# Women and Trachoma

Achieving Gender Equity in the Implementation of SAFE



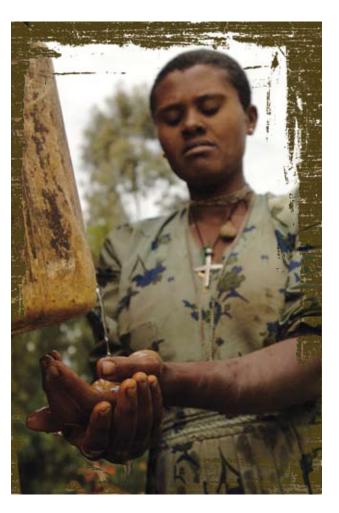
THE CARTER CENTER



THE ELFENWORKS FOUNDATION in harmony with hope<sup>in</sup>

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Achieving Gender Equity in the Implementation of SAFE





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# ACKNOWLEDGEMENTS

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# WOMAN OF AFRICA

Sweeper Smearing floors and walls With cow dung and black soil, Cook, ayah, the baby tied on your back, Vomiting, Washer of dishes, Planting, weeding, harvesting, Store-keeper, builder, Runner of errands, Cart, lorry, Donkey...

> Woman of Africa What are you not?

Excerpt from *The Song of Ocol* by the Ugandan Poet Okot p'Bike

# CONTENTS

# 

Surgical Program Planning and Delivery13
Barriers to Surgery
Economic and Social Barriers15
Individual Factors
Seasonal and Daily Calendars18
Community-Based Solutions to Improve Access to Surgery
Approaches to Surgical Delivery: Facility-Based vs. Campaign-Based19
Counseling
Counseling Before Surgery
Counseling After Surgery20
Follow-up of Trichiasis Surgery21
Monitoring and Evaluating Surgical Program:
Setting Targets
Guidelines for Monitoring23
Guidelines for Record Keeping

# Chapter 3 — Reaching Men and Women

with Antibiotic	. 26
Implementation of Antibiotic Distribution	. 27
Setting Targets	. 27
Community Mobilization	28

Training of Distribution Teams
Antibiotic Distribution and Pregnancy
Approach Options: Central Site vs. House to House . 29
Distribution Delivery
Households with Absent Men
Monitoring for Gender-Specific Coverage
Distribution Records
Coverage Survey
Chapter 4 — Behavior Change and Gender36
Understanding Behavior Change
Gathering Information About the Community38
Survey of Information Sources
Promotion of Positive Behaviors
Reaching Men to Encourage Behavior
Change Among Women
Development of Health Education Materials with a Gender Perspective
Identifying Subgroups42
Designing Health Education Materials
Pretesting Health Education Materials43
Producing and Distributing Education Materials45
Radio
Chapter 5—Achieving Equity in F and E48
Hygiene and Gender-Specific Risks
Cultural Practices: Taboos and Rituals
Cultural Divisions of Labor
Building Capacity of Village Committees52
Children as Agents of Change: School Health52
Appendices
A: Sample Forms for Monitoring Surgery
<ul><li>B: Sample Forms for Antibiotic Distribution 66</li><li>C: Tools for Conducting Background</li></ul>
Research for Health Education

# FOREWORD

#### By Former U.S. President Jimmy Carter

We all have common goals for our families. We want our children to be healthy, for there to be peace and stability in our homes, for our children to do well at school, and for their lives to improve. But in those parts of the world where trachoma is a sad fact of life, people live very different lives from ours. The division of labor and household chores is strongly gender based, and there is no equality between men and women. Children harbor the bacteria that cause trachoma, and, while caring for them, women are exposed to infection more frequently than their husbands, whose responsibilities are outside the home. As a mother's disease progresses and her evelashes begin to rub and slash her cornea, those same children—often girls—return her love by dropping out of school to do their mother's chores and care for her. In this way trachoma disproportionately affects women and sets young girls, the next generation of women, on a path of perpetual poverty.

After visiting trachoma-endemic communities around the world, Rosalynn and I have witnessed all of this firsthand. All too often when village leaders introduce us to people who are suffering from trachoma or who have been saved from blindness by a simple operation, three out of every four are women. And when we visit their homes the children are reluctant to come out of their modest huts because they have no shoes or good clothes and are embarrassed to show themselves to visitors.

The World Health Organization has set the year 2020 as the target to eliminate blindness resulting from trachoma. This is a difficult but achievable target. To get there we must have inclusive community-based programs that offer freedom from trachoma for all, but that also specifically and deliberately target women and girls. Women must be reached with health education so that they can protect their children from trachoma. They must be reached with treatment to cure their



Former U.S. President Jimmy Carter greets a woman during a trip to see trachoma control efforts in the Amhara region of Ethiopia.

current infections. They must have access to water and sanitation, and they must be able to benefit from eyelid surgery in a way that they can easily access it. The "Women and Trachoma" manual uses case study examples, illustrations, program success stories, and step-by-step guidelines to enable the managers and planners of trachoma control programs to provide a gender-equitable SAFE strategy. I encourage students and those involved in trachoma control programs to use this manual and apply all that is relevant to their countries to ensure that the needs of women are not overlooked. Together, we can turn blinding trachoma from an accepted sad fact of life to a condition of the past and free families from this terrible disease.

