UNITING TO COMBAT
NEGLECTED TROPICAL DISEASES

NEGLECTED TROPICAL DISEASES: WOMEN AND GIRLS IN FOCUS

Summary report of meeting held on July 27–28, 2016 in London, UK

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EXECUTIVE SUMMARY

The Uniting to Combat Neglected Tropical Diseases (NTDs) community is committed both to ending these diseases of poverty and to ensuring that no one is left behind.

This report highlights findings from a literature review and an interactive meeting that set out to assess knowledge about the impact that NTDs and mass drug administration (MDA) programs have on women and girls and identify opportunities to improve access and strengthen the value and positive impacts of MDA for women and girls. It builds on recent commitments by key donors and stakeholders in the *Joint Announcement on Implementation of Agenda 2030 Accelerating Progress Towards Gender Equality* to increase focus and investments towards closing the core gender data challenges.

The Uniting to Combat NTDs: Women and Girls in Focus meeting was held on 27–28 July 2016 in London. Prior to the meeting, a student-faculty team from the University of Washington School of Public Health Strategic Analysis, Research & Training (START) Center conducted a landscape review of peer-reviewed and grey literature and key informant interviews centered on three thematic areas exploring gender considerations in NTDs addressed through MDA programs:

1. **Impact of NTDs on women and girls**
2. **Delivery of NTD programs by women and the impact of women in the workforce**
3. **Reach of the MDA platform and access by women and girls**

At the meeting, presentations summarizing the landscape review and key informant interviews were followed by discussions on the strengths and limitations of existing NTD data and programming with respect to each of the themes as well as opportunities to address the gaps and utilize what we know across different contexts. The following key points were developed by the meeting participants:

- Neglected tropical diseases can disproportionately impact and disadvantage women and girls in some contexts due to biological and cultural reasons that differ by setting and pathogen.
- Mass drug administration programs appear to be well positioned to reach marginalized populations and address the inequalities that women and girls experience due to NTDs.
- Applying a gender equity lens in NTD program design and delivery may position programs to improve gender mainstreaming practices and service delivery for women and girls.
- The NTD community should take the opportunity to align messaging and advocacy efforts to engage donors, health ministries, and partners from other health sectors to be strategically placed to promote Sustainable Development Goal (SDG) 3: Good Health and Well-being and 5: Gender Equality.

Key recommendations from the meeting participants include:

A. Improve the way we work. There are existing areas that can be incrementally strengthened that would significantly improve and support the women and girls and NTDs agenda.

1. Ensure that sex- and age-disaggregated information is collected, preserved, and utilized in ongoing and future programs and research.
2. Modify existing and ensure new monitoring and evaluation (M&E) protocols and tools include collection and analysis of sex- and age-disaggregated data to further our understanding of the equity and reach of NTD programs and strengthen communication messaging.
3. Prospectively ensure that research protocols include the collection and analysis of sex- and age-disaggregated data.
4. To help promote gender equity, actively engage female recipients of MDA, caregivers, and community drug distributors (CDDs) in program design, delivery, and monitoring and evaluation.

B. Take the next steps. In parallel to what can be done in the NTD community's routine programmatic work, there are a few recommendations that would require additional support in the medium term.

1. Strengthen implementation of existing gender-related study protocols and continue to support where gender-related work is already happening, including:

   a. Field test the survey tool in the WHO's field guide on '*Integrating a gender, equity and human rights focus into national programming on preventive chemotherapy and transmission control for neglected tropical diseases*' to be implemented in national programs to identify and address equity issues, with a particular focus on gender.

   b. Share the work resulting from the Countdown consortium's gender team funded through the Department for International Development (DFID), and pursue issues and opportunities to address equity.
2. Convene a working group/task force to identify follow-up operational research based on analysis of past and current data and the knowledge/program gaps they reveal.
3. Identify, adapt, or develop frameworks to help the NTD community understand and communicate impact, challenges, and opportunities for NTD programming and gender equity in the NTD landscape and context.

To help promote gender equity, actively engage female recipients of MDA, caregivers, and community drug distributors (CDDs) in program design, delivery, and monitoring and evaluation.

