

# South Sudan ARISE - END Fund

## Results from the Root Cause Analysis in Kapoeta North



*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 Neglected Tropical Diseases (NTDs), most of which are readily 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, 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 \(who.int\)](https://www.who.int/south-sudan/ntd)

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,

#### **KAPOETA NORTH SOUTH SUDAN**



#### **AWERIAL COUNTY SOUTH SUDAN**



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 lymphatic filariasis and onchocerciasis.

This report presents an overview of the findings from the RCA conducted in Kapoeta North between July 19 and August 2, 2024, along with thematic analysis of the results, challenges and key recommendations.

## Root Cause Analysis

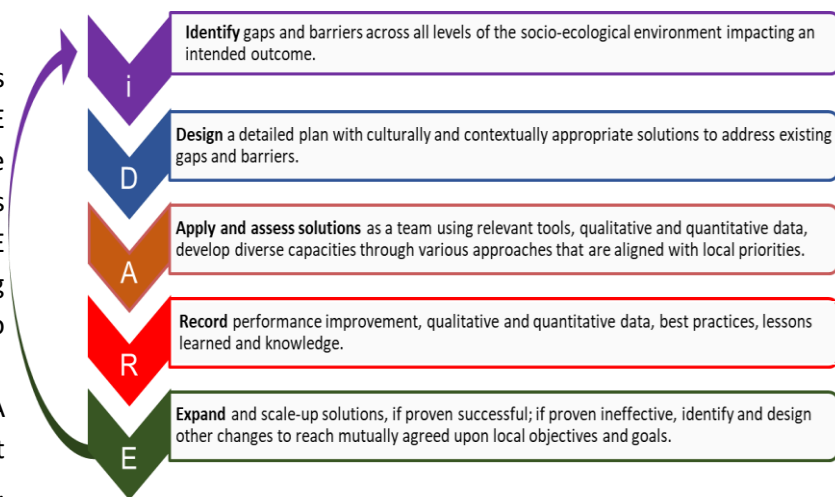
In July 2024, a core GESI Team comprising the MOH, GESI Focal Person, an ARISE team representative, and a WI-HER Consultant traveled to Kapoeta North to conduct an RCA.

## Objective

The main objective of the RCA was to ascertain and address barriers that impeded the coverage of the most recent January 2024 trachoma MDA in Kapoeta North.

## Methodology

The approach for the RCA 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). 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 Kapoeta North. 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 trachoma are community-informed and driven, WI-HER engaged and trained community influencers and conducted stakeholder meetings.

## Sampling Design

Simple random sampling was used for the household survey targeting individuals who did not take MDA during the last campaign in Kapoeta North. This method was chosen due to its ease of implementation and ability to provide a straightforward, statistically valid representation of the large and dispersed population across various payams and bomas. By giving each individual an equal chance of selection, simple random sampling minimizes bias and facilitates accurate analysis, making it an efficient approach for understanding MDA noncompliance in the region.

### Data Collection

Data collection was conducted using a digital data collection tool (KoboToolbox) where a structured questionnaire was administered using digital tablets to gather qualitative and quantitative data on MDA acceptance, access, and use. The questionnaire is included as an appendix to this report. The key indicators focused on identifying barriers related to GESI, including socioeconomic factors and intersectional barriers that hinder full MDA coverage.

### Data Triangulation

Meetings with stakeholders, including local authorities such as the Commissioner and County Health 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 data findings and analysis was discussed and validated.

### Data Analysis

Statistical and thematic analysis was conducted on the survey data to identify patterns and correlations between different variables and MDA noncompliance. Additionally, thematic analysis was applied to the data obtained from stakeholder meetings to extract key themes related to barriers to MDA.

## Stakeholder Meetings

Logistical planning for the RCA in Kapoeta North involved selecting and training data collectors and securing approval from local health authorities. After meeting with the County Health Supervisor, the team received security clearance to proceed with the survey. A stakeholders' meeting was held with 12 key participants, including the County Health Director and Commissioner, who emphasized early planning and prepositioning, community mobilization, and effective communication. Challenges discussed included limited water points hindering MDA coverage, misinformation about trachoma drugs causing infertility and blindness by herbalists who believe that MDA programs negatively impact their market., and the need for eye care services. Stakeholders recommended upgrading water sources into motorized water yards, organizing mass awareness campaigns involving local women and community members led by boma chiefs to raise awareness and dispel myths, and deploying mobile teams to reach remote areas.

Stakeholders appreciated the integration of GESI into ongoing NTD programs, noting the positive impact on women and persons with disabilities. They called for continued efforts to ensure equal opportunities and participation for women in community affairs, reinforcing the importance of the GESI approach in improving health outcomes in South Sudan. The most recent MDA in January 2024 was noted as the most successful so far, with continued camping in communities and mobile outreach suggested.

## 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. It emphasized the importance of interpreting the questionnaire 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 and requested printed handouts for reference.

## 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, hence, improving program effectiveness, and achieving better health outcomes.

A comprehensive training session was held in late July at the County Health Department (CHD) office, bringing together 16 Community Influencers, including the County Health Director, with equal male and female representation. 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 trachoma prevention, control, and elimination. Through the training, significant gaps in trachoma efforts were addressed, and the critical roles of the Community Influencers in driving behavior change were emphasized. The training concluded with the formation of the county GESI team, chosen for their active participation and passion for becoming influential community leaders. Boma Chiefs underscored the importance of involving local authorities in grassroots initiatives. Key objectives included understanding trachoma transmission, defining iDARE, the importance of behavior change techniques, and addressing barriers to MDA access and acceptance.



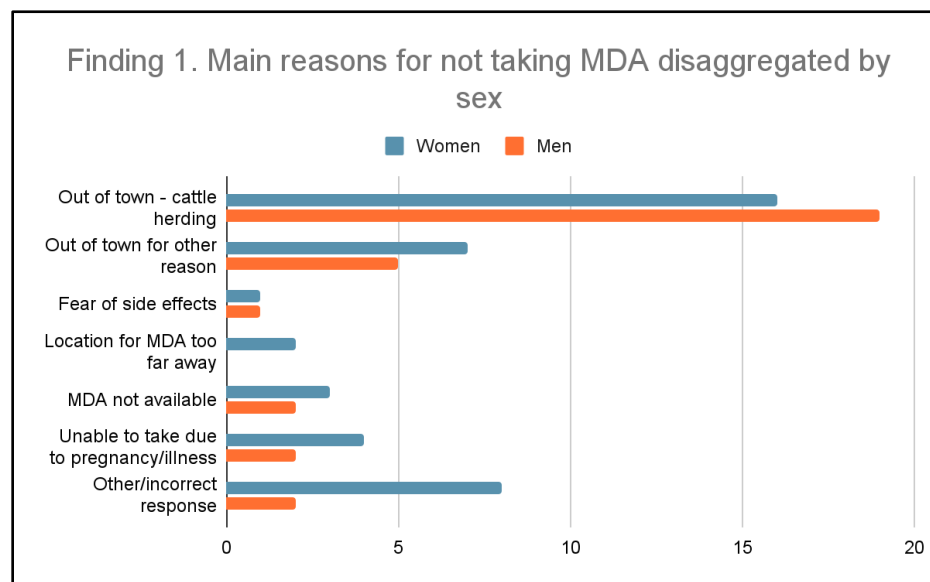
**Community Influencer training, July 2024, Kapoeta North County. Photo credit: South Sudan Ministry of Health**

## Findings & Thematic Analysis

The RCA in Kapoeta North County was conducted with a total of 72 respondents, including 41 female respondents and 31 male respondents. Respondents came from 4 payams, 9 bomas, and 29 villages.

