



# Women and Trachoma

**Achieving Gender Equity in the Implementation of SAFE**

THE  
CARTER CENTER



KCCO



Kilimanjaro Centre for  
Community Ophthalmology





# Acknowledgements

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After reading the manual, we would encourage your feedback to help inform future iterations of *Women and Trachoma* manuals. If you would like to provide feedback, please scan the QR code below to complete a survey.



Front cover left and center photos: Ethiopian women and their daughters stand proud in their fight to eliminate trachoma from their communities. Photo credit: Brent Stirton/Getty Images for International Trachoma Initiative

Front cover right photo: In Dorum, a village in Mirriah, Niger, a woman of 83 years arrives at a trichiasis surgical camp hoping for the operation that will allow her to care for her grandchildren while her daughter manages a busy household. When asked why she wanted TT surgery, she replied, "I am old. My legs are nothing. I cannot carry wood or draw water from the well. What can I do? With healthy eyes, I can sit on my mat and watch the grandchildren. It is not much, but this I can do. Yes, I am old, but old women can still give." Photo credit: Aryc Mosher/USAID

Opposite page: Two Ethiopian Health Extension Workers, Alemetu Metalign and Terengku Mulat, aid the fight to eliminate trachoma by coordinating transport and dissemination of treatments to their community. Photo credit: Brent Stirton/Getty Images for International Trachoma Initiative in collaboration with The Carter Center





Maasai women from Sekanani, Kenya, prepare to greet visitors with a traditional song.  
Photo credit: Leeshia Crayton/International Trachoma Initiative



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# Acronyms

<b>AIDS</b>	Acquired Immunodeficiency Syndrome	<b>POS</b>	Powder for oral suspension
<b>ATO</b>	Annual treatment objectives	<b>MDD</b>	Music, dance, drama
<b>BCC</b>	Behavior change campaign	<b>MDA</b>	Mass drug administration
<b>CDD</b>	Community drug distributors	<b>MOES</b>	Ministry of Education and Sports
<b>CHW</b>	Community health worker	<b>MORDOR</b>	Oral macrolides to reduce deaths with an eye on resistance
<b>CTA</b>	Community treatment assistant	<b>NTD</b>	Neglected tropical diseases
<b>DHO</b>	District Health Office	<b>NGO</b>	Non-governmental organization
<b>F&amp;E</b>	Facial cleanliness and environmental improvement	<b>SAFE</b>	Surgery, antibiotics, facial cleanliness, environmental improvement
<b>FGC</b>	Full geographic coverage	<b>SDG</b>	Sustainable development goals
<b>GET 2020</b>	Alliance for the Global Elimination of Trachoma by 2020	<b>TEO</b>	Tetracycline eye ointment
<b>GTMP</b>	Global Trachoma Mapping Project	<b>TF</b>	Trachomatous inflammation-follicular
<b>HDA</b>	Health Development Army	<b>TF<sub>1-9</sub></b>	Trachomatous inflammation-follicular in children ages 1-9 years
<b>ICTC</b>	International Coalition for Trachoma Control	<b>TI</b>	Trachomatous inflammation-intense
<b>IDP</b>	Internally displaced persons	<b>TS</b>	Trachomatous scarring
<b>ITI</b>	International Trachoma Initiative	<b>TT</b>	Trachomatous trichiasis
<b>KCCO</b>	Kilimanjaro Centre for Community Ophthalmology	<b>WASH</b>	Water, sanitation, and hygiene
<b>LGA</b>	Local Government Area	<b>WER</b>	Weekly Epidemiological Report
<b>LHW</b>	Lady health worker	<b>WHO</b>	World Health Organization
<b>LHWP</b>	Lady Health Worker Project		



# Foreword

Kenyan activist Wangari Maathai was the first African woman to receive the Nobel Peace Prize in 2004. As a member of Parliament and former Assistant Minister for Environment and Natural Resources, her political passions included environmental and gender issues. She once said, **"I'm very conscious of the fact that you can't do it alone. It's teamwork. When you do it alone you run the risk that when you are no longer there nobody else will do it."**

Each of us—men, women, girls, and boys—want for ourselves, our families, and our communities to be healthy, to be happy, and to have peace. To achieve and sustain our common goals and objectives, we cannot do it alone. We must work as a team. However, a society's gender norms often mean that women and men have different roles and responsibilities, opportunities and constraints. This inequality causes women to contract trachoma in greater numbers than men, with an even larger negative impact on their families and communities.

The World Health Organization has set the year 2030 as the target to eliminate trachoma as a public health problem. This is achievable; though to achieve this target we must work together to change this imbalance—we must elevate, profile, highlight, and include women in everything we do. We must deliberately target women (and girls) to ensure they have the necessary tools and access to resources to prevent and treat trachoma in themselves, their families, and their communities.

Gender-focused community-based programming that deliberately targets and reaches women and girls must include women in decisions for all aspects of the SAFE strategy. We reach children through their mothers; both

benefit from behavioral health education and improved access to water and sanitation. The prevention of blindness and excruciating pain from trachomatous trichiasis enables those affected women to contribute fully to their families and communities.

Achieving elimination of trachoma requires a team effort. Empowering women in trachoma endemic communities and in trachoma elimination programs will help eliminate trachoma. The "Women and Trachoma" manual second edition uses historical experience, case study examples, illustrations, program success stories, and step-by-step guidelines to enable us, as a team, to provide a gender-equitable SAFE strategy. We hope this manual is a tool that you will use, as part of a team, to end trachoma as a public health problem.

We all deserve to be healthy, to be happy, and to have peace. We cannot do it alone—but together, we can make the world a better place.

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A South Sudanese woman is examined for trachomatous trichiasis (TT).  
Photo credit: The Carter Center

## Chapter 1

# Introduction: Trachoma and Gender

This manual will provide anyone interested in increasing equality in the use of eye care services, trachoma in particular, in low- and middle-income countries with the knowledge and skills necessary to ensure that programming and service provision are gender-sensitive. It will provide strategies, formulated from program experience, on how to improve gender equity service provision, considering nuanced approaches to programming; it will serve programs as they move towards the elimination of trachoma as a public health problem, as well as during transition planning and post-elimination. While the focus of this manual is on gender and trachoma, addressing gender equity in trachoma control has many collateral benefits in the broader health and development agenda. This manual:

- **Provides evidence for why programs should consider gender roles and responsibilities** when working to reach the global goal of eliminating trachoma as a public health problem by 2030.
- **Explains how to revise existing monitoring tools** to better assess the progress of programs toward the thresholds for the elimination of trachoma as a public health problem.
- **Provides varied experiences from all World Health Organization (WHO) regions** on how to engage women and girls in aspects of trachoma programming.
- **Offers practical solutions to challenging problems of behavioral change** related to the use of surgical services, hygiene and sanitation practices, and improved environmental conditions.
- **Suggests how programs can facilitate gender-nuanced approaches to transition planning** to ensure individuals are not left behind after elimination thresholds have been met.
- **Includes insight into engaging women in trachoma elimination** not only as recipients of services, but also in service provision in terms of human resource capacity.



## Box 1

### International Coalition for Trachoma Control (ICTC) Resources



ICTC has many preferred practices manuals to aid programs in designing and implementing trachoma interventions.

This manual, previously published in 2009, has been updated to include lessons learned through activity implementation in endemic regions and findings from research that has become available since the previous edition. A new chapter on 'Gender Representation in Human Resources' has been included to reflect the increasing presence of women in the technical and leadership space. Since the last publication, many preferred practices manuals have been developed through ICTC and other entities; therefore, this manual will focus on issues and programming impacted by gender while referencing additional resources for more in-depth information of specific subject areas.

This updated Women and Trachoma manual is not meant to provide specific programming guidance such as how to organize a surgical camp or manage mass drug administration (MDA) activities, as these are already available in previously published manuals from ICTC and partners; instead, it is meant to provide strategies and preferred practices for including gender considerations in implementation, gleaned from

years of activities in various country programs. These lessons can be modified and applied to other context-specific programming in order to enhance interventions of surgery, antibiotic distribution, facial cleanliness, and environmental improvement (SAFE) to achieve elimination of trachoma as a public health problem.

### What is trachoma?

**Trachoma, caused by the bacteria *Chlamydia trachomatis*, is the leading infectious cause of blindness in the world.** Trachoma can be easily transmitted from person to person through regular physical contact, shared linens, and flies that carry the bacteria from ocular and nasal discharge. A lack of access to water and sanitation are also considered to be important factors in trachoma transmission and endemicity, notably in rural settings. Over time, repeated infections result in the development of scar tissue on the inside of the eyelid (the tarsal conjunctiva), which causes the eyelashes to turn inward, touching the cornea. This condition is known as trachomatous trichiasis (TT).

## Trachoma Grading Card

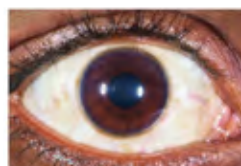
### The Five Signs of the WHO Simplified Trachoma Grading Card

#### GRADING GUIDELINES

- Each eye must be examined and assessed separately.
- Use binocular loupes (x2.5) and adequate lighting (either daylight or a torch).
- Signs must be clearly seen in order to be considered present.

**Normal eye:** The eyelids and cornea are observed first for inturned eyelashes and any corneal opacity. The upper eyelid is then turned over (everted) to examine the conjunctiva over the stiffer part of the upper lid (tarsal conjunctiva)

Normal conjunctiva is pink, smooth, thin, and transparent. Over the whole area of the tarsal conjunctiva there are normally large deep-lying blood vessels that run vertically.



**Trachomatous Inflammation – Follicular (TF):** the presence of five or more follicles in the upper tarsal conjunctiva.

Follicles are round swellings that are paler than the surrounding conjunctiva, appearing white, grey or yellow. Follicles must be at least 0.5mm in diameter, i.e., at least as large as the dots shown below, to be considered.



**Trachomatous Inflammation – Intense (TI):** pronounced inflammation thickening of the tarsal conjunctiva that obscures more than half of the normal deep tarsal vessels.

The tarsal conjunctiva appears red, rough, and thickened. There are usually numerous follicles, which may be partially or totally covered by the thickened conjunctiva.



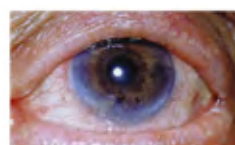
**Trachomatous Scarring (TS):** the presence of scarring in the tarsal conjunctiva.

Scars are easily visible as white lines, bands, or sheets in the tarsal conjunctiva. They are glistening and fibrous in appearance. Scarring, especially diffuse fibrosis, may obscure the tarsal blood vessels.



**Trachomatous Trichiasis (TT):** at least one eyelash rubs on the eyeball.

Evidence of recent removal of inturned eyelashes should also be graded as trichiasis as seen in the trachomatous trichiasis photo below.



**Corneal Opacity (CO):** easily visible corneal opacity over the pupil.

The pupil margin is blurred viewed through the opacity. Such corneal opacities cause significant visual impairment (less than 6/18 or 0.3 vision), and therefore visual acuity should be measured if possible.

When the eyelashes touch the cornea, they cause incredible discomfort and damage, which can lead to blindness. Boys and girls ages 1-9 years are more at risk than adults of trachoma infection, and adult females are two times more likely to develop TT than adult males.

Evidence of infection can be detected even during infancy, with clinical signs of inflammation evident at six months of age. Throughout late childhood and early adulthood, scarring of the inner eyelid can be detected.

In late adulthood, the presence of in-turned eyelashes and abrasion of the cornea cause vision loss. Although trachoma is commonly thought of as a progressive disease, not all infections with ocular chlamydia will result in the same manifestations that appear in the grading scale. Not all people with trachomatous inflammation develop scarring on the inside of the conjunctiva, and not all people with conjunctival scarring develop TT. Further, not all cases of TT lead to blindness.



### Box 3

## WHO 2021-2030 NTD Roadmap



The WHO 2021-2030 Neglected Tropical Diseases (NTD) Roadmap, built on global NTD prevention, control, elimination, and eradication progress to date, aims to “end the neglect and attain the Sustainable Development Goals”. As a high level strategic and advocacy tool, the Roadmap mainstreams 20 NTDs through three main pillars of action: accelerating programmatic actions, intensifying crosscutting approaches, and changing the operational model and culture of achieving targets. These pillars are prioritized through improved scientific knowledge, more effective operational methods, increased awareness from the local to global levels, and multi-sectoral collaboration across stakeholders. Ownership of NTD programs is focused at the country level with clearer delineations of responsibility outlined, thus leading to stronger accountability to deliver interventions and achieve meaningful and sustainable impact.



### What is gender?

The WHO defines gender as “the characteristics of women, men, girls and boys that are socially constructed.” The definition “includes norms, behaviors, and roles associated with being a woman, man, girl or boy, as well as relationships with each other” and notes that “[A]s a social construct, gender varies from society to society and can change over time.” It also specifies that, “gender interacts with but is different from sex, which refers to the different biological and physiological characteristics of females, males, and intersex persons, such as chromosomes, hormones, and reproductive organs.” Gender identity is also separately defined as related to but different from gender and sex. Gender identity refers to “a person’s deeply felt, internal and individual experience of gender, which may or may not correspond to the person’s physiology or designated sex at birth.” This manual will focus on looking at trachoma through a gender lens.

### Box 4

## WHO Definitions of Gender, Sex, and Gender Identity

**GENDER**—“The characteristics of women, men, girls and boys that are socially constructed. This includes norms, behaviors and roles associated with being a woman, man, girl or boy, as well as relationships with each other. As a social construct, gender varies from society to society and can change over time”

**SEX**—“The different biological and physiological characteristics of females, males, and intersex persons, such as chromosomes, hormones, and reproductive organs”

**GENDER IDENTITY**—“A person’s deeply felt, internal and individual experience of gender, which may or may not correspond to the person’s physiology or designated sex at birth”

## The global challenge of trachoma

According to the 2022 31st Weekly Epidemiological Report (WER), from the WHO, there are an estimated 125 million people living in areas that warrant treatment with antibiotics, facial cleanliness, and environmental improvements. Though the vast majority of the global at-risk population resides in the African region (105.7 million), disease is still present in the Americas, Eastern Mediterranean, South-East Asia, and Western Pacific regions. The strategy endorsed by the WHO to achieve the elimination of trachoma as a public health problem is the SAFE strategy. This integrated approach both treats existing cases of active trachoma and TT and

prevents further transmission within the community. SAFE strategy interventions include surgery and other management to correct TT, MDA to reduce the burden of infection, health education to increase personal hygiene and facial cleanliness, and the promotion of sanitation to reduce transmission. When implemented together, the four components have been demonstrated to reduce the overall prevalence of clinical signs of trachoma.

Through the collaboration and dedication of ministries of health, implementing partners, and donors, great progress has been made toward the elimination of trachoma as a

### Box 5

#### The SAFE Strategy



**SURGERY** is used to reverse the in-turned eyelashes of patients with TT. Lid surgery is a fairly simple procedure that can be offered in the community or at health centers. Patients are often afraid of the operation and offering community-wide surgery is the best way of getting good compliance. Lid surgery takes away the pain of lashes scratching the eyes but does not remove the scarring or restore sight.



**ANTIBIOTICS** are used to treat active trachoma and to reduce the reservoir of infection in a community. Topical tetracycline eye ointment (TEO) applied to the eyes every day for six weeks will treat active trachoma. Alternatively, the drug azithromycin can be taken orally in tablets (or liquid for children) to treat active trachoma. The WHO recommends that all individuals in communities where the prevalence of active trachoma exceeds five percent of boys and girls ages 1-9 (denoted as TF<sub>1-9</sub>) be treated annually with antibiotic therapy.



**FACIAL CLEANLINESS** refers to the promotion of improved hygiene. Dirty faces are associated with trachoma infection. A boy or girl with active infection is more likely to transmit trachoma if they have a dirty face and those who are not infected may be more likely to become infected with trachoma if they have a dirty face. Discharge from the eyes and nose attracts eye-seeking flies that can bring the infection or carry it to other people. Rubbing the sore and dirty eyes with a cloth, bed sheets, or a caregiver's shawl/piece of clothing can contribute to the transmission of trachoma. Trachoma control programs must convey that it is desirable for girls and boys to have a clean face and that this should be their usual state.



**ENVIRONMENTAL CHANGE** in a community is necessary for long-term protection from trachoma. The disease persists where people live in poverty with crowded living conditions and where there is insufficient basic infrastructure for water, sanitation, and waste disposal. Unless such conditions change, trachoma is likely to return after antibiotic treatment is completed.



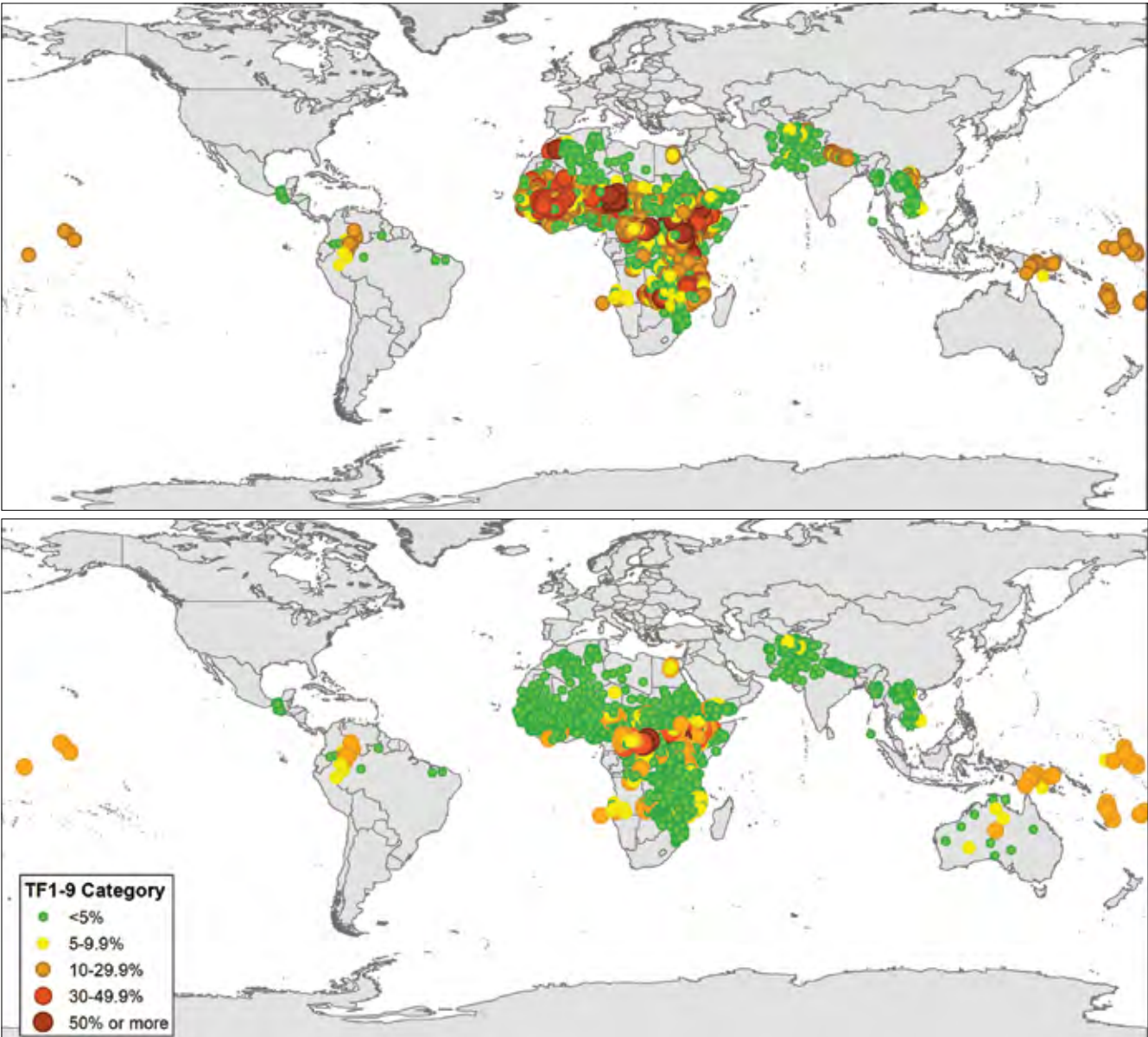
public health problem; since 2002, there has been a 92% decrease in the number of people at risk of blindness from trachoma. Thanks to this progress, as of late 2022, 15 countries were officially validated by the WHO for eliminating trachoma as a public health problem.

The achievements observed throughout the global trachoma program have been possible due to knowledge sharing and implementation of preferred practices, developed largely through ICTC, which brings together partners to share ideas and enhance programming within country-specific contexts.

Box 6

Comparing TF<sub>1-9</sub> Prevalence (2015) to Current TF<sub>1-9</sub> Prevalence (2023)

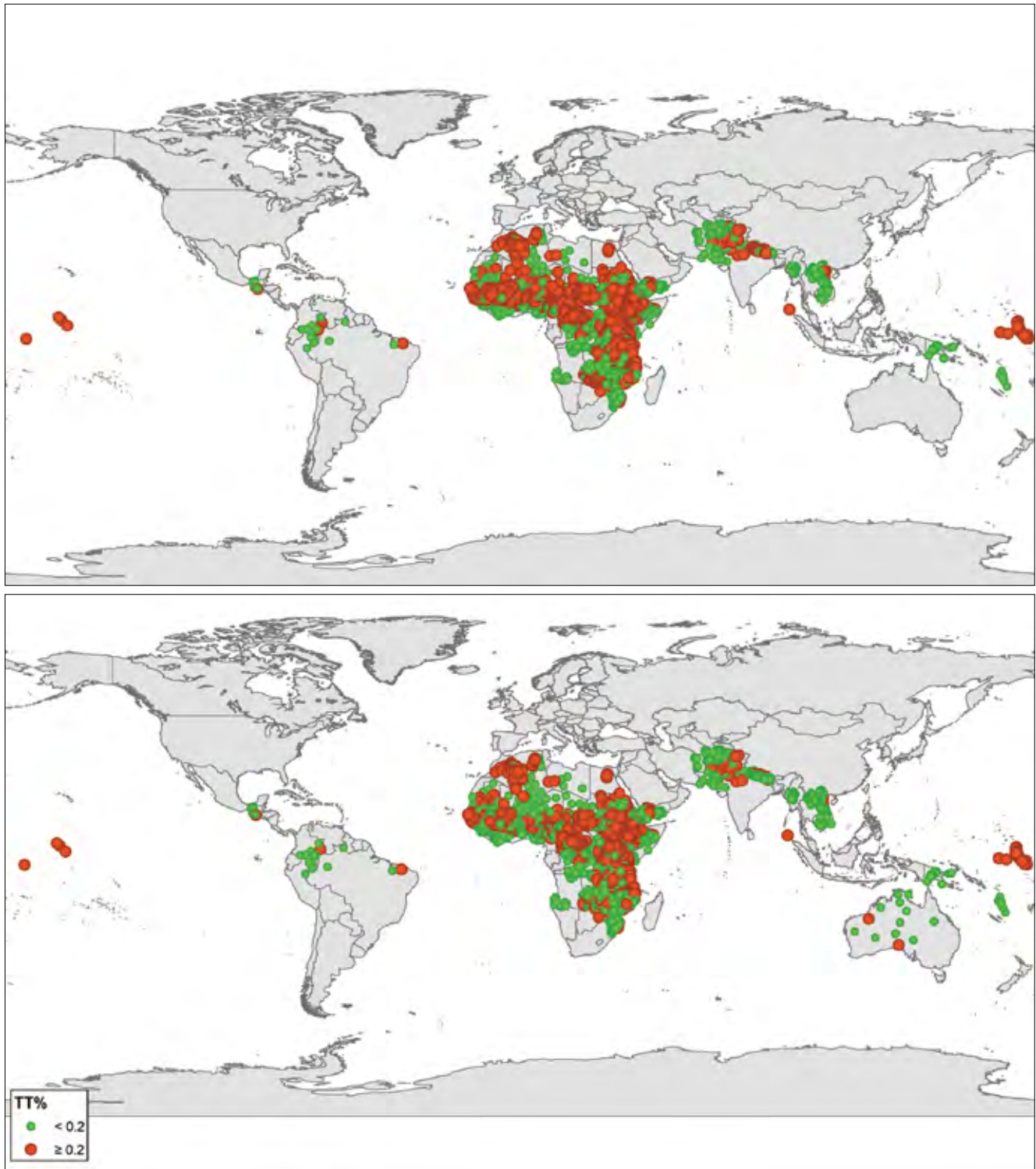
Although there are still trachoma endemic areas in Asia, Australia, the Americas, and the Middle East, the highest concentration of disease is found in Africa. This map shows the approximate distribution of trachoma endemic areas across the globe starting from the Global Trachoma Mapping Project (GTMP) in 2015 to 2023.



