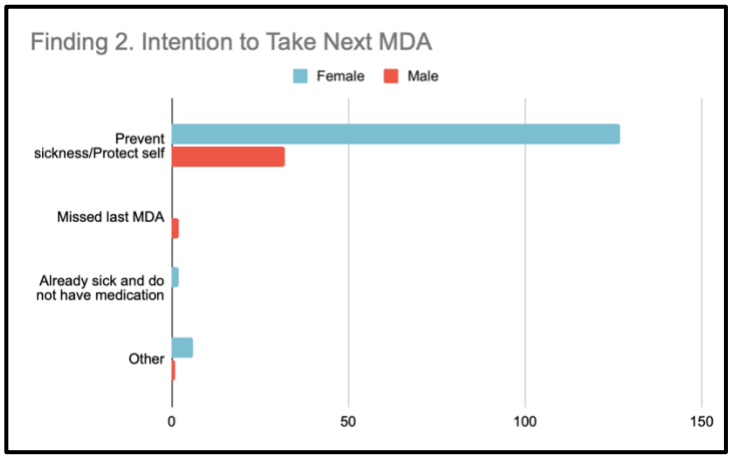


Finding 1 (Main Reasons for Not Taking MDA): The data indicates that the primary reason for not participating in MDA is being away from home, with 28.9% (55 out of 190) of the respondents noting thusly; additionally, 20% (38 respondents) did not take MDA because they wanted to protect themselves from getting sick, 17.9% (34 respondents) claimed that MDA was unavailable (distributors did not come,

campaign did not reach their area, or there was a lack of drugs), for instance a nomadic pastoralist expressed "*It is the distance and the rain, when I was in the cattle camp and there was no way for the doctor to reach there, which was the reason I did not take the medicine.*" Another 10% (19 respondents) said that they missed MDA due to being in the cattle camp. Other factors include working at home/homesteading, impacting 5% (9 out of 190), 5.3% (10 out of 190) expressed that they lacked information or confidence in the campaign, and pregnancy or illness, affecting 8% (8 out of 190) of respondents. A small number of participants cited distance from MDA (6 out of 190) and being limited by their physical disability (1 out of 190) as reasons for non-participation. 5.3% (10 out of 190) provided responses that were either unrelated to the question or indicative of miscommunication. Responses to barriers preventing access to MDA were mixed. Many respondents reported no barriers, noting peaceful conditions, freedom of movement, and no intimidation or community violence. However, some mentioned specific challenges such as poor roads, flooding, long distances, and limited resources like money and food as occasional obstacles.

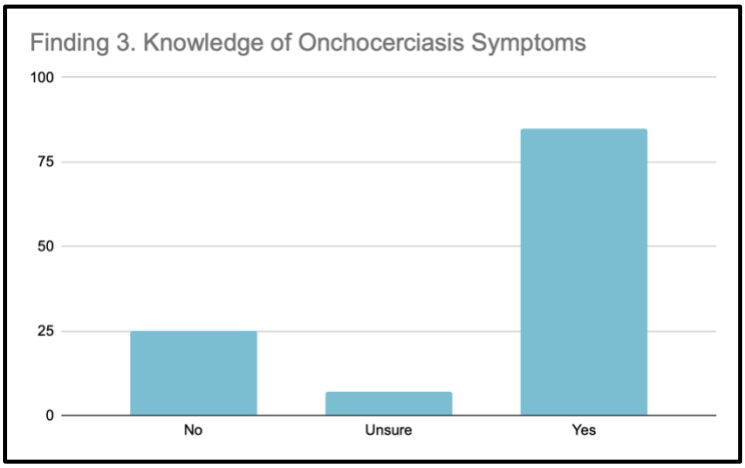
Overall, this finding highlights the need for better accessibility and communication, particularly about MDA availability and dates, and targeted interventions for those frequently out of town by setting up mobile camps and clinics. Addressing mobility issues, possibly through mobile camps and clinics, could significantly enhance MDA coverage.

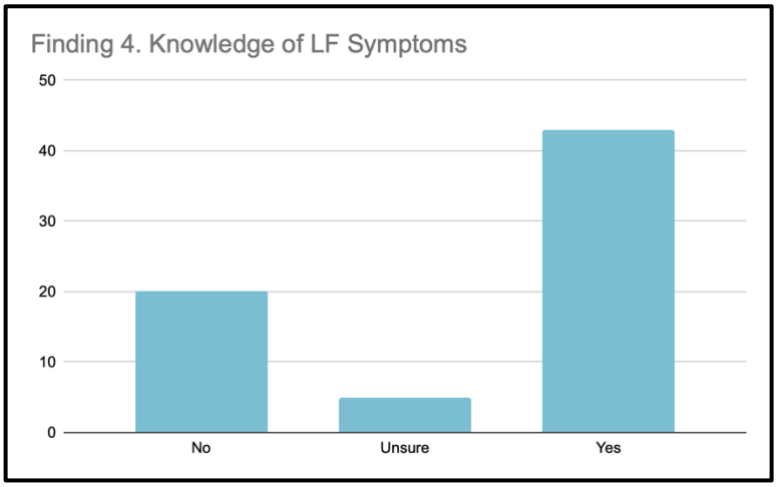
Finding 2 (Intention to Take Next MDA): 93.5% of respondents (159 out of 170) plan to take the next MDA primarily to prevent sickness or protect themselves from onchocerciasis and LF. A small percentage (1.2%, 2 out of 170) aim to participate in the next MDA because they missed the last one. Another small percentage (1.2%, 2 out of 170) are already sick and are in need of medication, and 4.1% (7 out of 170) cite other reasons, such as wanting to protect their community and expressing that "*MDA drugs are good not like other drugs,*" indicating that while prevention is the main motivator, some respondents have different or additional considerations for participating in the MDA.



Finding 3 (Knowledge of Onchocerciasis Symptoms): The data reveals that out of the 190 respondents, 117 (61.6%) had heard of onchocerciasis, meaning that 73 (38.4%) respondents reported having never heard of onchocerciasis. Of the 117 respondents that had heard of onchocerciasis, a significant majority, 72.6% (85 out of 117), are knowledgeable about the symptoms or signs of onchocerciasis. However, there is still a notable portion of the population that lacks this awareness. Specifically, 6% (7 out of 117)

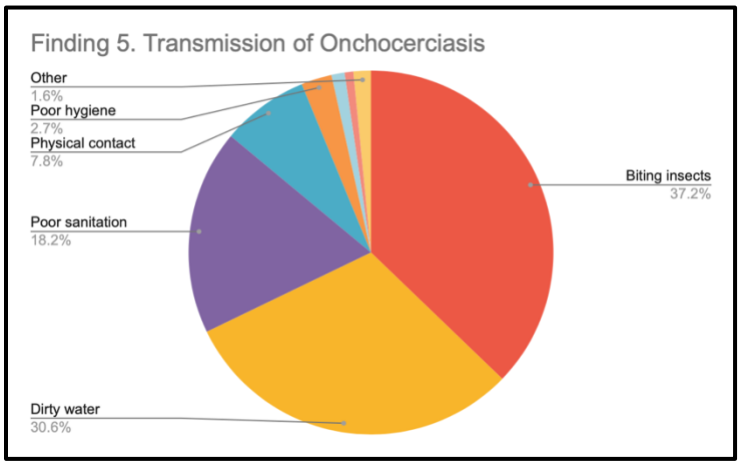
of respondents are unsure about the symptoms. Additionally, 29.9% (35 out of 117) do not know the symptoms of onchocerciasis. A participant of the IDP FGD did not seem confident in naming symptoms and expressed that they were unaware of onchocerciasis in their area ("*Eyes problems? That is what is OV. We don't know any way, whether these sicknesses are in this place"*). The presence of 38.4% never hearing of onchocerciasis and 35.9% of respondents who are either unsure or unaware of onchocerciasis symptoms suggests a need for targeted educational campaigns.



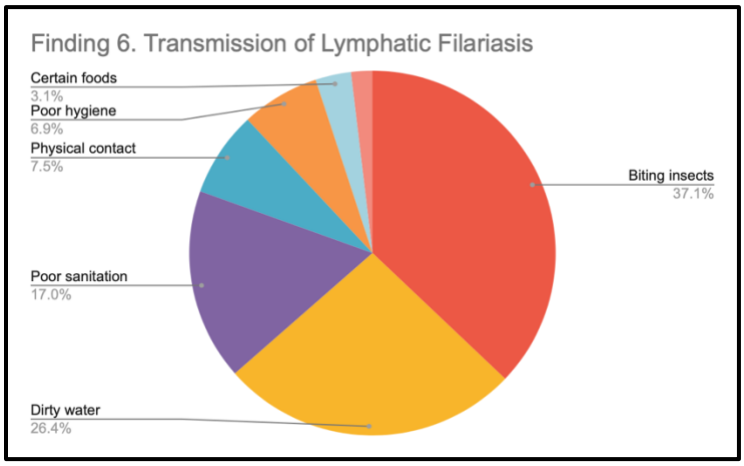


Finding 4 (Knowledge of LF Symptoms): The data shows that only 68 out of 190 respondents (35.8%) were familiar with LF, while a substantial 122 respondents (64.2%) had never heard of the disease. Among those aware of LF, a notable 63.2% (43 out of 68) demonstrated knowledge of its symptoms. However, gaps in awareness persist, as 7.1% (5 out of 68) expressed uncertainty regarding the symptoms, and 29.4% (20 out of 68) lacked knowledge about them. A nomadic pastoralist expressed how foot pain is normal, so they are unsure when it is due to LF (*"we often have normal pain in our feet and do not know it is an elephant foot disease, but the government is the one who comes and tells us it is an elephant foot disease and brings the medicine, but we here consider ignorantly it just as a pain"*). *Furthermore, an IDP* expressed "*Elephant foot has not come here. In Dinka land if someone has swollen foot means he/she has stepped on some sickness*" showing that they did not associate symptoms with having the disease. The large

proportion of respondents unfamiliar with LF (64.2%) and those uncertain or uninformed about its symptoms (36.8%) emphasizes the need for focused educational outreach efforts.

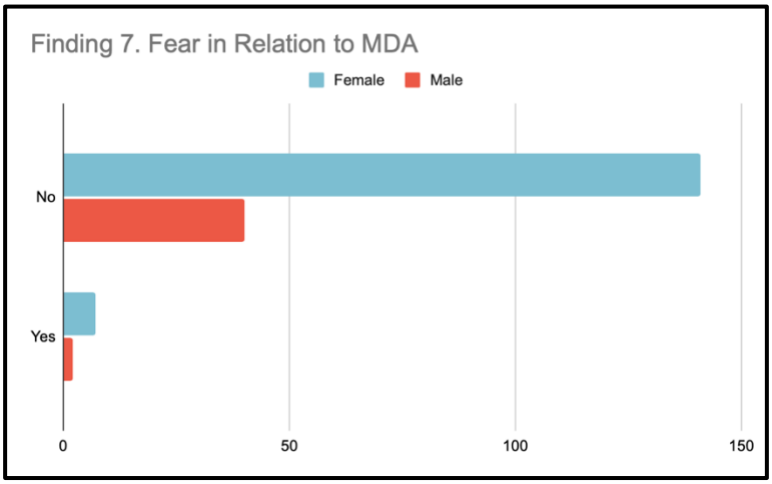


Finding 5 (Transmission of Onchocerciasis): Participants had the opportunity to answer with more than one way of how they believe onchocerciasis to be transmitted. Most respondents (37.2%) said that biting insects are the main way onchocerciasis is transmitted. The next most common belief was transmission by dirty water (30.6%), followed by poor sanitation (18.2%). A nomadic pastoralist explained that "*If she is a woman in the cattle camp like this, she fetches water from the water stream without filter and then she brings water and in it frogs and if there is no filter to filter the water then the water is poured in the pot and cook porridge with germ in the water. The germ in the water, she does not know and she cooks it with porridge and is eaten and the sickness which was in that germ becomes malaria and fever*." Some responses believed that physical contact (7.8%) is a mode of transmission, including another nomadic pastoralist, saying "*it is transmitted by wearing clothes of the sick person or sleeping on his bed.*" Fewer answers mentioned poor hygiene (2.7%), certain foods (1.2%), and supernatural causes (0.8%).