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

**Finding 1 (Main reasons for not taking MDA disaggregated by sex):** The data indicates that the primary reason for not participating in MDA is being out of town, with 49% (35 out of 72) of the respondents,

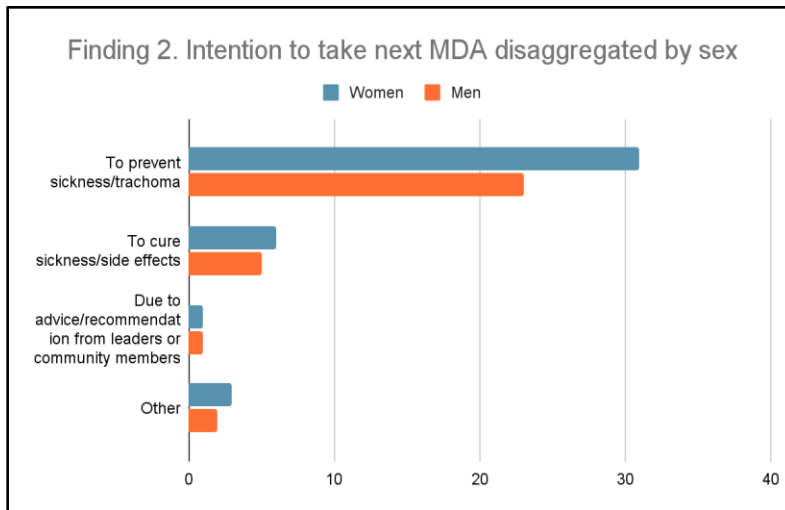


particularly more males (19) than females (16), missing MDA due to cattle herding. An additional 17% (12 out of 72) were out of town for other reasons, showing that a highly mobile population is a significant barrier to participation across men and women. Other factors include pregnancy or illness, affecting 8% (6 out of 72) of respondents, and

the unavailability of MDA, impacting 7% (5 out of 72). A small number of participants cited fear of side effects (2 out of 72) and transportation challenges (2 out of 72) as reasons for non-participation. Fourteen percent (10 out of 72) provided responses that were either unrelated to the question or indicative of miscommunication. Furthermore, when asked “Are there any barriers that prevent certain groups from accessing trachoma MDA?” respondents illuminated barriers including “*medication is scarce, too few drugs,*” “*not knowing the venue for MDA Campaign,*” “*people in cattle camps, who are far away,*” “*old and vulnerable people, can't travel distant place,*” and the fear of side effects. These barriers should be addressed to increase equitable access to MDA. 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 disaggregated by sex):** Seventy-five percent of respondents (54 out of 72) plan to take the next MDA primarily to prevent sickness or trachoma. Another 15% (11 out of

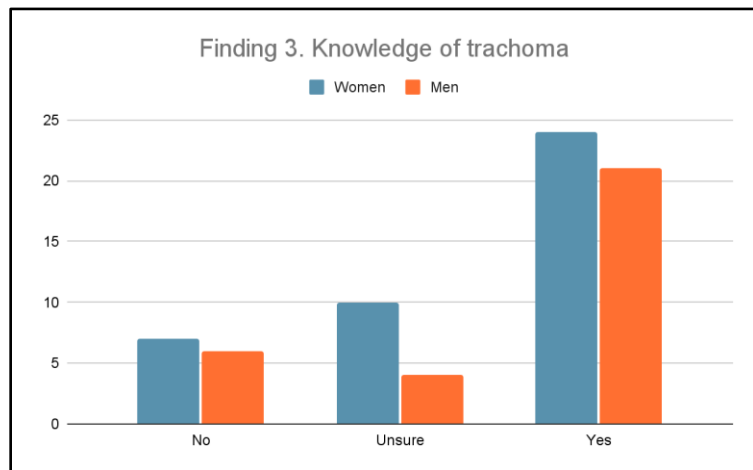




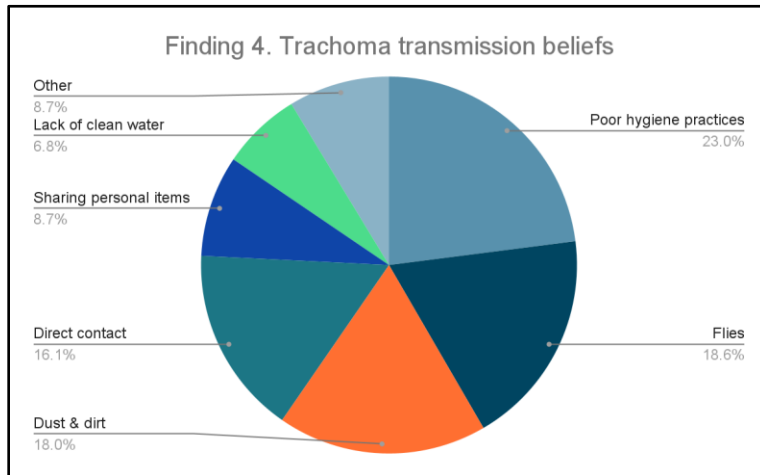
72) aim to participate to cure sickness or side effects, reflecting a mix of preventive and curative beliefs about MDA. A small percentage (3%) are influenced by advice, and 7% cite other reasons, indicating that while prevention is the main motivator, some respondents have different or additional considerations for participating in the MDA.

**Finding 3 (Knowledge of trachoma):**

The data reveals that out of the 72 respondents, a significant majority, 63% (45 out of 72), are knowledgeable about the symptoms or signs of trachoma. However, there is still a notable portion of the population that lacks this awareness. Specifically, 19% (14 out of 72) of respondents are unsure about the symptoms. Additionally, 17% (12 out of 72) do not know the symptoms of trachoma. The presence of 37% (26 out of 72) of respondents who are either unsure or unaware of trachoma symptoms suggests a need for targeted educational campaigns; furthermore, this was gendered, with 41% of female respondents being unsure of/not knowing symptoms, versus 32% of male respondents. Thus, these efforts should focus particularly on women, as



they represent a significant portion of those lacking knowledge, to improve awareness and ultimately enhance the effectiveness of trachoma prevention and treatment initiatives.