Box 7

## Global TT<sub>>15</sub> Prevalence (2015) vs. Current TT<sub>>15</sub> Prevalence (2023)

This map shows the approximate distribution of TT prevalence across the global starting from the GTMP in 2015 to 2023.





It is clear that by adulthood, women are more likely to have TT compared to men, regardless of their age.

## Trachoma and gender

**As stated previously, surveys have shown that women are more likely to suffer from TT and blindness.**

Though some research has shown a slightly elevated risk for girls, there is little evidence to suggest girls are more biologically susceptible to infection than boys; although some evidence suggests that girls account for a higher proportion of the community load of *Chlamydia trachomatis*. Rather, the differences in risk of infection between girls and boys—similar to that between adult women and men—are more related to gender differences in their roles from an early age as caregivers to infants and other children in their birth families, and years of having and raising their own children.

Heavy bacterial loads may also explain why persistent infection is more common in girls, though this can vary depending on the setting. In a longitudinal study, similarly matched boys and girls with severe active disease were traced seven years later. Girls had conjunctival scarring rates about 2.5 times higher than that of boys. This indicates that factors other than biology may be involved. It has been suggested that women, as compared to men, are more susceptible to trachoma infection (and therefore TT) due to their disproportionately high contact with children, who show the highest prevalence of active infection.

Research from the Amhara region in Ethiopia has indicated that risk factors associated with increased odds of TT include increasing age, female gender,



A lady health worker (LHW) supervisor measures out powder for oral suspension (POS) for MDA in Khyber Pakhtoon Khawash Province, Pakistan. Photo credit: Dr. Zahid Awan/Christian Blindness Mission

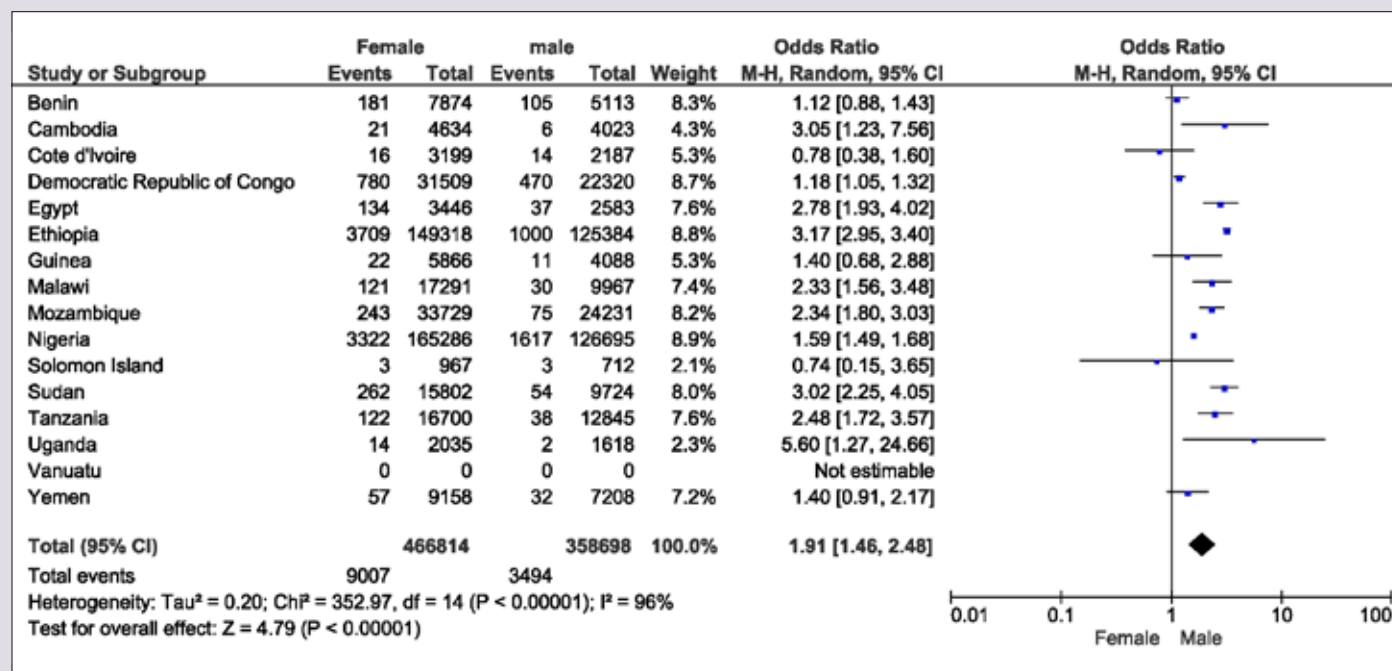
children with TT in the household, and increasing proportion of children with active trachoma. This can also extend to girls as well, as it is not uncommon for girls as young as five years of age to be responsible for the care of infants and other children. This pattern persists into young adulthood as women and girls serve as the primary caregivers for their families. Marriage at an early age, followed by many years of having and raising children, increases the risk of infection and reinfection from children.

It is clear that by adulthood, women are more likely to have TT compared to men, regardless of their age. A meta-analysis of the GTMP prevalence surveys (2019) including 2.1 million people from 22 countries around the world showed that, where TT requires a public health intervention, women were 1.9 times more likely to have TT compared to men. The excess risk ranged from 1.6 (Nigeria) to 3.2 (Ethiopia). The recent meta-analysis confirms findings from similar work in 2009 in which the excess odds of TT in women was 1.8, compared to men.

Figure 1

## Forest Plot of Odds Ratios

A meta-analysis of available prevalence survey data was performed to determine the overall summary odds of trichiasis in women compared to men. The vertical line shows the overall odds ratio. Individual survey odds ratios are weighted by the size of the sample.



## The role of gender

**In most cultures, an individual's gender defines appropriate social roles, behaviors, and expectations.**

There is immense diversity in gender roles both within and across different countries and regions, not limited to ethnicity, urban and rural areas, or socioeconomic strata. In the context of appreciating this diversity, certain generalizations of gender roles guide our approach to increasing the effectiveness of public health initiatives. For example, in some patriarchal societies in Africa, such as the Toposa in South Sudan or the nomadic Fulani in West and Central Africa, men typically provide resources for the family while women are responsible for housework, child care, and agricultural activities. Using generalizations about gender roles to guide programming is inherently risky as it can lead to using gender exploitative approaches that fail to recognize the changing gender norms and the work of local reformers.

In patriarchal societies, women are often responsible for the majority of household work. This does not always mean women are restricted to the household, but refers to the role women play in completing domestic tasks such as cooking, collecting water and firewood, cleaning the family compound, and caring for children and sick family members. In some cases, household chores can place women at disproportionately higher risk for health problems than men. For example, cooking indoors over an open fire without proper ventilation is associated with excessive levels of aerial pollutants. Women in these societies are responsible for caring for the sick, which exposes them to infectious agents more regularly than men. Women also spend more time surrounded by children, increasing the likelihood of infection with diseases that are more prevalent in children, such as trachoma.

Where the load of “women’s work” becomes too much for a single adult woman, young girls or elderly women assist in these duties. This disadvantages women across generations, exposing young girls to the same health risks as their mothers. Because the type of work women perform is often geographically limited to their houses and villages, it can be intimidating or even prohibited for them to venture beyond their homes. This can be exacerbated in conflict settings where communal violence may specifically target women and girls. Where women do not experience a great deal of mobility outside of the community, they generally have less access to health care services which can sometimes lead to decreased confidence and trust in people and organizations from outside of their community.

## Women’s roles in effecting change

**Although it is easy to generalize about the condition of women in patriarchal societies, gender relations are far more nuanced and complex.** In any given society, the division of labor among men and women has evolved over time to facilitate survival and economic stability. Individual men and women exist within the bounds of their social constructs, but they are not uniformly governed by them. Feminine and masculine characteristics are generally accepted by both sexes within a culture as normal. Social structures provide a framework for acceptable behavior and define cultural expectations. Both men and women can effect change within their households and communities; however,



Young girls in the Oromia region of Ethiopia wash their hands and faces with clean water from a protected well.  
Photo credit: Steven Adams/Pfizer

the means to achieve such change will differ for each individual. This is dependent not only on gender, but age, economic status, and family history (in addition to other measures of status and access). In general, women in resource-poor settings have less access to education and are less involved in local community decision-making processes than men. Individual autonomy is often hindered by their domestic responsibilities. Such a characterization, however, discredits the numerous methods women employ to engage with their communities, local governments, and markets.

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Women are often portrayed as passive members of society, when in reality they are active participants in their communities, enacting change through available mechanisms to improve the well-being of their families and households. Programs can learn from and work through women already working as change agents in their community to identify pathways to overcome gender-based constraints, and even identify gender-based opportunities, to achieve better health outcomes.





Community drug distributors (CDD) from Sekanani village showcase a “shuka” worn by Maasai women as a behavior change campaign (BCC) tool to encourage washing children’s faces to prevent the spread of trachoma. Photo credit: Leeshia Crayton/International Trachoma Initiative

## Economic decision-making

**In many resource-poor settings, a woman’s financial dependence on men has a variety of consequences.** Diseases that disfigure or disable women, such as TT, leprosy, lymphatic filariasis, or a developmental deformity can block marriage prospects. Physical deformity can also be the basis of divorce or abandonment if it occurs during marriage. Women may disguise illness or develop coping strategies in order to maintain stability in the marriage while delaying medical attention. In many cases, women must decide when to ask for resources and will prioritize men’s and children’s needs over their own. In situations of financial strain, resources are often used for boys before girls, further reducing access to health care among girls and young women. For example, access to education will be preferentially given to boys if a choice is required, leaving the girls at home to help their mothers. In addition, families with limited resources and food insecurity may seek out early marriage for their daughters in countries where education is not free, where dowries are still practiced, and/or where there is a high risk of other forms of gender-based violence in the community.

## Sustainable Development Goals and gender

Following the Millennium Development Goals established in 2000, the United Nations developed the Sustainable Development Goals (SDGs) in 2015 as a “call to action to end poverty, protect the planet, and improve the lives and prospects of everyone, everywhere.” A framework for achieving this target is outlined across 17 Goals, including Goal 5, which specifically aims to achieve gender equality and empower all women and girls. The impact of gender is also inherent across the SDGs through a gender mainstreaming approach and by advocating and ensuring a gender perspective across program design and delivery. For example, the health outcomes include SDG 3.1: reduce the global maternal mortality ratio and SDG 3.7: ensure universal access to sexual and reproductive health care services. Trachoma elimination falls under SDG 3.3, which states the goal to “end the epidemics of Acquired Immunodeficiency Syndrome (AIDS), tuberculosis, malaria and neglected tropical diseases, and combat hepatitis, water-borne diseases and other communicable diseases” by 2030. Trachoma control programs should embrace the formal and informal opportunities for innovation specific to both men and women, boys, and girls. With gender-equitable programming, it is possible to reduce exposure to trachoma risk factors, increase access to preventive and curative health services, and build local capacity to sustain long-term reductions in trachoma incidence and prevalence. As the global program works to decrease the number of people suffering from trachoma, we must enhance the programming that is targeted to those at risk and leave no one behind. Additionally, as programs look to enhance programming, the role of gender and how to address barriers for equitable service provision should be considered.

## Box 8

# Sustainable Development Goals



### GOAL 1

End poverty in all its forms everywhere



### GOAL 2

End hunger, achieve food security and improved nutrition and promote sustainable agriculture



### GOAL 3

Ensure healthy lives and promote well-being for all at all ages



### GOAL 4

Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all



### GOAL 5

Achieve gender equality and empower all women and girls



### GOAL 6

Ensure availability and sustainable management of water and sanitation for all



### GOAL 7

Ensure access to affordable, reliable, sustainable and modern energy for all



### GOAL 8

Promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all



### GOAL 9

Build resilient infrastructure, promote inclusive and sustainable industrialization and foster innovation



### GOAL 10

Reduce inequality within and among countries



### GOAL 11

Make cities and human settlements inclusive, safe, resilient, and sustainable



### GOAL 12

Ensure sustainable consumption and production patterns



### GOAL 13

Take urgent action to combat climate change and its impacts



### GOAL 14

Conserve and sustainably use the oceans, seas and marine resources for sustainable development



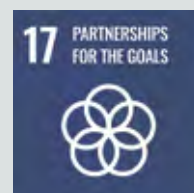
### GOAL 15

Protect, restore and promote sustainable use of terrestrial ecosystems, sustainably manage forests, combat desertification, and halt and reverse land degradation and halt biodiversity loss



### GOAL 16

Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels



### GOAL 17

Strengthen the means of implementation and revitalize the global partnership for sustainable development

## Suggested reading

Callahan K, Ogale YP, Palmer SL, Emerson PM, Hopkins DR, Withers PC Jr, Ngondi JM. Trachoma control as a vehicle toward international development and achievement of the millennium development goals. *PLoS Negl Trop Dis*. 2014 Sep 18;8(9):e3137. doi: 10.1371/journal.pntd.0003137. PMID: 25232728; PMCID: PMC4169372. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4169372/>. *This analysis shows how the SAFE strategy is a good example for how to meet the millennium development goals set by the UN.*

Commission on Social Development. Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. Geneva, World Health Organization; 2008. *This WHO document presents an outline of the challenges to delivering equitable health care at the global level. A holistic approach is used to understand a broad range of factors that determine access.*

Congdon N, West S, Vitale S, Katala S, Mmbaga BBO. Exposure to children and risk of active trachoma in Tanzanian women. *American Journal of Epidemiology*. 1993;137:366-372. *Women who are in child caretaking roles are more likely to have active trachoma. This paper provides some evidence for understanding how the roles and responsibilities of women contribute to their excess risk of trachoma.*

Cromwell EA, Courtright P, King JD, Rotondo LA, Ngondi J, Emerson PM. The excess burden of trachomatous trichiasis in women: a systematic review and meta-analysis. *Transactions of The Royal Society of Tropical Medicine and Hygiene*, 2009; 103(10): 985-992. *A meta-analysis of trachoma surveys (prior to 2008) that calculated the excess risk (age-adjusted) of trichiasis in women compared to men. This has been updated with GTMP baseline survey data as part of George Moyo's University of Cape Town Masters student dissertation.*

Emerson PM, Burton M, Solomon AW, Bailey R, Mabey D. The SAFE strategy for trachoma control: using operational research for policy, planning and implementation. *Bulletin of the World Health Organization*. 2006;84:613-619. *This article reviews the evidence from operational research that has led to the adoption of the SAFE strategy for the control of trachoma.*

Ending the neglect to attain the Sustainable Development Goals: a road map for neglected tropical diseases 2021–2030. Geneva: World Health Organization; 2020. License: CC BY-NC-SA 3.0 IGO. *This details the WHO's development goals over the next 10 years.*

International Coalition for Trachoma Control (ICTC), Transition planning for mass drug administration (MDA) of Zithromax®, March 2019 [https://www.trachomacoalition.org/sites/default/files/content/resources/files/ICTC\\_TransitionPlanningMDA\\_041619\\_FINALonline.pdf](https://www.trachomacoalition.org/sites/default/files/content/resources/files/ICTC_TransitionPlanningMDA_041619_FINALonline.pdf). *This guide provides insight on how to transition programs from MDA to surveillance and local public health supportive care.*

International Coalition for Trachoma Control (ICTC), Transition planning for Facial cleanliness and Environmental improvement, March 2019. <https://www.trachomacoalition.org/resources/transition-planning-facial-cleanliness-and-environmental-improvement>. *This guide shares strategies for how to incorporate F&E into local public health facilities for sustainability.*

International Coalition for Trachoma Control (ICTC), Micro-planning for effective Zithromax® Mass Drug Administration, December 2015. <https://www.trachomacoalition.org/sites/default/files/content/resources/files/ICTC%20MDAMicroPlanningGuide%20042016%20v5.pdf>. *This guide shared how to effectively plan and evaluate MDA campaigns.*

International Coalition for Trachoma Control (ICTC), Supportive Supervision for Mass Drug Mariotti SP, Pararajasegaram R, Resnikoff S. Trachoma: looking forward to global elimination of trachoma by 2020 (GET 2020). *American Journal of Tropical Medicine and Hygiene*. 2003;69 (suppl 5):33-35. *This article summarizes the successes and challenges in the global effort to eliminate trachoma.*

McCauley, A. P., West, S., & Lynch, M. (1992). Household decisions among the Gogo people of Tanzania: determining the roles of men, women and the community in implementing a trachoma prevention program. *Social Science and Medicine*, 34(7), 817-824. doi:10.1016/0277-9536(92)90368-z. *This study provides insight on how to target subpopulations within the community to aid in health intervention planning and uptake.*

Moyo, G. (2019). Global burden of trichiasis in women as compared to men: Findings from the Global Trachoma Mapping Project. (). Faculty of Health Sciences, Department of Surgery, University of Cape Town, South Africa. *This article details the results of meta-analysis of the Global Trachoma Mapping Project since its inception in 2005.*

Nash SD, Chernet A, Moncada J, Stewart AEP, Astale T, Sata E, Zerihun M, Gessese D, Melak B, Ayenew G, Ayele Z, Chanyalew M, Lietman TM, Callahan EK, Schachter J, Tadesse Z. Ocular Chlamydia trachomatis infection and infectious load among pre-school aged children within trachoma hyperendemic districts receiving the SAFE strategy, Amhara region, Ethiopia. *PLoS Negl Trop Dis*. 2020 May 18;14(5):e0008226. doi: 10.1371/journal.pntd.0008226. PMID: 32421719; PMCID: PMC7259799. *This study highlights the epidemiology of Chlamydia trachomatis (Ct) infection and load among preschool aged children living in areas under the SAFE strategy in the Amhara region of Ethiopia.*

Resnikoff S, Pascolini D, Etya'ale D, Kocur I, Pararajasegaram R, Pokharel GP, Mariotti SP. Global data on visual impairment in the year 2002. *Bulletin of the World Health Organization*. 2004;82:844-852. *This bulletin provides data from population-based surveys around the world that were used to create estimates of the global burden of vision loss and their causes, including trachoma.*

Rilkoff H, Tukahebwa EM, Fleming FM, Leslie J, Cole DC (2013) Exploring Gender Dimensions of Treatment Programmes for Neglected Tropical Diseases in Uganda. *PLOS Neglected Tropical Diseases* 7(7): e2312. <https://doi.org/10.1371/journal.pntd.0002312>. *This study details the importance of gender-specific training for community drug distributors with an emphasis on pregnant and breastfeeding women.*



Solomon AW, Kello AB, Bangert M, West SK, Taylor HR, Tekeraoi R, Foster A. The simplified trachoma grading system, amended. *Bull World Health Organ.* 2020 Oct 1;98(10):698-705. doi: 10.2471/BLT.19.248708. Epub 2020 Sep 3. PMID: 33177759; PMCID: PMC7652564.

Ul Hassan E, Kelly M, Waititu T, Olobio N, Kabona G, Mkocha H, Kivumbi P, Mwale C, Mubangizi A, Mugume F, Baayende G, Mayeku R, Massangaie M, Mbofana MA, Cumaio M, Sisay A, Mersha T, Courtright P. Productivity, efficiency, and gender equity of community mobilisation approaches in trichiasis campaigns: analysis of programmatic data from seven sub-Saharan Africa countries. *International Health* 2022;14, Suppl 1: i24-i28. <https://doi.org/10.1093/inthealth/ihab086>. Program-based research showing the gender-specific impact of community-based case finding compared to non-specific mobilization approaches on presentation to trichiasis outreach. Men outnumbered women if non-specific approaches were used while women outnumbered men when community-based case finding approaches were used.

United Nations. (2022). The Sustainable Development Goals Report 2022. The United Nations Publications. *Using the latest available data and estimates, the SDG Report 2022 monitors global progress on the 2030 Agenda for Sustainable Development and provides a reality check on the devastating impacts of multiple crises affecting people's lives and livelihoods.*

West SK, Munoz B, Mkocha H, Hsieh YH, Lynch MC. Progression of active trachoma to scarring in a cohort of Tanzanian children. *Ophthalmic Epidemiology.* 2001;8:137-144. *This seven-year cohort study of children details the association of the incidence of scarring with constant severe trachoma, age, and female gender.*

Wharton-Smith A, Rassi C, Batisso E, Ortu G, King R, et al. (2019) Gender-related factors affecting health seeking for neglected tropical diseases: findings from a qualitative study in Ethiopia. *PLOS Neglected Tropical Diseases* 13(12): e0007840. <https://doi.org/10.1371/journal.pntd.0007840>. *This article details how gender influences health and acceptance of health services.*

World Health Organization. (2022). Weekly Epidemiological Record: WHO Alliance for the Global Elimination of Trachoma, progress report on elimination of trachoma, 2021 (WER No. 31, 2022, 97, 353–364). <https://www.who.int/publications/i/item/who-wer9731-353-364>. *This annual report provides updates on the global trachoma program and the successes over the past year.*

Zerihun, N. (1998). Impact of trachoma among rural Ethiopian women. *Ethiopian Journal of Health Sciences*, 8(1), 53-59. *This paper gives insight into the interaction between gender and trachoma from the perspective of rural Ethiopian women.*



Tropical Data surveys being conducted in Tanzania as a Training of Trainers exercise. These trainings build the capacity of national programs to have certified TT trainers in their countries. Photo credit: Sumon Ray/International Trachoma Initiative



Pictured here is a young girl from a Trachoma endemic region in Ethiopia. Photo credit: Brent Stirton/Getty Images for International Trachoma Initiative

## Chapter 2

# Gender Representation in Human Resources

### The trachoma control workforce

**Successful implementation of the SAFE strategy requires an extensive and diverse workforce.** From coordinating the trachoma response in collaboration with the national government and distributing antibiotics, to planning for and carrying out surgery, each individual woman and man plays a key role towards achieving this success and driving trachoma control programs forward. This chapter focuses on these roles and how to improve gender representation across the trachoma workforce.