# INTRODUCTION: TRACHOMA AND GENDER

his manual will provide anyone interested in increasing equality in use of eye care services in developing countries with the knowledge and skills necessary to ensure that trachoma control programs are gender-sensitive. While the focus of this manual is 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 trachoma control efforts should consider gender roles and responsibilities in order to reach the goal of GET 2020: the global elimination of blinding trachoma by the year 2020.
- Explains how to revise existing monitoring tools to better assess the success of programs in eliminating blinding trachoma.
- Provides experiences from a number of African countries on how to engage women and girls in aspects of trachoma control.
- Offers practical solutions to challenging problems of behavioral change related to use of surgical services, hygiene and sanitation issues, and improved environmental conditions.

#### What Is Trachoma?

Trachoma is an infectious eye disease caused by *Chlamydia trachomatis*. Over time, repeated infections result in the development of scar tissue on the inside of

# Normal Eyelid



**Trachomatous Inflammation — Follicular (TF)**: The presence of five or more follicles of at least 0.5 mm in the upper tarsal conjunctiva.



Trachomatous Inflammation — Intense (TI): Pronounced inflammatory thickening of the tarsal conjunctiva that obscures more than half of the normal deep tarsal vessels. (Photo shows TF and TI.)



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



**Trachomatous Trichiasis (TT)**: At least one eyelash rubs on the eyeball, or there is evidence of recent removal of in-turned eyelashes.



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

*Figure 1.1.* The World Health Organization standardized grading system for trachoma.

the eyelid (the conjunctiva), which pulls the eyelashes toward the cornea. This condition is known as trichiasis. When the eyelashes touch the cornea they cause incredible discomfort and damage, which can lead to blindness.

The severity of trachoma can be identified using the simplified grading system, which classifies trachoma

into five distinct grades based on the presence of the clinical signs of the disease: trachomatous inflammation follicular (TF); trachomatous inflammation intense (TI); trachomatous scarring (TS); trachomatous trichiasis (TT); and corneal opacity (CO). Grades TF and TI are most commonly seen in children between 3 months and 10 years of age, while the more advanced stages of disease—TS, TT, and CO—are typically found in adults. However, in hyperendemic settings, it is not uncommon to see trichiasis in children and young adults. Figure 1.1 illustrates the five different clinical signs of trachoma disease.

Trachoma has a variety of biological consequences throughout the life span, from early childhood through late adulthood. 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, and 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 result in trichiasis. Not all people with trachomatous inflammation develop scarring on the inside of the conjunctiva, and not all people with conjunctival scarring develop trichiasis. In addition,



not all cases of trichiasis lead to blindness.

# Trachoma and Gender

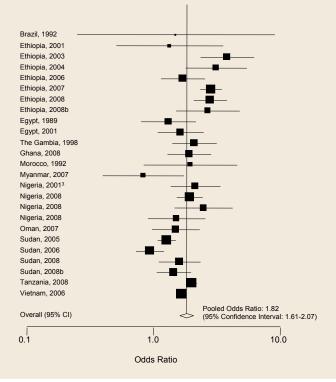
There is evidence from surveys carried out in many trachomaendemic countries that significantly more women than men are blind due to trachoma. The evidence for a sex-linked predisposition for infection among women and girls is inconclusive. The excess risk for and complications of trachoma borne by women through the course of the disease suggest that factors other than biology are involved. It has been suggested that women are more susceptible to trachoma infection (and therefore trichiasis) due to their disproportionately high contact with children as compared to men.

Ocular Chlamydia is spread through direct personal contact, shared sleeping spaces, towels, and clothes, contact with flies that carry the bacteria from ocular and nasal discharge. In young children the prevalence of active disease seems to vary, with a slight excess risk for girls (although in some surveys the prevalence of active trachoma in girls was lower than in boys). The differences in the prevalence of active trachoma between girls and boys are not as significant as they are between women and men. There is little evidence to suggest girls are more biologically susceptible to infection than boys; however, there is some evidence that suggests that the girls account for a higher proportion of the community load of Chlamydia trachomatis. Heavy bacterial loads also may explain why persistent infection is more common in girls. 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.

It is not uncommon for girls as young as 5 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. Research has shown that for each additional child with active trachoma in a household there is a subsequent additional risk of trichiasis in the mother.

It is clear that by adulthood, women are more likely to have trichiasis compared to men, regardless of their age. A recently prepared meta-analysis of trachoma surveys from around the world showed that, overall, women were 1.8 times more likely to have trichiasis compared

An Ethiopian woman and child.



**Figure 1.2.** 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.

to men. The excess risk ranged from 1.3 to 3.9 in eight countries. In individual surveys where this analysis has been undertaken, it has been demonstrated that women have a statistically significant increased risk of trichiasis (see Figure 1.2).

While there is good evidence to show that women generally have higher rates of blinding trachoma, the absence of good, context-specific behavioral research limits our understanding of the specific gender roles that contribute to the progression from infection to blindness. Figure 1.4 shows the gender-specific risk of developing blinding trachoma.