INTRODUCTION

The Uniting to Combat Neglected Tropical Diseases (NTDs) community is committed both to ending these diseases of poverty and to ensuring that no one is left behind. This includes improving knowledge about the impact that NTDs and NTD interventions have on women and girls of all ages, in all regions of all countries. To spearhead this effort, a range of stakeholders met in London, 27–28 July 2016 for the *Women and Girls in Focus* meeting to explore the topic of women and girls in NTDs by evaluating existing evidence and defining a path forward (see Annex 1 for list of participants). The objectives of the meeting were to gather and assess:

1. Existing qualitative and quantitative research evidence to demonstrate the impact of NTDs on women and girls;
2. Evidence about the role/impact of women on the delivery of NTD programs; and
3. Evidence of access and equity of NTD interventions for women and girls.

BACKGROUND

Neglected tropical diseases are a group of treatable and preventable diseases that continue to affect over one billion of the world's most impoverished, marginalized, and remote communities. They are both a consequence and cause of poverty, thriving where access to clean water, sanitation, and healthcare are limited.

Their impact on individuals and communities can be devastating. Many of them cause severe disfigurement and long-lasting or permanent disabilities. They affect the life expectancy, education, and economic opportunities of affected individuals and the communities they live in.

Five neglected tropical diseases – lymphatic filariasis (LF), onchocerciasis, schistosomiasis, soil-transmitted helminthiases (STH), and trachoma – can be prevented through mass drug administration (MDA) or preventive chemotherapy (PC)[1]. Since 2000 more than 5 billion preventive treatments have been delivered for NTDs. The Sustainable Development Goals (SDGs) (neglected tropical diseases are explicitly mentioned under Target 3.3[a]) are underpinned by the principle of 'leaving no one behind', meaning that all goals have to be delivered for all people everywhere, including women and girls. Furthermore, Target 5 calls for the 'achieve[ment] of gender equality and empowerment of all women and girls'. While gender equity strives for equality among all genders, special attention is needed to ensure that women and girls, a population that is often disenfranchised, are not lost in that effort by understanding how gendered power relationships are experienced and addressing those dynamics. Consequently, these SDGs are specifically complemented by the updated Global Strategy for Women's, Children's and Adolescents' Health 2016—2030 which lists 9 areas[b] for action that need to be taken into consideration when planning and implementing national health programs[2].

Stakeholders at the Women and Girls in Focus meeting discussed whether a sufficient body of evidence exists to support a value proposition to invest in mass drug administration (MDA) programming as they specifically reach and meet the needs of women and girls. To provide a contextual basis for this discussion, the Strategic Analysis, Research & Training (START) team at the University of Washington School of Public Health was commissioned to provide a summary and framing of the current evidence with respect to understanding and addressing gender considerations in NTDs. The START team's review focused on three thematic areas of interest: the impact of NTDs on women and girls; delivery of NTD programs by women and the impact of women in the workforce; and the reach of the MDA platform and access by women and girls. The summary of evidence and framing were developed through a review of the published and grey literature, key informant interviews with selected topic experts, and adaptation of existing gender frameworks. The summary informed discussions at the Women and Girls in Focus meeting (see Annex 2 for list of sources) and provided a basis for participants to explore the potential gains of NTD programming designed to address the unique challenges facing women and girls. Participants at the meeting formed two working groups to analyze the literature review findings. One group reviewed the findings from an evidence perspective, and the other from a program and policy perspective.

Prior to the meeting, participants were invited to complete a survey identifying their perspectives on the following topics: gaps in the evidence for the three themes; what evidence is needed to advance the women and girls agenda; and what data/evidence would be most influential for different stakeholders. The most common knowledge gaps identified by participants who completed the survey were:

- Lack of available and accessible quality sex- and age-disaggregated data
- How to include gender considerations during program design and delivery, which could have implications in the way programs are monitored and data collected
- Reach and treatment of pregnant women through MDA
- A need for a deeper understanding of the interaction between HIV and NTDs, particularly female genital schistosomiasis

The survey results helped inform the subsequent discussion at the meeting.