Almost all gender-based research focuses on individuals suffering from trachoma without examining the trachoma control workforce itself, highlighting a gap in knowledge and understanding of the true gender representation within trachoma control programs globally.



## Case Study 1

### Sudanese Female Ophthalmic Surgeons Focused on Saving Sight

**Even in the shade, it was 105 degrees Fahrenheit (40 degrees Celsius).** It can be challenging to focus in that kind of heat, but Dr. Saisabil Omer and Dr. Mayasa Mustafa were committed to providing TT surgery to the men and women who came to the clinic in Al Fashaga locality, Gedarif state, Sudan.

The TT surgeries the two women provide only take about 20 minutes per eye, but require days of planning for these clinics to happen.

First, there is the eight-hour drive from the capital, Khartoum, to Al Fashaga. Once the team arrives at the clinic site, they spend one or two days looking for patients in need of surgery. Announcements are made via the radio and a megaphone attached to a truck that drives around the village. Ministry of Health personnel also walk through villages talking to residents and looking for TT cases.

Thanks to this mobilization, the clinic receives patients for TT surgery and a steady stream of women and men eager to be examined for other eye conditions as well by the visiting eye doctors. Residents know this is likely their only chance to be seen by an eye health professional, as the nearest eye clinic is in the state's capital, three hours away by public transport.

To be an ophthalmologist in Sudan, one must have six years of university and two years of general medicine practice, with one of those years completed as part of national service. Though doctors learn about TT surgery in school, the TT surgical outreach camps provide them with hands-on experience. Drs. Mustafa and Omer both enjoy participating in the camps because they get to help people in need. The surgeons mentioned that, "These people are poor and cannot afford to come to Khartoum."

The surgeons conducted 20 surgeries in two days at Al Fashaga. The camps move locations every one to two days for two weeks assisting those in need. With each move, they must load all the surgical tables, chairs, and the generator back into the vehicles and set them up again at the next stop.

Omer and Mustafa and the other resident ophthalmologists supporting the Federal Ministry of Health's trachoma elimination program have a lot of work ahead of them, but they are determined to reach the community members in need.



Dr. Saisabil Omer and Dr. Mayasa Mustafa arriving at a clinic to perform TT surgery on patients in Sudan.  
Photo credit: Angelia Sanders/The Carter Center

**The camps move locations every one to two days for two weeks assisting those in need. With each move, they must load all the surgical tables, chairs, and the generator back into the vehicles and set them up again at the next stop.**



## Case Study 2

# Trachoma Elimination in the Pacific Islands

**Eliminating trachoma in the remote Micronesian Island nation of Kiribati is a delicate mix of logistical challenges and medical and environmental activities.**

Kiribati is a collection of 33 mainly atoll islands in the central Pacific Ocean, about 4,900 km (3,044 mi) north east of Brisbane, Australia.



In the fight to eliminate trachoma, Raebwebwe Taoaba, Kiribati's National Trachoma Coordinator, works diligently to coordinate MDA across 33 atolls. Photo credit: The Fred Hollows Foundation

At the forefront of the trachoma effort is Raebwebwe Taoaba, the Ministry of Health's Trachoma Coordinator. Raebwebwe was a registered nurse who undertook training and became a medical assistant and practitioner. Her role involves supporting the training for nurses and health workers, developing education materials, and organizing the complexities of distributing antibiotics for MDA.

"In Kiribati we have scattered islands, including Christmas Island, and we have to travel extensively. We have limited water sources and poor hygiene," Raebwebwe said.

"In the capital the distribution of water is okay, but it is overcrowded and people live in extended families. In the outer islands there is better access to water and sanitation but still we need to work on changing behavior."

Through concerted efforts, the aim for endemic Micronesian Island programs is to eliminate trachoma as a public health problem in Fiji, Kiribati, Solomon Islands, and Vanuatu through implementing the WHO's recommended SAFE strategy. When Kiribati's activities began in 2016, it had the highest prevalence of trachoma in the region. To date, Kiribati has implemented two rounds of MDA as well as environmental improvement, facial cleanliness, and hygiene education.

**COMMUNITY ROLES.** The roles involved in a trachoma control program vary widely depending on which components of the SAFE strategy are tackled within a specific community. These can include TT Case Finders who work to identify cases of TT (S component) in their communities, Community Drug Distributor (CDD)/Community Treatment Assistant teams who ensure widespread antibiotic distribution (A component), or health educators who ensure communities understand how to prevent trachoma transmission (F&E component). Alongside these direct program implementation roles are support roles including data recorders, drivers, operating room cleaners, cooks, community mobilizers, security guards, and water collectors, among others.

**MANAGEMENT ROLES.** A more permanent core team plays an overarching supervisory and support role by ensuring that trachoma control programs are effectively planned, coordinated, and implemented on schedule. This team not only includes trachoma technical staff but also finance, logistics, supply chain, and human resource roles. This team is the backbone of any trachoma program, whether based within a national Ministry of Health department or alongside the national government through external local or international organizations.

## The complexity of the workforce

**WORKFORCE GENDER GAP.** Typically, in any given trachoma surgery, antibiotic, or health education campaign, men and women can both contribute. There is always a role within the trachoma workforce for individuals of varying identities and experiences, including people experiencing disabilities, pregnant and lactating women, literate or illiterate, old or young; however, the predominantly patriarchal cultures of trachoma endemic countries have led to a male-heavy workforce within the sphere of NTDs. The majority of paid roles outlined above are filled by men. Almost all gender-based research focuses on individuals suffering from trachoma without examining the trachoma control workforce itself, highlighting a gap in knowledge and understanding of the true gender representation within trachoma control programs globally.

**PERSPECTIVES OF WOMEN WORKING IN THE FIELD OF TRACHOMA.** As part of creating this chapter, a 'Women Workforce Survey' was conducted in 2021 among women working in trachoma. The survey was translated into Arabic, English, French, Portuguese, and Spanish and sent to women who are working and have worked in trachoma endemic countries at the governmental and/or non-governmental organization (NGO) level. Forty-nine women completed the survey, representing the working experience at all technical and administrative levels, as well as all WHO regions. Their responses provided insights into the current challenges and opportunities experienced by women in the trachoma workforce space.

**EDUCATION AND TRAINING.** The criteria for certain roles, notably central coordination and management roles, demand a high level of education and work experience. Often, in trachoma endemic regions, women and girls do not have equal access to education and training as men and boys and inevitably these more technical positions are filled by men. When considering campaign-specific roles, however, there is much wider scope for women to participate, especially for activities that include an integrated training component. CDDs

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"There is a need for engendering the SAFE strategy to ensure participation of women the fight of trachoma; raising gender awareness and educating men on the importance of having women leaders championing trachoma initiatives in the community."

– Country Director, Health NGO, Africa

and TT Case Finders, for example, receive basic training on trachoma and its modalities at the beginning of a surgery or MDA campaign, which has the potential to make the roles more accessible to women. Given the team-based structure of these community roles, it is possible for those with low literacy levels to participate. The margin for error within the activity is mitigated through close supervision of the teams and through support within the teams from more experienced individuals.

**FAMILY RESPONSIBILITIES.** Women and girls in trachoma endemic regions are often married by their mid-teens and have one or more children by the age of 18. Early marriage and motherhood can limit the years of education pursued and consequently their ability to qualify for skilled roles. This puts them at a distinct disadvantage when seeking gainful employment, as the additional responsibilities of childcare must be considered. Responses from the Women Workforce Survey identified maintaining a family and work balance as one of the main challenges for women in trachoma programs. That said, women with established families tend to know each other, have connections within the community, and are trusted and accepted at the local level. Women also know firsthand the main challenges faced by the women and girls in their communities, including how to best support them with trachoma treatment and prevention.



### Case Study 3

## A Positive Force for Trachoma Elimination in Ghana

**Dr. Agatha Aboe supported trachoma elimination programs in her home country of Ghana for over 10 years.** Her role included providing technical guidance to trachoma programs in endemic countries and ensuring everyone followed the SAFE strategy, international standards, and preferred practices. Throughout her work she has remained a keen advocate for women in leadership.

Agatha is a doctor by profession, with a specialization in ophthalmology and background in community health.

"My passion in trachoma elimination is about saving the sight of people and ensuring that people don't fall into the cycle of poverty due to this avoidable blinding disease. I have a lot of passion for trachoma elimination, so much that I don't want to do anything else. I want to work hard to see a world free of trachoma."

In 2018, Ghana became the first country in sub-Saharan Africa to eliminate trachoma, thanks in part to Agatha's leadership and sheer determination.

"The day that the WHO announced that Ghana had eliminated trachoma and gave us the validation letter, my heart was overjoyed. It had been my dream to see that day come and I felt so proud to be on the forefront of that success. It's a lifetime achievement and one I look forward to supporting other countries with."

But reaching this milestone was no easy feat; like all great achievements, it came with its own challenges.

"There was a period when the attention was more focused on distributing treatment through MDA and trachoma surgeries, but lacking on water and sanitation. I didn't want communities to see an increase of trachoma because they did not have clean water and adequate sanitation in place."

Thankfully, progress was made to address that challenge and the development of clean water and sanitation became more common across Ghana. Where these resources were once lacking, Agatha expressed, "The communities are now very clean."

When asked what advice she would give to endemic countries during their own journey to eliminate trachoma, Agatha said: "Women need to be included in the fight to eliminate this blinding disease. Women play a huge role in ensuring their children are kept clean and that there is water in their communities."

"We need to have women coming together to make sure that we fight this terrible disease. To make it a thing of the past, all around the world. Wherever there's a presence of trachoma, and at every level of elimination effort, you will find women there."

"My mother and father really inspired me throughout my childhood. When I was a young girl my parents saw that I was intelligent, and my father told me that I would be a great doctor and someone who would help many people in the future. My family has always been very supportive and I know my husband and children are proud of me. I have carried that inspiration and support throughout my life."



Dr. Agatha Aboe checks a child's eyes during a trachoma screening campaign in Zimbabwe. Photo credit: Sightsavers



#### Case Study 4

### An Epidemiologist's Commitment to Trachoma Elimination

**Tigist Astale, an epidemiologist in Ethiopia, has faced down angry dogs, runaway cattle, and crocodile-filled rivers.** She supervises extensive field work in far-flung locations across the Amhara Region of Ethiopia—a region with a considerable burden of trachoma. Thanks to her commitment to gathering quality data, the trachoma control program continues to implement effective interventions to help reduce blindness in Amhara.

Tigist's higher levels of education in health promotion, global health, and epidemiology have enabled her to focus her career on supporting health programs such as trachoma.

Tigist supervises surveys that assess the impact of program interventions. This includes securing ethical clearance from relevant oversight bodies, organizing training for trachoma graders, and organizing the necessary logistics for survey teams to reach districts throughout the Amhara region. The effort to carry out these surveys is impactful, as they can help the trachoma control program improve its interventions.

"I always wanted a research position," Tigist said. "I enjoy looking for more evidence for the program so we can make better decisions."

Monitoring trachoma-related outcomes in a region as rural as Amhara comes with challenges.

"The main challenge is accessing rural homes when there are no roads that reach the villages," Tigist said. "In some situations, survey teams walk 10 hours or more through woods and over mountains to access the villages."

In addition to access, Tigist faces other barriers as well.

"Dogs cause problems, particularly in rural highlands where every household owns a dog to guard their home," says Tigist. During a recent survey, Tigist faced down three angry dogs while visiting a remote household.

Despite these issues, Tigist said she is proud of the work her survey teams do, and she remains committed to reducing the burden of trachoma in Ethiopia.



Tigist Astale assists field teams during trachoma impact surveys in Ethiopia's Amhara region. As a Carter Center epidemiologist, her work includes securing ethical clearance from relevant oversight bodies, organizing trainings for trachoma graders, and working out the logistics required to move survey teams across many districts. Photo credit: Scott Nash/The Carter Center

**RESPECT WITHIN THE WORKPLACE.** According to respondents from the Women Workforce Survey, younger women, especially if single/unmarried, can face challenges maintaining authority when placed with less dedicated individuals or older male colleagues. Respondents to the Women Workforce Survey identified challenges specific to women in the trachoma

workforce including being heard and taken seriously, whether by peers or among community leaders; sexism and disrespect from males; and cultural norms barring their ability to fully participate in interventions (for example, local chiefs only allowing males to address their communities).

Table 1

## Women Workforce Survey Responses

CHALLENGE	PERCENTAGE OF RESPONDENTS (N=49)	ADDITIONAL NOTES
Being heard/having to prove capacity	22.5% (9)	Repeatedly having to prove one's capacity to colleagues and other stakeholders
Work-life balance	20% (8)	Raising children and holding a job
Cultural norms (dress codes, lack of access to other women)	20% (8)	Women may not all be permitted by male family/community members to participate
Sexism/disrespect from male individuals	12.5% (5)	Male colleagues and males in the intervention communities
Travel insecurity	12.5% (5)	Notably in remote areas
Lack of female representation in senior roles	10% (4)	Especially women of color in senior roles
Lack of infrastructure for women when traveling	7.5% (3)	Lack of privacy, menstrual hygiene infrastructure
Overlooked for promotions over male colleagues	5% (2)	Despite equivalent or superior experience
Lack of literacy	2.5% (1)	A barrier to accessing activities and participating in them
No challenges	22.5% (9)	

## Preferred practices for inclusivity in human resources

**RECRUITMENT.** Throughout all stages of the recruitment process, inclusivity and flexibility must be considered in a trachoma control program to strongly support the participation of women in the trachoma workforce. Recruitment through local authorities (national, regional, or district level) and community leaders ensures a level of local ownership and participation which can be leveraged to ensure stronger female representation for paid temporary roles such as team supervisors, drug distributors, TT Case Finders, and community mobilizers.

Recruiting for the most physically active roles often yields a relatively youthful workforce, notably young men and women in their final years of education or recent high school graduates. These individuals tend to have a goal of attending higher education or gaining good work references and will work towards this by participating in health campaigns such as trachoma control activities. As such, recruiting for roles requiring literacy (such as data recorder or team leader) from town centers generally produces a higher number of female applicants. While there are no concrete rules on the percentage of females to employ for different types of roles, beginning the recruiting process with the intention of hiring a diverse and qualified workforce can lead to a higher proportion of women than would otherwise be considered. In addition, equal pay amongst men and women in similar roles is an important component to show that the work contribution is equally valued regardless of the worker's gender.

**ACCOMMODATING A DIVERSE WORKFORCE.** To prevent the exclusion of pregnant women or women with young children and no childcare options, prioritize them for more stationary roles such as data keeping, or in a team that allows them to remain in a central location, that does not require overnight travel, and is closer to their homes. This is also applicable to recruiting people with disabilities. In some cases, women will not disclose that they are pregnant or have young children until they have completed all the training for their role. It is therefore important to establish from the outset that pregnancy will not mean they cannot work but it must be taken into consideration during planning. For example, providing a transportation stipend for a family member or caregiver to support working mothers during work trips is an accommodation that could increase trust and support women in the workforce. Trachoma programs should aim to remain flexible, allowing women to bring children to work, and have breaks for breastfeeding, where possible and safe.

**TECHNICAL REPRESENTATION.** In more technical roles, the first challenge is attracting women to apply, and the second is finding qualified female candidates within the applicant pool, given the previously mentioned barriers for women to education and training. Bearing this in mind, a minimum quota of women to be hired can be established before beginning the recruitment process based on the available workforce. In doing so, even if the women candidates are less qualified or experienced on paper but are able to meet the minimum expected competencies, many of the other required skills can be gained through experience and with supportive management.

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"In our organization, we frequently try to hire women CDDs and supervisors but often struggle to identify educated women in the communities we serve. This might involve broader support of education initiatives or organizations that seek to fund education for women...As the majority of our TT cases are women, we absolutely need to scale up women-centered health education."

– Mid-level supervisor, Health NGO, Africa



## Case Study 5

### A Young TT Case Finder's Story

**Female TT Case Finders are vital to the success of efforts to locate individuals suffering from TT and to prevent irreversible blindness due to trachoma.** With a disease that disproportionately affects women, having other women on the frontline ensures that people are not left behind. Case finder Aishatu Ahmed, from Bauchi state in Nigeria, tells her story.

"Because of my track record distributing the oral polio vaccine, I was selected to be a TT Case Finder," says Aishatu.

"I became disabled when I was a child, but my disability doesn't stop me from doing my job as a TT Case Finder. The community cooperates with me so that I can do my work successfully."

When Aishatu is not doing her case finding work, she practices tailoring at school. "When I come back from school, I rest, and then I start my case finding work. I go house-to-house to check for trachoma to make sure no one is missed out."

Not everyone can do this job. Because of traditional or religious customs, male TT Case Finders cannot enter households unless there is a man at home. This means that some women are at risk of missing out on surgery that could prevent them from going blind, simply because the TT Case Finder is male.

"Being a woman is very important as a case finder because it means I can enter most homes. When I enter a home, I greet the family and explain why I'm there. Then, I check their eyes for TT. If I see someone with TT, I explain to them that surgery will help them. I tell them the place and time they can go to for surgery and that they won't have to pay for their treatment. I also educate people about how, after surgery, they should continue to take their medication and how they can look after their personal hygiene to help keep them safe from infection in the future. I am calling to all women who are thinking about becoming a case finder, I say come, join hands and work together to help people—they should not have to go blind. Let's help them to get surgery."



Wearing a face mask and washing her hands more often means that Aishatu can continue her work safely during COVID-19. Photo credit: Sightsavers

**"Being a woman is very important as a TT Case Finder because it means I can enter most homes."**

– Aishatu Ahmed

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**“Organizations should actively pair early and mid-career women with senior leaders who can actively support their career advancement.”**

– Senior-level supervisor, Health NGO, Africa & Eastern Mediterranean

**WORKING CONDITIONS.** It is essential to ensure that candidates are aware of the challenges of the job and for organizations to establish systems to provide targeted support for women, thus encouraging the retention of female staff. Depending on the context, trachoma control programs can involve camping, hiking, long work hours, working in areas with poor sanitation facilities, and long periods of time away from home. This is taxing to all involved, regardless of sex, but especially for women in societies where the responsibility of maintaining a home is primarily theirs, or cultural taboos exist around men and women cohabitating. Where feasible, activities can be organized to ensure women are not away from home for extended periods of time, supporting childcare costs for women who will be away from their families, and organizing culturally appropriate accommodation for overnight activities. Additionally, the more locally technical staff are based, the less work takes them away from their family, thereby making it easier for them to continue working with the program. Finally, once they have gained experience and demonstrated competence in trachoma campaigns, additional steps can be taken to ensure continued employment for women in trachoma, such as transitioning from short-term activity-based roles to long-term management roles which can provide them a level of stability and job security.

#### **REPRESENTATION IN SENIOR MANAGEMENT.**

Systemically, there is a lack of female representation in senior roles within the sphere of NTDs, and trachoma is no exception. Survey respondents highlighted that women feel overlooked for promotions in preference of their male counterparts, or pigeon-holed into stereotypically “supportive” roles as deputies or support staff and thus perhaps do not always receive proper recognition for their work. In some cases, this can be based on qualifications, which women may have less time and opportunity to pursue. Organizations working in NTDs can provide increased supportive training for women to pursue further education, ensure promotions are transparent and merit-based, and encourage female employees to pursue more senior roles. It is worth noting that a lack of women in the workforce and leadership can extend beyond the male and female divide and encompass a lack of advancement due to other barriers based on prejudices against a person’s ethnic background or disabilities.





Esther, an ophthalmic nurse, performing a TT grading examination for trachoma prevalence surveys. Photo credit: Lion's Aid Zambia

#### Case Study 6

### Fighting Myths: Female Grader in Zambia

**To determine the prevalence of trachoma in a district, national programs use the technical skills of trachoma 'graders'.** Grading requires examining the eyelids of community members to look for signs of trachoma. Employing female trachoma graders can be very beneficial to communities in Zambia, particularly since female graders are able to interact more comfortably with female community members than their male counterparts.

Esther is an ophthalmic nurse based in Chilubi Island, situated in Zambia's Northern Province. She is also a lecturer at Chilubi College of Nursing and Midwifery. Esther has been participating in trachoma surveys since 2018 and enjoys participating in community projects.

"I enjoy providing eye care services to people in hard-to-reach areas because that is where the services are most needed," she said. Esther shared that there are a lot of myths in the rural areas and therefore a need for continued health education. She interacts frequently with people whose cultural beliefs have resulted in behaviors that negatively impact eye health in their communities. To address this, she interacts with women and men in the communities to provide them with the relevant information to avoid diseases.

"I enjoy participating in trachoma surveys because I get to provide a service to a lot of vulnerable people."

As a trachoma grader, Esther has experience working in many rural districts in Zambia. So far, she has participated in impact and surveillance surveys in 26 districts in the country.

Esther shared that solid organization by the principal investigator and partners promotes the smooth collection of data during surveys. Receiving prompt feedback during the surveys also helps increase the quality of the data and encourages the teams to meet their targets in the field.



## Suggested reading

McKinsey Global Institute. The power of parity: Advancing women's equality in Africa. 2019. <https://www.mckinsey.com/featured-insights/gender-equality/the-power-of-parity-advancing-womens-equality-in-africa>. This report explores the "power of parity" for Africa, looking at the potential boost to economic growth that could come from accelerating progress toward gender equality.

Pariona A. Prevalence of Child Marriage Around the World. World Atlas, 25 April 2017. This article provides general background on child marriage around the world and statistics by continent.

Theobald S, MacPherson EE, Dean L, et al. 20 years of gender mainstreaming in health: lessons and reflections for the neglected tropical diseases community BMJ Global Health 2017;2:e000512. Drawing on a synthesis of relevant literature, the tacit knowledge and experience of the authors, and discussions at a meeting on women, girls, and NTDs, this analysis paper distills five key lessons from over 20 years of gender mainstreaming in health.