#### The Global Challenge of Trachoma

Although trachoma was once a public health problem worldwide, it was eliminated from North America and Europe in the early 20th century due to a combination of control efforts and improved standards of living. Trachoma now largely affects people in low socioeconomic conditions in the rural, often remote areas of Africa, southeast Asia, Central and South America, the Middle East, and Australia. Regions such as the Sahel and the Nile and Rift valleys of Africa are settings of limited economic development, low sanitation coverage, and poor access to preventive health care. Although there are still pockets of disease in the Middle East, Asia, the Americas, and Australia,

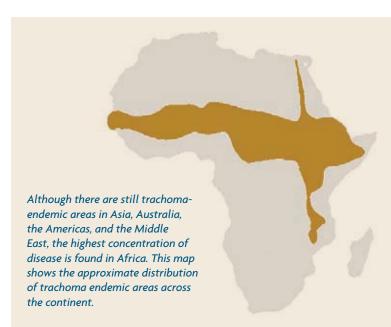


Figure 1.3. Map of trachoma-endemic countries.

control efforts in these regions, combined with increased economic development, have resulted in major reductions in trachoma infection. The majority of the case studies and examples in this manual feature the African context, because the continent accounts for the largest proportion of global trachoma and trichiasis. Figure 1.3 shows the distribution of trachoma endemicity across the African continent, with endemic areas found within an estimated 57 countries.

#### Box 1.1 SAFE Strategy for Trachoma Control

Surgery is used to reverse the in-turned eyelashes of patients with trichiasis. 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.



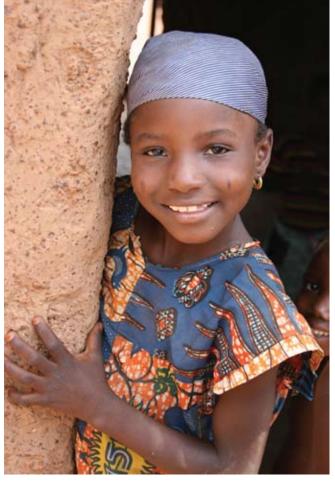
Antibiotics are used to treat active trachoma and to reduce the reservoir of infection in a community. Topical tetracycline eye ointment applied to the eyes every day for six weeks will treat active trachoma. Alternatively, the drug azithromycin can be taken orally in tablets (or liquid for infants), and one dose per year will treat active trachoma. The World Health Organization recommends that all individuals in communities where the prevalence of active trachoma exceeds 10 percent of children ages 1 to 9 be mass-treated with antibiotic therapy.

Facial cleanliness refers to the promotion of improved hygiene. Dirty faces are associated with trachoma infection. Children with dirty faces are more likely to transmit trachoma if they have an active infection or get trachoma if they are not infected. 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 mother's shawl can contribute to the



transmission of trachoma. Trachoma control programs must convey that it is desirable for children to have a clean face — and that this should be the usual state.

nvironmental 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 will return after antibiotic treatment.



A young girl from a formerly trachoma endemic region in Ghana.

As part of the World Health Organization's Vision 2020 initiative, the Alliance for the Global Elimination of Trachoma by the year 2020 (GET 2020) was formed in 1997. The GET 2020 Alliance supports international organizations, nonprofit groups, and national trachoma control programs to coordinate efforts to eliminate blinding trachoma.

The strategy endorsed by the World Health Organization (WHO) to control trachoma, known by the acronym SAFE is an integrated approach to prevent new trachoma infections and to control and treat existing cases of trachoma and trichiasis. SAFE stands for Surgery, Antibiotics, and Facial Cleanliness and Environmental Change (see Box 1.1). SAFE strategy interventions include surgery to correct trichiasis, mass antibiotic distribution 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.

# The Diverging Risks of Exposure to Trachoma

Over the course of their lives, women spend more time with children than men. Because young children are the reservoirs of trachoma infection, contact with them can result in more frequent trachoma infection. This gender-specific exposure to trachoma risk factors places women at a higher risk for trachoma infections and subsequent blindness. Although both men and women can develop trichiasis, the odds of trichiasis are greater among women than men.

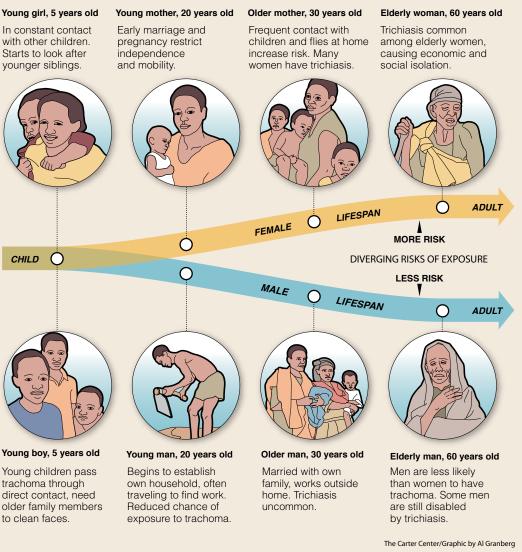


Figure 1.4. Gender-specific life stages and trachoma.

An impact evaluation of implementation of the full SAFE strategy was conducted in Southern Sudan and demonstrated reductions of trachoma signs in children

up to 90 percent. In 2008, Ghana completed a national evaluation of trachoma-endemic areas that demonstrated reductions in the prevalence of TF and TT well below the intervention thresholds established by the WHO. Morocco and Niger have also reported significant

# Box 1.2

#### The Difference Between Gender and Sex

Sex is the term used to distinguish males and females on the basis of their biological characteristics.

Gender refers to the socially constructed characteristics used to distinguish men and boys from women and girls. achievements in the elimination of blinding trachoma as a public health problem.

## The Role of Gender

In most cultures, gender defines appropriate social roles, behaviors, and expectations (see Box 1.2). There is immense diversity in gender roles both within and among different countries and regions, not limited to ethnicity, urban and rural areas, and 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 paternalistic societies in Africa, men typically provide resources for the family, and women are responsible for housework, child care, and, increasingly, agricultural activities.