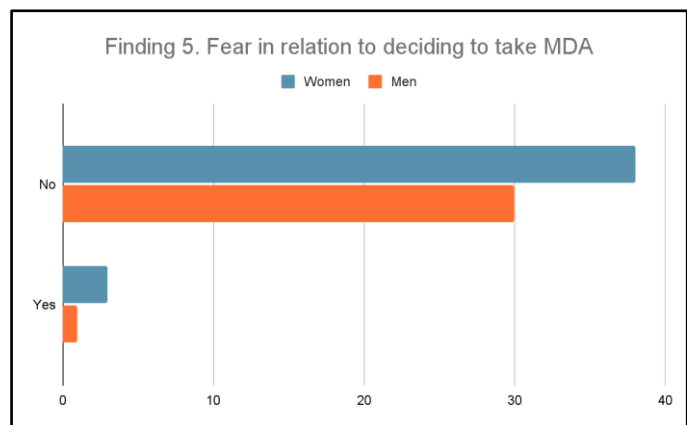


**Finding 4 (Beliefs about trachoma transmission):** A majority of respondents (37, or 51.4%) pointed to “poor hygiene practices” as the main way trachoma is transmitted. The next highest choice was “flies” (30, or 41.7%), then “dust and dirt” (29, or 36.1%) and “direct contact” (26, or 36.1%). Only 14 respondents chose “sharing personal items,” and 11 respondents chose “lack of clean water.” Fourteen respondents chose “other,” and common answers here

were relating to God/curses or “it happens on its own.” This finding illustrates the need to conduct community outreach and training related to trachoma and its transmission.

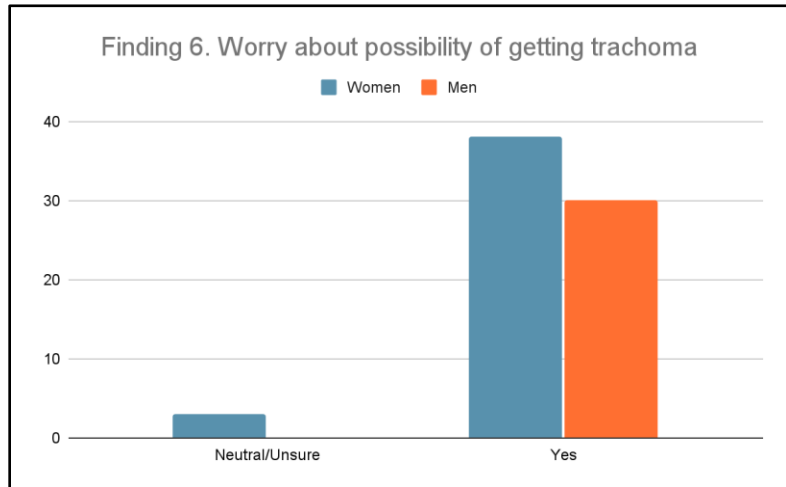
**Finding 5 (Fear in relation to deciding to take MDA disaggregated by sex):**

The data indicates that there is a strong acceptance of MDA among both women and men, with 94% of respondents not expressing fear about participating. Although women exhibited slightly higher levels of fear (7%) compared to men (3%), the overall fear levels are minimal. 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; 28% of respondents said that they do not know the purpose of MDA, and 14% of respondents chose “neutral/unsure” in response to the prompt “If you take MDA, you will be protected against trachoma.”



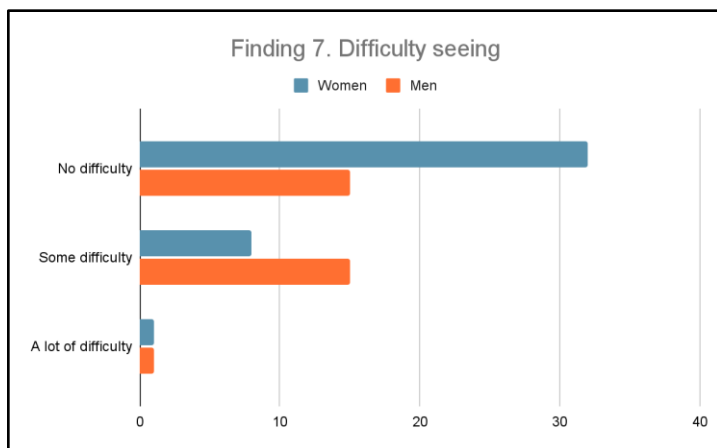
**Finding 6 (Trachoma risk perception disaggregated by sex):**

The data divulges that the majority of respondents, both male and female, perceive a significant risk of contracting trachoma. Specifically, 96% (68 out of 71 respondents) expressed concern about the possibility of getting trachoma, with 93% of females and 100% of males showing worry. Only a small fraction (4%) were neutral or unsure, all of whom were women, primarily due to concerns about blindness (one response: *“the most concerning aspect of trachoma is its potential to cause irreversible blindness if left untreated”*), with few mentioning itching or infection as potential risks. One respondent did not answer because they were unfamiliar with what trachoma is, highlighting a potential gap in awareness. The findings suggest a strong awareness and concern about trachoma among both sexes, with a slight variation in the specific concerns associated with the disease.



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Fear of what would happen if men and boys, versus if women and girls, get trachoma was different. As one respondent noted, *“Men are far away in cattle camps where there is no water,”* and frequently, respondents noted that men are exposed to environmental conditions and have poorer hygiene, and that *“Men bath together in the river”* which was associated with a higher risk of trachoma. For women and girls, risk was associated with poor hygiene practices and engaging with children without sufficient washing.



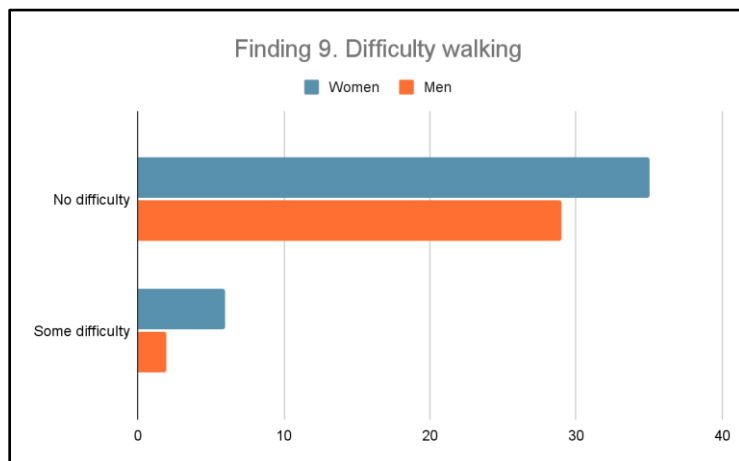
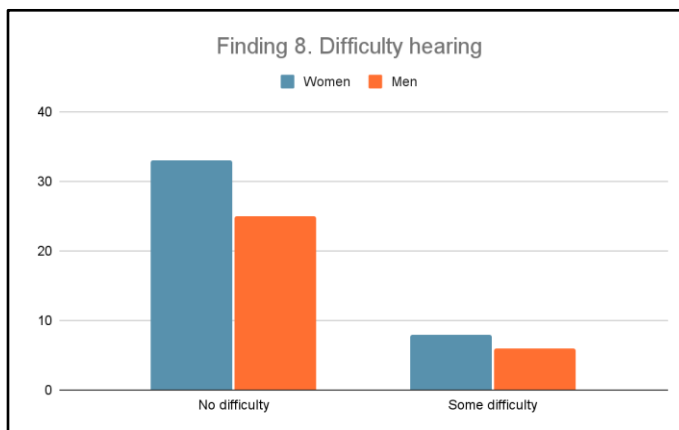
**Finding 7 (Difficulty seeing disaggregated by sex):**