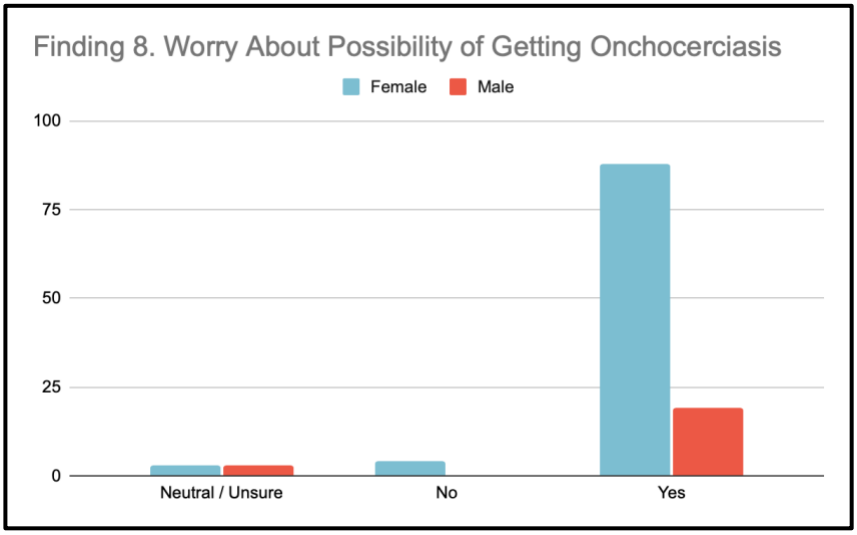
Finding 6 (Transmission of LF): Most participants believed that LF is transmitted by biting insects, accounting for 37.2% of responses. Following this, 30.6% responses pointed to dirty water as a source of transmission. Beliefs about poor sanitation were less common, making up 18.2% of responses, with physical contact accounting for 7.8%. Less frequently mentioned were poor hygiene (2.7%), certain foods (1.2%), and supernatural causes (0.8%). A Boma Health Worker (BHW) stated that contact with the wet ground is a mode of transmission by saying "as the supervisor in the Boma, challenges I found in the campaign, was the distance when you go during farming season, you walk for hours on foot without gumboot as in time of June when the land is wet, you can encounter such diseases."

Finding 7 (Fear in Relation to MDA): The data indicates a strong acceptance of MDA among both women and men, with 95.3% (181 out of 190) of respondents not expressing fear about participating. Although men exhibited slightly higher levels of fear (4.7%, or 7 out of 148) compared to women (4.8%, or 2 out of 42), the overall fear levels are minimal. For the 9 respondents who expressed concern in relation to MDA, they are worried about side effects, becoming disabled, and pregnancy. A BHW expressed that the reason for fear is due to side effects of medicine ("*The concept of Dinka people have is bad, because when someone hears a reaction or side effect of the medicine").* This suggests that most individuals are confident in the safety and necessity of MDA, though targeted communication may still be needed to address the concerns of the small minority who expressed apprehension. Yet respondents also were not necessarily knowledgeable about MDA; 10% (19 out of 190) of respondents said that they do not know the purpose of MDA, and 1.1% (2 out of 190) of respondents chose "neutral/unsure" in response to the prompt "If you take MDA, you will be protected against onchocerciasis and lymphatic filariasis."



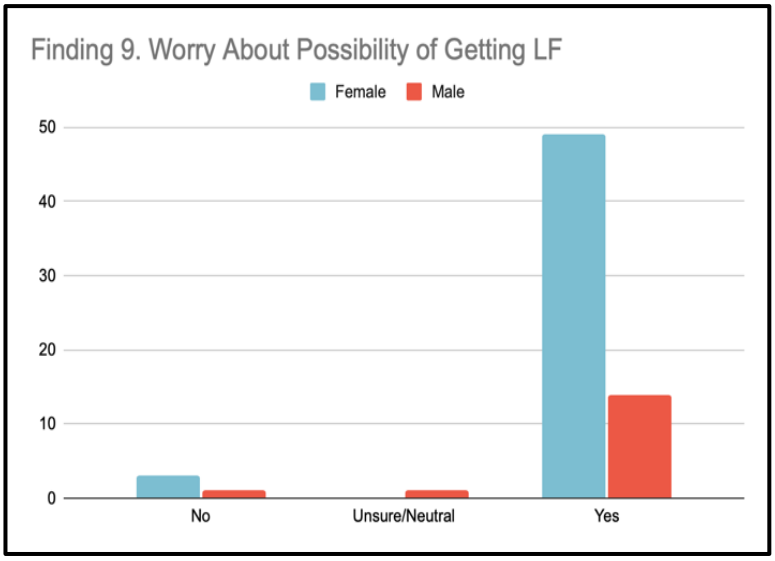
Finding 8 (Onchocerciasis Risk Perception): A majority of respondents, both male and female, perceive a significant risk of contracting onchocerciasis. Of the 117 respondents that had heard of onchocerciasis, 91.5% (107 out of 117) expressed concern about the possibility of getting onchocerciasis, with 92.6% of females and 86.4% of males showing worry. Only a small fraction (5.1%) were neutral or unsure and an even smaller fraction (3.4%) expressed no worry towards getting onchocerciasis. Reasons for concern were due to becoming disabled and experiencing blindness. Many concerns from respondents focused on disruption of their day-to-day activities and onchocerciasis negatively impacting their ability to provide ("*Livelihood productivity will stop as I'm the engine machine to the family*"). Other concerns from respondents include discussion of different onchocerciasis symptoms, receiving treatment, their quality of life in general, and feelings of sadness due to the disease ("*You hate yourself for your strength which you won't get right away*"). The findings suggest a

strong awareness and concern about onchocerciasis among both sexes, with a slight variation in the specific concerns associated with the disease.



Perceived risks of onchocerciasis were comparable for men and boys versus women and girls, though linked to different activities. Respondents frequently noted that men and boys are more exposed to environmental conditions due to tasks like farming, tending to livestock fishing, and hunting and may have poorer hygiene. One respondent stated "*Men and boys are normally use to swim in dirty water,*" which was seen as increasing their risk of onchocerciasis. For women and girls, the perceived risk was tied to poor hygiene practices and activities such as collecting firewood and fetching water.

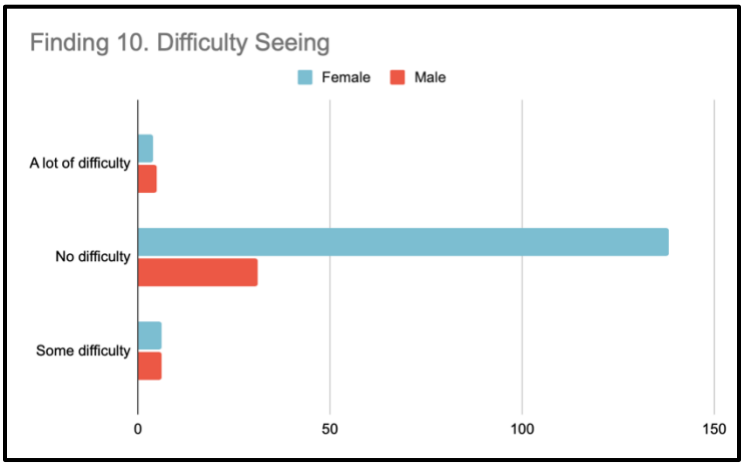
Finding 9 (LF Risk Perception): The data indicates that most respondents, regardless of gender, perceive a significant risk of contracting LF. Among the 68 individuals familiar with the disease, 92.6% (63 out of 68) expressed concern about the possibility of contracting it, with 94.2% of females and 87.5% of males showing worry. Only a small percentage (1.5%) were neutral or unsure, and 5.9% expressed no concern. The main fears were related to the potential for disability, body weakness affecting daily functioning, other symptoms of LF, and fear of death. As one respondent mentioned, "*Laziness will encourage because it is ignited by LF,*" and others voiced concerns like "*My concern will be death befall my way.*" Additional worries included public awareness, breastfeeding, and the need for regular MDA campaigns, with one respondent saying, "*Asking government to carry out*

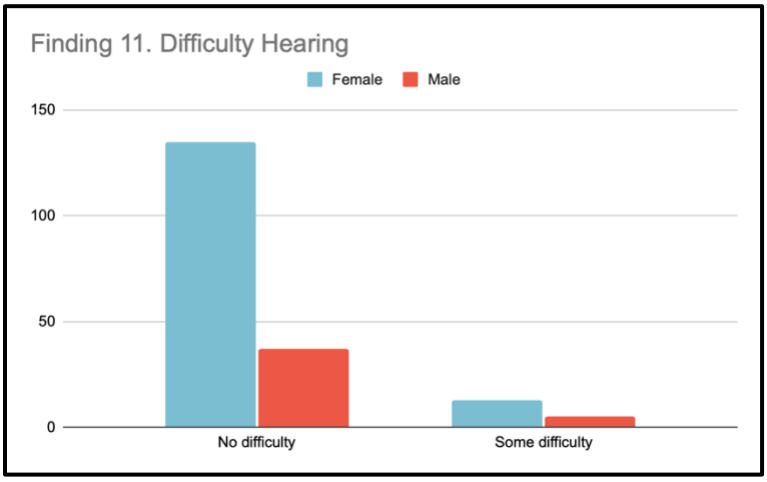


regular campaign." These findings indicate strong concern and awareness about LF among both genders, with slight differences in the specific concerns.

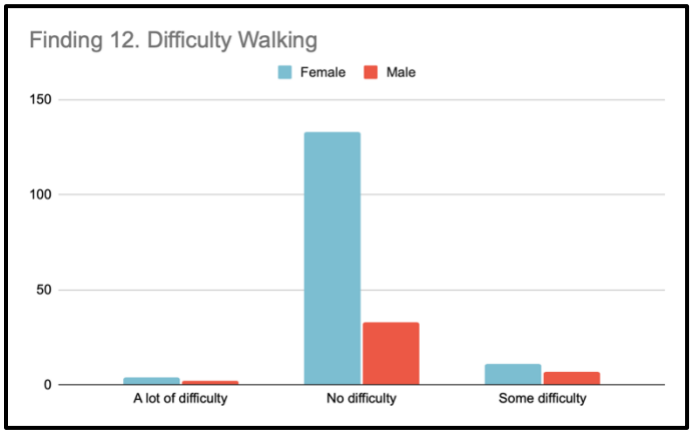
Perceived risks of LF were comparable for men and boys versus women and girls, though linked to different activities. Respondents frequently noted that men and boys participate in various bush or forest activities, like hunting and gathering wood, as high-risk behaviors for LF ("*Men and boys are at risk when hunting wild animals in the bushes*"). Water-based activities such as fishing and swimming in rivers, were also commonly linked to transmission risks. Farming and general movement in forested regions were additional perceived threats, with some respondents specifically mentioning contact with potentially infected animals ("*Forest hunting will cause infection when the prey of infected animal*"). Women and girls were identified as being at risk due to activities like collecting firewood and fetching water from rivers, pools, or streams, often in bushy or dirty areas. Other tasks, such as washing clothes at water sources or searching for food in the bush were also linked to increased exposure to contaminated environments and mosquito bites ("*Wild foods searching in the bushes will let the mosquito bite you and it's the threat*"). These activities were commonly perceived as contributing to the risk of LF.