#### **Gender-Specific Activities**

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, fetching 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 are responsible for caring for the sick, which exposes them to infectious agents more regularly than men. Women are 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, venturing beyond these bounds can be

#### Case Study 1.1 Family Decision Making in Ethiopia

In rural Ethiopia, the Anteneh family struggles to support themselves through subsistence farming. Husband and wife, Wolde and Seratu have four children. Although they have encouraged their children to go to primary school, their eldest daughters Sirgut and Tigist remain at home to help their mother fetch water and firewood, tend their animals, watch after their younger siblings, and assist with farming. Their eldest son, Abebe, left the family two years ago to work in a nearby town. He returns to help the family during the intensive farming seasons. Of the family's limited financial resources, the father has control over spending and makes decisions about renting land, making home repairs and participating in community projects. His wife is responsible for maintaining the household and taking care of the family. With the limited resources she receives from her husband, she prepares their regular meals and looks after sick children and her elderly relatives. Even though Seratu contributes significantly to the economic and social stability of her household, she must seek permission from her husband before she can spend money, leave the community, or participate in other activities.

Right: A Nigerien woman sells food for her personal income.

threatening and prohibited. Where women do not experience a great deal of mobility outside of the community, they generally have less access to health care services. This can lead to less confidence and trust in people and organizations from outside.



A woman from Sudan.

# Economic Decision Making

In many resource-poor settings, a woman's financial dependence on men has many consequences. Diseases that disfigure or disable women, such as trichiasis, leprosy, lymphatic filariasis, or developmental deformity can block marriage prospects. This leaves the woman as a burden to her family. Physical deformity also can



be the basis of divorce or abandonment if they occur during marriage. Often women disguise illness or develop coping strategies 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 also used for boys before girls, further reducing access to health care among girls and young women.

## Women's Capacity to Effect Change

Although it is easy to generalize about the condition of women in paternalistic 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,

#### Box 1.3 Gender Equity and the Millennium Development Goals

Four of the eight Millennium Development Goals include a gender component:

- Goal 1: Eradicate extreme poverty and hunger
- Goal 2: Achieve universal primary education
- Goal 3: Promote gender equality and empower women
- Goal 4: Reduce child mortality
- Goal 5: Improve maternal health
- **Goal 6:** Combat HIV/AIDS, malaria and other diseases
- **Goal 7:** Ensure environmental sustainability
- Goal 8: Develop a global partnership for development

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 decisionmaking 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. Women are often portrayed as passive members of society, when in reality they are active participants in their communities who enact change through their own mechanisms to improve the well-being of their families and households. Case Study 1.1 shows how gender affects the decisions made in one Ethiopian family.

#### **Millennium Development Goals and Gender**

When the United Nations established the Millennium Development Goals (MDGs) in 2000, it set formal targets for public health, education, and economic development programs and institutionalized the promotion of gender equity. The MDGs provide a useful framework for considering the impact of gender on access to health services and on education and economic opportunities. Half of the eight MDGs are directly related to the gender-balanced implementation of the SAFE strategy. The inclusion of gender-specific program design and delivery will promote gender equality and empower women (MDG 3), reduce child mortality (MDG 4), improve maternal health (MDG 5), and ensure environmental sustainability (MDG 7).

To eliminate blinding trachoma, gender must be considered in the implementation of the SAFE strategy. Trachoma control programs should embrace the formal and informal opportunities for innovation specific to both men and women. 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.

### **Suggested Reading**

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 document, produced by WHO, presents an outline of the challenges to the delivery of 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 of the evidence for understanding how the roles and responsibilities of women contribute to their excess risk of trachoma.

Courtright P, West SK. Contribution of sex-linked biology and gender roles to disparities with trachoma. *Emerging Infectious Diseases*. 2004;10:2012-2016. This article explores the evidence *base for gender disparity in blinding trachoma*. The data suggest that exposure to trachoma risk factors is associated with gender.

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.

Frick KD, Basilion EV, Hanson CL, Colchero MA. Estimating the burden and economic impact of trachomatous visual loss. Ophthalmic Epidemiology. 2003;10:121-132. Using data from trachoma surveys the authors have estimated the potential productivity loss due to trachoma blindness (\$2.9 billion) and disability-adjusted life years lost due to trachomatous visual impairment (39 million DALYs).

Geneau R, Lewallen S, et al. The social and family dynamics behind the uptake of cataract surgery: findings from Kilimanjaro region, Tanzania. British Journal of Ophthalmology. 2005;89:1399-1402. Although addressing cataract surgery, this paper provides a rich description of the various social factors, primarily within households, that affect how people use eye care services. 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.

Melese M, Alemayehu W, Friedlander E, Courtright P. Indirect costs associated with accessing eye care services as a barrier to service use in Ethiopia. *Tropical Medicine and International Health*. 2004;9:426-431. Using population-based data this article shows some of the differences between men and women in terms of use to of services and the reasons for not using available surgical services (for both cataract and trichiasis).

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. Data from population-based surveys around the world were used to create some estimates of the global burden of vision loss as well as the causes, including trachoma.

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. In this seven-year cohort study of children, the incidence of scarring was independently associated with constant severe trachoma, age, and female gender, suggesting that these children have different host responses to infection and that they represent a high-risk subgroup.

Zerihun N. Impact of trachoma among rural Ethiopian women: An occupational health issue. *Revue Internationale du Trachome et du Pathologie Oculaire Tropicale et Subtropicale et de Sante Publique*. 1998;143-149. This paper gives a good insight into the interaction between gender and trachoma from the perspective of rural Ethiopian women.