The data on difficulty seeing, disaggregated by sex, reveals that out of 72 respondents, the majority, 47 (65%), reported no difficulty seeing, including 32 females (45%) and 15 males (21%). A total of 23 respondents (32%) reported some difficulty, with 8 females (11%) and 15 males (21%) experiencing this issue. Only 2 respondents (3%) reported a lot of difficulty, split evenly between 1 female (1.5%) and 1 male (1.5%). 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 8 (Difficulty hearing disaggregated by sex):**

The data on difficulty hearing, disaggregated by sex, communicates that a significant majority of both females and males reported no difficulty hearing. Specifically, 33 out of 41 females (81%) and 25 out of 31 males (81%) indicated no difficulty hearing, making up a total of 58 individuals, or 81% of the total sample. In contrast, a smaller proportion of participants reported some difficulty hearing, with 8 females (19%) and 6 males (19%) experiencing such issues, totaling 14 individuals (19% 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.

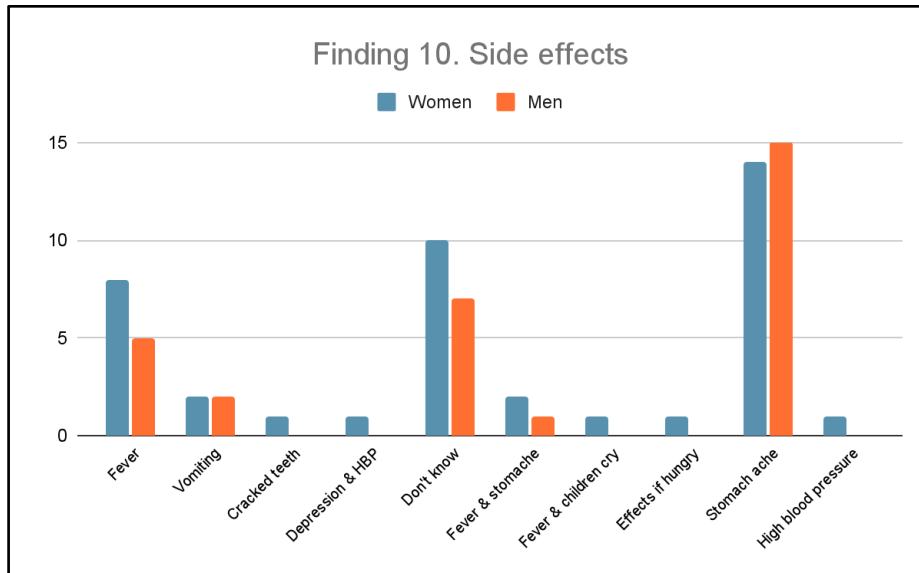


**Finding 9 (Difficulty walking disaggregated by sex):**

Out of 72 respondents, 64 (89%) reported no difficulty walking or climbing steps, while 8 (11%) reported some difficulty. Among female respondents, 35 out of 41 (85%) reported no difficulty, and 6 (15%) reported some difficulty. In contrast, 29 out of 31 male respondents (94%) reported no difficulty, and only 2 (6%) reported some difficulty. This indicates that while most respondents do not have

any difficulty walking, there are still some individuals who experience such difficulty, particularly among women.

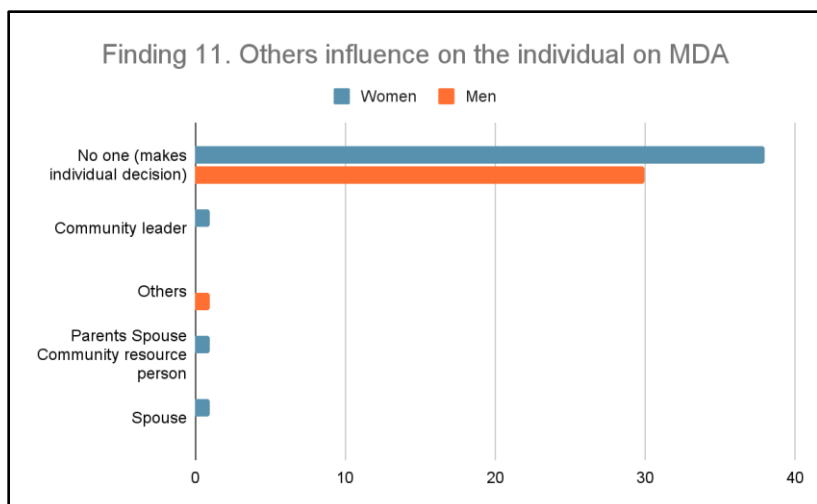
**Finding 10 (Side effects of MDA disaggregated by sex):** The data demonstrates that stomach pain or stomachache is the most frequently reported side effect of MDA, noted by 32 respondents (45%), including 16 females and 16 males. Fever is also a common concern, mentioned by 17 respondents (24%), with 11 females and 6 males. Vomiting is less commonly reported, with 4 respondents (6%), equally split



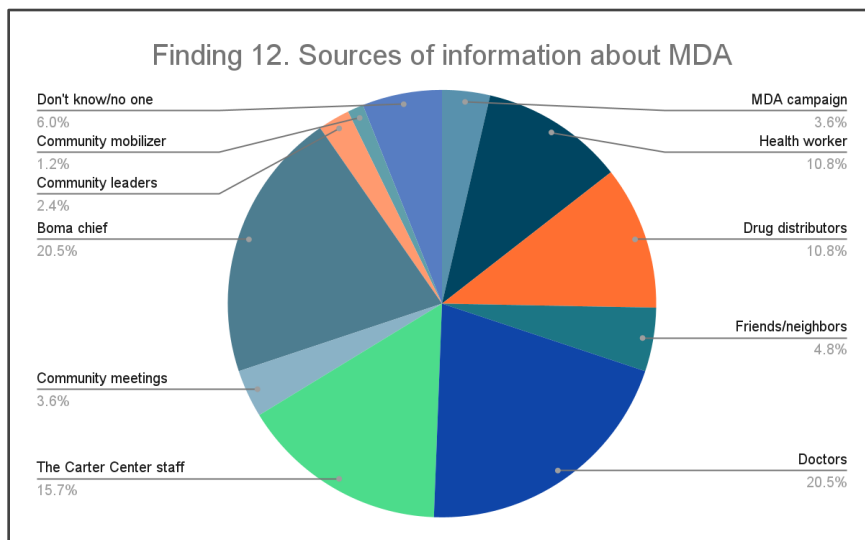
between females and males. Lesser-mentioned or uncommon side effects include cracked teeth, depression, and children crying, each mentioned by only 1 respondent; high blood pressure was mentioned twice. A notable portion of respondents, 18 in total (24%), indicated they do not know about MDA side effects, reflecting a potential gap

in awareness, with 10 females and 7 males expressing this uncertainty. Finally, one respondent (1.4%) mentioned a misconception that MDA might affect the body if taken on an empty stomach, suggesting possible misunderstanding. Although most respondents said that there is no difference in side effects experienced by men and women, some respondents believed that there is a difference (i.e., *“Man mostly fever, woman and children vomiting because man has strong blood”*). This also indicates that while prevention is the main motivator, a small number of respondents consider other factors, suggesting the importance of reinforcing preventive health messaging.