Finding 10 (Difficulty Seeing): The data on difficulty seeing, disaggregated by sex, reveals that out of 190 respondents, the majority, 169 (88.9%), reported no difficulty seeing, including 138 females (93.2%) and 31 males (73.8%). A total of 12 respondents (6.3%) reported some difficulty, with 6 females (4.1%) and 6 males (14.3%) experiencing this issue. Only 9 respondents (4.7%) reported a lot of difficulty, between 4 females (2.7%) and 5 male (11.9%). This suggests that while most respondents do not experience vision difficulties, there remains a significant portion who report some or a lot of difficulty seeing.





Finding 11 (Difficulty Hearing): The data on difficulty hearing, disaggregated by sex, communicates that a significant majority of both females and males reported no difficulty hearing. Specifically, 135 out of 148 females (91.2%) and 37 out of 42 males (88.1%) indicated no difficulty hearing, making up a total of 172 individuals, or 90.5% of the total sample. In contrast, a smaller proportion of participants reported some difficulty hearing, with 13 females (8.8%) and 5 males (11.9%) experiencing such issues, totaling 18 individuals (9.5% of the total sample). The consistency in proportions between males and females suggests that hearing difficulties affect both genders relatively equally in this group. Overall, hearing impairment is not a widespread issue within the surveyed population, affecting only a minor segment.



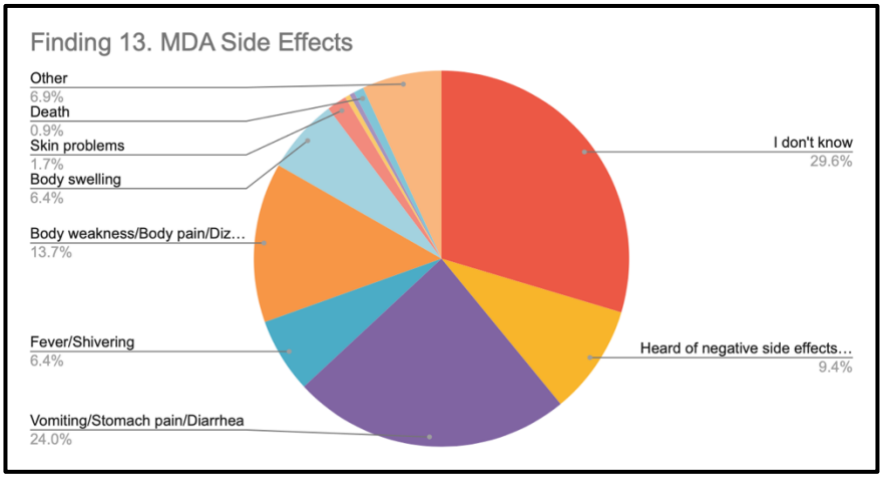
Finding 12 (Difficulty Walking): Out of 190 respondents, 166 (87.4%) reported no difficulty walking or climbing steps, while 18 (9.5%) reported some difficulty and 6 (3.2%) reported a lot of difficulty. Among female respondents, 133 out of 148 (89.9%) reported no difficulty, 11 (15%) reported some difficulty, and 4 (2.7%) reported a lot of difficulty. In contrast, 33 out of 42 male respondents (78.6%) reported no difficulty, 7 (16.67%) reported some difficulty, and 2 (4.8%) reported a lot of difficulty. This indicates that while the majority of respondents reported no difficulty with walking or climbing steps, men reported slightly more difficulty walking or climbing steps than women.

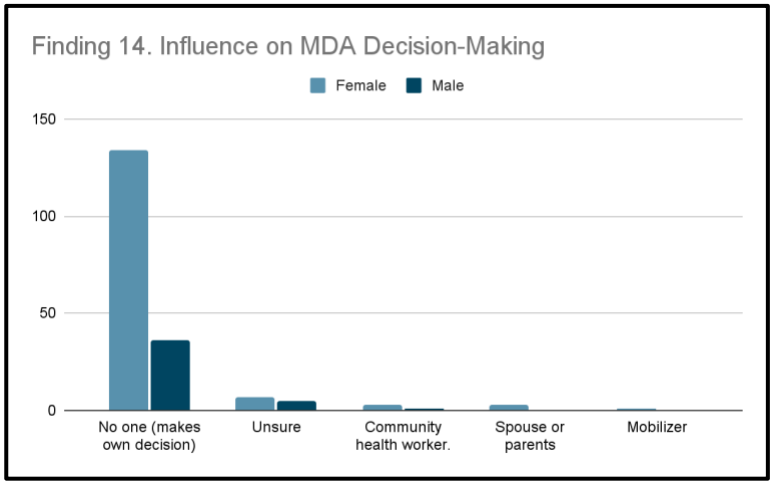
Finding 13 (Side Effects of MDA):[12] The majority of responses, 29.6% (69 out of 233), illuminated that participants did not know of any side effects related to MDA, including 55 females and 14 males. 9.4% of responses showed that participants had heard of negative side effects, but did not specify. During a focus group discussion, a BHW said "*Once a girl who entered puberty took the medicine, but at the night she fell unconscious, and she was taken to the hospital, and nothing was found in here body. Such things create*

[1] "Other" responses include: answers that did not address the question.

[2] One participant said "joining bones," which we interpreted as joint pain.

fear in other people," showing an example of how others' experiences influence MDA acceptance. Stomach issues, including vomiting and diarrhea, is the most frequently reported side effect of MDA, noted in 56 answers (24%), including 45 females and 11 males. Body pain/weakness is also a common concern, mentioned in 32 answers (13.7%), with 26 females and 6 males. Fever and shivering were less commonly reported, with 15 answers (6.4%), with 11 females and 4 males. Lesser-mentioned or uncommon side effects include body swelling, most commonly in legs, (6.4%, 15 answers), skin problems (1.7%, 4 answers), and death (0.9%, 2 answers). A notable portion of answers (69, or 29.6%) indicated that participants do not know about MDA side effects, reflecting a potential gap in awareness. One respondent mentioned a misconception that MDA might affect the body if taken on an empty stomach, suggesting a possible misunderstanding ("*I heard that it disturb when you never eaten anything*").

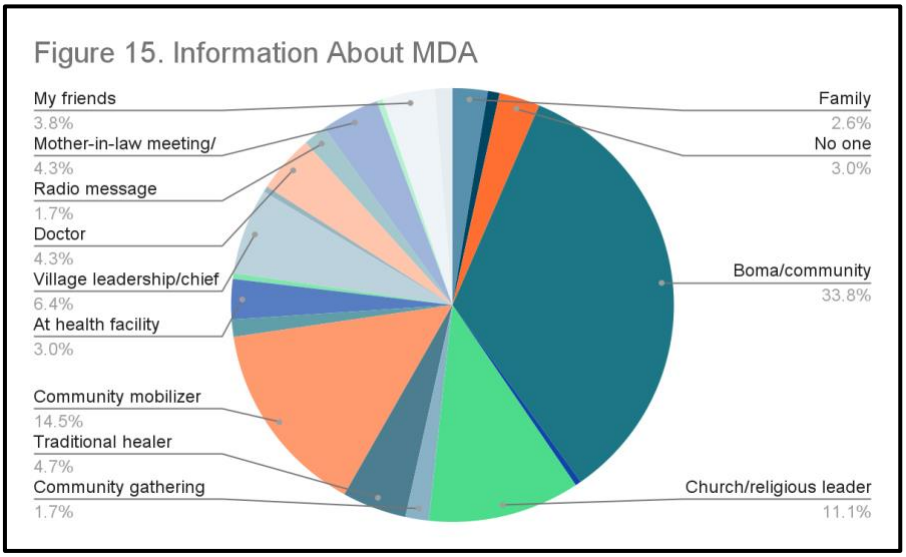




Finding 14 (Others' Influence on the Individual on MDA): The data illuminates that the majority of respondents, 170 out of 190 (90%), reported making decisions independently, with 134 females and 36 males indicating they are not influenced by others. Twelve respondents (6%) said they were unsure; four (2%) cited a community leader as an influence; 3 (1.5%) mentioned a spouse or parents; and 1 (0.5%) mentioned mobilizers. Overall, the data underscores the predominance of personal judgment over external influences in the decision-making process among the respondents.

Additionally, most respondents felt that men and women have equal access to information about onchocerciasis (95%) and LF (97%) prevention and treatment. Where respondents included an explanation for their answers, most pointed to the lack of access to information about MDA general, or *"Lacking of BHW in the community."*

Finding 15 (Information about MDA): Relevant to decision-making and influence, respondents shared what they are told about MDA and where they access this information.

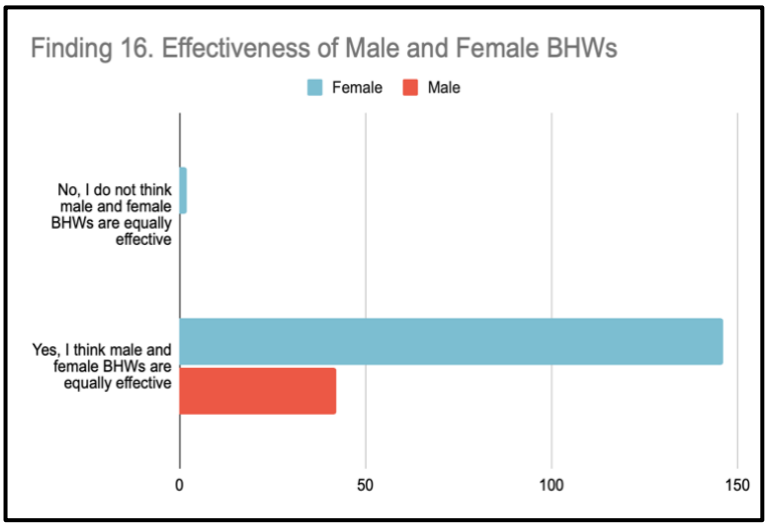


Boma/community health worker/drugs distributors received the most mentions (79, or 34% of mentioned sources of information), followed by community mobilizers (34, or 15%), then church/religious leaders (26, or 11%), and then village leadership/chiefs (15, or 6%), traditional healers (11, or 5), and doctors and mother-in-law meeting/ mother-to-mother group/ women's leader at 10, or 4% each. Remaining responses were mentioned fewer than 10 times, and included family, school, agricultural groups, community gatherings, vaccinators, at the health facility, chemists, village broadcasters, radio messages, midwives, friends, other, and no one. It is important to highlight the 7 responses of "no one," indicating that they did not receive information about MDA from any source.

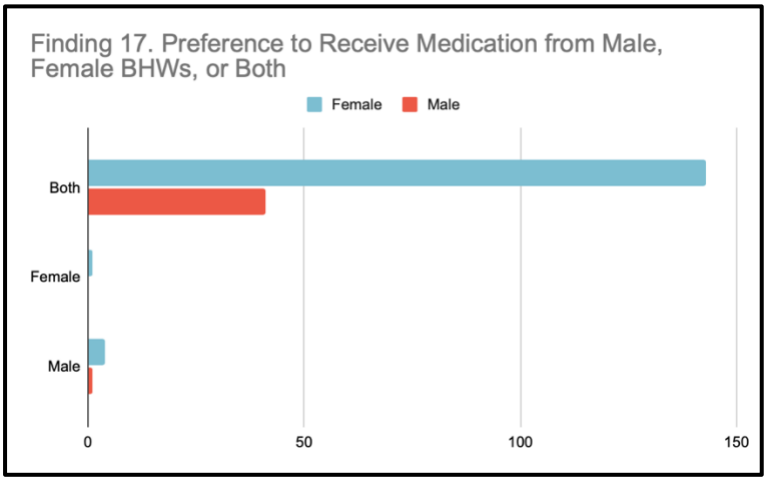
In terms of what information respondents received about MDA: respondents received information that it is essential to eat before taking MDA drugs to avoid side effects. Many were informed that these drugs protect against diseases such as LF, onchocerciasis, and other NTDs. Instructions often emphasized following dosage guidelines carefully, with healthcare workers or vaccinators distributing the drugs and providing guidance. However, some respondents reported receiving little to no information about MDA, possibly due to absence from previous distributions or gaps in communication. A suggestion from an IDP was that "*It should be through communication to be announced at worshiping places or through phone, or representatives or it would be good to health workers move from house to house such that blind people can have access in their places*." Another suggestion from a nomadic pastoralist was for information to come from cattle camp leaders "*because cattle camps' leaders are always mobile with us*."