The Sustainable Development Goals (SDGs) are underpinned by the principle of 'leaving no one behind', meaning that all goals have to be delivered for all people everywhere, including women and girls.

a. SDG Target 3.3: 'By 2030, end the epidemics of AIDS, tuberculosis, malaria, and neglected tropical diseases […]'

b. Countries and their partners need to implement nine actions simultaneously towards achieving the Global Strategy for Women's, Children's and Adolescents' Health 2016—2030 objectives: (1) country leadership; (2) financing for health; (3) health systems resilience; (4) individual potential; (5) community engagement; (6) multisector action; (7) humanitarian and fragile settings; (8) research and innovation; and (9) accountability.

FINDINGS

This section presents working hypotheses, a summary of evidence, and meeting discussion for each of the three themes. Each theme was based on an initial working hypothesis. After the presentation of findings from the literature review and informant interviews, participants formulated a new working hypothesis to help guide the discussion of each theme.

THEME 1

IMPACT OF NTDS ON WOMEN AND GIRLS

Hypotheses

The initial working hypothesis was that women and girls experience the impact of NTDs more severely than men and boys. The body of evidence presented at the meeting demonstrated differential exposures, biological vulnerabilities, and physical impacts on women from NTDs. However, evidence about socio-cultural impacts such as stigma and socio-economic impacts such as poverty was not as comprehensive. Participants revised the working hypothesis to: neglected tropical diseases can disproportionately impact and disadvantage women and girls in some contexts due to biological and cultural reasons that differ by setting and pathogen. Women and girls experience the impact of NTDs differently from men and boys, and more sex-disaggregated data that include socio-cultural and socio-economic factors are needed to better understand how these factors influence exposure, vulnerability, and health impacts for both females and males.

Summary of evidence

The START team's literature review of the five NTDs for which MDA is the key intervention found evidence of differential risk factors for acquiring NTDs, and the unequal – sometimes inequitable – impacts of NTDs on females compared to males.

Differences in exposure, vulnerability, access to treatment, and health outcomes exist between men and women but are not well understood or systematically documented[3-5]. Furthermore, little evidence exists detailing the extent to which current NTD programming addresses distinct needs of the female population. In some instances the differences are from biological differences between men and women. For example, pregnancy causes females with chronic helminth-infections to be more vulnerable to severe helminth-associated anemia[3, 6]. In many cases, the differences in exposure and vulnerability are due to inequities stemming from traditional gender roles.[c] For example, adult women are two to four times more likely than men to develop trichiasis because they are more likely to be infected through close contact with children[8]. Gender norms may also impede socioeconomically disadvantaged women in endemic areas from accessing necessary preventive interventions or morbidity services. For women, disability and disfigurement resulting from infection limits their employment and marriageability, impacting their social and economic wellbeing[4]. In line with traditional gender norms in many contexts, even women and girls who are not infected with NTDs may also suffer social and economic consequences if they are expected to take time away from education or work to care for family members with severe NTD morbidity.

Several studies identified gender and other socio-cultural factors that place women at greater risk of exposure to NTDs relative to men. For example, two-thirds of water collection is performed by women and girls which puts females at higher risk for developing schistosomiasis in endemic areas[9].

Most of the literature identified focused on the sex-specific physical impacts of NTDs (e.g., schistosomiasis-associated gynecological morbidities). A limited number of studies examined the differential socio-cultural and socio-economic impacts of NTDs among women and girls. For example, women with LF-associated morbidities such as elephantiasis have fewer opportunities for marriage[10], which could cause further stigmatization and lower economic capacity. In 2003, projections from Frick and colleagues estimated that among prevalent cases, women account for 80% of Disability Adjusted Life Years associated with trachomatous blindness and visual impairment[11].

Expert interviews highlighted the under-appreciation of the increased biological vulnerability for women to develop certain NTD-associated morbidities such as female genital schistosomiasis and helminth-associated anemia in pregnant women[3].