A young girl waits to have her eyes examined for trachoma by Dr. Anasaini Cama, a Tropical Data Master Grader from Fiji, during a training of trainers exercise for the Pacific region in Guadalcanal, Solomon Islands. Photo credit: Research Triangle Institute



A woman being led to transportation after receiving TT surgery in Niger.  
Photo credit: The Carter Center

## Chapter 3

# TT Management: Evidence of Gender Inequity, Improving Programs, and Monitoring Progress

**Trachoma control efforts over the past three decades have led to a significant reduction in blindness due to trachoma.** As of June 1, 2022, estimates suggest that there are 1.7 million people with TT due to trachoma worldwide, a significant reduction in the burden of TT since the estimate of 7.6 million in 2002. However, women still suffer disproportionately from TT, accounting for up to 86% of total TT cases in some regions.

The focus of TT management is to reach elimination thresholds, defined by WHO at the administrative unit as  $<0.2\%$  TT unknown to the health system in adults aged 15 years and above (denoted as  $TT_{\geq 15}$ ). While some countries are still scaling up TT management programs, others are reaching this threshold and scaling down these activities while ensuring long-term management of incident cases. Regardless of the setting, understanding gender-related issues and barriers in TT management is critical to successfully reaching elimination.

TT is a painful, debilitating condition that limits the activities of daily living and therefore strongly impacts women who are often responsible for the majority of household caretaking duties, as well as childcare. Surgery is an intervention that confers almost immediate relief to people living with TT, improving quality of life, and enabling them to participate in the daily activities of their households. Relief from TT has a knock-on effect in the household; for example, children (usually girls) who had to take on activities to support their mothers suffering from TT can return to school.

Surgery is appropriate for most, but not all cases of TT; epilation (the removal of misdirected lashes using forceps or tweezers) is a viable management approach in some cases. Surgery is generally performed by non-physician TT surgeons in outreach settings as close to the population in need as possible. Preferred practice guidelines for all aspects of a TT program have been developed, adapted, and adopted in trachoma endemic settings.



**7.6 MILLION**  
people with TT (estimated)



**1.7 MILLION**  
people with TT (estimated)





Annie loves her work as a community volunteer and it fills her with joy whenever the people she has identified are able to get the treatment they need.

Annie Mukubi, a trained TT Case Finder, can walk up to five kilometers in a day to reach potential TT patients in neighboring communities. Photo credit: Sightsavers

#### Case Study 7

### Case Finder in Zambia Helps Her Community

**Annie Mukubi has been volunteering in her community as a TT Case Finder since 2000.** She has attended three training sessions on different topics related to trachoma, and since receiving her TT training, she's identified five cases of severe TT.

About once a week, Annie walks up to five kilometers to visit different neighboring communities. In addition to conducting initial trachoma screenings, she also educates people on the importance of face and hand washing. She finds that people listen attentively to her.

When Annie identifies a case of TT, she finds out when a surgeon will be at the nearest health clinic and advises the patient when to go. She emphasizes the importance of managing TT, ensuring they know that if they don't take action, they can later become blind, which will affect their ability to work. People are often very excited to hear that their issue can be treated; however, she knows that accessibility of health centers remains a barrier to receiving treatment.

In November 2016, she met a woman who had been suffering from TT since 1983. The woman would spend a lot of time complaining about the pain and had her children help remove her eyelashes. Annie was able to find the mother and her children and identify the condition as TT. Annie provided trachoma education to them and informed them that there was a solution other than tweezing eyelashes.

Annie loves her work as a community volunteer and it fills her with joy whenever the people she has identified are able to get the treatment they need. Preventing blindness is meaningful to her and she says she wants to continue doing this work.

Annie has six children, who are incredibly proud of the work she does for their community. Perhaps once they finish school they will follow in their mother's footsteps as a volunteer or pursue a career in health care.



Table 2

## Publications on the Acceptance of TT Surgery

STUDY SITE (DATE OF PUBLICATION)	ACCEPTANCE OF TT SURGERY		IMPLICATION OF FINDINGS
	WOMEN	MEN	
Vietnam (2004)	F:M ratio from surveys = 1.99, while F:M ratio from surgery = 2.32		Women were receiving surgery at rates higher than anticipated from recent surveys
Tanzania (2004)	F:M ratio from surveys = 2.24, while F:M ratio from surgery = 3.67		
Ethiopia (2004)	Data by sex (for TT only) not presented		Use of services (for cataract, TT, spectacles) associated with being male (OR=1.42, 95% CI 1.01-1.94)
Tanzania (2007)	Overall = 46% Village leader program = 56.8% School teacher program = 41.6%	Overall = 44% Village leader program = 36.4% School teacher program = 47.8%	Some approaches are more effective to reach women. Women from multi-generational households are more likely to have surgery compared to women from single generation households
Ethiopia (2012)	Data by sex not presented		Women were less likely to have been offered surgery compared to men
Egypt (2015)	60%	81.5%	Interventions led to 3.4-fold increase in trichiasis surgical coverage but, women were still less likely to receive surgery compared to men
Nigeria, Ethiopia, Malawi, Mozambique, Tanzania, Uganda, Kenya (2022)	87%	84.7%	Once people are at outreach, acceptance is similar for men and women.  Outreach in settings where house-to-house case finding was used = 65.4% women.  Outreach in settings where non-targeted community mobilization was used = 55.2% women.  This suggests that challenges are evident prior to outreach.

Achieving equitable access to and use of TT management options among men, women, and children requires program managers to design surgical interventions that reflect the potential impact of gender on case finding, counseling, attendance at outreach sites, and acceptance of surgery or other case management. Understanding the constraints that prevent women and men from attending outreach is a critical first step.

Acceptance of surgery is the last in a series of steps including case detection, referral, and presentation at outreach. Early research in Vietnam and Tanzania, and more recently in several African countries, show that women accept surgery at the same proportion of men; however, in other settings such as Ethiopia and Egypt, the acceptance of TT surgery has been lower among

women compared to men. Local context matters and the reasons for variance in acceptance among men and women in these settings often differ. It appears that the limited decision-making capacity of women acts as a barrier to their ability to access services. In all trachoma endemic settings, it is important to understand how both men and women navigate the various steps to receive TT management. Only then can programs successfully achieve elimination of TT as a public health problem.

This chapter presents existing evidence for gender-specific case finding, referral, attendance at outreach, surgical delivery, and follow-up, in addition to strategies that help to ensure gender equity in program outcomes. This chapter also includes recommendations for monitoring and evaluating program performance based on gender-specific indicators.

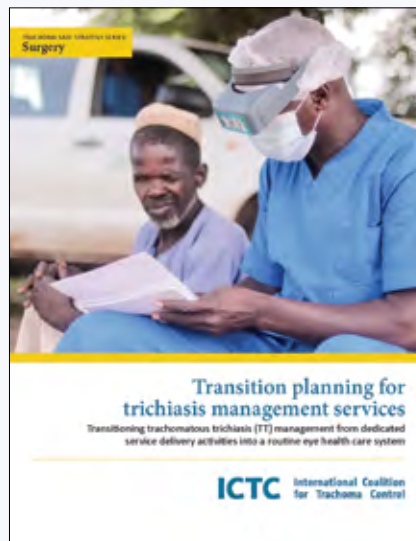
## Planning for TT management in an administrative unit

Where the prevalence of TT<sub>>15</sub> unknown to the health system is 0.2% or greater (among adults aged 15 years and above), programmatic approaches to surgery or other management is indicated, based on the WHO guidelines for trachoma elimination. If the prevalence is <0.2%, and thus the elimination threshold has been reached, it does not mean that TT does not exist but rather that the management of remaining TT cases should be addressed through routine clinical services.

While it might be attractive to use prevalence figures to generate an estimated number of TT cases in a district and set this number as a target, this is not recommended. These are only estimates and the true number of TT cases can be considerably smaller or larger than the estimate. Where TT is a public health problem, the focus of planning should be on achieving “full geographic coverage” (FGC), which starts with house-to-house case finding in all communities of a district. The implication of FGC is that all adults, men and women, are seen by a TT Case Finder, examined for TT and, if suspected, their names are recorded for an upcoming outreach event nearby. This is followed by assessment during the outreach and, if TT is confirmed, the appropriate management is provided. In a few settings, surgical outreach is still organized without systematic case finding, but this is becoming less common.

### Box 9

#### ICTC Transition Planning For Trichiasis Management Services



### Case Study 8

#### TT Case Finders and Gender

**TT case finding in the community is now the foundation of both TT management activities in a district and the demonstration that FGC has been reached.** Despite the central importance of TT case finding, there is little evidence on the impact of the gender of TT Case Finders on outcome (e.g., coverage, acceptance).

A study in two districts in Tanzania assessed case finder and outreach records and collected qualitative data through direct observation of case finding activities, as well as through interviews and focus groups discussions with female and male TT Case Finders.

In both districts, more male than female case finders were recruited. There was no significant gender difference in relation to the outcomes of TT campaigns (coverage, productivity, or acceptance). The qualitative research component, however, highlighted some gender differences in how case finders contribute to the campaigns. There is some evidence suggesting that female case finders were more active in supporting suspected and confirmed TT cases to access available services than male case finders.

Trachoma programs may benefit from integrating gender considerations in the design and implementation of case finding campaigns—e.g., in monitoring gender differences among case finders and the relationship with key outcomes; in ensuring an adequate balance of female and male case finders in different contexts; and in the training of case finders on how to handle situations where women with TT are not empowered to make a decision about being examined and accepting surgery.



Three women from the Oromia region of Ethiopia stand together in the fight to eliminate trachoma. Photo credit: Brent Stirton/Getty Images for International Trachoma Initiative

## Understanding the potential barriers to receiving services for TT

**A range of barriers to surgery can limit the success of TT outreach, from social and economic factors to individual disability and access challenges.** The social consequences of disability are commonly understood. They may include less autonomy, reduced self-esteem, infrequent participation in community activities, and limited decision-making authority within a household. In virtually all trachoma endemic settings, the reasons for failure to use existing TT surgical services will vary between men and women, however, certain characteristics related to complex social roles and responsibilities are likely to be common.

There are different ways to consider these barriers to successful TT management and there is no single “right way” of overcoming them. It is best to approach understanding of potential barriers from a problem-solving perspective rather than a perspective of allocating blame. Dividing various potential barriers into a hierarchy starting with awareness, access, and acceptance can provide useful insight into the barriers that women face which are likely to be different from barriers that men face. These can also differ across trachoma endemic regions. Furthermore, barriers are not static; as a program addresses one barrier it may become aware of others, or if an intervention is not culturally sensitive, it may exacerbate existing barriers. In each setting, it is helpful for health staff to explore potential barriers separately for men and women and identify possible solutions.

In terms of both the monetary and opportunity cost of attending surgery, these will affect not only the male or female patient but can also extend to other members of their family or household. The patient must take time away from income-generating activities and/or household and caregiving responsibilities while their support network must compensate for their absence and postoperative disability. Minimizing the barriers listed in Table 3 (pg. 37) by providing free surgery, transport, and meals for the patients and a person to accompany them home can help increase surgery acceptance. Furthermore, planning surgery outreach should take into account seasonal work to decrease the indirect cost of attending.

There may also be value in determining whether gender-disaggregated data for cataract surgery in the population is available and whether efforts have been undertaken to address the gender gap. This can serve as a proxy for access to eye care. A framework for this exploration is given in Table 3. The investigation of gender-specific barriers helps program staff to better outline each activity necessary to ensure men, women, girls, and boys receive appropriate TT management.



Table 3

## Example Interview Questions for Identifying Potential Strategies to Address Barriers to the Use of TT Management Services

	POTENTIAL SOLUTIONS	
	WOMEN	MEN
<b>BARRIER = AWARENESS</b>		
What is the best approach to provide information regarding TT and its management?		
Who, besides the trichiasis case, in the family needs to be aware of TT and its management?		
<b>BARRIER = ACCESS</b>		
What is a reasonable distance to travel to reach a surgery outreach site?		
When a person becomes widowed or a widower, does this change their role or position or ability to make decisions?		
Does a TT case need an escort to attend outreach? If so, who should the escort be?		
Are there any financial considerations to access surgery? If so, who provides financial support?		
If funds are available for surgery, are their barriers to allocating these funds to the TT patient based on gender?		
What time constraints (work, childcare, etc.) do people have that may limit access and how to address them?		
What roles in society do people have that may influence their ability to access TT services? How can these be managed?		
Are there any special considerations, dictated by religion or society that must be addressed at the outreach?		
If patients are elderly and/or with disability, who cares for them and needs to be involved in obtaining access to outreach?		
<b>BARRIER = ACCEPTANCE</b>		
Is counselling more accepted if it is conducted in same-sex groups?		
What are people most fearful of (regarding TT surgery)?		
Who in the household, besides the TT patients, needs to be counseled for the patient to receive surgery?		
Is fear of a poor outcome a barrier? If so, how can this fear be addressed?		
Do patients need to be seen by a same-sex health worker due to religious or societal norms?		

#### Case Study 9

### Women Microfinance Groups in Tanzania

**In nomadic populations (mostly Maasai) in Tanzania, one of the main challenges reported by TT Case Finders is that many women would only accept to be examined by a case finder with the explicit approval of their husbands.** Also, while some women and men with TT have reservations about undergoing TT surgery, women are more likely than men to refuse further examination or surgery to prioritize daily household duties. These sociocultural barriers can partly be addressed by increasing awareness about TT and the benefits of surgery and other management options, preferably not only through short-term campaigns but by also empowering agents of change at the community level.

In Ngorongoro district in Tanzania, partnerships with women microfinance groups have proven effective at increasing acceptance of eye care services among women, including for TT surgery. Women in microfinance groups are often the “movers and shakers” among women in the community. Group members receive a one-day basic training on eye conditions and work as ambassadors on an ongoing basis to encourage and facilitate access to eye care services. In exchange, implementing partners offer these groups incentives; for example, partnering with national microfinance experts that can offer short-term training to these groups to support and strengthen their income-generating activities. Experience has shown that microfinance groups can be very effective in reaching the unreached and empowering the unempowered.

## Leave no one behind

**The first field-based activity of a TT program is house-to-house case finding.** There has been a greater focus recently on house-to-house case finding rather than general mobilization for several reasons, among which is the recent evidence that programs using house-to-house case finding had 1.5 times as many women, compared to men, presenting at surgery outreach compared to programs using general mobilization. Put another way, the ratio of women to men found with TT using house-to-house case finding is similar to the ratio found in the global data (1.8 to 2 women with TT<sub>>15</sub> per man with TT<sub>>15</sub>), and is much lower in settings where general mobilization was used. House-to-house case finding is therefore considered much more likely to ensure that we leave no one behind compared to less targeted approaches.

In a review of case finding in several countries, the proportion of trained female TT Case Finders varied considerably. For example, in Nigeria and Tanzania, 53% of case finders were women, compared to only 21% in Mozambique. In Sudan, 57% of case finders were women, but women only made up 19% of case finding supervisors. It is the responsibility of the program managers and community to identify who should be trained as TT Case Finders and it appears that in some countries, men are more likely to be chosen. There is no evidence of the relative effectiveness of male and female case finders. It is recognized, however, that in some societies, female case finders will have better access to women in households. In some settings, male family members need to provide agreement for a woman to be examined by a case finder and to seek TT management. Understanding gender-related dynamics of decision-making in a specific population is essential for ensuring that programs reach both women and men with services they need, and for providing inclusive methods to support and increase the opportunities for women and girls to both participate in TT outreach activities and attend outreach services as equitably as men or boys.

Table 4

## Parameters for Monitoring Utilization of TT Surgical Services

STEPS IN TT MANAGEMENT PROCESS	POTENTIAL VARIABLES TO MONITOR GENDER-SPECIFIC OUTCOMES
1. Case finding	% of case finders who are male and female % of suspected cases (men and women) who attend outreach
2. Outreach	% of confirmed TT cases (men and women) who have surgery % of men and % of women presenting to outreach who were diagnosed with TT
3. Follow-up	% of surgical cases (men and women) who receive follow-up at each recommended time period % of surgical cases (men and women) with no postoperative complication (at 7-14 days and, if possible, at 3-6 months)

### Case Study 10

## Gender Considerations in Zambian Programming

**Viola Sanene has been supporting trachoma work in Zambia since 2012 when she was first trained as a trachoma grader.** She has also been trained in TT surgery. Her high level of commitment resulted in her being trained as a national trainer, allowing her to instruct and supervise other graders and surgeons.

Throughout her work, she has been to over 80 districts out of the 116 in Zambia where she has supervised TT surgeries and the collection of survey data.

Viola has called for gender sensitivity in all areas of service distribution to ensure gender equality. She believes that to achieve equality, service delivery should be flexible to accommodate the schedules and needs of both men and women in the communities. The reasons and social responsibilities that prevent adult women and men from accessing eye health services vary from community to community; therefore, Viola recommended conducting a survey before the delivery of a trachoma program, to establish which gender has higher rates of trachoma and to understand why they are underserved. Viola shared that, “these social responsibilities are shaped by traditional beliefs in communities and should also be assessed so that we can better understand approaches that should be taken to ensure that our interventions are accepted.”



Viola Sanene conducts an eye acuity test for a young girl.  
Photo credit: Lion's Aid Zambia

“All the praises and gratitude go to the people who make it possible for this work to be accomplished.”

— Viola Sanene





Dr. Menbere Alemu (pictured right) is the Ethiopia Country Representative for International Trachoma Initiative in Ethiopia and an ophthalmic surgeon who participated in the launch of the GTMP by leading the training of the graders. In the three years with the GTMP, more districts had been surveyed than in the previous 10 years, catalyzing a huge expansion in the global program. Here, Dr. Alemu is examining a patient for TT in Shashamane Zuria Woreda, Oromia Region, Ethiopia. Photo credit: Brent Stirton/Getty Images for International Trachoma Initiative

## Program-based approaches to TT management

**When case finding is used, surgery outreach is generally organized across communities in a particular catchment area.** While outreach has many advantages, including reducing distance to services as a barrier, it does require more financial and human investment compared to the routine provision of TT management at health facilities. One major challenge that has been recognized in successful case management is that some suspected TT cases identified by case finders in the community do not present to the outreach site. While case finding may cover communities well, if the women and men identified do not reach the outreach site, they cannot be served by the program. There is currently no evidence regarding whether women or men identified by TT Case Finders as suspected TT cases are more or less likely to present to outreach. Similarly, there is no evidence to suggest that female or male case finders are better at ensuring suspected cases attend the outreach; however, it is key that case finders are men and women from the local community, as this provides an innate level of trust and ensures the support and participation from local authorities. Having both male and female case finders can also help programs address gender dynamics in outreach activities.

As noted earlier, once people are identified with TT, there is conflicting evidence on whether there is lower acceptance of TT surgery among women compared to men. This suggests that programs need to consider the variety of potential gender-specific barriers in planning an outreach (Table 3). It also suggests that quality gender-sensitive counseling is needed at the outreach site. Counseling guides are available, but in some cases, counseling has not included the right people. In settings where cultural norms typically require that a male family member provides approval for surgery, counseling may need to include both the woman with TT and whichever family member she needs. Although TT is very rare in young people, girls living with unoperated TT have bleak social and economic prospects and therefore special consideration is needed for them. In addition to counseling patients individually, surgical activities can be used to educate other family members on the importance of treatment and prevention. Social support for attending surgery must be secured within the household, which can be accomplished through educating all members of the household, particularly those with decision-making power to appreciate and act on the need for women to get surgery.

## Case Study 11

### Pakistan's Lady Health Workers Program

The Lady Health Worker Program (LHWP) has been operating in Pakistan since 1994, with the goal of providing primary care services to underserved populations in rural and urban areas. LHWs are deployed by the government throughout all five provinces of Pakistan. These workers are attached to a local health facility, but they are primarily community-based, working from their homes.

The Trachoma Elimination Project, which began in April 2018 with the aim of reducing extreme poverty in Pakistan by eliminating trachoma as a public health problem, collaborated with the LHWs in target districts. LHWs have been trained by the Project to identify TT patients and refer them to the project field team. The field team then provides further screening, advises patients for surgery, and organizes surgery for them during upcoming outreach camps.

Gender is considered in programming by:

- Ensuring that women in rural areas are able to be served by female staff and employees.
- Making services accessible through organizing camps in their area, upgrading which services are available to them locally, or expanding the capacities of local health staff.
- Accessing women in rural areas directly with health sensitization and education, since they likely have limited access to print or electronic media.



A former TT patient who no longer suffers from TT and was able to resume her studies after being referred to a surgery camp by LHWP. Photo credit: The Fred Hollows Foundation

#### AN UNUSUAL CASE OF TRICHIASIS IN PAKISTAN

Fahima is a 22-year-old student from a remote village outside of Chitral, Pakistan. Three years ago, Fahima began suffering from intense itchiness and pain in her eyes, which she originally believed to be caused by seasonal allergies. In reality, it was caused by trichiasis, though it is rare for TT to be found in young individuals. The pain became progressively worse, which made it difficult to sleep at night and to close her eyes properly. This began affecting her school work, since the pain made it tough to focus, and studying at nighttime was nearly impossible. Unfortunately, this caused her to become withdrawn and affected her confidence. Fahima's family could not afford to send her to an eye specialist to diagnose and treat the issue. They unsuccessfully tried to fix the pain with home remedies.

During routine house visits, the LHW informed Fahima about the local work of the Ministry of Health's National Trachoma Elimination Project which provides surgeries free of charge. She was then referred to the surgical camp in her district, provided transportation, and her surgery was completed without any cost to her.

Fahima is now able to focus on her studies pursuing a Master of Science in Zoology. Her grades have improved tremendously since her procedure, she is able to complete her own daily chores, and she is back to socializing with friends. Others have remarked on the increased confidence they see in her since she received her surgery. Fahima shared that she is so happy and grateful to the program for changing her life and taking her pain away.

"During exams we [would] all sit in open air under the sunlight, I was unable to concentrate on my paper due to pain in [my] eye with direct sunlight. After surgery I have no such issue and work on my papers with ease."

— Fahima



## Follow-up of TT surgery

**Postoperative follow-up should be provided at one day, 7-14 days, and 3-6 months after surgery to all who have had surgery or epilation.** The same barriers that prevent women from using TT services likely also limit their ability to access follow-up. Among other strategies, programs need to ensure that follow-up is provided as close to the community as possible and that adequate counseling is provided on the importance of attending follow-up at the specified postoperative timepoints. In some endemic areas, the lack of incentives provided during follow-up decreases the likelihood of patients attending. Similar to the initial attendance for surgery, the economic and social costs of attending follow-up must be considered.

At present, there is little information on the differences in access to follow-up between men and women or on the differences in postoperative outcomes, specifically postoperative TT, between men and women. A population-based study in Egypt noted that postoperative TT was more likely to occur in women although their acceptance of surgery was lower. The reasons for this difference are not well understood but indicate a need for further investigation. In all TT<sub>>15</sub> endemic settings, if data indicate meaningful differences in postoperative TT between women and men, the program should evaluate the surgical delivery system. Door-to-door follow-up can be considered as an approach to improve postoperative care, but is notably time-consuming and costly.