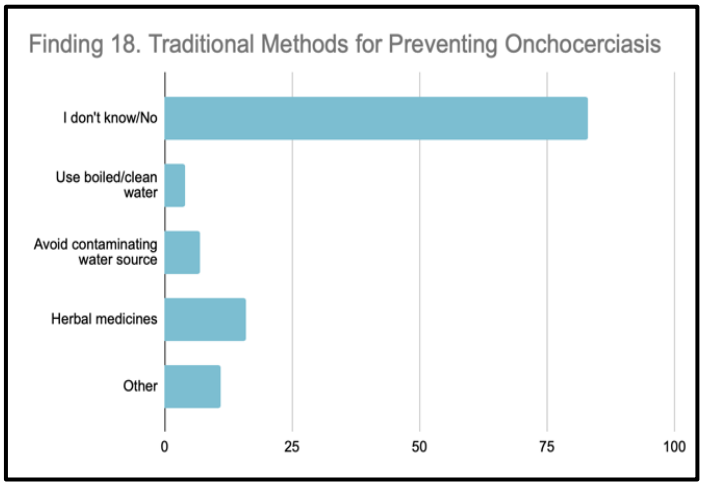
Finding 16 (Effectiveness of Male and Female BHWs): The data displays a strong consensus among respondents that male and female BHWs are equally effective, with 98.9% (188 out of 190) of participants, including 146 females and 42 males, expressing this belief. This overwhelming agreement suggests that both genders are perceived to provide similar levels of care and effectiveness in their roles as BHWs, which is a positive indicator for gender equity in health service delivery. Only 1.1% (2 out of 190) of respondents, which are two females, do not believe that male and female BHWs are equally effective. When asked why they found male and female BHWs to not be equally effective one female said "*Male are strong and*

flexible in medical services meanwhile are not," showing their preference towards male BHWs. The other said "*Because I don't normally see them in the hospital,*" referring to the lack of men she sees in health settings. This minority view indicates that there may be isolated perceptions or experiences where the effectiveness of BHWs is seen as gender-dependent, though this is not a widespread sentiment. After asking the Overall, the data highlights a strong confidence in the abilities of both male and female BHWs, suggesting that gender does not significantly impact the perceived quality of healthcare provided by BHWs in this community.



Finding 17 (Preference to Receive Medication from Male, Female BHWs, or Both): The data discloses that an overwhelming majority of respondents, 96.8% (184 out of 190), prefer to receive medications from both male and female BHWs, with this preference equally strong among both females (143 out of 148) and males (41 out of 42). This suggests a broad acceptance and comfort level with receiving healthcare from BHWs of either gender, reflecting trust in the professionalism and competence of both male and female health workers and echoing the data in finding 17 above. An IDP expressed, "*No bad person. We do not mind. They are all good*." Only 0.5% (1 out of 190) of respondents, a female, expressed a preference for receiving medications exclusively from female BHWs, citing that "*Men always traveled anyhow and rough to patients when you came at wrong hours*." 2.6% (5 out of 190) of respondents, four females and one male, expressed a preference for receiving medications exclusively from male BHWs. Two females and one male stated that this is due to a lack of women working in the facilities. The remaining two females expressed this is due to men's "*strength and determinatio*n" and because "*women are not perfect.*" This highlights a specific, albeit very limited, cultural or personal consideration where gender plays a role in healthcare preferences. Overall, the data indicates that most people are comfortable receiving medications from either gender, reinforcing the effectiveness of a gender-diverse health workforce in the community.



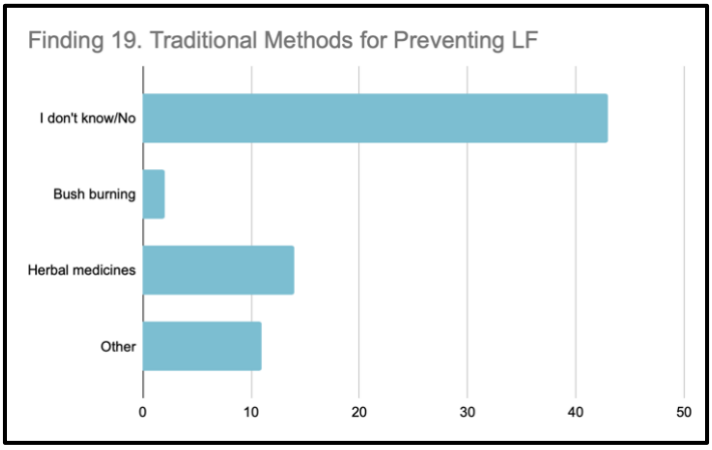


Finding 18 (Traditional Methods for Preventing Onchocerciasis):[34] Out of a total of 121 responses from 117 participants, the majority of answers (83, or 68.6%) indicated that there were no known traditional methods or respondents were uncertain of any for preventing onchocerciasis. A smaller number of answers (4, or 3.3%) described using clean or boiled water for bathing and drinking, while other answers (7, or 5.8%) mentioned avoiding contamination of water sources by refraining from swimming, showering, or urinating in them. Sixteen answers (13.2%) pointed to herbal remedies, where "*herbal medicine oil is applied to soften the skin and do away with it*." Other preventive measures noted included staying in cooler environments, covering food and water, keeping distance from infected individuals, maintaining environmental cleanliness, and relying on religious influences ("*Unless help from God*"). Religious influence was also present in FGDs with the elderly person saying, "That is the reason we go to the hospital and when God directs doctor to good medicine then we get good health."

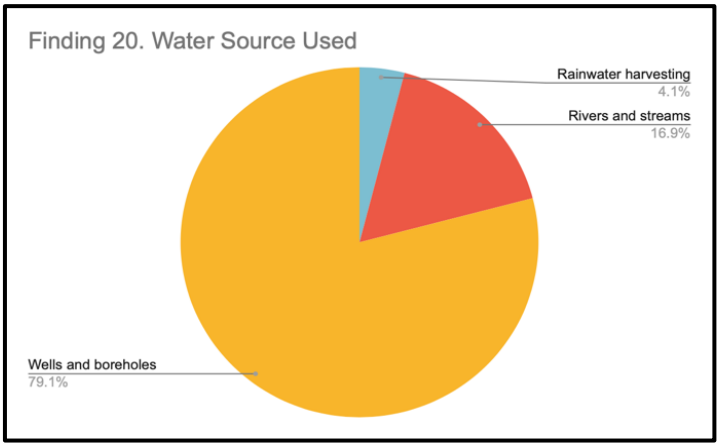
[3] One respondent noted "local media" as a prevention method, which we interpreted as "local medicine," as this is likely an error in language translation.

[4] "Other" responses include: "Yes," "Unless help from God," "To stop moving from the bushes," "Stay in cold a place," "Bush burning," "Do not leave food or water uncovered," discussion of distancing themselves from those infected, and quotes related to keeping things clean.

Finding 19 (Traditional Methods for Preventing LF):[56] There were 70 responses in total and most answers (43, or 61.4%) indicated that there are no known traditional methods or that respondents were unaware of any traditional methods for preventing LF. However, 14, or 20% mentioned herbal medicine as a preventive approach ("*Traditional healing through traditional herbs is the method*"). Additionally, 2 answers (2.9%) cited bush burning as a preventative measure. Other answers included actions like preventing water source contamination by animals and bodily fluids ("*Use a different water source for animals*"), maintaining distance from infected individuals, and promoting environmental cleanliness. A member of the elderly community stated, "It is God who takes care of us."



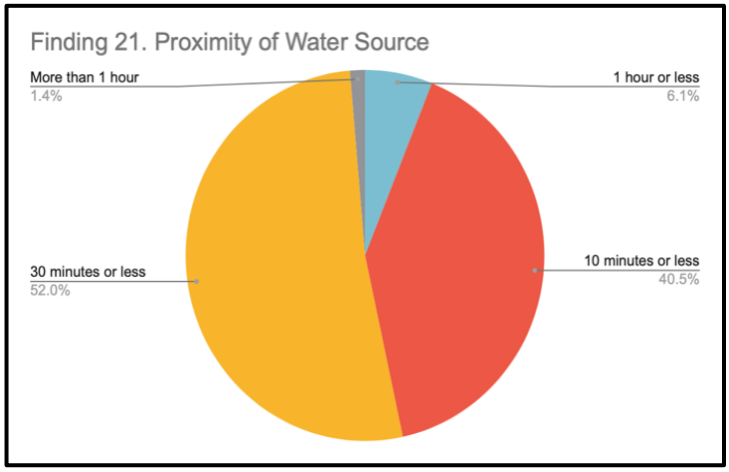
Finding 20 (Water Source Used) and Finding 21 (Proximity of Water Source): The data shows that among the 190 respondents, 79.1% (150 out of 190) primarily rely on wells and boreholes as their main water source, while 16.9% (32 out of 190) depend on rivers and streams. During the elderly FGD one participant talked about issues with boreholes, saying "*We get them from borehole, are few and have got broken and no repair. Now we drink water full of frogs in the streams.*" The remaining respondents, 4.1% (7 out of 190), harvest rainwater as their main water source, and 1 respondent relies on surface water from lakes and ponds. The accessibility of these water sources varies significantly, with most respondents reporting relatively close access. Data shows that 52% (97 out of 190) of respondents lived within 30 minutes of their primary water source and 40.5% (76 out of 190) lived 10 minutes or less from their water source. However, a small portion, 1.4% (3 out of 190), travel more than



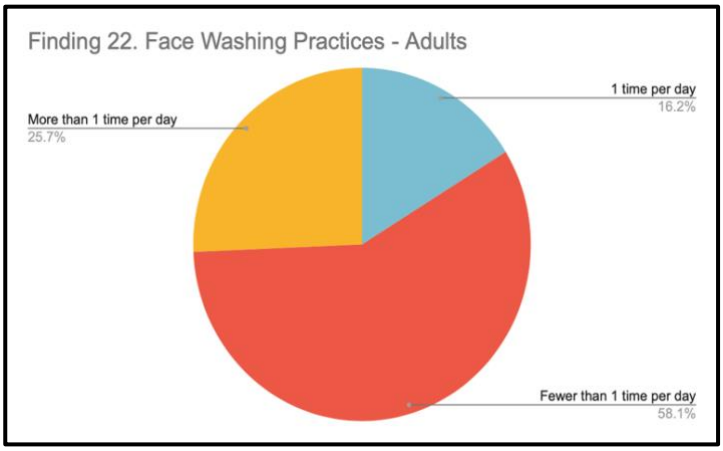
[5] Three respondents noted "local media" as a prevention method, which we interpreted as "local medicine," as this is likely an error in language translation.