Discussion

Discussion following the presentation of findings revolved around the following areas:

1. **Framing the impacts** — An agreed-upon explicit theory of change is needed to explain what factors are necessary to make a positive difference to women and girls. Participants indicated that expansion of evidence surrounding NTD impacts should be broadened to identify and assess not only the impacts of NTDs on women and girls, but also the impacts of MDA and related NTD interventions on women and girls, the impacts of NTDs for women and girls as primary caregivers, and the wider context-specific drivers of impacts (e.g., existing gender norms).

2. **Learning from others** — Participants emphasized the importance of learning from both other health programs (e.g., leprosy) and other sectors (e.g., water and sanitation) to build a more comprehensive NTD-gender framework that assesses a wider range of socio-cultural and socio-economic factors than those currently presented. Factors influencing vulnerability to NTDs, responses, and impacts may include violence, discrimination, access to care, and laws and policies. Other public health programs and sectors have already undertaken work to make their programs more gender-responsive and equitable for women and girls. This would help NTD programs take a more systematic approach and discuss issues and opportunities in a more defined way.

3. **Knowledge gaps** — Knowledge gaps were identified in many areas.

   a. Knowledge about how socio-economic and other factors such as poverty, education, stigma, and disability intersect with gender was identified as a key gap in the findings.

   b. The importance of age-disaggregated data was also emphasized given the differences in risk and impact for adult women compared to young girls or adolescents.

   c. Reporting, sharing, and making use of sex- and age-disaggregated data to highlight the potential impacts for women and girls at national and sub-national levels needs to be improved. There is, however, the challenge of making context-specific data generalizable to other settings and populations.

   d. A further challenge lies in making use of sex- and age-disaggregated data to better identify the reasons for differences between males and females in coverage, outcomes, and impacts, i.e., undertaking a gender analysis[d] and concretely using it to improve the delivery of programs.

Participants suggested one option for improving knowledge of NTDs and gender in the short term is to use existing monitoring and evaluation (M&E) frameworks for MDA and include additional survey questions to help fill data gaps as part of the existing routine process. Other avenues include making use of the specialized skills and expertise in other sectors, such as Ministries for Women and Social Affairs and academia, to assist in undertaking gender analyses of existing data for improved program design. Participants suggested a call to organizations to submit examples of how collection and analysis of sex- and age-disaggregated data have influenced change in NTD/MDA programs in countries in order to demonstrate the value of collecting this data. Another, more qualitative need, is to collect women and girls' perspectives in endemic countries to build a compelling narrative about how NTDs affect them. The fifth anniversary of the London Declaration (2017) was proposed as a focal point for sharing case studies and stories about the impacts of NTDs on women and girls.

Reporting, sharing, and making use of sex- and age-disaggregated data to highlight the potential impacts for women and girls at national and sub-national levels needs to be improved.

c. WHO defines 'gender' as characteristics of women and men that are largely socially created, while 'sex' refers to characteristics that are biologically determined (7)
d. An analytical process used to identify and interpret gender differences and the extent to which gender roles and power dynamics between men and women in a specific context influences rights, opportunities, and access to resources available to men and women (12)

THEME 2

DELIVERY OF NTD PROGRAMS BY WOMEN

Hypotheses

The initial working hypothesis was that female community drug distributors (CDDs) were more effective at delivering treatment and therefore should be utilized in the delivery of MDA. Evidence supported that NTD programs were strengthened with female CDDs. However, the evidence did not address the extent to which women benefited from CDD positions. The literature review and subsequent discussion highlighted that when examining MDA programs through a gender equity lens, they have the potential to serve as a vehicle to promote female empowerment but this needs to be documented.

Participants cautioned about unintended consequences of including women as CDDs that could potentially be negative or disempowering, as women may be volunteered and this may reinforce women working in roles without pay or incentives. The participants then developed a new working hypothesis: MDA programs that empower women, could potentially achieve better health and social outcomes. Participants also emphasized the need to ensure that women and girls in endemic countries participate, make decisions, and/or lead in the planning, design, and measurement of NTD programs.