### Case Study 12

## The Importance of Female TT Surgeons

**Yagana Mustapha Umar is from Briniwa Local Government Area (LGA) in Jigawa State, Nigeria, where she works at the general hospital.** She trained as an ophthalmic nurse at the National Eye Centre in Kaduna. Her certification as an ophthalmic nurse led to the establishment of the eye clinic in Briniwa, where she became the head of the center.

Yagana was connected to the national TT program through the State NTD office. She was selected and invited to be part of the 2018 TT Surgeon and Assistance Training. Her work experience has primarily been within the hospital, but thanks to the program she has also had the opportunity to move around the state to different LGAs.

In the past, women were not included in public health interventions due to cultural and religious reasons. Yagana believes the TT program is now better designed to recruit women as TT Case Finders and provide equal opportunities for men and women. Of the 23 people trained as TT surgeons in Jigawa State, two were women. This shows progress and Yagana feels there should be more deliberate efforts to have additional women trained as TT surgeons.

She talks about the efficacy of the outreach program, when it comes to raising awareness of eye disease: "With TT surgical outreaches I am able to understand that people are aware of the disease but know nothing or little about the cause, therefore I feel the need to provide even more awareness and education".

Yagana shared that she feels very happy to be part of the project. It has given her the opportunity to give back to her community and provided her with a sense of fulfillment as a health care professional.

In the past, women were not included in public health interventions due to cultural and religious reasons. Yagana believes the TT program is now better designed to recruit women as TT Case Finders and provide equal opportunities for men and women.



## Monitoring program delivery

**The establishment of a monitoring system enables providers and partners to assess all steps in the TT management program, from case finding to presentation at outreach, to surgical acceptance and outcome assessment.** These data will help identify gaps in service delivery as well as assess progress towards elimination. It has been noted that there can be considerable variation in the ratio of TT in men and women, between countries and even within countries. For example, baseline survey data from Ethiopia suggests a larger female to male ratio of TT cases compared to similar data from Nigeria.

The foundation for all monitoring and analysis is the collection of sex-disaggregated data. Table 4 (pg. 39) lists some of the routine parameters that programs should consider including in their monitoring systems to better inform future programming. Data can also be analyzed to identify gender gaps in TT cases specific to a particular subgroup such as a religious or ethnic minority or nomadic population within the program area.

## Transition post elimination

**When TT is no longer identified as a public health problem, program activities, including community-based case finding and outreach, will cease and TT management activities will be managed within routine clinical services.** Unfortunately, many routine clinical services, such as cataract surgery, already suffer from a lack of gender equity and many trachoma endemic countries do not have sufficient health infrastructure to support routine TT services yet. This is an opportunity for eye care program staff to assess all aspects of their service delivery model and identify strategies to reduce gender inequities. Furthermore, trachoma elimination programming should work toward longer-term transition mechanisms that will provide more gender-equitable clinical services even while TT<sub>>15</sub> prevalence figures remain high.

## Suggested reading

Courtright P, West S. Contribution of Sex-linked Biology and Gender Roles to Disparities with Trachoma, Emerging Infectious Diseases, 2004; 10(11):2012-6. *This article summarizes information on the role of gender in the epidemiology of trachoma, from active trachoma through the life course to trichiasis.*

Cromwell EA, Courtright P, King JD, Rotondo LA, Ngondi J, Emerson PM. The excess burden of trachomatous trichiasis in women: a systematic review and meta-analysis. *Transactions of The Royal Society of Tropical Medicine and Hygiene*, 2009; 103(10): 985-992. *A meta-analysis of trachoma surveys (prior to 2008) that calculated the excess risk (age-adjusted) of trichiasis in women compared to men. This has been updated with GTMP baseline survey data as part of George Moyo's University of Cape Town Masters student dissertation.*

International Coalition for Trachoma Control. Training Curriculum for Trichiasis Case Identifiers, Atlanta, GA. 2016;7. <https://www.trachomacoalition.org/resources/training-curriculum-trichiasis-case-identifiers>. *ICTC manual on the training of community-based case finding. A revised manual will be available mid-2023.*

Mahande M, Tharaney M, Kirumbi E, Courtright P. Uptake of trichiasis surgical services in Tanzania through two village-based approaches, *British Journal of Ophthalmology*, 2007;91:139-142. *Research that showed that while overall uptake of trichiasis surgery by gender was similar using two different village-based mobilization approaches, there were gender differences according to household characteristics, indicating a need to focus support on particularly vulnerable women.*

Mousa A, Courtright P, Arminee K, Bassett KB. A Community-based Eye Care Intervention in Southern Egypt: Impact on Trachomatous Trichiasis Surgical Coverage, *Middle East Afr J Ophthalmol*, 2015; 22(4): 478–483. *Research highlighting low baseline uptake of trichiasis surgery among women, the positive impact of a community-based case finding program but, still evidence of residual excess burden of trichiasis in women.*

Palmer SL, Winskill K, Patterson AE, Boubacar K, Ibrahim F, Namata I, Oungoila T, Kane, MS, Hassan AS, Mosher AW, Hopkins DR, Emerson PM. 'A living death': a qualitative assessment of quality of life among women with trichiasis in rural Niger. *International Health*. 2014;6:291–297. *Qualitative study demonstrating the significant negative impact of trichiasis on women, above and beyond the risk of vision loss.*

Rabbani, F., Shipton, L., Aftab, W. et al. Inspiring health worker motivation with supportive supervision: a survey of lady health supervisor motivating factors in rural Pakistan. *BMC Health Serv Res* 16,397(2016). <https://doi.org/10.1186/s12913-016-1641-x>. *This article provides an analysis of CHW motivation working in low- and middle-income countries and how certain factors influence the health education of women and girls.*

Rajak SN, Habtamu E, Weiss HA, Bedri A, Zerihun M, et al. Why Do People Not Attend for Treatment for Trachomatous Trichiasis in Ethiopia? A Study of Barriers to Surgery, *PLOS Neglected Tropical Diseases*, 2012; 6(8): 4-8. *This large population based study showed that the barriers to receiving surgery for trichiasis reported by men and women were different, suggesting that programs need to consider gender-specific factors when designing activities to improve uptake.*

West S, Nguyen MP, Mkocha H, et al. Gender equity and trichiasis surgery in the Vietnam and Tanzania national trachoma control programmes. *British Journal of Ophthalmology*. 2004;88: 1368-1371. *In this study, women and men presenting to trichiasis outreach were equally likely to receive trichiasis surgery.*



CDDs in Egypt prepare registers and dosing poles in the field for an MDA campaign. Photo credit: Genevieve LaCon/International Trachoma Initiative

## Chapter 4

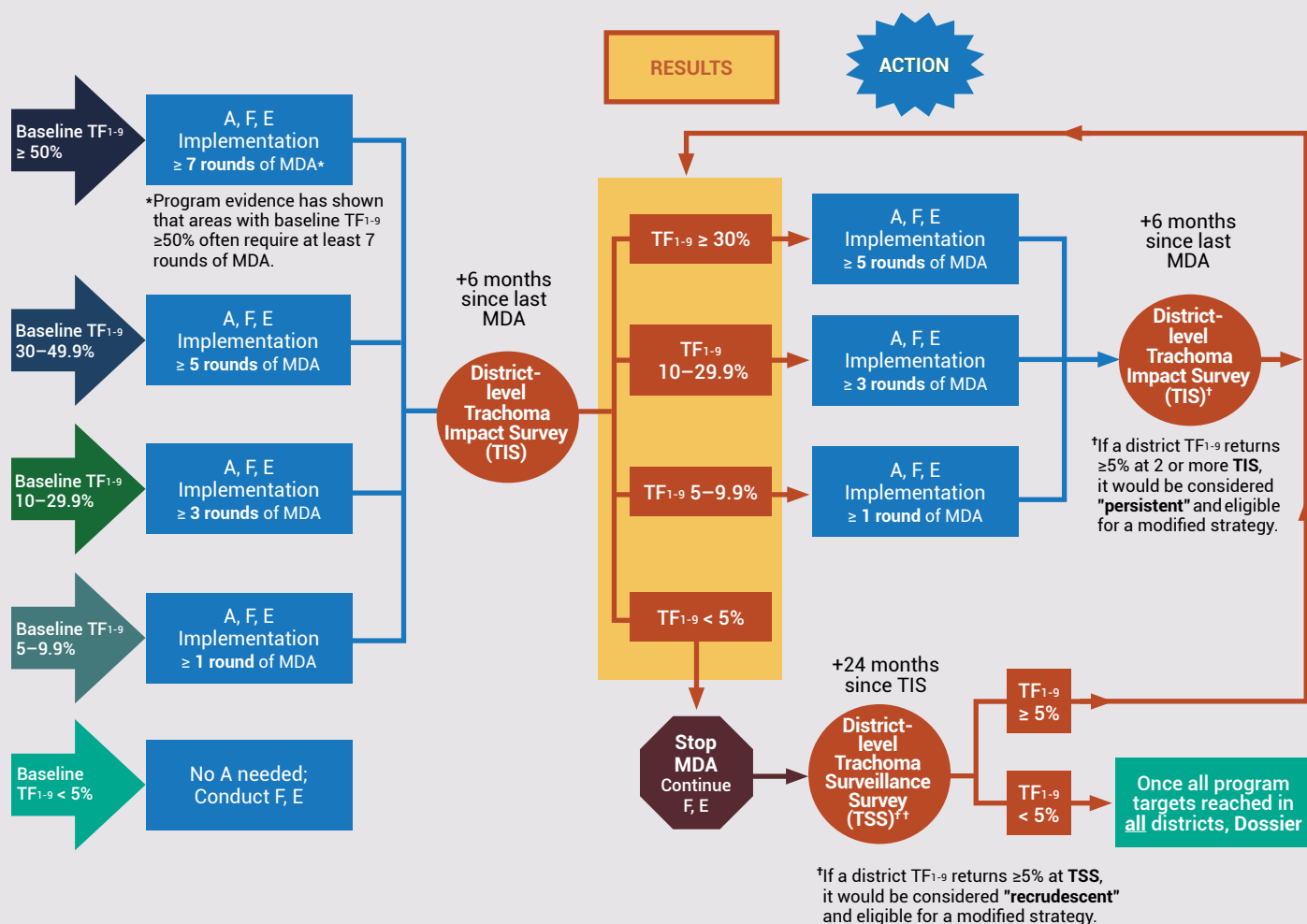
# Reaching Communities with Antibiotic

**Where the prevalence of clinical signs of TF<sub>1-9</sub> exceeds 5% in a health district, WHO recommends mass treatment with antibiotics to the total eligible population (anyone over six months of age).** MDA is conducted for a period of time determined by the district-level prevalence established during a population-based prevalence survey. Once the recommended number of annual treatments are given, an impact survey is conducted at least six months after the last treatment to determine whether MDA should be stopped or continued. Most people are treated with a single annual oral dose of azithromycin or Zithromax® donated by Pfizer Inc. while children under 6 months of age receive TEO. Mass administration of antibiotics decreases the prevalence of active trachoma within a community. Repeated regular mass treatments with antibiotics, combined with health education and environmental improvement, contribute to the elimination of trachoma as a public health problem, measured by TF falling below the elimination threshold of TF<sub>1-9</sub> <5%.

Figure 2

## Diagram on Decision-Making of the Antibiotic Treatment of Trachoma

Trachoma endemic countries typically use the following decision-making guidelines throughout programming to reach the elimination threshold of  $TF_{1-9} < 5\%$ .



Since children are the main reservoir of trachoma infection, it is imperative that antibiotic distribution programs intentionally target boys and girls and their caretakers, most often women, because they are at an increased risk of multiple infections over time. These repeat infections lead to conjunctival scarring, a higher risk of TT, and potentially blindness later in life. A

gender-equitable antibiotic delivery program requires community and household support for distribution activities, a distribution strategy that ensures women are given equal opportunity to participate, and gender-specific monitoring to ensure progress toward achieving annual targets.



## Implementation of antibiotic distribution

**To implement a gender-equitable antibiotic distribution program, national trachoma elimination programs need to think beyond monitoring the total quantity of drug distributed.** It is recommended to create a strategic plan to target women, boys, girls, and other groups who are at the highest risk of trachoma.

### Setting targets

**Programs calculate antibiotic distribution forecasts using estimated population data for targeted districts, which may be further refined by conducting a census.**

Gender-specific targets can be calculated in a similar fashion with subgroups identified as relevant.

To calculate annual treatment objectives (ATOs), program managers would do the following:

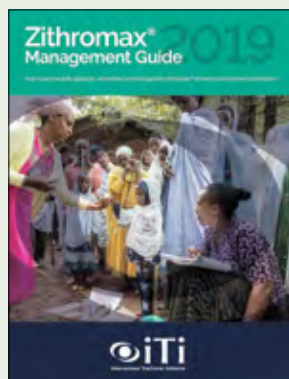
- Estimate the total population in at-risk areas, minus 2% for children younger than six months of age = Total eligible population
- Calculate the percentage of men, percentage of women, and percentage of girls and boys within the total eligible population to determine the ATO for each subgroup

### Community mobilization

**The introduction of a drug distribution program to a community poses unique challenges.** Program managers need to ensure that community leaders, local government, and the health service staff are knowledgeable about the distribution, involved in

the planning stages of distribution, and included in community mobilization activities. Both male and female figures of authority should be included in community mobilization, ensuring that any gender-specific concerns of men and women are addressed prior to distribution. Failure to secure support among community leaders could lead to low acceptance of the distribution among the general population. MDA sensitization for leaders and decision-makers should be designed to limit the spread of inaccurate information, skepticism, and rumors about the drug.

The method of community mobilization should also be considered strategically and based on gender analysis of media access and use. Many programs use megaphones, radio announcements, or other modes of communication to inform communities of scheduled distribution activities. It is essential to choose one or more sources of media to which the target population has access. (For information on how to create an effective health messaging campaign, see Case Study 16 in the Behavior Change Chapter pg. 58.) Generally, multiple media sources are required to reach various subgroups. It is important to consider the different sources and practices used by men and women to acquire information as they may have different levels of access to the same source of information. For example, there may be a radio present in the household, but women may not have access to the radio or may not be allowed to select the programming. In this situation, the way to encourage participation of the whole family may require not only to target messaging to male heads of households who listen to the radio regularly but also to identify other information sources that women and girls have direct access to.



#### Box 10

### Zithromax® Management Guide

The Zithromax® Management Guide is a manual developed by ITI to help guide country programs through the calculation of antibiotic need, reception, storage, and safe distribution of antibiotics for trachoma. It is available in Arabic, French, Portuguese, and Spanish on the ITI website (<https://www.trachoma.org/zithromax-management-guide>).

Nancy's motivation to work with the DHO in the fight against trachoma comes from personal experience; as the breadwinner of her family, she has witnessed firsthand the effects of blindness.

#### Case Study 13

### Community Health Worker Finds Personal Motivation for Trachoma Elimination Work

Nancy is a 36-year-old community health worker (CHW) at Kaanja Rural Health Centre, under the Sioma District Health Office (DHO) in Zambia. In addition to her full-time employment at the facility, Nancy is also actively involved in community engagement programs and the fight against trachoma in her community. Nancy's motivation to work with the DHO in the fight against trachoma comes from personal experience; as the breadwinner of her family, she has witnessed firsthand the effects of blindness.

Nancy lives with her 65-year-old mother and 82-year-old grandmother who are both victims of eye maladies. Her grandmother was diagnosed with TT. Her mother has been complaining of itchy eyes and difficulty seeing since 2019, but with no eye clinic or resident ophthalmic staff in the area, she has yet to be seen by a medical professional about her eye issues.

"When I heard about the trachoma MDA, I took it upon myself to sensitize my community on the importance of participating in the activity," shared Nancy. She has been traveling around the Kaanja Central Village teaching her community about the effects of trachoma, in particular educating women. When asked about her motivation, Nancy shared that there were many myths and misconceptions about trachoma MDAs in her community and a lack of reliable information about MDA. This encouraged her to focus on behavior change as the solution to the problem. She wanted to prevent anyone in her community from going blind which would require them to be cared for by another person. "Taking care of a blind person is difficult, it will affect you emotionally, physically, and financially. It is bad that my grandmother is already blind."



Nancy, a CHW, was motivated to educate women on the effects of trachoma due to misconception in her community about MDA. Photo credit: Lion's Aid Zambia

## Box 11

### Equitable Delivery of SAFE Among Diverse Households



#### Male-headed households

Use targeted health education to encourage male-headed households to include their wives and children in trachoma outreach and distribution campaigns, such as supporting travel to distribution points. Consider means of education such as radio, religious leaders, local opinion leaders, and public group education, such as presentations at markets or other gatherings.



#### Female-headed households

Use “mop-up” activities after the main distribution to serve areas where there is believed to be a high proportion of female-headed households. Include female health workers on distribution teams. Explain to community leaders the need to follow-up with these households.

### Approach options: Central-site vs. house-to-house

**Mass distribution of antibiotics is organized at the district level and delivered either from a centralized site or from one household to the next.** Distribution campaigns typically identify fixed sites and rely on community mobilization to attract participants from nearby communities. The advantage of this approach is that both women and men in the communities can be involved in the selection of the distribution sites as well as the time and day of the distribution to help ensure gender equitable distribution. District-level distribution and local engagement also help overcome logistical barriers such as lack of transport for the distribution teams, poor accessibility, and limited staff. Record keeping and stock management also become easier.

House-to-house distribution requires training distribution teams from local communities to administer the antibiotic and monitor stock. Although individual acceptance of the drug may be higher if offered at the household or community level versus a centralized site, this method requires a larger investment of time and resources, both on behalf of the program and the distributors. Accurate record keeping requires literacy and organizational skills in at least one of the distribution team members. Stock management must also be considered as drugs can be allocated to many distributors and collecting any unused portion (the first step of “reverse logistics”) may be more complicated.

Depending on the community context and village/district housing set-up, a combination of central site and house-to-house distribution can also be used.

Each type of distribution has distinct advantages and disadvantages. Programs must look at the specific circumstances for each district and choose the best distribution method with the highest potential for quality, equitable coverage.

### Considerations for gender equity in quality distribution

**Whether distribution is conducted at a central location or house-to-house, programs should consider the following guidance to ensure equitable, efficient distribution:**

- **Hire adequate staff** and, where possible, include at least one female on each distribution team
- **Specific roles can be assigned** to each member of the distribution team to increase efficiency and minimize wait times, especially for women with small children
- **Schedule MDA around the local calendar** so that the community is available to attend the distribution or is home when the distribution team visits the household
- **Collect census information**, when appropriate, to understand who received drug and who refused. Information such as age and sex can help programs determine if coverage was equitable



## Training of distribution teams

Program managers are responsible for overseeing the preparatory activities preceding distributions, but the on-the-ground success of an MDA campaign is dependent on well-trained and supervised local distributors, regardless of the campaign delivery method. Before each MDA, programs should train all distributors to administer the drug per protocol and conduct relevant health education for recipients. Training the distributor to provide the appropriate health education to the appropriate audience can be challenging, but by selecting a few key messages for each group, including those designed to target women and children in particular, can encourage equitable distribution.

Employing both male and female distributors for each distribution team can help ensure access to female-headed households, will allow women who present for distribution an opportunity to discuss their concerns with another woman, and will encourage the representation of women in all areas of the public health system.



One of the hallmarks of the global program to eliminate trachoma is a strong base of evidence and data. Here, Dr. Paul Emerson, Director of the International Trachoma Initiative, is reviewing the individual participant records collected during MDA with Alemetu Metalign, a CHW, in Mecha Woreda, Amhara Region, Ethiopia. Photo credit: Brent Stirton/Getty Images for International Trachoma Initiative

Table 5  
Gender-Specific Barriers to Participating in MDA

TARGET GROUP	POTENTIAL BARRIERS	INCLUSION EFFORTS
Women residing in male-headed households that require joint decision-making to participate in MDA	Without joint approval, females and children are less likely to participate	Plan MDA during a time when male heads of house are at home and can discuss consent with spouse for their family to participate, if needed
Women and girls of special populations	Geographic mobility, mistrust of Western medicine, timing of MDA, decision-making ability within social structure	Train drug distributors to address concerns through health education, plan MDA during a time when all parts of the nomadic community (women, girls, men, and boys) are in the same physical location
Men and boys of nomadic populations	Geographic mobility, mistrust of Western medicine, timing of MDA	Include community leaders in distribution planning, engage in cross-border collaboration



CDDs in Yemen carry educational materials during trachoma MDAs to disseminate information on how to identify and prevent infection. Photo credit: Ministry of Health, Yemen

## Box 12

### MORDOR Study

In 2018, the *New England Journal of Medicine* published a study of the effect on mortality under five years of age when giving one dose of Zithromax® antibiotic to children aged one month to five years, every six months for two years, compared to giving a placebo to children of the same age. The study, now known as MORDOR from the French study title “*Macrolides Oraux pour Réduire les Décès avec un Oeil sur la Résistance*” (oral macrolides to reduce deaths with an eye on resistance), was a randomized double-blind trial conducted in sub-Saharan Africa, notably Niger (West Africa), Tanzania (East Africa), and Malawi (Southern Africa).

The study was developed following a 2009 case-control trial in trachoma endemic areas of Ethiopia which highlighted the effectiveness of MDA of oral azithromycin on overall childhood mortality. The MORDOR I study included 1,512 communities from Niger, Tanzania, and Malawi, and over 190,000 children between one and 59 months. Biannual doses of oral azithromycin or placebo were provided to each child over two years with results showing a 14% reduction in all-cause mortality, with a significant 18% reduction in Niger. Azithromycin was especially effective in children between one and five months of age, preventing one in four (25%) deaths.

The MORDOR II study extended biannual doses of azithromycin in the randomized Niger communities for an additional year and showed similar effectiveness of the antibiotic on childhood mortality in the third year of treatment compared to the first year. Furthermore, childhood mortality decreased significantly when the placebo-treated communities received azithromycin treatment.



## Case Study 14

### MORDOR Study—Tracking a Reduction in Childhood Mortality

**Birni N'Gaouré is a town in the Dosso region of southern Niger.** Here, in a dimly-lit office, is an entire wall of square cubby holes brimming with colorful binders. There are hundreds on one wall, more on another, and even more stacked on a hutch in the hallway. Despite the cheerful colors, each folder contains multiple “verbal autopsies” of Nigerien babies and young children who have died within the timeframe of the two year international MORDOR I study (see Box 12, pg. 50).

These reports are part of a three-country replication study that corroborates an observed strong link between MDA of the broad-spectrum antibiotic azithromycin for trachoma elimination and a subsequent sharp decline in mortality among children under five years old.

It takes a special kind of person to gather information about a child's death from bereaved parents. Mariama Tiemogo is one such person.

Tiemogo is a professional nurse from Niger's capital, Niamey. She works on the MORDOR field team, taking swab samples to monitor babies' and children's health over time in an area of the country that, up until implementation of the study, had not received azithromycin MDA due to the area's low prevalence of trachoma.

These reports are part of a three-country replication study that corroborates an observed strong link between MDA of the broad-spectrum antibiotic azithromycin for trachoma elimination and a subsequent sharp decline in mortality among children under five years old.