[6] "Other" responses include: "Use short-cut for defecation," "Use a different water source for animals," "Yes," "To clean around the houses," "Avoid random movements," discussion of distancing themselves from those infected, and quotes related to swimming in the water source

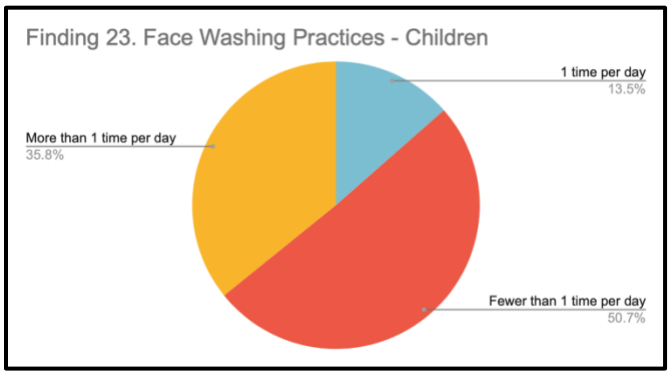
an hour to reach their water source. The remaining 6.1% (14 out of 190) of individuals responded saying they had to travel up to an hour to reach the water source. Of those who rely on wells and boreholes, 40.7% (61 out of 150) said that they travel 10 minutes or less to the water source. This analysis indicates that while wells and boreholes are more accessible water sources for the majority, there are still significant disparities in access time, with a minority facing challenges in reaching their water sources, especially for those relying on rivers and streams. A nomadic pastoralist expressed their lack of access to safe water even if they travel far distances by saying, "*The place we get water is even in the pool and when the rain has rained we go for half an hour and in dry season we go hours like three or four hours, we walk and walk far distance, and in rainy season we just take water here in pools, we drink and bath the same pools cattle drink and cross, even if they are far."* Improving access to water sources could significantly enhance the community's water security.



Finding 22 (Face Washing Practices - Adults): Among the 190 respondents, 25.7% of adults (49 out of 190) wash their face more than once per day. However, 58.1% (109 out of 190) wash their face less than once per day. This group represents a significant portion of the population that might benefit from targeted health education and interventions to improve their face-washing habits. Meanwhile, 16.2% (32 out of 190) wash their face once per day. Overall, the majority of respondents do not engage in frequent face washing, which could cause them to be at higher risk, indicating the need for continued public health efforts to promote optimal hygiene practices.



Finding 23 (Face Washing Practices - Children): For face washing among children, 72 out of 190 (35.8%) are washed more than once per day, while 29 (13.5%) are washed once per day. Over half of children, 89 (50.7%), have their faces washed fewer than once per day.



Findings Specific to FGDs and KIIs

Finding 24 (Transportation Challenges for BHWs): Data from the FGDs and KIIs revealed ways in which members of Awerial County think BHWs could be better supported to distribute medicine. A common theme was expressing the need for improved transportation among BHWs, specifically through access to motorcycles, as stated by a BHW ("*transport should be made avail to help health workers reach out, such supports make the work easy to do*"). Reasons to provide better transportation include increasing coverage to distribute a greater amount of vaccines to more members of the community ("*the other side of the river, cannot be reached quickly and the medicines finish on the way, those who are far there, the medicines finish in the meddle on the way before the afternoon, this unless when motorcycle is provided which can take people for medicines distribution").* Additionally, increased access to motorcycles would help BHWs distribute medicine more efficiently and protect the usability of medications (in consideration of expiration/the effect of prolonged exposure to the elements on medicines; "*when I went to some places, the places are far from each other and you don't motorcycle to carry medicine. So you find some medicines are affected by sun, it can ruin them*.").

Additionally, a participant suggested providing adequate footwear to those who are distributing medicine "*a gumboot should be provided, because workers move in the grass and there is fear of ground things and this case medicine will reach all people and no people will be left out and disease is reduced*."

Finding 25 (Illiteracy Among BHWs): Illiteracy among some BHWs was identified as a challenge ("*some of us do not know how to read or write. We have people who just listen and understand in their hearts. Also, we have those who are literate, so the help is shortage to the others, but supports go to all of them.*"). This lack of literacy among some health workers limits their ability to effectively use written resources, such as instructions for administering medicines or guidelines for treating disease. As one participant explained, "*like the way the medicine is used we do not know them well, and if a good doctor does not come, we cannot be*

able to know the new diseases and the way of treatment." These insights suggest a need for targeted training and support for non-literate health workers.

Finding 26 (Supplies to Prevent Transmission): When discussing modes of transmission during FGDs, multiple participants highlighted the urgent need for mosquito nets as a preventive measure. One participant from the IDPs group stated, "*We don't have nets, even now mosquitoes have increased. We need mosquito nets.*" Another echoed this concern, saying, "*If you are people of OV and, as you said, it is caused by mosquitoes, then you provide us mosquito nets*." These statements highlight the importance of not only addressing treatment, but also providing essential supplies to prevent the spread of the disease.

Finding 27 (Food Insecurity): Qualitative data reveals concerns about food insecurity, with participants emphasizing the need for food aid and its link to health and productivity. A nomadic pastoralist stated, *"The government should provide food and health for both human beings and animals."* Similarly, a youth participant highlighted the relationship between hunger and health issues saying, "*The government should address issues related to hunger, the things that bring sickness*." Food insecurity was also linked to climate change, as an elderly community member noted "*because people are starving, because cultivation isn't longer good."* Food insecurity not only affects the general population's health, but also undermines MDA implementation. It impacts the ability of BHWs to perform their duties effectively. One BHW explained "*we need to increase the budget because some would walk hours without food, which need to increase the budget of the field workers,"* and emphasized that providing food during fieldwork would improve their productivity ("*the way to make good and makes work advance is to give us things we eat there on the way*"). Food insecurity can reduce MDA uptake amongst communities due to fears of side effects on an empty stomach, competing survival priorities, limited awareness, weakened health, access barriers, and social exclusion.

Finding 28 (Number of Distributors and Mobilizers): Participants expressed the need for an increased number of distributors and mobilizers to expand coverage and campaign awareness. A BHW stated "*those who go there are few in numbers even if the go here and there, they still not reaching far villages,"* emphasizing that a greater number of distributors would allow them to reach more of the target population. Another BHW emphasized the role of mobilizers in community engagement by saying "*if we want to increase information, we need to increase the number of mobilizers who should be given microphones and go out to villages and on trees to announce to people about the coming of the medicine team*." These insights demonstrate that scaling up the number of distributors and mobilizers, along with ensuring that they have effective communication tools, could enhance the reach and impact of MDA campaigns.

Challenges

The effective implementation of MDA for onchocerciasis and LF faces numerous challenges that can significantly impact participation rates and the overall success of the treatment program. These challenges are multifaceted, encompassing issues related to accessibility and mobility, knowledge and awareness, physical vulnerabilities, perceptions and attitudes, behavioral practices, and equity in health service delivery. Each of these areas presents specific barriers that need to be addressed to ensure that MDA programs reach their full potential, particularly in remote and underserved communities.

The following section provides an in-depth examination of these challenges, drawing on both quantitative and qualitative findings and insights from stakeholders, to offer a comprehensive understanding of the obstacles hindering MDA participation and the strategies needed to overcome them.

Accessibility and Mobility Challenges

A highly mobile population and limited accessibility significantly hinder participation in MDA programs. Finding 1 reveals that **28.9%** of respondents cited being away from home as the primary reason for not participating in MDA, with an additional **10%** missing MDA due to commitments like cattle herding (*“I wasn't at home”; "I was in cattle camp last time;” "I was committed with work at home.*"). Poor infrastructure, such as inadequate roads and flooding, alongside limited resources like money and food, further compound these accessibility issues. Stakeholders have identified these factors as significant barriers, particularly in remote areas where access to health services is limited. Addressing these challenges through the **establishment of mobile clinics** and **improved transportation infrastructure** is essential for enhancing MDA coverage.

Supply Issues/Lack of Access

Similarly, supply-related challenges significantly impact participation in MDA initiatives. When asked why people don't participate, respondents indicated that access to MDA services is often hindered by inadequate distribution. Respondents said that *"MDA drugs didn't reach some households"*; *"the whole of our village didn't receive MDA, that reason I failed to participate”*; *"no drugs being brought to Nhom-diang village”*; and *"the drugs distributors were not reaching our village."* These responses indicate that there were insufficient drug supplies in their areas. These issues stem from logistical obstacles such as poor infrastructure, limited availability of distribution personnel, and geographical constraints that prevent MDA teams from reaching remote communities. These supply challenges not only reduce overall program effectiveness but also highlight the need for strategic improvements such as bolstering supply chain mechanisms, ensuring adequate drug quantities are available, and

expanding distribution networks to cover underserved areas. Additionally, **deploying more outreach teams** could enhance the reach and reliability of MDA services, ultimately fostering higher community participation and treatment adherence.

Limited Knowledge and Awareness

A significant gap in community knowledge and awareness poses a major challenge to effective MDA participation. Findings 3 and 4 highlight that **38.4%** of respondents have never heard of onchocerciasis and **64.2%** are unfamiliar with LF, respectively. Additionally, misconceptions about disease transmission persist, as evidenced by Findings 5 and 6, where many respondents incorrectly believe that onchocerciasis and LF are transmitted through dirty water and poor sanitation. Furthermore, Finding 13 shows that **29.6%** of respondents are unaware of potential side effects of MDA, while **9.4%** expressed uncertainty about these side effects. Additionally, when asked where they receive information about MDA, **7** participants noted lack of information (i.e., *"the information didn't reach me"*). This emphasizes the urgent need for **enhanced health education** to bridge these knowledge gaps, particularly focusing on accurate information about disease symptoms, transmission pathways, and the safety and benefits of MDA.

Perception and Attitudinal Challenges

While the perception of risk for onchocerciasis and LF is high among the population (Findings 8 and 9), translating this concern into consistent MDA participation remains challenging. Fear of MDA participation is generally low (Finding 7, with only **4.7%** expressing fear), yet concerns about potential side effects, such as stomach issues and body weakness (Finding 13), contribute to these attitudinal barriers. Stakeholders recognize the importance of addressing these fears through **targeted communication strategies** that emphasize the safety and efficacy of MDA, thereby fostering greater trust and willingness to participate.

Water, Sanitation and Hygiene (WASH)

Poor hygiene practices increase the risk of communities contracting and spreading infection. In addition to preventing the spread of infectious diseases, WASH plays a vital role in the treatment and care of those affected by them. Essential WASH-related behaviors for preventing NTDs include using latrines and washing hands and faces with soap and water. Findings 22 and 23 indicate that **58.1%** of adults and **50.7%** of children wash their faces fewer than once per day, increasing their risk of infection. Additionally, Findings 20 and 21 suggest that inconsistent access to clean water further hampers proper hygiene practices. Stakeholders emphasize the necessity of **integrating hygiene promotion into MDA programs** to support comprehensive disease prevention efforts. Additionally, improving **water**

infrastructure and ensuring equitable access to clean water can support better hygiene practices and reduce disease transmission.

Supervisory Challenges in MDA Implementation

A recurring issue highlighted by participants was the **lack of commitment among MDA supervisors** at various administrative levels. This absence of adequate supervision is viewed as a significant barrier to achieving full MDA coverage in Awerial County. Participants stressed that without proper oversight, the impact of MDA efforts is severely diminished, resulting in lower coverage rates and decreased health outcomes in the region.

Inaccurate Population Data

The Ministry of Health relies on **outdated population statistics,** particularly those derived from the 2008 South Sudan Population and Household Census. The population of Awerial County has significantly increased since 2008, with some estimates suggesting it has tripled. Consequently, the reliance on these outdated figures has led to many villages in Awerial being underserved in terms of MDA coverage; this also created a challenge in planning appropriately for the GESI assessment. Updated demographic data is necessary to inform better planning and resource allocation for public health initiatives.