Two young Ethiopian girls.

# 2 GENDER EQUITY AND SURGICAL PROGRAM DELIVERY



rachoma control efforts over the past two decades have led to a significant reduction in blindness due to trachoma. To maintain this momentum and continue to reduce infection and subsequent blindness, new challenges must be met with the same enthusiasm and resources with which trachoma control was initiated. To prevent new trachoma infections and reduce the incidence of trichiasis, we must apply our knowledge of genderspecific risk factors to develop new programmatic approaches to trachoma control.

Surgery is an intervention that confers almost immediate relief to people living with trichiasis, improving quality of life and enabling them to participate in the daily activities of their households. Although blinding trachoma is seen in both sexes, women suffer disproportionately from trichiasis. Trachoma control programs should ensure that access to surgery is available to all those who are suffering with trichiasis, whether they be men; women; or members of minority ethnic groups, distant or nomadic communities, or groups on the fringe of society. Achieving equitable access to surgery among men, women, and children requires program managers to design surgical interventions that reflect the impact of gender on individual surgical uptake, community mobilization, and prevention of recurrence. Unless trachoma control programs target women for trichiasis surgery, it will not be possible to reach elimination targets.

This chapter presents existing evidence for genderspecific surgical delivery, strategies to implement a gender-equitable surgical program, and recommendations for monitoring and evaluating program performance based on gender-specific indicators. Case Study 2.1 introduces the topic with the stories of two girls who faced surgery.

#### Surgical Program Planning and Delivery

The World Health Organization (WHO) guidelines recommend national trachoma control programs assess trichiasis prevalence in adults ages 15 years and older in district-level surveys. Where the prevalence of trichiasis exceeds 1.0 percent in the whole population, intervention with surgery is warranted. Although prevalence data are not currently used to plan sexspecific surgical interventions, the sex and age of survey participants are usually collected during trachoma prevalence surveys. With no need for additional surveys, national programs can use these data to refine surgical delivery programs, set sex-specific targets and develop health education tools to attract the most affected subgroups of the population.



An Ethiopian woman displays the tweezers she uses for epilation.

#### **Barriers to Surgery**

The social consequences of disability are commonly understood. They include less autonomy, reduced self-esteem, infrequent participation in community activities, and limited decision-making authority within a household. Trichiasis is a debilitating disease, regardless of whether patients have strong family networks to support their daily maintenance. Trichiasis patients are isolated by their condition. In virtually all trachomaendemic settings, the reasons for failure to use existing trichiasis surgical services will vary between men and women, however, certain characteristics related to complex social roles and responsibilities are likely to be common.

To increase the uptake of surgery among individual patients, program planners should first ask, "Why are patients not presenting for surgery?" To answer this question, the surgical program should understand that economic costs, social factors, and health system challenges inhibit successful surgical delivery.

#### Case Study 2.1 Trichiasis in Girls

#### Nyakier Mabor Gai, Southern Sudan

"My name, Nyakier, means 'one who was born while crossing the River Nile.' I was born far from home in Unity state when my mother traveled across the River Nile seeking care because she suffered from trichiasis. I don't know my exact age, though my mother believes I am eight years old. She is the first of my father's four wives and supports me and my seven siblings by farming. My father has a small business in another town, and I do not see him often.



Nyakier before (at left) her trichiasis surgery. On the road to recovery, she noticed significant improvement even a few weeks after surgery (at right).

"A few years ago my eyes started hurting me — they were tearing and sensitive to smoke and light. My eyelashes started touching my eyes about six months ago. I haven't been able to open my eyes in the sunlight, so I sit in the shade with the elderly while my friends go out to play. The most I could do was pound and grind cereals for my mother, because I was nearly blind. None of my friends or family knew what to do about my eye pain. My mother prayed that I could receive medical attention, and I could only cry thinking of my hopeless future.

"Now since my surgery, I have been telling everyone I see suffering with trichiasis that they should go to the clinic and be helped. Now that I can see, I told my family that I want to go to school and become a successful person. My mother wants to build a better home for us next to town so I can attend school with my siblings. I want to be an example to others who are suffering from trachoma, to show them that they can be treated and live a successful life."

#### Hadiza Adamou, Niger

While waiting to be screened for trichiasis surgery, 15-yearold Hadiza Adamou recounted her struggle with trichiasis. Hadiza has suffered from trichiasis since she was a young child. According to her sister, 20-year-old Zara, someone placed a spell on Hadiza, which caused her condition. Her family paid a magician to remove the spell, but his magic had no effect on her suffering. Because it was so expensive to use the magician to help Hadiza, her family did not attempt to do anything else to treat her trichiasis.

Several years ago, Hadiza's mother died, leaving her sister Zara to serve as the primary caretaker of the family. Her sister described Hadiza as a "big worry for the home" because "it takes a lot of time to care for her, and she cannot go to school or help around the household." Although they expect her to be independent, there is little hope for her future.

Zara reported that her family, including her father, was very supportive of her sister's surgery. They fear that if her eyesight does not improve, "they will have to look for an old man who wants a second or third wife to have more children. She will not be able to ask for a dowry."

Nyakier's and Hadiza's stories are similar to those of other young women in trachoma-endemic countries. Although the girls lack access to regular health care and medical services, they are hopeful for their future after treatment. Increasing uptake of surgery among young girls is dependent on educating families, particularly fathers, on its long-term benefits.