**Finding 11 (Others’ influence on the individual on MDA disaggregated by sex):** The data illuminates that the majority of respondents, 68 out of 72 (94%), reported making decisions independently, with 38 females and 30 males indicating they are not influenced by others. This demonstrates a strong tendency towards individual decision-making among participants. Only 1 respondent (1.5%) cited a community leader as an influence, while another 1 (1.5%) mentioned “others” without further specification. One respondent (1.5%) noted that their spouse influences their MDA-related decision, while another 1 respondent (1.5%) indicated that their parents, spouse, and a community resource person influences them. These responses indicate that these factors have a minimal impact on decision-making.



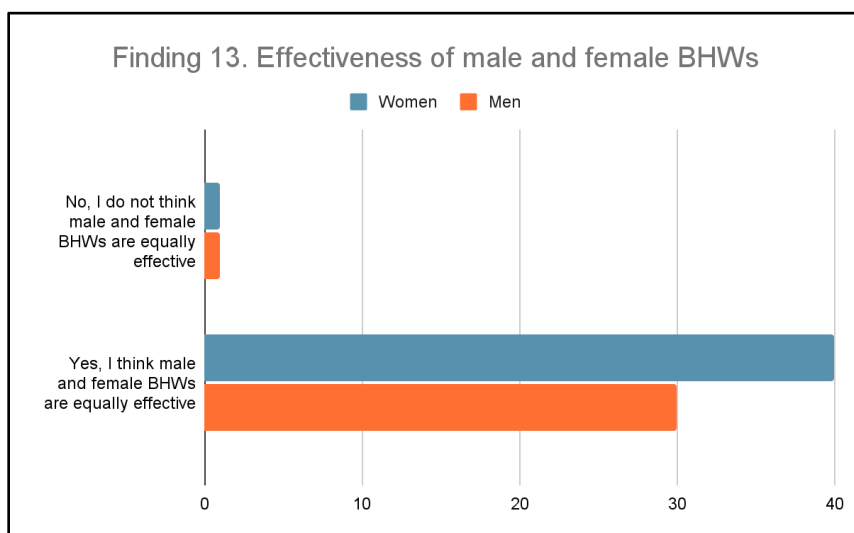
Overall, the data underscores the predominance of personal judgment over external influences in the decision-making process among the respondents. Notably, although most respondents felt that men and women have equal access to information about trachoma prevention and treatment, one respondent noted that *“Different activities given to particular gender in that women are always at home men can move freely hence getting information can be easy for them.”*



**Finding 12 (Information about MDA):** Relevant to decision-making and influence, respondents shared what they are told about MDA and where they access this information. A majority of respondents (17, or 20.5% each) pointed to doctors or boma chiefs as their source of information about MDA, followed by The Carter Center Staff (13, or 15.7%). Importantly, 6%, or 5

respondents, indicated that they did not receive information about MDA from any source. In terms of what information respondents received about MDA, respondents noted that they were told that trachoma MDA can prevent eye disease/blindness/trachoma.

**Finding 13 (Effectiveness of male and female BHWs disaggregated by sex):** The data displays a strong consensus among respondents that male and female Boma Health Workers (BHWs) are equally effective,

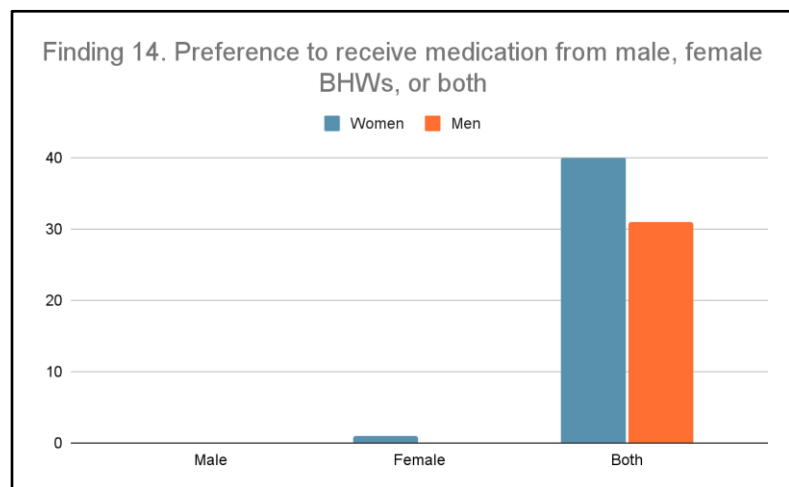


with 97% (70 out of 72) of participants, including 40 females and 30 males, expressing this belief. This overwhelming agreement suggests that both genders are perceived to provide similar levels of care and effectiveness in their roles as BHWs, which is a positive indicator for gender equity in health service delivery. Only 3% (2 out of 72) of respondents, one female and

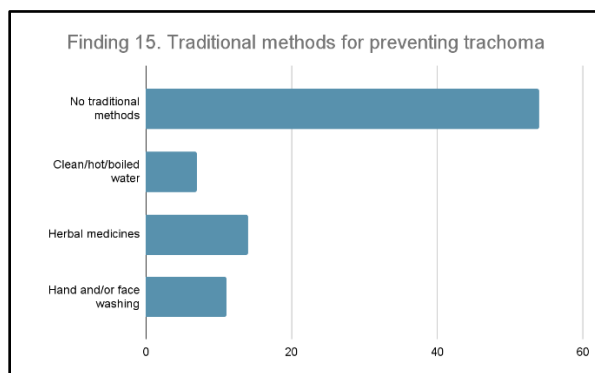
one male, do not believe that male and female BHWs are equally effective. This minority view indicates that there may be isolated perceptions or experiences where the effectiveness of BHWs is seen as gender-dependent, though this is not a widespread sentiment. Overall, the data highlights a strong confidence 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. This finding supports the notion that health interventions can rely on both male and female workers without concerns about differing effectiveness based on gender. This optimistic finding is tempered, though, by the fact that when asked “What do you think about the Boma Health Workers (BHWs) in your community?,” 11 respondents (15.4%) noted that there are actually no BHWs in their village (“*They don't come to our village*”; “*Sincerely I don't know about health workers in the village*”) and one respondent said “*They are dormant, they don't tell us about any health related practices.*” Of these twelve respondents, 5, or 41.7%, were from Kateok village; otherwise, respondents without access to BHWs were from Nyebuyayit (1), Woyamong (2), Nasuranit (1), Buya (1), Kadanya (1), and Napeichoke (1).