Autonomy in Decision Making

Although the vast majority of respondents (**90%**) report making MDA-related decisions independently (Finding 14), a small percentage express uncertainty about their autonomy due to influences from parents, spouses, and community leaders, indicating that social and familial pressures can still impact participation. Stakeholders highlight the need for empowering individuals, especially women, through **community engagement** and **education** to reinforce **autonomous decision-making** in health-related matters.

Equity and Effectiveness Challenges

Perceptions of gender equity in the effectiveness of BHWs are overwhelmingly positive, with **98.9%** of respondents believing that male and female BHWs are equally effective (Finding 16). However, addressing the small disparities where some respondents do not share this view is essential for ensuring equitable health outcomes. Additionally, Finding 17 shows a strong preference for receiving medications from both male and female BHWs (**96.8%**), supporting the effectiveness of a gender-diverse health workforce.

Information Dissemination

Effective communication channels are vital for the success of MDA programs. Finding 15 reveals that the primary sources of information about MDA are community health workers and drug distributors (**34%**), followed by community mobilizers (**15%**) and religious leaders (**11%**). However, a notable number of respondents (**7**) receive no information about MDA, highlighting gaps in information dissemination. Additionally, respondents emphasized the lack of access to information as a barrier, particularly in areas without active BHWs. Furthermore, during qualitative interviews, participants noted that increasing the number of distributors and mobilizers to expand coverage and campaign awareness is necessary, as well as better communication tools for MDA teams during campaigns. **Enhancing information dissemination through diverse and reliable channels** is necessary to ensure that all community members are informed about MDA availability, benefits, and procedures.

Traditional Beliefs and Practices

Traditional methods for preventing onchocerciasis and LF, such as herbal remedies and maintaining environmental cleanliness, are present but not widely practiced (Findings 18 and 19). The reliance on traditional beliefs can sometimes conflict with modern medical interventions, potentially affecting MDA participation. Stakeholders recognize the importance of **integrating culturally sensitive approaches that respect traditional practices while promoting evidence-based health interventions**.

BHW Tools and Support

During qualitative interviews, **illiteracy among BHWs** was highlighted as a key challenge to effective MDA campaigns. Additionally, **BHWs did not have adequate access to transportation**, such as motorcycles, to reach all community members; similarly, footwear for walking necessary distances was not sufficient.

Recommendations

Based on findings from the RCA, KIIs, and FGDs, several key areas for improvement have been highlighted. These recommendations aim to enhance the overall effectiveness of MDA efforts and ensure broader, more equitable participation. The recommendations are categorized into several focus areas:

1. Expand Mobile MDA Services to Reach Mobile Populations

- **Responsible Parties:** Ministry of Health, MDA Program Implementers, Local Health Departments
- Implement mobile MDA units to reach highly mobile groups, such as cattle herders, ensuring accessibility even for those often away from home.
- Schedule distribution times based on community movement patterns to maximize participation.

2. Improve Community Sensitization and Health Education Campaigns

- **Responsible Parties:** Ministry of Health, MDA Program Implementers, Local Health Workers, Community Leaders
- Develop targeted education campaigns to address common misconceptions about disease transmission and MDA side effects.
- Prioritize outreach to women, emphasizing the benefits of MDA and addressing fears of side effects, to bridge knowledge gaps and reduce participation barriers.
- Ensure that BHWs and other MDA campaign officers have access to adequate communication tools to make community members aware of ongoing campaigns.
- Provide targeted literacy support to BHWs.
- Increase the number of distributors and mobilizers to expand coverage and campaign awareness.

3. Enhance MDA Accessibility in Remote Areas

- **Responsible Parties:** Ministry of Health
- Improve transportation options to MDA sites to make these services accessible to more remote communities.
- Where possible, integrate MDA with other community services, like routine health checks or mobile clinics, to reach more people efficiently.
- Provide BHWs and other MDA personnel with motorcycles and/or improved transportation options, including adequate footwear for walking long distances in rural areas.

4. Address Physical Barriers to Participation through Inclusive Support Services

- **Responsible Parties:** MDA Program Implementers, Local Health Workers
- Provide additional support for individuals with sensory and mobility impairments to ensure they can participate in MDA activities.
- Equip MDA teams with mobility aids and clear communication materials to accommodate individuals with vision and hearing difficulties.

5. Strengthen Social Behavior Change and WASH

- **Responsible Parties:** Ministry of Health, Ministry of Education, Local Government, Health Workers, Community Leaders
- Promote personal hygiene and other preventative health behaviors through community workshops, and in schools, particularly in areas where hygiene practices are suboptimal.
- Engage schools, religious institutions, and community centers as platforms for health education to increase community buy-in and awareness.
- Provide mosquito nets to communities.
- Invest in building and maintaining water infrastructure, including wells and boreholes, in areas with limited safe water access to facilitate improved hygiene and reduce barriers to MDA participation.
- Ensure water sources are accessible within a short distance to minimize travel time, particularly in regions where participants currently travel over an hour to reach a water source.

6. Foster Community Autonomy in Health Decisions, Particularly Among Women

- **Responsible Parties:** Community Leaders, Religious Institutions, Local Women's Groups
- Promote programs that empower women in decision-making roles related to health, potentially through educational workshops and group discussions.
- Engage community leaders to advocate for women's autonomy in health-related decisions, reducing reliance on external influences and encouraging informed personal choices regarding MDA participation.

7. Standardize and Strengthen the Role of BHWs

- **Responsible Parties:** Ministry of Health, MDA Program Implementers, Local Health Departments, BHW Supervisors
- Ensure consistent presence of BHWs in all communities by addressing gaps in staffing and improving recruitment where BHWs are missing or inactive.
- Conduct refresher training for BHWs to reinforce MDA knowledge and communication skills, particularly focusing on addressing gender biases and building trust across genders.

- There is a need and opportunity to effectively monitor and oversee MDA distributors through a Supervisors' Coverage Tool, which can be used to assess coverage during MDA. Furthermore, Supervisors' Checklists are needed to ensure all steps of MDA are being implemented correctly and to empower supervisors.

8. Integrate Community Feedback Mechanisms to Continuously Improve MDA Services

- **Responsible Parties:** Ministry of Health, MDA Program Implementers, Local Health Departments
- Establish a feedback system to gather regular input from community members on MDA effectiveness, accessibility, and concerns, using this feedback to inform future programming.
- Hold periodic meetings with community representatives and stakeholders to review program progress and address emerging challenges.

9. Increase Engagement of Local Influencers to Improve Participation

- **Responsible Parties:** Community Leaders, Religious Leaders, Local Health Workers
- Partner with trusted community and religious leaders to disseminate accurate MDA information, emphasizing disease prevention benefits and addressing community-specific concerns.
- Encourage leaders to advocate for MDA participation, helping to build community trust and acceptance.

10. Develop Tailored Messages to Address Gender-Specific Perceptions of Risk and Preventive Practices

- **Responsible Parties:** Ministry of Health, Community Leaders, Local Health Workers
- Create gender-sensitive messaging to address specific risk perceptions and health practices relevant to men and women, helping to reduce stigma and misbeliefs about disease susceptibility and MDA benefits.
- Focus on engaging men and boys in discussions about hygiene and prevention practices linked to their outdoor work activities, and women and girls on hygiene practices related to domestic tasks.

11. Develop Culturally Tailored Interventions for Traditional Health Beliefs

- **Responsible Parties:** Ministry of Health, Local Health Workers, Community Leaders, Religious Institutions
- Address traditional health beliefs by integrating local cultural practices with scientifically accurate information, helping to dispel myths around disease causes, prevention, and the effects of MDA.

- Work with traditional healers and local influencers to incorporate culturally sensitive messaging that aligns with community values.

Annex I: Root Cause Analysis Questionnaire

Intro and consent

1. Did you take medication in the last MDA?
2. Have you received consent from the individual "client" to ask them questions about interests and opinions including on health and MDA?

Data enumerator and county/village info

3. What is the data enumerator's full name?
4. Are you collecting data for Awerial county?
5. What is the name of the Payam?
6a. What is the name of the Boma?
6b. What is the name of the Boma?
6c. What is the name of the Boma?
6d. What is the name of the Boma?
6e. What is the name of the Boma?
6f. What is the name of the Boma?
6g. What is the name of the Boma?
7. What is the name of the village?
8. Record your current location

Client's demographic info

9. What is your full name?
10. What is your age?
11. What is your sex?
12. What is your occupation? If not working, note that.
13. What is your marital status? Select the appropriate response below
14. Do you have difficulty seeing?
15. Do you have difficulty hearing?
16. Do you have difficulty walking or climbing steps?
17. Do you have difficulty remembering or concentrating?
18. Do you have difficulty with self-care, such as washing all over or dressing?
19. Using your usual language, do you have difficulty communicating, for example understanding or being understood?

General knowledge/attitude of health care system

20. When you or someone in your household has signs and symptoms of sickness, what do you do?
21. What is your nearest health facility?

22. How long does it take you to move from your house to the health facility?
23. Do men and women have equal access to healthcare in your community? Why?

Perceived risk/threat of onchocerciasis

24. Have you heard of onchocerciasis?
25. Do you know what the symptoms/signs of onchocerciasis are?
26. Can you tell me at least three symptoms/signs of onchocerciasis?
27. How is onchocerciasis transmitted?
27a. If "other," how is onchocerciasis transmitted?
28. How concerned are you about onchocerciasis?
29. Are you worried about the possibility of getting onchocerciasis?
30. What do you think would happen if you got infected with onchocerciasis?
31. How severe do you think getting infected with onchocerciasis is?
32. What concerns you the most about onchocerciasis?
33. Do you think onchocerciasis is a serious health problem in your community?
34. What measures do you take to prevent onchocerciasis in your household?
35. What do you think puts men and boys at risk of getting onchocerciasis?
36. What puts women and girls at risk of getting onchocerciasis?
37. Do women and men in your community have equal access to information about onchocerciasis prevention and treatment?
37a. If men and women do not have equal access to information, why is that?
38. Are there any traditional methods people in your community use to prevent onchocerciasis? If so, describe.
39. How does the community treat individuals with onchocerciasis? Are there differences based on gender or other social factors?

Perceived risk/threat of lymphatic filariasis

40. Have you heard of lymphatic filariasis?
41. Do you know what the symptoms/signs of lymphatic filariasis are?
42. Can you tell me at least three symptoms/signs of lymphatic filariasis?
43. How is lymphatic filariasis transmitted?
43a. If "other," how is lymphatic filariasis transmitted?
44. How concerned are you about lymphatic filariasis?
45. Are you worried about the possibility of getting lymphatic filariasis?
46. What do you think would happen if you got infected with lymphatic filariasis?
47. How severe do you think getting infected with lymphatic filariasis is?
48. What concerns you the most about lymphatic filariasis?
49. Do you think lymphatic filariasis is a serious health problem in your community?
50. What measures do you take to prevent lymphatic filariasis in your household?
51. What do you think puts men and boys at risk of getting lymphatic filariasis?

52. What puts women and girls at risk of getting lymphatic filariasis?
53. Do women and men in your community have equal access to information about lymphatic filariasis prevention and treatment?
53a. If men and women do not have equal access to information, why is that?
54. Are there any traditional methods people in your community use to prevent lymphatic filariasis? If so, describe.
55. How does the community treat individuals with lymphatic filariasis? Are there differences based on gender or other social factors?