Summary of evidence

A growing body of evidence on women's empowerment and health outcomes has gained considerable attention in maternal and child health literature[13] and has gained a following among researchers in the NTD community. These researchers posit programs designed to empower women may be more suitable to identify and reach disadvantaged and remote populations of women, thereby improving the health, social status, or earning potential of women at risk of becoming debilitated by disease[4, 14]. In communities where men are typically selected to act as community drug distributers, delivery of MDA programs by women may serve to improve the social status of women typically excluded from those roles[15]. However, in settings where women face extensive and time consuming domestic duties, shouldering the additional responsibility of drug distribution may serve to overburden women[16]. Therefore, context specific approaches are required to ensure women are empowered in MDA programs as drug distributors.

Some evidence suggests that MDA programs delivered by female community drug/medicine distributers (CDD/CMDs) can achieve equal or greater coverage, with less participant attrition compared to male counterparts[17-20]. Despite examples demonstrating that female CDDs may exhibit higher job performance, the majority of drug distributors are male[20-23]. Only two of the 14 studies[24, 25] reporting sex-disaggregated data documented a greater proportion of female compared to male drug distributers. In addition to the underrepresentation of women in CDD roles, the majority of MDA programs identified

in the literature review also reported CDDs were often volunteers. Studies have indicated local cultural and political structures may influence the selection of female drug distributers and, in some cases, the extent of their participation[19, 23, 24].

Discussion

Meeting participants concurred that more information regarding CDD selection criteria and selection practices are necessary. While national policies typically suggest that communities nominate CDDs, participants noted that there is limited knowledge about what actually happens in practice within countries and whether gender and power relationships shape selection processes. Specifically, there is a lack of knowledge about the criteria used to select drug distributers within communities. The NTD community could use information on CDD selection to assess if and how NTD programs empower female health workers.

Meeting participants provided examples of some countries (Tanzania and Ethiopia) where there is greater representation of women as community health workers (CHWs) relative to other countries. However, CHWs do not always serve as drug distributers during MDA campaigns. Conflating CHWs and drug distributors may obscure the actual representation of women among drug distributers[18, 21]. Meeting participants also noted that simply increasing representation of women in CDD roles without remuneration may unintentionally further reinforce gender roles that encourage women to participate in uncompensated labor. Additionally, since women and girls are often the de facto caretaker in their households, a lack of remuneration among female CDDs reinforces gender stereotypes that caring is women's work and something that does not merit recognition (paid or in-kind). Participants also cited a dearth of evidence detailing the lived experiences of female CDDs and the lack of an evaluation framework to assess whether MDA programs empower or exploit female CDDs. Unintentional negative impacts of MDA programs on female CDDs need to be further explored and understood. Therefore, a strong gender framework highlighting the importance of quantitative and qualitative data in addition to firsthand accounts from women and girls (as identified in Theme 1) is needed, as well as an established set of broad principles that can be adapted across different settings.

Evidence regarding gender equity in MDA program leadership was largely absent from the literature and discourse. Participants suggested that increased inclusion of women in the decision-making and program planning processes may address gender disparities in MDA program participation and leadership. Participants also stressed the importance of building and implementing a rapid assessment tool for assessing gender equity in delivery of PC by women and their participation in MDA programs. Building on and adapting gender equity tools used by other health programs and/or sectors was emphasized so that the NTD community could benefit from this experience and not duplicate time or resources developing such tools from scratch. Participants also recommended that NTD policy makers make a concerted effort to conduct gender-mainstreaming activities incorporating gender equity at all levels of NTD program design, implementation, evaluation, and delivery. Policy makers should also engage donors and other NTD stakeholders to support gender equitable participation and leadership in NTD programs.

Simply increasing representation of women in CDD roles without remuneration may unintentionally further reinforce gender roles that encourage women to participate in uncompensated labor.

THEME 3

REACH OF MDA PLATFORM TO ACCESS WOMEN AND GIRLS

Hypotheses

The initial working hypothesis was the MDA platform effectively reaches male and female populations and is gender neutral. Evidence from some countries indeed suggests that their national level MDA programs equally reach males and females. During discussion, participants developed a new working hypothesis that while MDA programs may be gender neutral, they are not necessarily gender equitable.