In addition, she has the awful duty of tactfully interviewing the heartbroken families of children who have died, in order to help researchers understand what children are dying from and what fatal illnesses the antibiotic may be preventing.

“It's sometimes quite painful to see the family's sadness, but as a nurse I have a job to do,” Tiemogo said.

As Niger is about 90 percent Muslim, Tiemogo usually starts the conversation by respectfully acknowledging the family's loss and offering the traditional Muslim condolence, “To Allah we belong and to Him we return.” She then gently inquires what the parents think caused the death. Using her nurse training to seek diagnostic information, she asks whether the child had shown symptoms such as fever, diarrhea, or rash, and for how long.

Frequently, Tiemogo finds herself playing the role of grief counselor. Bereaved mothers will often wail at the very mention of the child's name, she said. Tiemogo is understanding and empathetic, but she also is focused on her task.

“You just have to be patient, let them express their grief, comfort them, and get the answers you need,” she said, wiping sand from her eyes.

In Niger's male-dominated culture, Tiemogo is aware that little girls have their eyes on her and perhaps are dreaming of careers for themselves.

“It's a good feeling to be a woman doing important work,” she said, adding that grown women pay attention too. “Women say, ‘The work you are doing, even the men cannot do it!’”

Tiemogo and everyone else involved in MORDOR hope they can prevent too many more of those colorful folders from piling up.

“We in this program are very happy to know we are helping reduce child mortality,” she said.





Two female MDA distributors prepare to distribute antibiotic in villages in Sudan. Photo credit: Angelia Sanders/The Carter Center

## Do no harm

**One of the guiding principles of MDA is to do no harm.** Women, especially those who are mothers, can play an important role in safe drug delivery. Drug distributors must ensure that children under the age of seven years and anyone shorter than 120 centimeters should be offered powder for oral suspension (POS). Additionally, any individual of any age who may have difficulties swallowing tablets should be offered POS. Mothers, fathers or other caretakers can help children receive drug safely by taking small children aside to give them POS. All members of the community, regardless of gender, have a responsibility to ensure drug is distributed in an intentional and safe manner.

## Antibiotic distribution and pregnancy

**Pregnant and breastfeeding women, according to research and current medical practice, may safely take azithromycin.** If an individual expresses concern, however, she can be offered topical TEO instead.

## Reaching special populations

**Special populations are defined as refugees, migrants, internally displaced people (IDPs), indigenous groups, and nomadic groups.** Each should be identified to ensure that planning takes them into consideration using a gender-sensitive approach to address differences and inequities.

The concept of leaving no one behind as part of an equity-oriented trachoma elimination program requires an understanding of how to adapt the implementation of the SAFE strategy to special populations and different sociocultural settings. Effectively reaching special populations as part of MDA or TT program activities has been, and remains, a significant challenge due to context-specific factors.

The first challenge is geographic mobility, which is not unique to trachoma programs. The geographic mobility of women and children was found to be a key determinant of under-vaccination among nomadic pastoralists in Kenya. Even if geographic mobility may be more common among men and boys as cattle herders, existing social structures may lead married women who stayed at home to refuse MDA drugs if the husband is not present to provide consent. Thus, the second challenge of nomadic populations are the social structures that often limit decision-making by women who tend to have even less power than their static counterparts.

The third challenge is scheduling MDA campaigns. Ideally, they should be scheduled during periods of the year when CDDs are more likely to be available and when community residents are more likely to be “settled” at home (as identified in community registers). Scheduling the timing of MDA campaigns may require cross-border cooperation at the district or even country level by speaking with local community leaders to understand migration patterns.

A fourth challenge is that general health service acceptance among nomadic populations is often lower than among other population groups for a variety of reasons, including poor access, the use of traditional medicine, and low trust or mistrust towards Western medicine. For example, beliefs among women that

MDA drugs may be a contraceptive or affect male or female fertility as a side effect have been reported in several studies in nomadic populations. To increase acceptance of MDA among these populations, programs are encouraged to educate community and religious leaders on the epidemiology, treatment, and prevention of trachoma.

Among IDPs and refugees, a major challenge is ensuring they are able to access treatment, if warranted, in the place where they settle. Special efforts are underway to identify and target such affected men, women, and children among IDP and refugee populations in endemic countries. A starting point to understand these challenges could be engaging the national government and the United Nations High Commissioner for Refugees in the target areas to begin a dialogue on strategies to ensure equitable healthcare access.

Addressing all of these challenges requires efforts above and beyond those undertaken in static communities, meaning they are more costly. Systematic planning is required to consider how these challenges will be addressed, whether at the national level or between countries if nomadic populations move across borders. Second, strong community engagement and local mobilization strategies, co-developed with local male and female leaders and tailored to the local contexts, are necessary to ensure that there is a high degree of local ownership of the process. Good planning, local engagement, excellent training, and effective supervision will help these populations attain good MDA coverage and reduce the prevalence of trachoma.

## Monitoring for gender-specific coverage

**A follow-up assessment of distribution coverage immediately after MDA can be performed using distribution registers and tally sheets or by using a population-based survey to estimate gender-specific coverage.** Although it may not be necessary to evaluate coverage for all distribution activities in each intervention unit, routine assessments will allow the program to monitor how the program is reaching communities and make adjustments for improved results. For example, annual data comparisons can help highlight peak times or seasons when a nomadic

community tends to be in a specific area and when both women and men can be reached, which can then be used in the following year's planning.

Programs need to evaluate coverage by sex and age group so they can determine whether there are groups as a whole or within particular geographical areas being missed. If so, program staff can then identify how and where delivery needs to be intensified or redirected. Delivery methods, mobilization, and health education have the potential to systematically exclude specific subgroups including women who are of a particular age category, in a nomadic group, or are members of another minority community. To reach more equitable outcomes, program design should intentionally address gender-based constraints, including within subgroups, in the target communities being served.

## Distribution records

**WHO recommends that doses of azithromycin distributed be recorded at the time of treatment.** These distribution records can include a variety of information, but at minimum should note village, age, gender, and dose. Recording unnecessary information will slow down the distribution process. Teams should follow these guidelines:

- Every site and distribution team should use the same register format and compile each day's output into a summary table. Because long lines at distribution can deter potential beneficiaries, especially women with children if they do not have the time to wait, registers should not require unnecessary information.
- When registers are summarized, the distribution teams should include the total number of adult women, adult men, and children.

The compilation of sex-specific data from registers allows the district, regional, and national staff to monitor antibiotic distribution progress in terms of men, women, and children (boys and girls) reached. When the data show gender disparities, a reason can be noted so that the results can be more accurately assessed based on local conditions. Staff can determine population coverage by dividing the total number of doses distributed by the targeted population of the total intervention area, ideally disaggregated by sex and age.



#### Case Study 15

### Benefits of Female Community Drug Distributors in Sudan

**Dr. Balgesa Elkheir Elshafie** has experience working in various countries in Africa (Egypt, Kenya, Sudan, Tanzania) as a National Trachoma Coordinator, a trachoma researcher, an ophthalmologist, and a Program Director. When asked about women's participation in trachoma's SAFE strategy, she shared some patterns she has witnessed throughout her career and described the benefits of female community drug distributors.

- Due to social traditions, it is more accepted by families for women to approach households.
- Females are better equipped to answer critical health questions from female community members related to consuming azithromycin during pregnancy, lactation, etc.
- Females feel more comfortable expressing any side effects they experience from MDA to other women rather than communicating them to men. This increases the likelihood that the side effect or adverse reaction will be reported and attended to immediately.
- Females may be disinclined to share their actual age with male drug distributors for the purposes of recording MDA recipient data.
- If follow-up evening visits are necessary for those that missed distribution during the day, it is preferable for women to visit homes rather than men.
- Due to religious beliefs, some heads-of-household do not wish to have their homes visited by other men in their absence.
- Since health education and personal hygiene messages are primarily targeted towards females, females are better equipped to communicate these messages to others.

### Coverage surveys

Reliance on distribution records alone to measure coverage can lead to inaccurate conclusions of the success of an MDA campaign. These records can be unreliable because registers are sometimes incomplete, missing, or inaccurate. This also presents difficulties when reconciling distribution data with drug stock management records. To validate routine coverage estimates derived from the administrative data from distributions, programs can implement a cluster survey to estimate population coverage.

The findings from a coverage survey should be incorporated into the regular monitoring database for antibiotic distribution. If it appears that a specific subgroup is being missed for MDA, the program can follow up in these areas with additional health education, community mobilization, and possibly additional distribution "mop-up." Distribution registers and coverage survey results can be used to estimate the proportion of population subgroups who are receiving azithromycin (e.g., by age and gender), and then apply that to the annual targets. These data are not only relevant for planning purposes, but can be used for advocacy to raise funds for distribution activities. Furthermore, identifying the specific barriers that men, women, boys, and girls face, identified through these interviews, can provide insight on improving access for future distributions.

## Suggested reading

Adams, M.W., Sutherland, E.G., Eckert, E.L. et al. Leaving no one behind: targeting mobile and migrant populations with health interventions for disease elimination—a descriptive systematic review. *BMC Med* 20, 172 (2022). <https://doi.org/10.1186/s12916-022-02365-6>. This article provides an overview of interventions and strategies that have been conducted in East Africa to improve access to health services for mobile and migratory populations.

Ciciriello, A. M., Fairley, J. K., Cooke, E., Emerson, P. M., Hooper, P. J., Bolton, B., LaCon, G., & Addiss, D. G. (2022). Safety of Integrated Preventive Chemotherapy for neglected tropical diseases. *PLOS Neglected Tropical Diseases*, 16(9). <https://doi.org/10.1371/journal.pntd.0010700>. This publication highlights a review of safety measures and suggestions for MDA for neglected tropical diseases.

Desmond N, Solomon AW, Massae PA, et al. Acceptability of azithromycin for the control of trachoma in Northern Tanzania. *Transactions of the Royal Society of Tropical Medicine and Hygiene*. 2005 Sep;99(9):656–663. This article presents the results of focus group discussions, direct observation, and structured questionnaire responses to understand reasons for refusal of drugs in a community in Tanzania.

Ebert CD, Astale T, Sata E, Zerihun M, Nute AW, Stewart AEP, Gessese D, Ayenew G, Ayele Z, Melak B, Chanyalew M, Gashaw B, Tadesse Z, Callahan EK, Jenness SM, Nash SD. Population coverage and factors associated with participation following a mass drug administration of azithromycin for trachoma elimination in Amhara, Ethiopia. *Trop Med Int Health*. 2019 Apr;24(4):493–501. doi: 10.1111/tmi.13208. Epub 2019 Feb 10. PMID: 30674087; PMCID: PMC6850572. This article outlines factors to take into account when micro-planning and mobilizing communities to participate in MDA.

Feyisa, T. Bekele, D. Tura, B. Adem, A. Nugusu, F. To eliminate trachoma: Azithromycin mass drug administration coverage and associated factors among adults in Goro district, Southeast Ethiopia. *PLoS Negl Trop Dis*. 2022 Jun 27;16(6):e0010169. doi: 10.1371/journal.pntd.0010169. PMID: 35759466; PMCID: PMC9236244. This article details improving MDA coverage in adults by analyzing factors that may impact the odds of participation.

Francis V, Turner V. Achieving Community Support for Trachoma Control: A Guide for District Health Work. Geneva: World Health Organization; 1995. This manual details the steps to develop community support for SAFE strategy interventions. The text serves as a reference for the community mobilization process and provides guidelines for facilitating community education.

Gammino VM, Diaz MR, Pallas SW, Greenleaf AR, Kurnit MR. Health services uptake among nomadic pastoralist populations in Africa: A systematic review of the literature. *PLoS Negl Trop Dis*. 2020;14(7):e0008474. This article reviews the knowledge and attitudes of migratory populations in Africa and their access to and perceptions of health care services.

Gender equity in mass drug administration for neglected tropical diseases: data from 16 countries', *International Health*, Volume 11, Issue 6, November 2019, Pages 621–622, <https://doi.org/10.1093/inthealth/ihz026>. This article provides a comprehensive review on how countries have incorporated gender equity practices into strategies for the control and prevention of NTDs.

International Trachoma Initiative. (2019). Zithromax® Management Guide. International Trachoma Initiative. [https://www.trachoma.org/sites/default/files/2020-12/ITI\\_ZMG\\_ENG\\_121120\\_Online.pdf](https://www.trachoma.org/sites/default/files/2020-12/ITI_ZMG_ENG_121120_Online.pdf). A detailed guide on Zithromax® applications, distribution, and supply chain management for the elimination of trachoma.

O'Laughlin B. Missing Men? The Debate over Rural Poverty and Women-Headed Households in Southern Africa [Working Papers Series No. 252]. The Hague, Netherlands: Institute of Social Studies; 1997. This paper provides a description of households where a male head is absent. The author discusses the impact of changing labor trends on household composition.

Minority Rights Group International, A Double Bind: The Exclusion of Pastoralist Women in the East and Horn of Africa, 12 December 2008. <https://www.refworld.org/docid/494672bc2.html>. This publication provides insight on the exclusion of pastoralist women in leadership roles and provides evidence that NGOs should be at the forefront of advocacy for inclusion to improve health outcomes.

Mtuy TB, Bardosh K, Ngondi J, Mwingira U, Seeley J, Burton M, Lees S. Understanding hard-to-reach communities: local perspectives and experiences of trachoma control among the pastoralist Maasai in northern Tanzania. *J Biosoc Sci*. 2021 Nov;53(6):819–838. doi: 10.1017/S0021932020000553. Epub 2020 Sep 25. PMID: 32981544. The first part of two published articles, this paper analyzes perspectives and experiences of Maasai pastoralists in Tanzania.

Mtuy TB, Burton MJ, Mwingira U, Ngondi JM, Seeley J, Lees S. Knowledge, perceptions and experiences of trachoma among Maasai in Tanzania: Implications for prevention and control. *PLoS Negl Trop Dis*. 2019;13(6):e0007508. This the second of two articles that provides an in-depth look at the indigenous nomadic pastoralists of Tanzania and details their experiences and perceptions regarding MDA for trachoma in addition to the implications of not tracking and treating this population.

The Queen Elizabeth Diamond Jubilee Trust, Sightsavers, International Coalition for Trachoma Control. (2019). Trachoma Elimination in Africa: Lessons from two multi-country initiatives. Sightsavers. <https://www.sightsavers.org/wp-content/uploads/2019/07/Trachoma-Initiative-Report-Lessons-two-multi-country-initiative.pdf>. This publication reviews two partner organizations utilizing a participatory approach to provide feedback on Department for International Development supported country programs.

World Health Organization. Trachoma Control: A Guide for Program Managers [NLM classification WW 215]. Geneva; The World Health Organization's guide for trachoma control program implementation sets survey and other guidelines. This manual is a resource for anyone planning or evaluating SAFE strategy interventions.



A CDD measures POS to provide to children.  
Photo credit: Gabreez Production for Sightsavers

## Chapter 5

# Behavior Change and Gender

**This chapter will present tools for program managers to use in the development of gender-specific health education and behavior change programming.**

Several theories attempt to explain the process of behavior change among individuals and communities. Though different theories assign varying weights to individual and group factors, such as gender, family influence, education, and social learning, the steps to change are fairly similar. The first stage of behavior change is an individual's move from being unaware of the benefits of a behavior to knowledge of that behavior and its advantages. From there, the individual considers the behavior. After a period of intention, which varies by individual, the individual begins to practice the behavior, and then promotes the behavior to others. Individuals who are prone to adopt new behaviors or technologies before the majority of their peers are referred to as "early adopters."

A comprehensive health education and behavior change program for trachoma control has three main goals:

1. Educate target groups about the disease,
2. Convince the target group to adopt health-seeking behavior, and
3. Mobilize communities and local leadership to support the implementation of the trachoma control program.



## Understanding behavior change

**Before launching a health education program or behavior change campaign, a trachoma control program must identify its behavior change objectives.** The program should note existing positive behaviors and effective channels for communication. Such channels may not be the same for men and women or across the various subgroups in a community.

National programs have a wealth of resources among the members of their national trachoma task forces. These partners can provide valuable insight from earlier programs, discuss lessons learned, and relay successes and failures. They will also be able to identify areas of potential collaboration and funding for health education projects.

## Gathering information about the community

**To gather information about the communities in which a program operates, including sex-disaggregated data where possible, staff should conduct community-based interviews to generate information about cultural practices and attitudes regarding trachoma control, as well as gender norms, constraints, and opportunities.** These do not need to be formal interviews or complicated surveys. Staff can visit different communities and speak with the target audience and other influential community members, known as key informants. Including trusted community members—both men and women—alongside female and male interviewers may help produce more detailed answers about both community and individual habits. When working in a more patriarchal societal setting, male interviewers may be more successful in getting candid responses from village elders and male heads of household, while women in the community may be more comfortable discussing their experiences with a female interviewer. The goal of the interviews is to elicit information about participants' attitudes toward certain types of behaviors, their motivation for changing their behavior, and the sources of information they find



For children under six months of age, TEO is used to provide treatment for trachoma. Pictured here, a CDD is placing TEO on the eyelid of a child during MDA in Colombia. Photo credit: Ministry of Health, Colombia

trustworthy. Interviewers should probe for more detail when a male or female participant mentions something new. Discussion guides can be helpful to facilitate these information-gathering activities (see Appendix A, pg. 80). The guide serves as a reminder for the interviewer, listing the key questions to ask and suggested topics for discussion.

The information gathered during interviews can include both the responses provided by members of the target audiences as well as observations about the behaviors witnessed, such as food preparation and household water use, and details about the physical space. Once no new information is being gained from interviews, the data gathered can be organized into themes and concepts that relate to each subgroup of the population, such as male heads of household, elderly community members, and women with young children. The similarities and differences noted between groups can be used to identify positive behaviors already practiced by members of the target audience and to identify areas for growth.

## Case Study 16

### Media Habits Survey in Sudan

**After Sudan's national trachoma program conducted prevalence surveys between 2006 and 2010, The Carter Center conducted a media habits survey to better understand how those living in endemic regions access information and to determine the best avenue for sharing information related to the SAFE strategy.** East El Galabat locality was targeted for this project due to its endemicity. The media habits survey was adjusted to better match the community in which it would be conducted, including being translated into Arabic and shifting questions to match local demographics.

Twenty villages were randomly selected according to a population proportion sample and within each village, 15 households were randomly selected. Surveys were conducted at each of the 300 households with members of each target group.

The three groups targeted were:

- Male heads of household because of their influence on their families
- Mothers of children <5 years old because they have the most impact on the care of small children
- Male and female young adults aged 11–16 years because of their ability to influence both family and community members

As shown in the table to the right, media habit surveys can help programs understand how people like to receive information, from whom, at what location or venue, and at what time of day. This will vary depending on a variety of factors, including differences by age and gender.

The survey findings in this case study have continued to impact program decision-making for many years. Since the survey was conducted, the program still uses radio and posters to disseminate messages, but has also added social communication such as Facebook and WhatsApp, thanks to the increased community access to electricity and cell phones. Please see suggested reading (pg. 69) for a link to this document.

Findings from the survey helped to inform key decisions in regard to health messaging, including:

SURVEY FINDINGS	DECISION(S) MADE
The highest percentage of basic education was found in the young adults (11–16 years), 73.85%.	Target young adults primarily through schools.
When asked which tribe they are from, there was not a dominant tribal language.	Arabic was chosen as the main language for communication.
Only 11.92% of all survey participants responded that they own a TV. If they did report watching TV, it was mainly outside of the household, in a movie house, or at a neighbor's/friend's house. 71.6% of respondents replied they either sometimes or never watch educational TV programs.	Use primary sources of communication other than TV.
Listening to the radio was reported by 70% of respondents. The highest percentage of listening was reported in the morning, 28%. When asked which station they listen to, 64% of household heads and 40% of mothers reported Omdurman, the national radio station.	Broadcasting on the national radio station in the morning was determined to be the best method to reach the greatest number of people.
Participants were asked if they take a closer look when they see a new poster. 66.88% of household heads said yes, 43.62% of mothers said yes, and 61.13% of young adults said yes.	Focus on posters, stickers, and t-shirts with graphics or messages about trachoma or MDA.
Participants were asked, "If I want to hang a poster so everyone can see it, I will hang it in: the dispensary, in the market, or on a tree." 71.29% of household heads, 54.36% of mothers, and 62.54% of young adults said the market.	The market was determined to be a key area for disseminating messages.
When asked if there is someone in their village who gives trustworthy information, 72.38% said yes; and when asked who that person is, 42.09% of all respondents said that person was an elder (with the remaining percentage split between cattle camp leader, health worker, mayor, religious leader, and teacher).	Community and traditional methods of information dissemination would work best for this location.



## Identifying subgroups

Within a trachoma endemic district, there are many different groups of people, yet all may be affected by trachoma. The magnitude of the disease may differ among these groups as a result of the risk factors to which they are exposed. Program managers should use the findings from information gathering to identify these subgroups and segment them into different audiences. Examples of different population subgroups include nomadic, indigenous, ethnic, or pastoralists.

Audience segmentation allows a behavior change program to target different audiences concurrently. If interviews with key informants reveal that different groups of men and women respond to different forms of media, then individual health education tools should be developed to reflect those differences. Table 6 shows how messages can be tailored to specific audiences.



Sue-Chen, the National Trachoma Program Coordinator for Nauru, brings her training materials to the Environmental Department for Waste Management to train workers on trachoma prevention. Photo credit: Ministry of Health, Nauru

Table 6  
Example Health Education Messages, Separated by Audience and Possible Media

MESSAGE	TARGET AUDIENCE	MEDIA
"Bury human feces away from the compound and/ or construct a latrine"	Male and Female head of household	Radio
"Wash your daughters' and sons' faces in the morning, after meals, and before they go to sleep."	Mothers, Fathers	Religious leader
"Support your wife/mother in getting surgery" "Support your husband/father in getting surgery"	Men, young adult boys and girls Women, young adult boys and girls	Health worker education session
"Participate in azithromycin distribution"	Men, women, children	Community leader meetings, social mobilizers, radio
"Seek TT surgery"	Elderly women and men, adult caretakers	Health worker home visits, radio



## Survey of information sources

To know how best to promote behavior change messages to target communities, it is important to understand the most common, preferred, and influential methods of receiving information among each subgroup of the community. Before initiating a health education or mass media campaign, trachoma control programs should identify how information is spread using formative research that measures the frequency of use for each type of information source. These data can be analyzed to identify differences among genders, ages, or other subgroups within the intervention unit. Within the same communities, these information sources can change with time. This should be reflected by remaining up to date on local media sources over the course of a trachoma control program, which can span decades.

The following are steps for conducting a population-based survey of information sources using a quantitative approach. Behavioral questions could also be included in other programmatic population-based surveys such as TF and/or TT prevalence surveys.