**Finding 14 (Preference to receive medication from male, female BHWs, or both disaggregated by sex):**

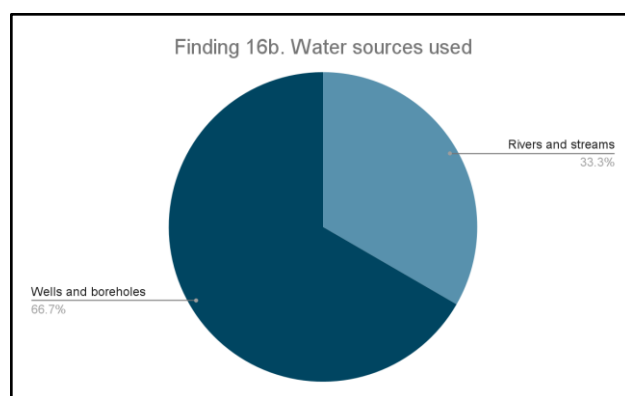
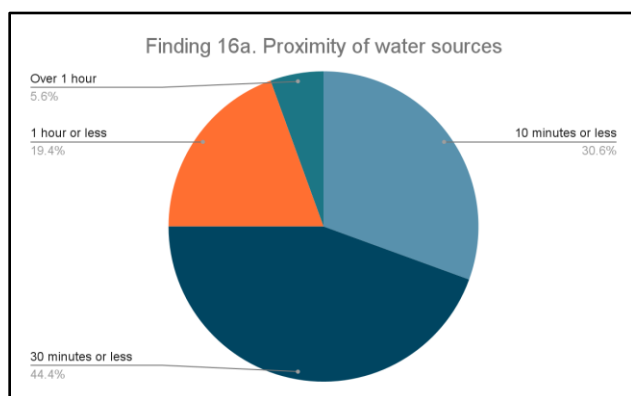
The data discloses that an overwhelming majority of respondents, 97% (70 out of 72), prefer to receive medications from both male and female BHWs, with this preference equally strong among both females (40 out of 41) and males (31 out of 31). This suggests a broad acceptance and comfort level with receiving 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 13 above. Only 1.4% (1 out of 72) of respondents, a female, expressed a preference for receiving medications exclusively from female BHWs, citing that certain diseases require the attention of female health workers only. This highlights a specific, albeit very limited, cultural or personal consideration where gender plays a role in healthcare preferences. Overall, the data indicates a strong preference for flexibility in healthcare provision, with most people comfortable receiving medications from either gender, reinforcing the effectiveness of a gender-diverse health workforce in the community.



**Finding 15 (Traditional methods for preventing trachoma):** A majority (54, or 72%) of respondents said that there are no traditional methods for preventing trachoma, although some (14, or 19.5%) respondents pointed to herbal medicines; one respondent referenced, *“use of herbs but not effective enough to treat eye disease.”* Seven respondents (9.7%) also highlighted the use of clean or hot/boiled water (*“We use hot water and soap to clean our face and body as a traditional method in my community”*) and 11 respondents, or 15.3%, referenced hand and/or face washing.



**Finding 16 (Water source):** The data shows that among the 72 respondents, 67% (48 out of 72) primarily rely on wells and boreholes as their main water source, while 33% (24 out of 72) depend on rivers and streams. The accessibility of these water sources varies significantly, with most respondents reporting relatively close access. For those using rivers and streams, 71% (17 out of 24) have access within 30 minutes or less, with 29% (7 out of 24) accessing it in 10 minutes or less. However, a small portion, 4% (1 out of 24), travel more than an hour to reach their water source. In contrast, for those relying on wells and boreholes, 88% (42 out of 48) can access their water source within 30 minutes or less, and 31% (15 out of 48) have it within 10 minutes. A smaller group, 8% (4 out of 48), takes an hour or less, and 6% (3 out of 48) need more than an hour to reach their 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. Improving access to closer and more reliable water sources could significantly enhance the community's water security.

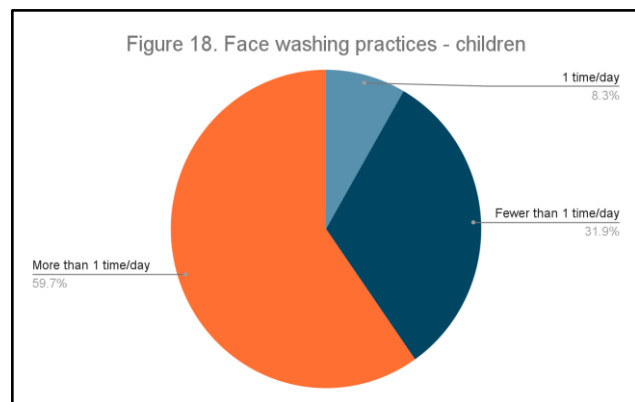
**Finding 17 (Face washing practices - adults):** The data on face washing practices among the 72 respondents reveals that 61% of adults (44 out of 72) wash their face more than once per day, suggesting a strong adherence to personal hygiene in this aspect. This majority indicates a positive behavior that could contribute to the prevention of hygiene-related diseases like



trachoma. However, 24% (17 out of 72) wash their face less than once per day, which may increase their risk of developing hygiene-related health issues. Based on information from stakeholders, this is generally due to poor hygiene practices and lack of water access. 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, 15% (11 out of 72) wash their face once per day, which is a moderate practice but still below the most protective behavior of washing more than once daily. Overall, while the majority engage in frequent face washing, there remains a notable minority that could be at higher risk due to less frequent washing, indicating the need for continued public health efforts to promote optimal hygiene practices.



**Finding 18 (Face washing practices - children):** The data on hygiene and health practices reveal key insights. For face washing among children, 43 out of 72 (60%) are washed more than once per day, while 29 (40%) are washed less frequently.



**Conclusion:** The analysis highlights several critical barriers to participation in MDA for trachoma, primarily related to a highly mobile male population, access to information, and fear of side effects. Challenges related to a nomadic lifestyle, especially among men engaged in cattle herding, limit MDA coverage. Knowledge gaps about trachoma symptoms and MDA’s purpose further impede participation, despite strong intentions to prevent sickness. Physical vulnerabilities, such as difficulty walking, particularly among women, also present challenges. Improving access to reliable water sources and enhancing hygiene practices are essential for effective disease prevention. Addressing these challenges through targeted interventions such as education, better communication and mobile health services could significantly improve MDA participation and trachoma prevention efforts.

## Challenges

The effective implementation of MDA faces numerous challenges that can significantly impact participation rates and 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 the 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 findings and insights from stakeholders, to offer a comprehensive understanding of the obstacles hindering MDA participation and the strategies needed to overcome them.