## Table 2.1 Types of Opportunity Costs for Women Trichiasis Patients

Transport	The need for an escort or assistance by another family member to access trichiasis surgical services prevents the caretaker from performing other tasks that contribute to the household economy. Walking long distances to access services (or reach other forms of transport) incurs other costs such as time and fatigue.
Child care	Patients require assistance from within households and communities to travel and remain at a trichiasis surgery facility or camp. Child care alternatives within their extended family or community must be identified. This may entail collateral costs absorbed by the community, which must be repaid later through the social network.
	There are often costs of social capital to be borne by women who seek assistance for child care and other responsibilities within the community.
Household tasks	Women cannot perform essential daily tasks, such as fetching water and firewood, cooking, and feeding small stock while away from home, and there may be little family support for them to be away. If a male member of the household must also travel with a woman, social support for surgery within a household may be further reduced. Women tend to view their responsibilities within the family to be of higher value than their own health care needs, reducing their willingness to be away from household responsibilities.
	A further difficulty may be the delegation of

responsibility to older children, usually girls who may otherwise be attending school.

## **Economic and Social Barriers**

Trichiasis patients must bear substantial costs to attend surgery, including, but not limited to, monetary costs such as paying for medical care and transport fees. For trichiasis patients who already live in poverty, these costs are enough to deter willing patients from seeking treatment. In particular, women with trichiasis may not have their own financial resources, or they may not be able to divert other household income to pay for medical care.

Monetary costs are not the only expense related to seeking surgery. In some cases, monetary costs are often exceeded by lost economic productivity and contribution to household labor. Economists often refer to these costs as "opportunity costs." An opportunity cost is the value of the alternative activity that is lost after making a decision to spend time doing something else. For example, if a woman presents for trichiasis surgery, her opportunity cost is the value of her time and labor had she spent the day taking care of her family or doing other household chores instead. Table 2.1 outlines the types of costs for trichiasis patients.

When programs consider the accessibility of a health service, the costs (both monetary and opportunity) are not carried by the patient alone. These costs are often extended to other members of the family or household. Not only will the patient spend time and energy to attend surgery, but also relatives and other caretakers must compensate for the patient's absence and postoperative disability. For a woman, access to surgical services often requires additional assistance from a family member. If surgery is too far away, the patient will not

be able to travel. If the amount of effort for a family to seek services is too great, the patient is not likely to attend—even if the program believes it is offering access to "free" surgery by not charging a fee for the operation itself. See Box 2.1 for potential barriers to surgery.

The absence of any member of a household who is seeking medical treatment incurs collateral costs for the rest of the family. Although it is not easy to assign a dollar value to the contributions of each family member, lost time and unperformed household chores are costly to those already on the economic margins of society. Box 2.2 shows an example of the time costs for surgery. Case Study 2.2 describes how surgery benefited one family.

## Box 2.1 Gender-Specific Barriers to Surgery

#### Men

- Seasonal work responsibilities, such as farming, cultivation, gardening
- Animal husbandry activities
- Travel for markets, work opportunities outside village

#### Women

- Decision-making capacity within the household
- Lack of social support to access surgery
- Inability to travel without an escort
- Inexperience with travel outside the village or nearby areas
- Daily domestic tasks, such as child care, cooking, cleaning
- Fetching water, firewood
- Farming
- Market activities, such as selling food or oil

#### Box 2.2

# Time Costs for a Patient to Attend a Surgical Campaign in Southern Sudan

Transport to camp	1 day walking
Screening and registration	1 day waiting for registration
Surgery	2 days waiting for surgery
Postoperative observation	2 days
Travel to return home	1 day walking
Meals missed	1 to 3 per day
Household tasks	1 week of work

# **Individual Factors**

Generating participants for trichiasis surgery is an educational process. In general, patients are uncomfortable and anxious when confronted with an invasive procedure about which they are unfamiliar. Individual trichiasis patients develop coping mechanisms to manage their condition and function within the limitations of their disability. If a trichiasis patient can cope with the condition well enough to still perform regular household chores, the risk of losing his or her limited ability as a result of a failed medical procedure is likely to discourage participation.



Case Study 2.2 A Spouse's Story: Trichiasis Surgery Benefits Entire Family

Accompanied by his wife, Nyaguon, Yuol Makeui traveled to Akobo, Southern Sudan for trichiasis surgery. Yuol, a 40-year-old subsistence farmer, has suffered from trichiasis for the past five years. He has noticed a dramatic reduction in his quality of life and capacity to provide for his family since developing blinding trachoma. Unable to perform any household chores or farming, Yuol cannot contribute to the family economy. His wife provides for the entire family, cultivates the fields, collects water — she is responsible for everything. For now, their teenage children must stay at home to help their mother with the farming and daily tasks, but they will marry soon and leave their parents.

After local health workers visited their village to announce the presence of a surgery camp, Yuol and his wife traveled the day's journey on foot to Akobo. Yuol was able to receive free trichiasis surgery after spending four days waiting at the Akobo hospital. Although his wife also has eye problems, her condition is inoperable. She fears that eventually she will become a burden to her husband and family. Fortunately, Yuol's trichiasis surgery has already begun to improve his vision, and Yuol hopes that after his recovery he and his wife will be able to care for their household together.

A group of people living with trichiasis from The Gambia were interviewed to determine their reasons for not seeking surgery. They reported a wide spectrum of reasons, including the perception that their symptoms were not strong enough to warrant treatment, and having had a previous bad experience with medical care. Other reasons included fear, preference for epilation or traditional treatment, family opposition to treatment, high opportunity costs, unavailability of an escort, and lack of information about the surgery or how to access services.