1. Define the target groups of interest (e.g., pregnant and breastfeeding women, women with children under five, married men, adolescent girls and boys, young children).
2. Randomly select between 8 and 20 villages (clusters) in each intervention unit.
3. Randomly select 10 to 25 households in each village. Consider the logistic capacity of the program to determine the number of villages that are feasible to reach.
4. Visit each household and interview all eligible members of each target group.
5. At each household, interview all of those in the target groups using a standard questionnaire. For example, if the target group is mothers, then all mothers in the selected household will be requested to volunteer to respond separately to the interview.
6. Enter the data in an analysis program. The responses then can be analyzed to calculate frequencies of responses among the different target groups.



A young girl in Yemen reads trachoma messages on CHW vehicles parked in her village. Photo credit: Ministry of Health, Yemen

The frequency of response for each type of media will be compared to determine whether there are better ways to reach each target group, or whether a single approach will suffice. The key is to discover which sources of information are available to the target population, and, of these, which sources are considered credible and trustworthy.

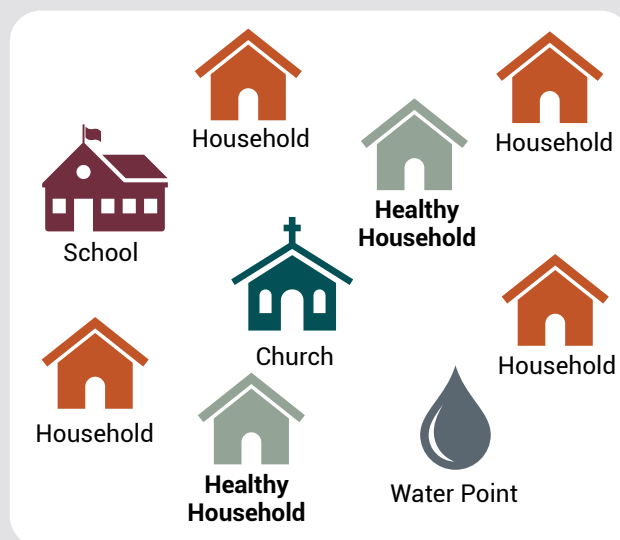
## Promotion of positive behaviors

If a program conducts research to identify community perceptions on hygiene, staff will likely notice current practices that already reduce the transmission of infectious disease. This is often called the “positive deviance model” of health promotion. This model argues that in each community, there are male and female role models (positive deviants) who practice behaviors that allow them to create better solutions to health problems than other community members with equal access to the same resources.

These existing positive behaviors should be promoted and encouraged through health education. It is easier to convince an audience to maintain or improve upon existing behaviors than it is to introduce a new practice. Existing practices can also be used to highlight the role of women in the community. For example, if some women in a community already sweep their households daily, then a message can be targeted to the other women, encouraging them to adopt the practice, while being careful to avoid gender exploitative messages, even if viewed as culturally appropriate. Additional messages can be developed to complement the main health education message, encouraging the audience to appreciate the advantages of positive behaviors while maintaining their dignity. Regardless, the focus should be fixed on simple, “do-able” messages from information sources people trust. Conversely, the health education program will fail if it is based on promoting behaviors impossible to adopt or uses media inaccessible to the target population. For example, a well-produced television show promoting daily showering with soap and hot water and the use of sewer-based sanitation will be of no use in a village that lacks electricity, television reception, piped water, or a public sewer system. This is an extreme example, but it illustrates the concept. See examples of messages for attainable behaviors in Table 6 (pg. 9).

### Box 13

## Positive Deviance Framework



The positive deviance approach seeks to identify existing resources and solutions within a community to solve community problems. Whereas traditional approaches to problem solving focus on gaps in community resources, the positive deviance method identifies the innovators women and men within communities and uses their adapted behaviors to promote change.

Steps to conducting a positive behavior inquiry:

1. **Identify** families that appear to have good hygiene and sanitation practices. Look for households where family members appear healthy.
2. **Compare** them with families who do not appear to have the same level of health and sanitation.
3. **Discover** which behaviors the “healthy households” practice that are different than the other households in the community.
4. **Choose** behaviors from healthy households that could be promoted within the community.
5. **Use** these behaviors as the base for health education messages.

In trachoma endemic settings, program managers need to develop and promote “do-able” messages. The positive deviance framework will help the program identify behaviors that are appropriate, feasible, and sustainable given the local context.

## Gender Considerations in Sindh Province, Pakistan

**Pakistan is a highly patriarchal society where men typically enjoy more power and privilege than women.**

Women face many challenges, including accessing healthcare services. They are often forbidden or discouraged from visiting health facilities, and if they do, may receive treatment too late.

Engaging women in the Pakistan Trachoma Elimination Project has played a significant role in ensuring the affordability, accessibility, and acceptability of treatments for eye conditions. It is usually easier for female staff to interact with female patients. They are able to identify issues and encourage patients to seek care for themselves and their families.

**Pakistan is a highly patriarchal society where men typically enjoy more power and privilege than women. Women face many challenges, including accessing healthcare services. They are often forbidden or discouraged from visiting health facilities, and if they do, may receive treatment too late.**

Zeenat is part of a farming family from the Kamber-Shahdadt district of Sindh, Pakistan. She has worked in the development sector for the last 27 years, three of which have been in the field of trachoma working as an F&E Coordinator in the Pakistan Trachoma Elimination Project. Her work takes place in the community: in schools, villages, basic health units, and district hospitals.

As part of the Pakistan Trachoma Elimination Project, Zeenat runs awareness sessions to teach men and women how to protect themselves from trachoma. She accompanies the field team, disseminates Information, Education, and Communication and Behavior Change Campaign (BCC) materials, gives lectures, and conducts demonstrations. Zeenat also runs awareness sessions in primary schools and teaches measures to help protect the pupils and their families from trachoma. She always ensures the privacy of the female pupils and staff members to ensure their comfort, since as a local person, she knows the local customs.

After receiving training from WaterAid International in Islamabad, Zeenat has passed on her knowledge to headmasters of schools and Lady Health Supervisors. LHSs are, "another cadre of CHWs working in LHW-P who are responsible for directly managing 25-30 LHWs. LHSs make monthly visits to each LHW to supervise their community case management skills during visits to community households."

Most people in rural areas of the district have no formal education, and are not aware of available health services. They also lack an understanding of eye diseases, especially trachoma. Cultural barriers exist in Zeenat's community, as most women are not allowed to go outside the boundary of their homes due to social customs and religious obligations. They are required to ask permission to go out and when they do, must be accompanied by a male relative. As a woman, Zeenat can reach other women while respecting their privacy and advising them on their health. This has brought about a significant step towards the elimination of trachoma.





Zeenat, a CHW, conducts awareness campaigns to inform communities about trachoma. Photo credit: Christian Blindness Mission

"In the beginning, it was very difficult for us to go in[to] the community and conduct awareness sessions. Sometimes local people did not allow us to interact with the women in their families; however, over time, as we have built a rapport with them, and with the help of influential people such as religious leaders, teachers, and elders, it has become much easier."

### PARTICIPATING IN INTERNATIONAL DAYS

Zeenat has organized and actively participated in Global Hand Washing Day, World Toilet Day, World Sight Day, World Environment Day, World Health Day, and World Water Day. She took the opportunity during these awareness-raising days to convey messages on the elimination of trachoma.

While working on this project, Zeenat has learned that to live a healthy life, a person must take care of facial cleanliness and hand washing, as well as the importance of available safe and clean drinking water, and the proper maintenance of latrines and waste disposal.

"If we want to eliminate trachoma which can cause irreversible blindness, we must follow the SAFE strategy recommended by WHO. In this way, we can surely eliminate trachoma from our district."

Cultural barriers exist in Zeenat's community, as most women are not allowed to go outside the boundary of their homes due to social customs and religious obligations.

#### Box 14

### Use Figures in Positions of Influence to Reach Women

To tailor messages that are meaningful to heads of households, community leaders, and individuals with influence in a community, program managers should identify the structures of power and hierarchy within the target community:

- **Which health behaviors do leaders identify as positive? Negative?**
- **Who manages household finances and how are they managed differently based on gender?**
- **Who has the autonomy to make decisions about health for themselves and their family?**
- **How are decisions about health made, taking into consideration available resources and the short- and long-term impacts?**

Health education can be used to provide an alternative model to empower individuals in positions of authority. Example positive messages include the following:

- **"As a religious leader, I encourage healthy behaviors for my community."**
- **"Surgery acceptance is a way I can make sure my younger family members can pursue other opportunities instead of needing to take care of me."**
- **"As an older woman in my community, people look to me as a role model to demonstrate healthy behaviors."**
- **"Using my spare money to pay for my wife's travel to have TT surgery is my responsibility as a husband."**
- **"Taking my wife to the clinic for surgery will increase the status of our household in the community by demonstrating my compassion and increasing our crop yield."**
- **"Ensuring my children have clean faces is my responsibility as a parent."**

Successful programs will understand power dynamics, group dynamics, and the various levels of culture within the community. Understanding the nuance and intersectionality of identities informs who to target for which health message.

### Encouraging behavior change by targeting community members with influence

**It is important to recognize that a variety of people influence behavior.** These include male and female heads of households, community and religious leaders, teachers, mothers-in-law, and even local government officials. Trachoma control interventions should target the family members who are the financial decision makers and have authority over household resources. Even though men may wield disproportionate control over the household in the majority of trachoma endemic communities, they are also vulnerable. Household leaders in resource-poor settings experience social stresses such as the following:

- Poor economic conditions
- Little to no formal education
- Heavy physical workload
- Pressure to provide for the family
- Lack of opportunities outside of the community
- Social and cultural expectations of being "strong," "a provider," and "the decision maker," when they may lack guidance or mentorship
- Unrealistic family expectations
- Peer pressure

There are typically community expectations that figures of authority will be able to protect and provide for their families. Failure to do so has severe social consequences for their status within their communities. Men and women with disabilities, such as TT, are at an increased disadvantage, requiring care rather than being in a position to provide care for their family or community. Given these pressures, household and community leaders can be encouraged to take an interest in the health of their family as a means to elevate status, ensure economic productivity, solidify their role as providers and caretakers, and to provide an opportunity for



community involvement. In a community setting, men and women are sensitive to group perception and approval and are unlikely to adopt behaviors that will contradict their definition of gender-normative behavior or status within the community. In turn, within each community are change agents that can be sought out to help programs navigate evolving gender norms and to avoid the risk of program messages reinforcing gender stereotypes. Box 14 (pg. 64) provides examples of messages that may resonate with figures of influence.

Targeting school-aged boys and girls through school-based health education messaging, provided by teachers or trachoma control program volunteers or staff, provides additional access to future heads of households and future community leaders.

## Development and design of health education materials with a gender perspective

**The data from information gathering will inform the national program as to what types of media are popular and available to the target population.** Programs should use the data collected to identify media that are perceived as persuasive, credible, trustworthy, attractive, and authoritative. For example, some societies that have a strong oral tradition of storytelling and sharing history benefit from messaging conveyed through drama, songs, and skits while others consider text-based media to be more valid. The rapid acceptance of text messaging on mobile phones and use of social media presents new platforms for reaching large sectors of the population, after first determining that there is both access to mobile phones and your target group can receive a signal. There is no one-size-fits-all approach to health education.



Mobile phones are a very useful way to communicate health messages via WhatsApp or radio. Here, a woman in Ethiopia communicates with her family via mobile phone. Photo credit: Brent Stirton/Getty Images for International Trachoma Initiative

Program managers should take the following steps when developing their education materials:

1. **Refine behavior change objectives** based on findings. Did the program learn anything new about the target audience? Are the behavior change goals still appropriate?
2. **Make a list of the key behaviors and messages to promote SAFE** (e.g., latrine use, face washing, participation in antibiotic distribution, surgery referral for TT cases).
3. **Determine which media are most appropriate for the target audience** and each key message. Not all behaviors are best suited to the same media. For example, promotion of latrine construction may be more effective through the radio, whereas promotion of antibiotic distribution may be better received by the target audience if done by CHW. Women and men may need to be targeted separately.
4. **Produce a draft** of the material.
5. **Pretest the material** with the target audience (e.g., through focus group discussions).
6. **Modify the material** based on the target audience's response.
7. **Pilot test the final version** with the target audience.
8. **Incorporate any last changes** into the final version.



# Pretesting health education materials

Health education materials should be pretested with the target audience, either with individuals or in small groups.

To do so, program staff should assemble a group of people (about 8 to 12 members) to whom the material is targeted. The group is asked to provide initial impressions of the new material. This assessment will enable the program to determine whether the material is generally accessible. If so, the program should have the focus group evaluate each component (e.g., page, skit, poster) of the material individually for content, clarity, and cultural appropriateness to measure how well the illustrations and descriptions represent real-life situations. Program managers can use the feedback from the pretest session to revise the material.

If possible, the artist designing the material (e.g., radio broadcaster, illustrator) should visit the local communities, which will enhance their ability to create accurate representations of the target population. See Box 15 (pg.66) for more specific instructions and an example of pretesting.

# Producing and distributing education materials

The production and distribution of health education materials must be coordinated within the context of a larger behavioral change program and correspond to the objectives of the overall behavior change program. Before producing copies of the materials, trachoma control programs should consider the quantity necessary, the method by which they will be distributed, and the most suitable time of year to conduct education activities. For example, if MDA is planned for the month of March, launching a health education campaign in February would help encourage support for the program. Likewise, incorporating the seasonal and daily calendar of the target audience into the schedule of interventions will ensure maximum levels of participation. If a program wants to target women, it should not do so during the hours of the day when women are not near their homes, nor should it attempt to conduct education during months when women are frequently busy with other tasks, such as gardening or harvesting. Distribution of health education materials must incorporate the program's annual targets for health education: number of facilitators and educators, logistic support for the production and delivery of the materials, and the regular supervision of the program in the field. Table 7 discusses planning around community calendars.

## Box 15

## Pretesting Health Education Materials

Pretesting allows each target audience to provide an opinion on the relevance, appropriateness, and understandability of new health education materials. With the development of gender-specific health education materials, program managers should make sure that media intended for a specific target audience is tested with that audience. For example, if a communication is specifically intended for mothers with young children, test the material with this group. If testing a flip chart with an illustration of women at home, staff should ask questions such as:

- Does her cookstove look like yours?
- Does her home look like yours?
- Is her headscarf tied correctly?
- What do you think she is doing?
- Is anything missing from this picture?

Once each component of the material is analyzed, ask the testers to discuss it as a whole:

- What were the main messages conveyed by this chart?
- Are the messages in the correct order?
- What did you understand from the content?
- How could the media be improved?

Table 7

## Planning Education Around Calendars

The table below shows an example of the daily calendar for married men head of households and the women with children they live with in rural Niger. Program managers can create a similar calendar showing a typical day's activities for each target subgroup in their specific communities.

TIME OF DAY	LOCATION, ACTIVITIES	POTENTIAL COMMUNICATION OPPORTUNITY
MEN		
Early morning	Mosque, prayer	Religious leader after prayer
Morning	At home, eating breakfast, preparing for day's work	Radio broadcast
Midday meal	In field, planting, harvesting	Loudspeaker announcements through fields and rural areas
Evening	At home or at neighbor's home, socializing	Radio broadcast, meeting with community leaders
WOMEN		
Early morning	Making breakfast, helping children prepare for school	Radio broadcast
Morning	At home, cleaning compound, collecting water and firewood	—
Midday meal	Cooking, pounding grain, looking after own children and/or someone else's children	Informal women's groups, discussion during chores
Evening	Washing children, preparing for dinner, possibly socializing with neighbors	Radio messages directed at male head of household

## Radio

**Radio is a popular medium for conducting large-scale health education. In settings where women and girls have access, radio provides them the potential to access the world outside their communities.** Radio can provide generic information to reach both men and women, but is unlikely to reach those who do not have access to a radio or have control over the programming selection.

The survey to measure information sources described in this chapter outlines ways to assess patterns of radio use within a household (see suggested reading). For example, if the program determines that men are in control of the radio, then the program should use radio

as a means to educate men on how their families will benefit if they protect all of the affected male and female family members from trachoma.

Some trachoma control programs have invited women who have had TT surgery or who are volunteers with antibiotic distribution to hold discussions over the radio either alone or in small groups with an experienced facilitator. Hearing their 'peer influencers' over the air can be an effective way to involve women in trachoma control programming. Women's groups are an effective forum for women to discuss their health concerns and develop local solutions.

## Case Study 18

### Radio Messaging as a Behavior Change Tool

Radio Albichir—"Good News" in the Hausa language—is a 300-watt community radio station in Mirriah, central Niger that plays hip-hop and other popular music that listeners request by phone and online. But it does more than that: throughout the broadcast day, the station's on-air personalities work into their breezy chatter a litany of messages about health, hygiene, and community betterment.

One of those three-minute messages informs people that they can avoid trachoma through washing their faces frequently and keeping their environment clean to discourage flies that spread the infectious eye disease.

"This town is filthy in places, but since the trachoma message has been airing, it's getting cleaned up," says station director and jocular host Amadou Roufai Ousmane. "People are learning."

The large, historic city of Zinder is just a few miles away. There, a more powerful state-owned station called ORTN (Office of Radio and Television, Niger) performs a similar role for a wider regional audience.

ORTN's daytime hosts are Zara Oumarou and Rakia Adamou. Backed by a team of technicians in the well-appointed, modern studio, the two women take turns sitting at a checkerboard table and speaking into a microphone suspended at the end of a long boom. They and ORTN's other hosts pepper their shows with music, jokes, advice, official announcements, and oft-repeated messages about avoiding trachoma and other threats to health.

Women once stigmatized for their conditions have been given the opportunity to speak over the radio in Zinder about their experiences. After being successfully operated for TT, these women, mostly in their thirties, spread the word about how TT surgery changed their lives. They reported feeling empowered by the opportunity, knowing their testimony could be heard by their community, friends, and neighbors.

At both stations, everyone seems to enjoy their work and take their influence seriously.

"I am using my voice to guide people to more sanitary behavior," Radio Albichir's charismatic Ousmane says.

"I am not political, but this makes me feel like a leader of the community."

## Mobile phones and social media

**Mobile phones and social media are increasingly used to disseminate targeted health messages in communities as access to mobile devices increases and connectivity networks expand to reach more rural areas;** however, use of these media relies heavily on a level of literacy and the availability of mobile networks in all program target areas. To tackle this challenge, some national programs utilize voice messaging and videos via the phone application WhatsApp® to share information when mobile networks are strong.



## Suggested reading

Curtis V, Kanki B, Cousens S, et al. Evidence of behavior change following a hygiene promotion program in Burkina Faso. *Bulletin of the World Health Organization*. 2001;79(6). *Two population surveys were conducted to record the coverage of a hygiene-promotion program in Burkina Faso. The investigators found that hygiene promotion programs built on local research using locally appropriate communication methods were more likely to be effective. Trachoma Health Education Materials Library available from The Carter Center at <http://www.cartercenter.org/health/trachoma>.*

Dodson S, Heggen A, Solomon AW, Sarah V, Woods G, Wohlgenuth L. Behavioural change interventions for sustained trachoma elimination. *Bull World Health Organ*. 2018 Oct 1;96(10):723-725. doi: 10.2471/BLT.18.212514. Epub 2018 Sep 10. PMID: 30455520; PMCID: PMC6238993. *Understanding the challenge regarding funding constraints, the authors provide example of how to create and sustain behavior change activities for trachoma.*

Family Health International Institute for HIV/AIDS (2002) Behaviour Change Communication for HIV/AIDS: A Strategic Framework. Arlington; Family Health International. In: Durojaiye, C.O., Ed., Knowledge, Attitude and Practice of HIV/AIDS: Behavior Change among Tertiary Education Students in Lagos, Nigeria, 18. <http://eds.a.ebscohost.com.ezproxy.utech.edu.jm/ehost/pdfviewer/pdfviewer?vid=4&sid=d03af66f-275b-4f20-afd2-a25d42ee474d%40sessionmgr4002&hid=4105>. *This paper presents a strategic framework for designing a behavior change program. Although the context is HIV/AIDS prevention, the framework is applicable to other public health problems.*

Greenland K, White S, Sommers K, Biran A, Burton MJ, Sarah V, Alemayehu W. Selecting behaviour change priorities for trachoma 'F' and 'E' interventions: A formative research study in Oromia, Ethiopia. *PLoS Negl Trop Dis*. 2019 Oct 9;13(10):e0007784. doi: 10.1371/journal.pntd.0007784. PMID: 31596851; PMCID: PMC6785218. *Depending on the area of intervention, tailoring F & E materials is crucial to encourage uptake. The authors detail an example of this in Oromia, Ethiopia.*

Howard-Grabman L, Snetro G. How to Mobilize Communities for Health and Social Change. Baltimore, MD: Health Communication Partnership, based at Johns Hopkins Bloomberg School of Public Health; 2003. <http://ccp.jhu.edu/documents/8%20How%20to%20MobilizeComm%20chapter%205%20Act%20Together.pdf>. *This manual provides a "how-to" for community mobilization and education. The Johns Hopkins Center for Communication Programs has produced a variety of health education materials, including gender-specific health education program development.*

International Coalition for Trachoma Control. Questionnaire to Identify Information Sources and Media Habits (2009). <https://www.trachomacoalition.org/resources/questionnaire-identify-information-sources-and-media-habits>



Margeta Aleligne Tsega is a lay priest at the Coptic Church in North Mecha Woreda, Amhara Region, Ethiopia. His trichiasis was untreated for 12 years and was advanced when he got corrective surgery. Before the operation, he had a continuous stabbing pain in his eyes, was unable to read, and was always looking down to avoid the pain and sunlight. Today, he is able to read his Bible free of pain. Photo credit: Brent Stirton/Getty Images for International Trachoma Initiative

Sternin M, Sternin J, Marsh D. Designing a Community-Based Nutrition Program Using the Hearth Model and the Positive Deviance Approach: A Field Guide. Westport, CT: Save the Children USA; 1998. *This paper applies the positive deviance approach to the development of nutrition programming. It illustrates the steps of identifying healthy households and selecting behaviors for promotion with real-world examples.*

Tidwell JB, Fergus C, Gopalakrishnan A, Sheth E, Sidibe M, Wohlgenuth L, Jain A, Woods G. Integrating Face Washing into a School-Based, Handwashing Behavior Change Program to Prevent Trachoma in Turkana, Kenya. *Am J Trop Med Hyg*. 2019 Oct;101(4):767-773. doi: 10.4269/ajtmh.19-0205. PMID: 31392952; PMCID: PMC6779218. *This article reviews a study conducted in 67 schools on handwashing education. The overall findings showed that handwashing practices was high after the first 12 months of the intervention and then decreased slowly after 18 months and 24 months.*



Before the Kishurmourok Primary School in Narok, Kenya, received a solar-powered water tank, the students had to walk two kilometers to collect water for the school day. Here, the students are expressing the positive impact the water tank has brought to their daily lives. Photo credit: Leeshia Crayton/International Trachoma Initiative

## Chapter 6

# Achieving Gender Equity in Facial Cleanliness and Environmental Improvement

**Trachoma infection is a community disease. It is not sufficient for a few individuals alone to adopt better practices. Prevention of trachoma through hygiene and sanitation promotion should be seen as a community priority.** To reduce the transmission of trachoma infection, programs need to frame the problem as a family health concern and present all members with relevant information, appropriate interventions, and feasible approaches to reducing the risk of infection. When programs recognize the decision-making authority of women in trachoma endemic communities and the areas where women are able to influence change at the household level, they can begin to design interventions and health education messages that empower and support both women and men to meet the hygiene and environmental needs of their families.