- 1) Accessibility and Mobility Challenges:** A highly mobile population and limited accessibility significantly hinder participation in MDA programs. For instance, men involved in cattle herding experience high mobility, making it difficult for them to consistently participate in MDA efforts (*see finding 1*). This finding was also identified by stakeholders as a significant barrier to effective and consistent MDA participation, particularly in remote areas where access to water and health services is limited. Additionally, 5.6% of respondents spend more than an hour reaching their primary water source (overall 69.4% of respondents spend more than 10 minutes accessing their primary water source) which exacerbates difficulties in maintaining hygiene practices critical for trachoma prevention (*see finding 16*).
- 2) Limited Knowledge and Awareness:** A gap in knowledge and awareness presents a major challenge to effective MDA participation. For instance, 41.4% of female respondents were either unsure of, or did not know, the symptoms of trachoma compared to 31.3% of male respondents; this limits their ability to engage in prevention activities (*see finding 3*). Additionally, 24% of respondents expressed uncertainty about the side effects of MDA, revealing a critical need for enhanced health education (*see finding 10*). Additionally, stakeholders emphasized the need to bridge the knowledge gap, particularly among women, regarding trachoma and the benefits of MDA. The fear of side effects was identified as a critical area requiring targeted health education to improve participation rates.
- 3) Physical Vulnerability:** Health-related challenges such as sensory impairments were highlighted, with 19.4% of respondents (19.5% of women versus 19.4% of men) reporting hearing difficulties (*see finding 8*) and 34.7% (22% of women versus 51.6% of men) reporting vision difficulties (*see finding 7*), which create barriers to accessing health information and participating in MDA. Additionally, 11% of participants reported difficulty in walking or climbing steps (14.6% of women versus 6.5% of men) which could impact their ability to engage in MDA activities (*see finding 9*). Stakeholders noted that sensory impairments and physical limitations, particularly among women, were significant barriers to effective MDA participation; tailored interventions are thus necessary to address these vulnerabilities.
- 4) Perception and Attitudinal Challenges:** The perception of trachoma risk is high among the population (95.8% recognize the risk) (*see finding 6*) but converting this concern into consistent MDA

participation remains a challenge. Although fear of MDA participation is generally low (5.6% overall), it is slightly higher among women at 7.3% versus 3.2% for men, indicating a minor but notable attitudinal barrier (*see finding 5*). Stakeholders similarly discussed the challenge of translating awareness into action. While the overall perception of risk was high, the slight increase in fear among women was recognized as an attitudinal barrier that needs to be addressed to improve participation rates.

- 5) Behavioral and Practice Challenges:** Inadequate hygiene practices, particularly regarding face washing, were identified as a significant behavioral challenge. With 23.6% of respondents washing their face fewer than one time per day (*see finding 17*) and 31.9% washing their children’s faces fewer than one time per day (*see finding 18*), there is a clear need for improved hygiene practices to support trachoma prevention. Stakeholders emphasized the importance of improving hygiene practices as a key factor in trachoma prevention.
- 6) Autonomy in Decision Making:** Importantly, although 94.4% of respondents expressed that they make decisions related to MDA independently, 7.3% of women (versus 3.2% of men) expressed uncertainty about their autonomy in decision-making related to MDA participation, referencing parents, spouses, and community leaders/members as people who influence their decisions (*see finding 11*). Stakeholders also emphasized this barrier.
- 7) Equity and Effectiveness Challenges:** Perceptions of gender equity in the effectiveness of Boma Health Workers (BHWs) are generally positive, with 97.2% of respondents feeling that male and female BHWs are equally effective (*see finding 13*). However, addressing even small disparities, such as the 2.8% of respondents who did not agree that female and male BHWs are equally effective, is essential for ensuring equitable health outcomes. Stakeholders also acknowledged the need for continuous efforts to maintain and improve equity in health service delivery, particularly in addressing the small but notable disparities in perceptions of BHW effectiveness. Furthermore, 15.4% of respondents (mainly from Kateok village) noted that their village doesn’t actually have BHWs, and one respondent noted that although their village has BHWs, they are “dormant.”

## Recommendations

Based on findings from the RCA, 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. **Improving Accessibility and Mobility (*Responsible Party: Ministry of Health*):** The challenges related to accessibility and mobility emerged as significant barriers to MDA participation. The stakeholders echoed these concerns, emphasizing the need for mobile health services to reach nomadic populations, particularly those in cattle camps, and the necessity of improving infrastructure such as water access. Therefore, it is recommended to implement mobile health services and establish temporary MDA sites in highly mobile areas, while also improving infrastructure by building accessible water sources closer to communities to support hygiene practices.
2. **Enhancing Knowledge and Awareness (*Responsible Parties: Ministry of Health; Community Influencers; Community Leaders; Boma Health Workers; MDA Teams; The Carter Center/Local Organizations*):** Lack of knowledge and awareness about trachoma and MDA was identified as a crucial barrier, particularly among women. Stakeholders underscored the importance of targeted health education campaigns, especially focusing on women, to address these gaps. These campaigns should be culturally sensitive and delivered through trusted community figures to effectively bridge the knowledge gap and dispel fears surrounding MDA. Consequently, it is recommended to launch targeted health education campaigns that focus on increasing awareness and knowledge about trachoma and the importance of MDA.
3. **Addressing Physical Vulnerabilities (*Responsible Party: Ministry of Health*):** Physical vulnerabilities, such as sensory impairments and mobility challenges, presented significant barriers to MDA participation. Stakeholders highlighted the need to provide tailored assistance to these individuals, such as visual aids, community health workers trained in sign language, and transportation services for those with mobility challenges. As a result, it is recommended to provide special assistance for individuals with physical vulnerabilities, ensuring they receive the necessary support to participate in MDA.
4. **Changing Perceptions, Attitudes, and Sociocultural Norms (*Responsible Parties: Ministry of Health; Community Influencers; Community Leaders; Boma Health Workers; MDA Teams; The Carter Center/Local Organizations*):** Perceptions and attitudes towards MDA, particularly among women, were identified as barriers that need to be addressed to improve participation. The data indicated that women in particular had concerns about the risks associated with MDA, which hindered their participation. Relatedly, cultural and social norms were found to limit women's participation in MDA. Stakeholders recognized the significant role these norms play and discussed the need for community-driven approaches, including involving women more actively in the planning, communication, and implementation of MDA programs, to challenge them. Engaging community leaders, including boma chiefs, elders, religious figures, and representatives of women and persons with disabilities, is crucial

in promoting gender equity and social inclusion in health participation; it is recommended to engage these leaders in community dialogue sessions and gender-sensitivity training to shift harmful norms and increase women's participation in MDA.