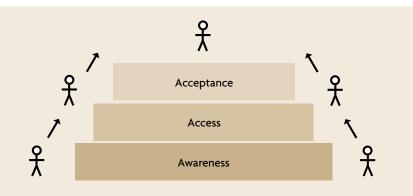
Once program planners understand why patients are not able or willing to present for surgery, they need to ask, "What needs to be in place to enable people to

Table 2.2 Addressing Patient Anxiety About Trichiasis Surgery



Follow-up for trichiasis surgery can be conducted at the patient's home.

Factor Contributing to Anxiety	How to Address the Problem	
Fear of the unknown	Provide positive testimony from age and sex peers, either in person or on the radio	
	Enable friends to attend surgery together because group participation with age mates reduces individual fears	
Medical instruments that are intimidating and unfamiliar	Use a trusted medical staff and system	
Lack of accurate information about the surgery	Use preoperative counseling to educate both patient and caretaker	
Fear that the procedure will be painful	Suggest a friend or relative accompany the patient for support	
Fear that the trichiasis will return	Explain to patient that regular follow-up of surgical outcome will be conducted	
Staff at the health facility who are not perceived as being friendly and caring	Provide individual pre- and postoperative counseling Provide lunch for patients and their guides	



Awareness: Trichiasis sufferers become aware that services are available for their condition to be treated; household members become aware that trichiasis can be treated and that there are long-term benefits to productivity and social standing; community leaders become aware of the collateral impact of less blindness in the community and help programs reach patients.

Access: Barriers to access are removed so that patients are able to travel to surgical sites and can afford to leave their households, and the community supports their treatment. Solutions include reducing time, distance, and costs to participate; having patients travel in groups with age mates; and implementing targeted health education to increase knowledge.

Acceptance: Patients recognize their ability to obtain services and seek care, including overcoming the fear of the procedure, feeling comfortable with the risks, and perceiving that the community and household are willing to support their treatment and recovery.

seek surgery?" Table 2.2 provides examples of how program managers can address patient fears. At the community level, program managers can consider the social and cultural challenges to trichiasis surgery using the model presented in Figure 2.1.

In addition to examining the community and social barriers to uptake, the program should examine the health system to identify opportunities to enable participation. Ultimately, if trichiasis patients are not presenting for surgery, it indicates that the health system has not succeeded in reaching the population. It is the role and responsibility of the health system and its personnel to understand the barriers, determine whether they are structural or sociocultural, and then adapt surgical program delivery to meet these challenges. Using the same

Figure 2.1. Acceptance model for community mobilization.

pyramid model, health system development can be understood as:

- Awareness. Health system personnel and partners recognize the need to be responsive and accountable to patients.
- Access. The health system reduces structural barriers to access by offering surgery free of charge, providing transport, scheduling surgery activities at times of the day and year that participants can attend, and organizing mobile surgery campaigns and recruitment. Operators in endemic communities should be trained and equipped for routine treatment and follow-up of trichiasis cases.
- Acceptance. The health system interacts at the community level by engaging with community leaders and providing pre- and postoperative counseling.

## Seasonal and Daily Calendars

For both women and men, cost and time away from work may vary seasonally. Trachoma control programs need to be creative to find solutions to increase the ability of all trichiasis sufferers to seek care. Programs have a responsibility to schedule surgical interventions when patients are able to attend. Furthermore, by scheduling interventions during the appropriate season, participation may be higher.

## Community-Based Solutions to Improve Access to Surgery

Program managers can conduct the following activities to make surgery more accessible to patients:

Provide inclusivity in decision making.

Target health education and community mobilization to mothers-in-law, fathers, husbands, and local community and religious leadership. Often it is necessary to direct educational efforts at men to reach women. The surgical program should promote the intervention as being for the benefit of all, not just the recipient.

- Enlist the help of community volunteers, health extension workers, and trained school teachers. Encourage them to identify, counsel, and recruit all cases in their villages before the surgical campaigns begin.
- Identify barriers to attendance. Do women complain that they cannot attend due to household duties? Use existing women's groups, youth groups, or radio listening clubs to offer patients help with household duties, child care, and farming. Encourage communities to organize child care within the village. Assistance can be given for free, then reciprocated if the opportunity arises.
- Facilitate surgical campaigns within or near target communities. Programs should reduce transportation and time barriers to attendance where possible.
- Provide opportunity for follow-up. Designate community members or health extension workers to serve as a resource for patients who experience complications. These cases can be referred to the nearest health facility for follow-up.
- **Encourage TT patients to come in groups.** Group participation from within home villages overcomes individual fears and reduces travel time.



## Approaches to Surgical Delivery: Facility-Based vs. Campaign-Based

Trachoma control programs usually implement a combination of facility-based and campaign-based approaches to surgical delivery. Facility-based trichiasis surgeries are performed as part of routine procedures conducted at health facilities such as clinics, *dispensaires*, or rural health posts. Under this approach, recruitment is mainly passive, either self-presentation or presentation after a referral from a local health worker. Surgical output is dependent on the simultaneous presence of qualified medical personnel, supplies and equipment, and good supervision when the patient arrives.