Summary of evidence

The review for Theme 3 focused on assessing the reach of the MDA platform and access by women and girls. Some evidence suggests that, in general, MDA program coverage is gender equal at the national-level (i.e., minimal differences in coverage between men and women), but may not hold when examined at sub-national levels (i.e., at district or peripheral levels)[26]. High quality, comprehensive sex- and age-disaggregated data was limited, suggesting a data gap. Furthermore, information on sex-specific coverage by drug delivery method (e.g., school-based versus community-based MDA) was also limited.

Qualitative literature highlighted gender-specific barriers to MDA access, including differential attitudes towards MDA. For example, in a study of gender issues in the African Programme for Onchocerciasis Control (APOC) in three countries (Cameroon, Nigeria, and Tanzania) Clemmons and colleagues noted that men and women relate to MDA differently – 'women comply, men adhere' – however, these differences did not appear to have an impact on treatment coverage[23]. Another important barrier highlighted in the literature was the lack of knowledge among CDDs regarding MDA for pregnant and lactating women. Lack of CDD training on treating pregnant and lactating women can result in the exclusion of women eligible for treatment[5, 27].

Discussion

While sex- and age-disaggregated data were relatively sparse in peer-reviewed literature, participants noted that grey literature (such as progress reports) could be a rich source of sex- and age-disaggregated data. The World Health Assembly Resolution 60.25[28] on gender mainstreaming calls upon countries to collect and analyze sex-disaggregated data, conduct research on the factors underlying gender disparities, and use the results to inform policies and programs. Countries are therefore already required to collect and report on PC coverage using sex-disaggregated data. The World Health Organization (WHO) manual on *Monitoring drug coverage for preventive chemotherapy*[29] provides guidance for countries on how to routinely monitor and evaluate the delivery and effects of PC at all levels including collecting information about refusal of treatment. The manual also contains forms for collection and compilation of sex- and age-disaggregated data at the peripheral and district levels. Participants noted that while sex-disaggregated data is collected at the peripheral levels, data become aggregated along the

reporting pathway to the national level and WHO and the age- and sex-specific data are lost. Modifying data reporting practices from district to national levels could be a simple solution to obtaining sex-disaggregated data at national and global levels. In other settings, participants noted that logistical problems and rigid reporting forms and spreadsheets prevent the addition of columns to record sex- and age-disaggregated data, posing yet another barrier to needed data.

Other gaps in evidence include:

- How a program transitions from community-based approaches to school-based programs, which could impact women and girls differently than men and boys. The potential impacts of this are not well known.
- How survey results might or might not be generalizable to other settings or countries with similar contexts including NTD profile.
- How treatment might affect the burden of multiple NTDs among women and girls (i.e., treatment for co-endemic NTDs, which have geographic overlap).
- Whether sub-populations of women and girls are being missed entirely.

Meeting participants further emphasized the need to consider the topic through the lenses of different MDA delivery methods: school-based, house-to-house, fixed point, or special events (e.g., child health days). Validation coverage surveys of school-based MDA for schistosomiasis have been conducted by the Schistosomiasis Control Initiative (SCI) in rural sub-Saharan Africa. The surveys indicated that MDA programs exhibited equal male:female coverage (unpublished data from meeting participant). Moreover, since they used home-based survey methods (versus school-based), they were able to ascertain coverage among boys and girls not attending school and found no differences in coverage between boys and girls. Sex-disaggregated coverage in urban settings is unknown. Data on house-to-house and fixed-point delivery modes present a challenge as these data are often reported in aggregate, which makes it difficult to assess differences between males and females covered. For special event MDA programs, sex-disaggregated data are generally not collected.

Participants noted that regulatory and authoritative bodies must have clear and consistent messaging about the treatment of women of childbearing age. Clear guidelines for the proper administration of PC to pregnant and lactating women will avoid missed opportunities for treatment and inadvertent exposure of women for whom medication is contraindicated. Participants also noted that programs should collect follow-up data on women who had been inadvertently given medication while pregnant or lactating, and develop case studies to improve knowledge in this area. Drug distributors and communities can use this data to inform and improve knowledge about the medicines and their potential effects. Due to several barriers, meeting participants gave lower priority to engaging pharmaceutical companies to change labels and inserts to align with WHO recommendations.