Facial cleanliness and environmental improvement (F&E) programmatic activities can include hygiene promotion through targeted health education, school-based trachoma education, latrine construction, and water provision. Although F&E interventions will not be discussed individually in this manual, this chapter provides trachoma control programs with tools to encourage the acceptance of hygiene promotion among everyone in the community, with an added emphasis on women and children. The purpose of this chapter is to enable program managers to develop intervention plans that allow communities to participate in the design and delivery of F&E activities and ensure equitable access for women and men, girls and boys, to improve sanitation.

## Hygiene and gender-specific risks

**Gender-specific household tasks place women at an increased risk for trachoma infection.** Responsibility for child care includes the washing and bathing of young children, which is usually performed by mothers, female relatives, or young girls. Hygiene should be understood from a gender perspective. Gender informs hygiene behaviors, which place men and women at different risks. Although women are most often responsible for the hygiene of their sons and daughters, they may not be empowered to make decisions about the allocation of household resources (e.g., money, time) for hygiene purposes. This includes access to water, soap, towels, or washcloths (if used), and the time to teach hygiene to children. Decision-making freedom is generally more limited in areas or times of scarcity. Gender also informs the division of labor and household tasks, which affects exposure to trachoma. Table 8 presents household tasks and the corresponding risk factors to which adult and young adult men and women are exposed. Possible F&E interventions are also listed.



Trachoma can be prevented by improving personal hygiene, facial cleanliness and implementing environmental improvement in the areas of water and sanitation to reduce disease transmission. Here a woman is seen cleaning her face with water while another woman cleans her yard in a village of West Bengal, India. Photo credit: Avijit Ghosh/The Times of India

Table 8  
**How Gender Roles Can Affect Risk for Trachoma Infection**

INDIVIDUAL	GENDER ROLES	TRACHOMA RISK FACTORS	HOW TO ADDRESS WITH F&E
Men	Building Digging Farming Migrating for labor Conducting business at market	Fly contact Exposure to other endemic communities	Household latrines Face and hand washing
Women	Caring for children Cleaning household Caring for animals Farming, depending on local context	Fly contact Exposure to young children Exposure to poor sanitation in the household	Household latrines Face and hand washing Child hygiene promotion Feces burial, refuse disposal





Students wait to perform a traditional dance.  
Photo credit: James Kiyima/WaterAid

#### Case Study 19

### Improving WASH Through Music and Dance

**The Ugandan Music, Dance, and Drama (MDD) festival is an annual competition supported by the Ministry of Education and Sports (MOES).** Students showcase traditional dances, songs, poetry, drama, and speeches during the regional and national competitions. The MDD is a traditional and entertaining platform for communication that provides a friendly and effective entry point for sharing messages with students and the community. The theme for one year's competition was "Improve school Water, Sanitation, and Hygiene (WASH) for better health of children to enhance inclusive quality learning and development", which was selected by the MOES after collaborating with the Ministry of Health's Trachoma Elimination Program. It was through this interaction that the MOES realized the importance of WASH in schools and the need to share these health messages. Of the 44 schools that reached the finals, nine schools were from trachoma endemic areas. The incorporation of a WASH theme into existing education activities highlights the power of partnerships and integration, and involving students as change agents.

## Cultural considerations: Practices and beliefs

### Individual behaviors arise from community norms.

These unwritten rules govern how male and female members of a group manage their own behaviors, establish habits, and regulate their relationships with others. Although there are similarities among cultures that share the same language or religion, all communities have particular preferences of acceptable behaviors and interactions. Unique cultures and norms can also exist within subgroups of a community and even specific households. Behaviors related to food preparation, defecation, waste disposal, and physical contact have evolved based on traditional beliefs, many with the intent to reduce perceived threats to public health. Many of these beliefs may be inaccurate in light of current knowledge of infectious diseases, but they remain powerful influences on behavior.

Taboos are behaviors that are considered forbidden or unacceptable. For example, in many West African countries, it is taboo to eat or shake hands with the left hand because it is used for cleaning after defecation. Many taboos exist for a good reason and help maintain standards of cleanliness and hygiene within communities. Other beliefs may be based on local superstitions or religious practices and may not have any direct effect on the health of the community. Regardless, it is the program's responsibility to recognize how cultural norms and beliefs inform behavior and find creative ways to implement programming while respecting local cultures.

Most trachoma program managers are probably aware that changing community norms and behavior is a difficult and lengthy process. Women can be motivating change agents in their communities as they usually hold numerous responsibilities that influence the livelihood of their families. Practice and beliefs that women hold can therefore be passed down to their sons and daughters, instilling change throughout generations. Understanding a community's perception about gender, hygiene, and sanitation is key to designing targeted, successful sanitation interventions.

## Cultural divisions of labor

**Most cultures have some form of gender-specific division of labor.** For example, in rural sub-Saharan Africa, women are generally responsible for domestic tasks such as child care, cooking, and cleaning, whereas men are generally responsible for animal herding, construction, and heavy manual labor. In some communities, there is substantial overlap between the tasks men and women are permitted to perform. In more restrictive groups, there may be a distinct separation of labor between the sexes to the extent that men and women are not allowed to share duties. Although the primary responsibilities between men and women may be different, gender-based divisions of labor are often complementary. In female-headed households, women may take on traditionally male tasks, notably for widows.

Most hygiene and sanitation programs, including latrine and water-point construction, require a contribution from either the community or individual household. Such a requirement can have a significant impact on the acceptance of the intervention. For example, if a latrine project requires the household to dig the pit, a household where the male head is absent may not participate if women are not able to perform manual labor. If the objective is to reach high rates of latrine coverage, then the program should reconsider its implementation strategy for this demographic to ensure that female-headed-households are reached. For example, this may require male and female community volunteers to dig a latrine hole or paying someone to complete the work. Achieving high coverage with sanitation interventions requires programs to understand gender roles and to encourage all men and women to work in cooperation so that all members of the community can participate, regardless of physical capacity.

The latrine construction example above highlights the need to develop implementation strategies with a gender-equitable perspective. In the case of latrines, community development projects must be delivered in such a way that all demographic groups have access (e.g., men and women, rich and poor, young and old) which will ensure the highest rate of acceptance.



A health club student at the Naserian Primary School in Naroosura, Kenya, demonstrates how to wash his hands and face properly. Photo credit: Leeshia Crayton/International Trachoma Initiative

The following steps will ensure gender equity in community hygiene and sanitation projects:

- 1. Know the community.** Ask questions during information gathering and baseline/impact surveys, such as: What types of households exist in your target communities? What proportion of households has access to sanitation? Do men and women share latrines? Water points? Bathing areas? Who is responsible for washing children?
- 2. Mobilize for community involvement.** Hold stakeholder meetings to gain support for intervention among male leaders, female leaders, religious figures, and local government.
- 3. Develop the delivery approach.** Does the program have a delivery plan that ensures all members of the community have equal access? How will men and women each contribute? Is there anyone who will be excluded? Make a list of what is expected of each household and each household member. Remember to assign roles according to what is culturally appropriate in regards to gender.
- 4. Make a list of barriers individuals might encounter.** Consider how gender roles limit participation. Remember other underrepresented groups such as poorer households, people with disabilities, nomadic groups, ethnic minorities, and polygamous households.





Aberu, a teacher who is passionate about trachoma education in Tigray, Ethiopia. Photo credit: Light for the World

#### Case Study 20

### Teachers Against Trachoma in Tigray

**Aberu is a young preschool teacher at Hagere Selam Primary School in the district of Hinatalo Wajirat located in the Tigray region of Ethiopia.** She is one of the teachers who has participated in the training to equip teachers with the skills to convey trachoma health messages, which are key factors in the prevention of trachoma, for preschool girls and boys.

"It was a great opportunity for me. I have learned a very basic concept that is very useful for me as a preschool teacher. I used to teach upper classes like fifth and fourth graders. Teaching small children was a new experience for me and I took this training as a capacity development opportunity where I have learned techniques on how I can deliver content in a way that is suitable to preschool children," said Aberu.

The approach used in the training focused on how the teachers can break down trachoma messages to make them understandable for preschool children through a character called Toto. The children loved the approach and the character Toto and were excited when she was acting and speaking like him. It was fun and she witnessed how the children retained the messages they were given the next day during a question session about trachoma and its transmission and prevention.

"I always wondered about how we could entertain issues besides the main subjects that are also important for their wellbeing. The training has opened my eyes and shown me how to do that. After I demonstrated what I have learned in the classroom with the kids and saw how engaged and enthusiastic they were, I started thinking that I can also deliver my subject matters in the same interactive ways," said Aberu.



## Building capacity of village committees

**Achieving sustainable improvement through sanitation projects or other community development initiatives requires community support and commitment.** During the project planning stage, program managers should remember to build or strengthen a community management component as part of the implementation plan. Committees support the long-term functionality of the project. Committees can also provide women with institutionalized leadership roles that may not exist elsewhere in male-dominated local leadership structures.

### Case Study 21

## Children's Influence in Promoting Hygiene

**Roman Eyasu is a member of the Health Development Army (HDA) in Hintalo Wajirat district, in Tigray, Ethiopia.** Roman has been part of a five-month-long innovative pilot training focusing on health education for trachoma prevention which targets girls and boys below the age of six, and involves both school staff and selected community members.

"The first time I heard about trachoma prevention was from my young daughter, who came home from preschool and spoke about the importance of face washing. She asked for her own face cloth so that she would not have to share with her siblings, as she was taught in class. Once I heard this from her, I wanted to get involved and joined my fellow HDA members at the following training."

The training is geared towards equipping community members with tools for educating their networks and neighbors about trachoma prevention and has motivated Roman to set an example for her community by making changes to her own household.

"My house is now cleaner and safer for me and for my children. Before receiving the training, I never focused much on my children's hygiene, but now I follow their hygiene practices daily. I check their face and hand cleanliness, and I encourage them to check themselves before they go to school. This has made a big change in our family."

During the months of the ongoing pilot, many community members took the initiative to encourage facial cleanliness monitoring. Roman decided to purchase a mirror for her house and reports that it has been a major factor in helping her children stay clean. She also changed the latrine in her house to an improved latrine and the impact on her surrounding community was swift. "All the households in my network have constructed latrines after seeing my newly constructed latrine," says Roman. "After being an HDA for seven years, I now feel like people listen to me more. This made me motivated to continue trying to impact my community."

When asked about her wish for the future, Roman says, "my wish is to make all 30 households in my network 'model households', and for my kebele (village) to reach a status of 'model kebele'. I believe we can reach these goals soon."

## Children as agents of change: School health

**Primary and secondary school programming is a viable method to provide targeted health education for girls and boys.** In areas where school attendance is high among children, school health programs can make a significant impact. Other ways of reaching the younger population of a community include youth groups or clubs and local organizations. Initial assessments of health education targeting children and youth should use sex-disaggregated local data to determine how best to reach both girls and boys of the target age range, including any differences among children from special populations.

In most resource-poor countries, ministries of health and ministries of education work together to develop health education curricula for primary and secondary school students. School health programs use the existing education infrastructure to deliver disease prevention and health promotion information to children who likely do not have such access within their own households. In trachoma endemic areas, school health programs are used to promote hygiene and sanitation by installing latrines as well as face and hand washing areas while trachoma lessons are integrated into the standard curriculum to encourage both male and female students to continue these practices at home.

A variety of materials have been developed to educate students on trachoma. Exercise workbooks, games, cards, posters, stickers, and school notebooks are just a few examples of health education materials targeted to a school-age audience. Programs that use innovative materials, including those in local language or focusing on images rather than words, have been successful in motivating girl and boy students about trachoma control. Materials should include gender-sensitive content that shows both girls and boys engaged in positive health promotion activities. In addition, focus group testing by schools with parents can promote the best results without reinforcing harmful gender stereotypes.

School health programs are based on the theory that children are more open and willing to adopt new behaviors than adults. Children are often more willing to question existing cultural practices and beliefs and are often excited by new ideas and information. Because older children play a critical role in household maintenance and the care of younger siblings, there is a ripe opportunity for transfer of knowledge among children.

### Box 16

#### Components of School Health Programs

- 1. Make the community aware of the program.** Gain community support for health education among schoolchildren. Encourage local educators and leadership to publicly support the use of male and female children as agents of change and sources of health information.
- 2. Create a healthy school environment.** Install hand and face washing stations and latrines on school grounds; enforce use for boys, girls, and male and female educators and administrators. This will improve the overall cleanliness of the school environment and provide students with the opportunity to practice these behaviors.
- 3. Train educators in trachoma control and prevention.** Conduct one- or two-day trainings in collaboration with the local education department to ensure that both female and male instructors understand the importance of trachoma control and introduce participatory teaching methods.
- 4. Schedule regular health education sessions.** Encourage female and male educators to conduct hygiene checks each morning and hold lessons at least once a week. Create sanitation clubs, drama groups, hand and face washing leaders, and school-cleaning groups to encourage participation and practice of hygiene behaviors.
- 5. Encourage both male and female students to debate the health and hygiene situation of their communities.** During health lessons, instructors should involve all students in a discussion about the health problems in their communities. Explore causes and solutions.



The Super School of 5 superhero characters are used in WASH education to promote hygienic practices. Illustration credit: Sightsavers, Unilever, Lifebuoy, and UK AID

#### Box 17

### WASH Education for Children: Super School of 5

**The Super School of 5 is a 21-day school program established by Sightsavers to educate children about hygiene, particularly hand and face washing.** The program focuses on developing the habit of washing the face and hands during five key points of the day. The creators specifically chose 21 days because this has been shown to be the optimal time for people to learn a new habit.

In the program, children are introduced to five super heroes, each of which represents the five key times during the day to wash their faces:

- **Biff**  
(before breakfast)
- **Bam**  
(lunchtime)
- **Pow**  
(dinnertime)
- **Hairyback**  
(after the toilet)
- **Sparkle**  
(during bathing)

The superheroes in the story fight their arch nemesis, Nogood, who loves germs.

Throughout the 21 days, children learn games, songs, and dances to help them learn about hygiene, and are also encouraged to make up their own songs and draw murals. Schools have the chance to win prizes in competitions set up both within schools and between neighboring schools. At the end of the 21-day program, the children receive a certificate of completion.

As of 2022, more than 300,000 children have been educated by the Super School of 5 program and 3,700 teachers across 340 schools have been trained on hygiene behavior change.



## Case Study 22

### WASH at Ngagula Primary School

**Maureen Mwinga is the headmistress at Ngagula primary school, located in Chikankata, Zambia.** Ngagula school is one of the most remote and resource-limited schools in the country, with the most students yet few teachers. The nearest well is 2.5 km away, so children either carry water from home or take time out of class to walk and collect water. Time spent retrieving water means time away from learning.

When the Super School of 5 introduced an inter-school challenge for the best health messaging campaign, Miss Mwinga knew they would need to be creative to come up with solutions that used very few resources. Parents from the community wanted to help, so they suggested buying metal signs to hang around the school for the health messages. Miss Mwinga knew they wouldn't have the money to purchase signs or paint, so she came up with another solution. Instead, parents and students collected stones and bricks, then painted them with natural paint made from soil and water. Instead of expensive buckets and stands, the teachers used a five-liter container to create a hand washing station, which was tended to by class monitors to ensure it had water throughout the day for all to wash their hands. Their creativity continued when they noticed the soap kept falling out of the holder onto the dusty ground and children were washing their faces with dirty soap. Miss Mwinga found some empty plastic bottles at a workshop she went to and brought them back to the school. She cut them into secure holders for the soap and tied them to the washstands with string.

When the judges came to the school to inspect their health campaign, they were so impressed. Ngagula primary school won the contest, and received a water tank as the prize. In addition to winning the contest, Miss Mwinga heard from parents the impact the health campaign had on their students. They noticed a marked difference in the faces of the students and their cleanliness upon arriving home from school.

Miss Mwinga shared her philosophy that when creating a learning environment for children, you must combine academics and health. Combining the two ensures children stay healthy, are able to keep up their attendance at school, and not miss class.

They noticed a marked difference in the faces of the students and their cleanliness upon arriving home from school.



Maureen Mwinga, a creative headmistress at a primary school in Zambia, whose creative WASH health messaging campaign led to a new water tank for the school. Photo credit: Sightsavers, Unilever, Lifebuoy, and UK AID

## Suggested Reading

Curtis V. Hygiene: how myths, monsters, and mothers-in-law can promote behavior change. *Journal of Infection*. 2001;75–79. *The author of this article tries to understand hygiene behaviors from a social and cultural perspective, and argues that myths, taboos, and traditions are powerful determinants of health and behavior.*

Greenland, K., White, S., Sommers, K., Biran, A., Burton, M. J., Sarah, V., & Alemayehu, W. (2019). Selecting behaviour change priorities for trachoma 'F' and 'E' interventions: A formative research study in Oromia, Ethiopia. *PLoS Neglected Tropical Diseases*, 13(10), 1-19. doi:10.1371/journal.pntd.0007784. *Authors conducted formative research in a trachoma hyper-endemic area of Ethiopia to explore the behaviors which are likely to contribute to trachoma transmission. They found existing norms and enabling factors in this context favor the development of interventions to improve facial cleanliness as more feasible than those that reduce unsafe feces disposal.*

International Coalition for Trachoma Control. All you need for F&E toolkit: a practical guide for partnering and planning. 2015. <https://www.trachomacoalition.org/FandEplanningguide>. *This toolkit helps trachoma program managers and planners find potential partners and guides them through the process of planning for F&E. It contains practical planning tools that are structured along key steps.*

Pouramin P, Nagabhatla N and Miletto M (2020) A Systematic Review of Water and Gender Interlinkages: Assessing the Intersection With Health. *Front. Water* 2:6. doi: 10.3389/frwa.2020.00006. *The authors found a strong intersection between the water-gender nexus and health outcomes. For example, women are burdened as a result of their role as water purveyors, a lack of private and secure latrines disproportionately impact women, and women have less access to sustainable hygiene resources.*



A CDD Supervisor is responsible for verifying treatments were distributed to the community and reporting daily treatment numbers to the DHO, amongst other tasks. Supervising MDA takes community members away from their families for more than 8 hours a day to help support their community in the fight to eliminate trachoma. Pictured here, is a CDD Supervisor from Bulissa, Uganda who has neighbors watch her children for the duration of an MDA campaign to help her community. Photo credit: Gilbert Baayenda/ International Trachoma Initiative



# Appendix A: Sample Guide for Key Informant Interviews

## Questions for head of households and mothers with children under five years of age

### WATER USE AND FACE WASHING

- Where do you collect water from? (How far is it from your home?)
- What are the most important uses of water in your community? (Follow-up question: Why is \_\_\_\_\_ an important use of water?)
- If water in the household is limited, what will you use the water for? (Why have you chosen that use? Who makes decisions about the use of water?)
- How do you clean a child's face? (With water? Without water? What do you use?)
- What do you think about children with a clean face? (Why do you think that?)
- How do you feel when you see children with dirty faces? (Why do you feel like that?)

### DEFECATION

- How do you feel about people defecating in the bush? (Why do you feel that way?)
- How do you feel about people defecating in and around your village? (Why do you feel that way? Adults, children, babies?)
- Why do some people choose to defecate near the village? (Why do you think they choose that?)
- Why do some people choose to defecate in the bush? (Why do you think they choose that?)
- What do you think about digging and burying feces after defecating? (Advantages? Disadvantages?)

### COMMUNICATION

- Is there a person in the village to whom everyone listens and respects about health matters? (Who is this person? Why do you listen to him?)
- Are there traditional healers in the community? Do people listen to health messages given by this person?
- How would you feel about a woman in the community giving health education messages? (Does it matter what the message is? Who the woman is? Why does it matter?)

### SANITATION AND HYGIENE

- How do you feel about the level of sanitation in your community? (Describe sanitation practices in the community.)
- Is it a priority to have a clean compound? (What makes it a priority? Or not a priority?)
- Is it a priority to be physically clean? (What makes it a priority? Or not a priority?)

### FLIP CHARTS

- Look closely at these two flip charts. Which is easier to understand: drawings or photos?
- What do you like best? (Ask why the person likes that aspect.)
- What do you like least? (Ask why the person does not like that aspect. What could be done to make it better? How can the message be made more clear?)



## Case study credit

Case Study 1: Sudanese Female Ophthalmic Surgeons Focused on Saving Sight—*The Carter Center*

Case Study 2: Trachoma Elimination in the Pacific Islands—*The Fred Hollows Foundation*

Case Study 3: A Positive Force for Trachoma Elimination in Ghana—*Sightsavers International*

Case Study 4: An Epidemiologist's Commitment to Trachoma Elimination—*The Carter Center*

Case Study 5: A Young TT Case Finder's Story—*Sightsavers International*

Case Study 6: Fighting Myths: Female Grader in Zambia—*Lion's Aid Zambia*

Case Study 7: Case Finder in Zambia Helps Her Community—*Sightsavers International*

Case Study 8: TT Case Finders and Gender—*The Kilimanjaro Centre for Community Ophthalmology*

Case Study 9: Women Microfinance Groups in Tanzania—*The Kilimanjaro Centre for Community Ophthalmology and The United Republic of Tanzania Ministry of Health*

Case Study 10: Gender Considerations in Zambian Programming—*Lion's Aid Zambia*

Case Study 11: Pakistan's Lady Health Workers Program—*The Fred Hollows Foundation*

Case Study 12: The Importance of Female TT Surgeons—*Christian Blind Mission*

Case Study 13: Community Health Worker Finds Personal Motivation for Trachoma Elimination Work—*Lion's Aid Zambia*

Case Study 14: MORDOR Study—Tracking a Reduction in Childhood Mortality—*The Carter Center*

Case Study 15: Benefits of Female Community Drug Distributors in Sudan—*The Sudan Federal Ministry of Health*

Case Study 16: Media Habits Survey in Sudan—*The Carter Center*

Case Study 17: Gender Considerations in Sindh Province, Pakistan—*Christian Blind Mission*

Case Study 18: Radio Messaging as a Behavior Change Tool—*The Carter Center*

Case Study 19: Improving WASH Through Music and Dance—*The Carter Center*

Case Study 20: Teachers Against Trachoma in Tigray—*Light for the World*

Case Study 21: Children's Influence in Promoting Hygiene—*Light for the World*

Case Study 22: WASH at Ngagula Primary School—*Sightsavers International*

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