Knowledge of MDA

56. What do you know about the purpose of mass drug administration (MDA)?
57. Do you know the purpose of MDA?

Attitudes toward taking MDA

58. If you take MDA, you will be protected against onchocerciasis and lymphatic filariasis. Do you agree to disagree with this statement?
59. If you take MDA, you may experience bad side effects. Do you agree or disagree with this statement?
60. What do you know or have heard about MDA side effects?
61. What side effects would a man/woman experience, and why do you say so?
61a. Have you seen any person with these effects?
62. What are you told about MDA?
63. Who told you this information about MDA?
64. How reliable do you find these sources?
65. Where were you told this information about MDA?
66. Are there any barriers that prevent certain groups from accessing MDA? If so, describe.

Attitudes toward taking general medications

67. If you take medication(s) prescribed to you by a health professional to prevent a disease, you will be protected from that disease. Do you agree or disagree with this statement?
68. If you, or someone you know, experience side effects after taking MDA, what would you/they do?
68a. If "other," what would you/they do?

Perceived norms

69. Do you know of other people who did not participate in mass distribution of onchocerciasis and lymphatic filariasis medicines?
69a. Are these people men, women, or both?
70. What are the reasons people don't participate?
71 Do other men and women have different views about MDA from you?

71a. Why do other men and women have different views about MDA from you?
72. Do you feel that other men and women have better access to MDA than you?
72a. Why do you feel that other men and women have better access to MDA than you?
73. Did most people who are important to you (such as your partner, family, and friends) take MDA last year/last time?
74. When it comes to MDA, do you want to do what your partner/family/close friends think you should do?
74a. Why do you want to do what your partner/family/close friends think you should do?

Perceived behavioral control

75. Do you have any fear in relation to deciding to take MDA?
75a. What do you fear?
75b. Who influences you?
75c. How are you influenced?
76. If married, did your partner take MDA last time?
77. Is taking MDA completely up to you?
77a. Who decides for you?

Previous behavior

78. What is the main reason for not taking MDA last time?
79. Have you ever in the past taken MDA?
79a. The last time you took MDA, what was the main reason you took it?

Opinions about community medicine distributors/promoters and services offered

80. What do you think about the Boma Health Workers (BHWs) in your community?
81. Do you think that male and female BHWs are equally effective?
81a. Why do you think male and female BHWs are not equally effective?
82. Would you prefer to receive medications from a male BHWs, female BHWs, or both?
82a. Why do you prefer to receive medications from a male BHW?
82b. Why do you prefer to receive medications from a female BHW?

Intention taking

83. Do you intend to take the medication during the next MDA?
83a. Why do you intend to take the medication during the next MDA?
83b. Why are you unsure about taking the medication during the next MDA?
83c. Why do you intend to not take the medication during the next MDA?

WASH questions

84. What is your main water source?
85. How far is it from your home?

86. Is the water from this source available throughout the year?
87. Where do you go when you want to ease yourself (defecate)?
88. How do you dispose of children's feces?
[Note for the data enumerator: is open defecation practiced?]
89. When do you wash your hands?
90. What do you use when you wash your hands?
91. How often do you wash your face?
92. How often do you wash children's faces?

Annex II: Example Focus Group Discussion Guide:

Focus Group Discussions (FGDs) Guiding Questions with Nomadic Pastoralists

FGD Information:
Date: _____ Time: _____
Facilitator: _____ Note Taker: _____

Participants' information
County: _____ Payam:_____ Boma:_____
Number of participants: _____ Sex: _____
Age composition: _____
General description of the FGD venue (example: home, work, etc):
_____

BLUE CONTENT IS UNIQUE TO THE NOMADIC PASTORALIST FGD GUIDE. ALL OTHER CONTENT IS THE SAME IN ALL FGD GUIDES.

Participant code	County	Payam	Boma	M/F	Age	Description of the participant (IDP, Persons with disability,etc)	Remark
01							
02							
03							
04							
05							
06							
07							
08							
09							
10							

Introduction and greetings
Thank you for coming. The MOH, with support from partners, is conducting a study to understand how gender and social norms affect the operation and expected health outcomes of onchocerciasis and

lymphatic filariasis elimination interventions. The purpose of the discussion is to collect information relevant for improving gender equality and social and disability inclusion in onchocerciasis and lymphatic filariasis elimination interventions. The discussion will last about 1.5 hours. Do you have any questions?

[Wait a couple of minutes to ensure that the respondent has time to consider if they have any questions. Note down any questions from them and the answers you gave on a separate sheet of paper. Collect consent form. Then begin with the discussion questions.]

Domain	Questions	Probing Questions	Purpose of Question
Baseline/ Introduction	Activities 1. How do you typically spend your time? 2. Do those activities differ from others in your household? If so, how? Interests 3. What are your interests?	1. Probe for what they do on a workday vs. day off (beyond eat and sleep) and at extra-household level spaces (e.g. engagement in development programs and local institutions such as religious and traditional institutions, etc). 2. Probe for how activities differ by gender and age. 3. Probe for things that they feel strongly about (e.g., making money, caring for family, engaging with society)	Establish a baseline of how participants live their day-to-day life and what they value.
Conflict Impacts on Daily Life	Conflict Impacts on Daily Life, Norms, Institutions 4. How long have you been living here? Over the past couple of years, how have your daily life and activities changed? What factors have influenced these changes, and how have you adapted within your household and community?	4a. Explore how respondents' lives have been affected by changes in their community leadership or administration over recent years. 4b. If respondents left the community in recent years, probe for reasons why. ● How far did they travel? ● Did they feel safe traveling to that location? ● Who migrated during this time (entire household vs. specific individuals)? ● Probe for barriers to relocation or mobility in general (e.g., child-rearing, caretaking responsibilities, etc.).	Evaluate how recent events have impacted nomadic pastoralist communities, particularly in terms of any disproportionate challenges they may have faced. How have these experiences and the roles individuals took on during this period shaped current norms, behaviors, and needs within these communities? Consider how these changes have influenced social cohesion, traditional coping mechanisms, and

		4c. If respondents stayed in their community, what challenges did they face due to recent changes in local governance or community conditions? Probe for specific examples. 4d. Probe specifically for additional roles that people took on during recent years (e.g., community leaders, mediators, or other roles in response to community needs).	the financial standing of households. Explore the role of both informal and formal institutions in addressing these evolving dynamics.
	5. As nomadic pastoralist, have you faced any additional challenges over the past couple of years? Were there services and/or caregivers in place to support you with these challenges?	5a. If YES, probe for evidence of increased social solidarity. ● Give specific examples (i.e. increased resilience on collective action and resource sharing among households). ● Probe for IF and HOW local institutions may have been leveraged to foster increased cooperation and social solidarity. 5b. If NO change, explain why? 5c. Are there many IDPs in your community? If so, do you typically interact with them and how do you feel about their presence in your community?	
	6. How has your community changed over the past few years? Do people help each other? ● If yes, can you give an example? ● If not, why do you think that is?		
	7. What does your household look like? What	7. Probe for how many people are in their house. Is it a multigenerational home?	

	has changed over the past few years? (to assess- if they have lost a family member who might have been the breadwinner/ decision-maker in the house) 8. How does your household support itself financially? 9. Has this changed over the past few years? 10. What types of community activities, meetings, associations, and groups do you engage in? What support systems/groups/resources exist for nomadic pastoralists? 11. Have you seen changes in your participation in the community over the past couple of years? If yes, can you give an example? ● If not, why do you think that is?	8a. Probe for 'how' nomadic pastoralists and their specific household members may contribute financially 8b. Probe whether recent conflict has impacted income sources and coping mechanisms of nomadic pastoralists. 9a. Did participation in community affairs change over the past couple of years? 9b. Probe for reasons for lack, or constrained, engagement of nomadic pastoralists in community affairs (are meetings and membership to local informal and formal associations all-inclusive, voluntary, etc)? 9c. What kind of informal and formal institutional help is available to nomadic pastoralists especially in times of insecurity. 11a. If YES, probe for evidence of increased engagement of nomadic pastoralists in community affairs and their ability to receive support (whether formal or informal). ● Probe for additional support that may be needed to help nomadic pastoralists rebuild and recover from insecurity (e.g., psychosocial counseling, financial support, health access) 11b. If NO, probe for specific coping mechanisms that respondents used to mitigate impacts of insecurity.	

		• Probe for IF and HOW local institutions may have been leveraged to support nomadic pastoralists	
Access, Decision making powers and Perceptions of Health Care and Healthy Behaviors	Health Care 12. Where do you typically go or who do you typically go to for health services? 13. Who in the household makes decisions about children's health in the household? We want to know how things like age, gender, and other challenges affect getting health care and taking medicines for onchocerciasis and lymphatic filariasis. 14. Where or from whom do you typically learn about health and disease? 15. Do you think nomadic pastoralists have equal access to health care as the rest of the community? If not, why? 16. Do you encounter any stigma, stereotyping and marginalization?	12a. Probe on quality of care typically received; perceptions of care 12b. Probe on health infrastructure, availability of medicine, health worker quality of service provision, trust and perceptions of providers 12c. Probe on any changes in care seeking behavior or quality in recent years 13. Probe for intra-household bargaining powers and perceptions of the quality of care children are receiving in the community. 15a. Probe for how nomadic pastoralists access any type of health care service including school, community, and facility-based care. 15b. Do women and men in your community seek care equally? If not, why? 15c. What challenges may nomadic pastoralists face in accessing health care? 15d. Are all of the health services for nomadic pastoralists available in your community? 16a. Probe by whom and reasons (beliefs, including traditional or spiritual beliefs, values, etc.) that contribute to continuity of such negative encounters. 16b. Probe on any GBV-related impacts on access and care seeking behavior	Establish a baseline of how respondents access and accept health services and engage in onchocerciasis- and LF-relevant healthy behaviors. Explore the range of possible gender-, age-specific and insecurity-related barriers to receiving health services and related onchocerciasis and LF elimination interventions. Understand how and why gender gaps continue to exist in intervention programs. Understand how and why nomadic pastoralists have been commonly excluded in intervention programs.

		17. Probe for incidents of exclusion in health services based on disability.	
	17. If yes, does this affect your access to or acceptance of health services?		
		18a. Do you have access to water through a pump, well, pond, river, etc? How far do you have to walk to fetch the water?	
	Healthy Behaviors 18. Tell us about your access to clean water for drinking and self care.	18b. Probe on the challenges they encounter in accessing water, and maintaining hygiene and sanitation among different groups in the household	
		18c. How has this changed in recent years?	
		18d. Who in the household is responsible for fetching clean water? Who takes care of children's health and hygiene?	
		19. Probe for availability of private, shared, communal latrines and its utilization, and any changes in the past few years.	
	19. Where do you and other adults in the community usually defecate?		
	Psychosocial 20. From your knowledge, how do you think levels of [specific culturally appropriate word(s) in Dinka will be selected related to distress, anxiety, depression] have changed in recent years?	20. Probe: What are community members doing to take care of themselves and each other?	