As per suggestions relevant to Theme 1, the NTD community can follow up on whether disaggregated data are collected in practice, where disaggregation is lost in the reporting cascade, and what needs to be done to make better use of such data. Participants also agreed that a system is needed to allow for CDDs to openly discuss and communicate challenges in reporting disaggregated coverage to program leadership as well as other challenges they may face.

Participants suggested existing NTD data quality assurance and capacity building programs could serve as tools to collect and use sex- and age-disaggregated data and improve program coverage and effectiveness. Programs can use quality improvement tools to assess performance, address problems in real-time, and facilitate programmatic changes during drug administration. Participants identified ‘mop up’ as an existing strategy that could potentially improve equity in MDA program by reaching women and girls who may have been missed in initial distribution of drugs, but this would need to be documented. Participants also suggested reviewing existing data sources and identifying proxy measures for gender equity, opportunities for including additional questions, and strategies to make sex- and age-disaggregated data available for program planning and policy change. This could include building partnerships with other health programs and other sectors to expand potential data collection options. For example, NTD researchers can use the WHO pregnancy registry to determine whether inadvertent PC exposure is associated with adverse birth outcomes.

Modifying data reporting practices from district to national levels could be a simple solution to obtaining sex-disaggregated data at national and global levels.

CONCLUDING COMMENTS AND NEXT STEPS

Key Summary Points

- Neglected tropical diseases can disproportionately impact and disadvantage women and girls due to biological and cultural reasons that differ by setting and pathogen.
- Mass drug administration programs appear to be well positioned to reach marginalized populations and address the inequalities that women and girls experience due to NTDs.
- Applying a gender equity lens in NTD program design and delivery may position programs to improve gender mainstreaming practices and service delivery for women and girls.
- The NTD community should take the opportunity to align messaging and advocacy efforts to engage donors, health ministries, and partners from other health sectors and promote Sustainable Development Goal (SDG) 3: Good Health and Well-being and 5: Gender Equality.

Actions are underway to ensure women and girls are not left behind in the NTD agenda, however, more can be done. The NTD community has the opportunity to learn from the experiences of other vertical programs and sectors to implement best practices from gender progressive programs. A descriptive term that arose during the conference discussion is 'gender transformative'. In 2000, the President of the International Center for Research on Women, Geeta Rao Gupta, described a continuum of approaches to overcome gender inequity in programming[30]. On one end of the continuum is gender neutral programming, which does not recognize the distinction between male and female needs. In the middle is gender responsive programming, which recognizes differences between male and female needs. On the most progressive end is gender transformative programming that seeks to change gender norms to achieve equity[30]. Participants noted the need to improve the gender responsiveness of MDA in the short term and to also work towards leveraging the MDA platform as a means of achieving gender transformative approaches for women and girls in the long term. Participants identified the following recommendations and initial next steps.

Recommendations

Much progress has been made to incorporate gender mainstreaming into NTD programs, and even more can be achieved by building on what has been accomplished. As the NTD community better understands the intersection points and impact of gender and NTDs, there are actions that can be taken in the near and medium term to further foster and support gender equity and equitable programming.

A. Improve the Way We Work. There are existing areas that can be incrementally changed that would have a significant impact and support the women and girls and NTDs agenda. Perhaps the most foundational changes are around data collection and use. With the following areas addressed, our ability to have further insights into next steps will be greatly enhanced, either in supporting advocacy messaging or identifying and addressing gaps.

Women are frequently recipients of MDA and engaged as drug distributors, but we can move beyond this to a more intentional approach.

1. Ensure that sex- and age-disaggregated information is collected, preserved, and utilized in ongoing and future programs and research. Current WHO reporting forms include sex-disaggregated data, yet these data, when collected at the point of distribution, are not reported up when the data are aggregated, which is a lost opportunity for action. It will be important to understand where these data are lost so the integrity of information can be restored.
2. Modify current and ensure new M&E tools include sex- and age-disaggregated data as part of data collection and analysis to further our understanding of the equity and reach of NTD programs.
3. Prospectively ensure that research protocols require the collection of sex- and age-disaggregated data. Additionally, ensure that research is included in the operational research databank, NTD ConnectOR.[e] All research in the databank should strive to collect sex- and age-disaggregated data. Operational research pertinent to NTDs and studies collecting data should be identified so the landscape can be fully understood.
4. Women are frequently recipients of MDA and engaged as drug distributors, but we can move beyond this to a more intentional approach. Programs should actively engage female recipients of MDA, caregivers, and CDDs in program design, delivery, and monitoring and evaluation to help ensure their perspectives inform approaches to promote gender equity at all levels.