5. **Promoting Positive Behavioral Practices (*Responsible Parties: Ministry of Health; Community Influencers; Community Leaders; Boma Health Workers; MDA Teams; The Carter Center/Local Organizations*)**: Promoting positive behavioral practices, especially in terms of hygiene, is crucial for preventing trachoma. The data revealed that a significant number of households lacked access to soap and clean water, which affected their ability to maintain proper hygiene practices, particularly face washing. Stakeholders agreed on the importance of community-based initiatives to promote regular face washing and other hygiene behaviors. These initiatives should be supported by providing necessary resources like soap and clean water, and empowering women to make autonomous health decisions. Therefore, it is recommended to introduce community-based initiatives to promote hygiene practices and support women's autonomy in health decisions.
6. **Ensuring Equity, Effectiveness, and Accountability (*Responsible Parties: Ministry of Health, Boma Health Workers*)**: Equity and effectiveness in the delivery of MDA services, particularly by Boma Health Workers (BHWs), needs improvement. The data indicated that some women felt they did not receive adequate attention from BHWs, pointing to gender disparities in service delivery. Stakeholders emphasized the need for continuous training and support for BHWs to address these disparities and ensure that all community members benefit equally. Additionally, many respondents noted that BHWs aren't available in their villages. It is recommended to increase the number of BHWs stationed in villages, provide ongoing training for BHWs, and establish monitoring and feedback mechanisms to maintain gender equity and effectiveness in MDA services.
7. **Strengthening the Health System (*Responsible Party: Ministry of Health*)**: Weaknesses within the health system, such as insufficient training of BHWs and challenges in the drug supply chain, is a barrier to effective MDA delivery. Stakeholders emphasized the need for investment in the training of BHWs and strengthening the supply chain for MDA drugs. As noted in Recommendation 6, it is recommended to invest in training BHWs, as well as to ensure MDA outcomes. Furthermore, stakeholders emphasized the need to ensure that MDA teams have the necessary security escorts and logistical support to safely reach remote and insecure areas.
8. **Mitigating Economic Barriers (*Responsible Party: Ministry of Health*)**: Economic barriers were identified as significant impediments to MDA participation. Stakeholders discussed the importance of providing financial support mechanisms, such as transportation stipends or food vouchers, particularly targeting women and economically disadvantaged groups. It is recommended to provide financial support or incentives to mitigate these economic barriers and mobilize community-based savings groups to support health-related expenses.
9. **Improving Communication and Information Dissemination (*Responsible Parties: Ministry of Health; Community Influencers; Community Leaders; Boma Health Workers; MDA Teams; The Carter Center/Local Organizations*)**: Communication barriers, particularly in remote areas, were identified as challenges to effective MDA participation. The data indicated that some participants did not receive adequate information about the MDA program. Stakeholders emphasized the need for improved

communication strategies that employ multiple channels, such as radio broadcasts, community meetings, and printed materials, to ensure that all community members, especially women, receive accurate and timely information. It is recommended to enhance communication and information dissemination strategies to ensure comprehensive coverage and participation in MDA. Furthermore, to ensure effective communication, it is important to train local leaders, including boma chiefs, as community influencers to support MDA activities and promote positive health behaviors within their communities.

## Annex I: Root Cause Analysis Questionnaire

### **Intro and consent**

[Welcome to the root cause analysis/intention interview guide.]

[NOTE: Introduce yourself to the individual "client" you will be asking questions to. "I am (name) from the Ministry of Health, collecting data on individuals who missed treatment from the previous trachoma treatment campaign. This data will assist the MoH to better plan to reach everyone during the upcoming trachoma treatment campaign."]

1. Did you take medication in the last trachoma 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 information**

3. What is the data enumerator's full name?
4. Are you collecting data for Kapoeta North 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?
7. What is the name of the village?
8. Record your current location

### **Client's demographic information**

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 trachoma**

24. Have you heard of trachoma?
25. Do you know what the symptoms/signs of trachoma are?
26. Can you tell me at least three symptoms/signs of trachoma?
27. How is trachoma transmitted?
- 27a. If "other," how is trachoma transmitted?
28. How concerned are you about trachoma?
29. Are you worried about the possibility of getting trachoma?
30. What do you think would happen if you got infected with trachoma?
31. How severe do you think getting infected with trachoma is?
32. What concerns you the most about trachoma?
33. Do you think trachoma is a serious health problem in your community?
34. What measures do you take to prevent trachoma in your household?
35. What do you think puts men and boys at risk of getting trachoma?
36. What puts women and girls at risk of getting trachoma?
37. Do women and men in your community have equal access to information about trachoma 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 trachoma? If so, describe.



39. How does the community treat individuals with trachoma? Are there differences based on gender or other social factors?

#### **Knowledge of MDA**

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

41. Do you know the purpose of MDA?

#### **Attitudes toward taking MDA**

42. If you take MDA, you will be protected against trachoma. Do you agree to disagree with this statement?

43. If you take MDA, you may experience bad side effects. Do you agree or disagree with this statement?

44. What do you know or have heard about MDA side effects?

45. What side effects would a man/woman experience, and why do you say so?

45a. Have you seen any person with these effects?

46. What are you told about MDA?

47. Who told you this information about MDA?

48. How reliable do you find these sources?

49. Where were you told this information about MDA?

50. Are there any barriers that prevent certain groups from accessing trachoma MDA? If so, describe.

#### **Attitudes toward taking general medications**

51. 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?

52. If you, or someone you know, experience side effects after taking MDA, what would you/they do?

52a. If "other," what would you/they do?

#### **Perceived norms**

[NOTE: Perceived norms are beliefs about what most others do and motivation to comply]

53. Do you know of other people who did not participate in mass distribution of trachoma medicines?

53a. Are these people men, women, or both?

- 54. What are the reasons people don't participate?
- 55. Do other men and women have different views about MDA from you?
- 55a. Why do other men and women have different views about MDA from you?
- 56. Do you feel that other men and women have better access to MDA than you?
- 56a. Why do you feel that other men and women have better access to MDA than you?
- 57. Did most people who are important to you (such as your partner, family, and friends) take MDA last year/last time?
- 58. When it comes to MDA, do you want to do what your partner/family/close friends think you should do?
- 58a. Why do you want to do what your partner/family/close friends think you should do?

**Perceived behavioral control**

- 59. Do you have any fear in relation to deciding to take MDA?
- 59a. What do you fear?
- 59b. Who influences you?
- 59c. How are you influenced?
- 60. If married, did your partner take MDA last time?
- 61. Is taking MDA completely up to you?
- 61a. Who decides for you?

**Previous behavior**

- 62. What is the main reason for not taking MDA last time?
- 63. Have you ever in the past taken MDA?
- 63a. The last time you took MDA, what was the main reason you took it?

**Opinions about community medicine distributors/promoters and services offered**

- 64. What do you think about the Boma Health Workers (BHWs) in your community?
- 65. Do you think that male and female BHWs are equally effective?
- 65a. Why do you think male and female BHWs are not equally effective?
- 66. Would you prefer to receive medications from a male BHWs, female BHWs, or both?
- 66a. Why do you prefer to receive medications from a male BHW?
- 66b. Why do you prefer to receive medications from a female BHW?

**Intention taking**

- 67. Do you intend to take the medication during the next MDA?
- 67a. Why do you intend to take the medication during the next MDA?
- 67b. Why are you unsure about taking the medication during the next MDA?
- 67c. Why do you intend to not take the medication during the next MDA?

**WASH questions**

- 68. What is your main water source?
- 69. How far is it from your home?
- 70. Is the water from this source available throughout the year?
- 71. Where do you go when you want to ease yourself (defecate)?
- 72. How do you dispose of children's feces?  
[Note for the data enumerator: is open defecation practiced?]
- 73. When do you wash your hands?
- 74. What do you use when you wash your hands?
- 75. How often do you wash your face?
- 76. How often do you wash children's faces?