Onchocerciasis, LF, and MDA	21. What do you know about onchocerciasis and LF? Discuss general knowledge of disease transmission and symptoms/impact. 22. Do you know anybody who has onchocerciasis or LF, or has suffered from blindness? What is it like to care for someone with onchocerciasis or LF, or blindness or swollen limbs? 23. What do you know about MDA for onchocerciasis and LF? [After responses, provide brief description of Onchocerciasis MDA] 24. Do you remember when the last Onchocerciasis and LF MDA occurred? If yes, did you take the medicine when it was offered to you? If no, why not? Have you ever participated? 25. Who is likely to be missed by health services like MDA and why?	21. Probe for whether participants think onchocerciasis and LF is a risk to them. Probe about knowledge of WASH prevention behaviors. 22. Probe for the possible impacts that this caring role has had on the participant, their family or the community. What are the available health and social services? 23. Probe for sources of information and whether existing knowledge includes misinformation and distrust in MDA / government. Probe on incorrect perceptions of side effects. 24. Probe for why they may not remember the last MDA and why they may not have taken the medicine, if offered to them (consider showing a dosing pole or an example of the medicine to jog the memory) 25a. Do you expect access to and acceptance of MDA will be different for women and men, as well as persons of specific age groups? 25b. Probe for how men and women, including women household heads and women who are wives within male-headed households may face	How are participants involved in MDA and related onchocerciasis and LF elimination interventions? Are these services accessible to everyone? What types of decision-making power do these institutional practices entail?

		barriers to accessing health services like MDA. 25c. Probe for being away due to work/livelihoods, opportunity costs of going, condition of the distribution post, rationale for MDA, perception of low risk, government mistrust/associated with MDA, fear of side effects, fears (treatment will cause sterilization, infertility), etc. 25d. Are there any reasons you think that you might not participate in MDA in the future?	
Recommendations	Recommendations 26. How do you want to learn more about MDA? (Ex. through Community/street advertisements, community groups, schools, radio, leaders)? 27. Who would you like to receive the medicine from when the next MDA occurs? 28. Where do you think other community members would prefer to receive MDA medicines? 29. In your opinion - how can the government improve the onchocerciasis and lymphatic filariasis program so that all men, women, people with disabilities, boys and girls participate? 30. What challenges stand in the way of quality health services?	30. Probe for improvements to close GESI gaps they mentioned, improvements in MDA, improvement in caring for people with onchocerciasis and lymphatic filariasis	Understand emerging trends and solicit recommendations about what is (and isn't working) for fostering social inclusion and gender equality for onchocerciasis and lymphatic filariasis interventions.

Annex III: Example Key Informant Interview Guide

Semi-structured Key Informant Interview (KII) Guide with Boma Health Workers (BHWs)

Interviewer Information:
Date: _____ Time: _____
Interviewer: _____ Note Taker: _____

Respondent's information
Name: _____ Sex: _____
County: _____ Payam: _____
Boma:_____
General description of place of interview (example: home, work, etc):
_____

Meet and greet
Thank you again for the opportunity to interview you. The MOH, with support from partners, is conducting a study to understand how gender and social norms affect the operation and expected health outcomes of onchocerciasis and lymphatic filariasis elimination interventions. The purpose of the interview is to collect information relevant for improving gender equality and social inclusion in onchocerciasis and lymphatic filariasis elimination interventions. The interview will last about 1 hour. Do you have any questions?

[Wait a couple of minutes to ensure that the respondent has time to consider if they have any questions. Note down any questions from them and the answers you gave on a separate sheet of paper. Collect signed consent form. Then begin with the interview questions.]

1a	Do you think /feel that the MDA services are satisfactory here?
1b	Are there male or female groups in the community whose activities affect access to health information data? (Example religious or political public meetings, social celebrations, funerals or weddings).

2	For LF and onchocerciasis MDA, how are BHWs: Probe: How they are identified
	Probe: How they are selected
	Probe: How they are trained in your area/council
	Probe: Their selection process, who's selecting them (for equal opportunities, and to avoid favoritism/nepotism), and the involvement of the community in the process of selection of BHWs.
	Probe: Are men and women equally chosen?
	Probe: Did medical school and nursing school staff and students help BHWs in the most recent LF and oncho MDA?
3a	What kind of support do BHWs receive? How could this be improved? Probe: For available support
	● On Training,
	● Transport,

	● Motivation,
	● Payment
	● Supportive supervision
	How could this support be improved? Probe: ● On Training, ● Transport, ● Motivation ● Payment ● Supportive supervision
3b	Did you see the BHW job aids with pictures of morbidity?
	How were these used by BHWs?

4	What do you think about BHWs' knowledge and/or competencies?
	Probe: In your experience, how many drug distributors are there in each street/area of your village/boma?
	Probe: In your experience of the previous MDA exercise, were the drug distributors enough? If they were not enough, how many were needed?
	Where did the BHWs from your village/boma come from/live?
	Probe: Do you think men and women CDD have equal efficiency?
	Probe: if yes why
	if no, why not?
5	How do you evaluate the quality of health services in your community/area in terms of accessibility of MDA?
	Probe: What do you think can improve your work to become more efficient in reaching more people in urban MDA?
6	What are the main reasons why some people are not being reached with MDA?
	Probe: Timing of MDA
	Distance from health center
	Probe:

	Are there groups not being reached, e.g., ● Women, ● Adolescent boys, ● Nomadic pastoralists, ● Illiterate, etc.
	Probe: If migrants are mentioned, do these daily migrants belong to any specific village / boma/payam/region?
	Probe: What barriers exist for women and men to be reached in MDA? For example, ● Child care affordability, ● Safe transportation, ● Decision making, ● Convenient time to work, ● Being pregnant, and ● Not eligible to take medication
7	What are the main reasons why some people are refusing to participate in MDA?
	Who are these groups?
	Probe: ● Those who think that they are not at risk of getting infected with Lymphatic Filariasis or onchocerciasis ● Not eligible to take medication (People who are seriously sick Pregnant women, and children under five)
	Probe: Are there gender roles and traditions that influence the acceptability/ unacceptability of preventive medication?
	Probe:

	If eligibility is mentioned, how do you consider pregnant women, and lactating mothers while planning for community MDA?
8a	Is there any group/community/location that is consistently missed by all health programs including Polio, Malaria, HIV and NTD?
	Probe: What intervention was given to this group to solve the challenge of continuous absence from health programs
8b	Is there any community in the district that is particularly shunned (no one goes near them and why)?
	Why?
	Probe: Why do you think these groups/communities/locations are not reached?
	Probe: What are other programs doing to reach these groups/communities/locations?
9	How could LF and oncho MDA be improved?
	Probe: ● Time of MDA distribution (morning, day, or night), ● Distribution methods, ● Selection of BHWs at the community level, ● Training, ● Social mobilization
	Probe: What are other health programs doing from which the LF and oncho program could learn?
	Probe: Can LF and oncho MDA be included in other health plans? (Malaria, HIV, Family planning)
10a	Do you know the national NTD strategic master plan for 2023-2027
	Probe:

	How do you use it in your LF and oncho MDA coordination services in your district?

Sources of Information Activity Guide

In every source of information listed, please remember how frequently, how appropriately and how trusted.

Key:

- X= Rarely/Not appropriate/ Little Trust
- XX= Sometimes/Appropriate/Trust somewhat
- XXX=Often/Very appropriate/ Strong Trust

Sources of Information	How frequent			How appropriate			How trusted			Comments
	X	XX	XXX	X	XX	XXX	X	XX	XXX	
Radio										
Town Criers										
Neighbors										
Friends										
Church/Mosque										
Schools										
Community leader/Chief										
CDD										
Health Facility Workers										
Extension Agent (agriculture)										
Extension Agent (veterinary)										
WASH project staff										
Social media										
Posters										
Mobile clinic										

Directions for data collectors with card/pile sort:

1. Present the table to the group. Review the list of possible information sources on the left as a group. Add names,examples, or additions the group has during a brief brainstorm about the different sources of information. You can add sources of information that aren't already captured on the list.
2. Each member will have cards, each marked X, XX, and XXX. For each source of information, each participant will "vote" for how frequently a source of healthcare information is used (X=rarely, XX=Sometimes, and XXX=Often).
3. Next each member will use their cards to "vote" for how appropriate they feel the source is as a place to get healthcare information. (X=not appropriate, XX=appropriate, XXX-very appropriate).
4. Finally, each member will vote on how much they trust the healthcare information provided by each source (X=little trust, XX= trust somewhat, XXX=strong trust)
5. Votes will be recorded in the table as the number of participants voting for each level of frequency,appropriateness, and trust, for each information source.
6. After tallying results, open up a conversation on the exercise and how group members thought about and made their choices. Record reflections in notes/transcript or in the comments box of the table.

Annex IV: Example Consent Form for Qualitative Interviews

Consent to Participate in a Disability-Sensitive Gender Equity and Social Inclusion Assessment—Focus Group Discussion

Title of the Assessment: Gender Equity and Social Inclusion (GESI) Assessment Towards Onchocerciasis and Lymphatic Filariasis Elimination in Awerial County, South Sudan

Principal Investigator: Dr Yak Yak Bol

What Is the Assessment About?

We are asking you to take part in an assessment about how gender norms and roles impact achievement of onchocerciasis and lymphatic filariasis elimination in Awerial County, South Sudan. If you take part in this assessment, you will be one of about 100 people to do so. You are being invited to participate in an assessment because we value your unique perspective.

Who Is Leading the Assessment?

The person in charge of this assessment is Principal Investigator, Dr Yak Yak Bol (South Sudan Ministry of Health). This assessment is being funded by the END Fund.

What Is the Purpose of This Assessment?

Through this assessment we hope to learn how the different roles and status of women, men, and persons with disability affect their access to or use of treatment, via mass drug administration (MDA) for onchocerciasis and lymphatic filariasis in Awerial. Further, the assessment seeks to explore the ways gender and other social barriers, as well as emerging challenges, might affect MDA uptake and adoption of good sanitation and hygiene practices. Specifically, assessment findings will inform support to future MDA planning and implementation, particularly through activities led by the South Sudan Ministry of Health and the END Fund.

Do I Have to Take Part in this Assessment?

If you decide to take part in the assessment, it should be because you wish to volunteer. It is not mandatory. There will be no penalties or repercussions if you choose not to participate. You will not lose any benefits or rights you would normally receive if you choose not to volunteer. No one on the assessment team will behave any differently toward you or be upset if you choose not to participate in the assessment. Even if you decide to be part of the assessment now, you may change your mind and stop at any time. If you decide to withdraw before this assessment is completed, we will delete your responses. The assessment will be conducted in-person and in the participant's local language.

Where Is the Assessment Going to Take Place and How Long Will It Last?

If you consent, the focus group discussion will take place here and now and will last between one hour to an hour and a half.

What Are the Possible Risks and Discomforts?

To the best of our knowledge, the answers that you will provide have no more risk or harm than you would experience in everyday life.

If you find some of the questions we ask to be confusing or disturbing, we may be able to help you contact someone whose job it is to provide support.

Will I Benefit from Taking Part in This Assessment?

You will not personally benefit from taking part in this assessment, but the information you provide will be used to improve programming for onchocerciasis and lymphatic filariasis elimination and control in Awerial. It could therefore indirectly benefit the health of your community.

What Will It Cost to Participate?

There are no costs associated with taking part in this assessment.

Will I Receive Any Payment or Reward for Taking Part in this Assessment?

You will receive a 5 USD refreshments payment and 6 USD transportation compensation for taking part in this assessment.

Who Will See the Information I Give?

You will not be identified in any published or presented materials. Only the assessment team will have access to your name and to the collected data and the physical consent forms. All electronic data will be stored on computers with password protection, and written notes will be kept in a locked suitcase during the travel and in a locked filing cabinet upon return.

What If I Have Questions?

Before you decide whether to participate in the assessment, please ask any questions that come to mind. Later, if you have questions about the assessment, you can contact the members of the assessment team, specifically, Charles Kpiosa at +211 915 652 180.

What Else Do I Need to Know?

By providing your verbal consent you are agreeing to be in this assessment. Please be sure you understand what the assessment involves before you provide consent. We will give you a copy of this document for your records. We will keep a copy with the assessment records. If you have any questions about the assessment after you provide your consent, you may contact Mr. Charles Kpiosa, using the information provided above.

Assessment Participant Statement and Signature

I understand what the assessment involves, and my questions so far have been answered. I understand that my participation in this research assessment is voluntary. I agree to take part in this assessment.

_____ _____

Signature of Data Collector Attesting Verbal Consent Date