B. Take the next steps. In parallel to what can be done in the NTD community's current work, there are a few recommendations that would require additional support in the medium term.

1. Strengthen implementation of existing gender-related study protocols and continue to support where gender work is already happening, including:

   a. Field test the survey tool in the WHO's field guide on '*Integrating a gender, equity and human rights focus into national programming on preventive chemotherapy and transmission control for neglected tropical diseases*'. The tool is designed to be implemented in national programs to identify equity issues, with a particular focus on gender. Partners are encouraged to field test and support the implementation of this tool. Some partners were identified at the meeting and additional interested partners should contact Dr. Pamela Sabina Mbabazi at WHO NTD (mbabazip@who.int).

   b. Share the work resulting from the Countdown[f] consortium's gender team funded through the Department for International Development (DFID), and pursue issues and opportunities to address equity.
2. Convene a working group/task force to identify follow-up operational research based on analyses of past and current data and the knowledge/program gaps they revealed.
3. Align messaging and advocacy efforts to engage donors, health ministries, and partners from other health sectors and promote Sustainable Development Goal (SDG) 3: Good Health and Well-being and 5: Gender Equality. Share these messages through the Uniting partnership and other venues with NTD partners.
4. Identify, select, or develop frameworks to help the NTD community understand and communicate impacts, challenges, and opportunities for NTD programming and gender equity in the NTD landscape and context.

ACTION ITEMS

- **Coalition for Operational Research on NTDs (COR-NTD):** Women and Girls and NTDs will be featured as a topic for broader discussion as a plenary session at the upcoming COR-NTD meeting.
- **Register research:** In the operational research databank, NTD ConnectOR,[g] register research indicating what data are being collected.
- **Publication:** Key points and conclusions from the meeting will be shared via publication and used as the basis to support further publications building on meeting concepts and beyond.
- **Develop a working group/task force:** Each individual has a role to play in contributing to the actions and recommendations above. In order to facilitate and organize these outputs and drive these bodies of work forward, a working group/task force will be established with representation from researchers, implementation partners, donors, and advocacy partners.

e. http://www.ntdsupport.org/cor-ntd/ntd-connector
f. http://www.countdownonntds.org/
g. http://www.ntdsupport.org/cor-ntd/ntd-connector

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ANNEXES

Annex 1: List of Meeting Attendants

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Noelle Huskins Bill & Melinda Gates Foundation (BMGF)
Pamela Mbabazi World Health Organization (WHO)
Sarah Simpson EquiACT – Independent Consultant
Thoko Elphick-Pooley Uniting to Combat NTDs
Jane Wilbur WaterAid
Tanya Wood International Federation of Anti-Leprosy Associations (ILEP)
Anna Wickenden Canada Coalition Against NTDs
Harald Zimmer German Coalition Against NTDs
Fiona Fleming Schistosomiasis Control Initiative (SCI)
Amy Pennington Bill & Melinda Gates Foundation (BMGF) – Gender and Equity Team
Laura Senyonjo Sightsavers
Alexandra Bayfield Department for International Development (DFID)
Kate Pullen Malaria No More
Tijana Duric GlaskoSmithKline (GSK)
Louise Kelly-Hope Liverpool School of Tropical Medicine (LSTM)
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Lola Arakaki Strategic Analysis, Research & Training Center (START)
Debra Bara Children Without Worms (CWW)
Iain Jones Department for International Development (DFID)
Dirk Engels World Health Organization (WHO)
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Lauren Cutright Bill & Melinda Gates Foundation (BMGF) – Meeting Support

Annex 2: Literature Review References Theme 1

Lymphatic Filariasis

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Theme 2

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Theme 3

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