Where a large trichiasis surgical backlog exists, many national trachoma control programs implement trichiasis surgical campaigns to increase the number of surgeries provided. Surgical campaigns can be held at health facilities, schools, or other suitable locations and typically last one to two weeks. Before surgical campaigns begin, target communities should be informed

of the date and location of the campaign well in advance. Active health education and social mobilization are conducted to ensure people with trichiasis in target communities are aware of the service. Programs must ensure sufficient number

#### Box 2.3 Advantages to a Surgical Campaign

- Free surgery
- Presence of male and female trichiasis surgeons
- More opportunity for counseling and health education
- Presence of multiple ethnic groups among medical staff, patients, and administrators, which provides better availability of translators and a comfortable cultural context
- Opportunity for trichiasis patients to travel together, which reduces number of escorts from community and helps patients find the experience less isolating
- Large-scale participation increases community support and buy-in
- Health education opportunities to promote the SAFE strategy

of surgeons, consumables, and the presence of senior staff for supervision. Recruitment is proactive, and turnout for surgery is often high.

Surgical campaigns target the hard-to-reach groups: women, children, minority ethnic groups, people in distant communities, and poor families. The advantage of a campaign is that multiple surgeons and program support staff are active at the same time. Unlike routine surgery performed at a facility, where only one or two health workers are present, the campaign setting provides opportunities for additional health education activities in addition to pre- and postoperative counseling. See Box 2.3 for more advantages.

Surgical campaigns are often preferred by health staff. Difficult patients can be managed by more experienced surgeons while less-complicated patients can be operated on by those with less experience. Because additional support staff are present, the surgeons are able to focus on the needs of the patient while others handle registration, eye examinations, visual acuity assessment,

Case Study 2.3 Surgical Campaign: Health Worker Perspective



A trichiasis surgeon counsels a patient.

#### Yemane Desta, trichiasis surgeon, Amhara Regional State, Ethiopia:

"I was trained with a group of 30 in Debre Markos Hospital, and after certification I was given a set of new surgical instruments for use in the woreda health clinic. I have been trying to provide routine surgery for people at the woreda health clinic, but it has been difficult. I have other duties to perform on a day-to-day basis and in order to perform a trichiasis surgery, I have to stop what I'm doing to assemble the equipment and do all the preparation of the patient myself. Sometimes I give appointments to patients, and I think they must be disappointed because they don't come back. I really prefer working on the surgical campaigns. I meet up with my old colleagues again and there are no distractions to our work. Our teachers make sure that the patients we are given are not too complicated and the nursing assistants prepare the materials and counsel

the patients. It's so gratifying to be able to just work on the surgeries with my colleagues and to provide a service to several hundred people between us over a week or so. When the day's surgeries are over, we enjoy spending time with our friends away from home, and, yes, the additional allowance we get for being away from our post is appreciated, too."

and postoperative follow-up. In addition, the occasion for surgeons of varying levels of experience to work together offers a unique opportunity for health staff to share experiences, learn new skills and feel a sense of accomplishment. A health worker's comparison of facility-based and campaign-based surgery is presented in Case Study 2.3.

Health education tools can be employed to encourage potential patients to assume the risks and costs of surgery. Trichiasis surgery can be delivered in a patientfriendly manner through improved counseling, better organization of surgical delivery, follow-up, and regular monitoring.

# Counseling

Many patients who are unfamiliar with trichiasis surgery may not have confidence in the outcome. An individual's previous experience with medical care and perceptions of surgery will impact whether he or she is willing to have the operation. Fear of the procedure, potential worsening of vision, and the chance of unknown side effects contribute to the perception that the potential adverse effects of surgery may be worse than living with trichiasis.

As with any other medical procedure, it is normal for a patient to feel anxious or nervous before treatment. There is room for all trachoma control programs to enhance pre- and postoperative counseling services to patients, especially women and children. Although trichiasis surgery is not a complicated or lengthy procedure, patients are usually nervous and anxious before the operation.

# **Counseling Before Surgery**

Those providing counseling should be sure to leave adequate time for patients to ask questions. While the messages below are important to convey, it is equally important for counseling to be perceived by patients as a way to address their own concerns. Counseling before surgery should focus on the following messages:

- Surgery is the best way to correct the problem.
- Surgery will generally require about 10 to 20 minutes per eye.
- Surgery only involves the lid, not the eye itself.

- There will be some pain associated with surgery, but it will be minimal compared to the pain of lashes rubbing the eyeball.
- In some cases, additional surgery may be necessary a few years later.
- Routine follow-up may be needed, or the patient may need to return for suture removal or observation.
- Any vision loss that has already occurred will not be restored, but additional loss will be prevented.

Some patients will have other eye conditions leading to vision loss, in particular, cataract. The examination should include assessment of cataract and referral for cataract surgery as needed.

# **Counseling After Surgery**

The messages after surgery should focus primarily on postoperative care and prevention of recurrence. Counseling after surgery should focus on the following:

- Describe the purpose and use of any medications provided.
- Provide recommendations to relieve pain after surgery.
- Because there is the possibility of recurrence, tell the patient where to present for future care if needed.
- Encourage the patient to promote surgical intervention to other people who have trichiasis.
- Note that face washing is important, and improved personal hygiene and use of sanitation should be practiced among all members of the household.

These counseling guidelines will be beneficial to both male and female trichiasis patients. However, special consideration should be paid to the needs of women and girls during surgical campaigns. Girls living with unoperated trichiasis have bleak future social and economic prospects. In addition to counseling patients individually, surgical activities can be used to educate other family members on the importance of treatment and prevention. Trichiasis surgery is stressful for the entire family. Social support for attending surgery must be secured within the household, and can be accomplished through educating brothers, husbands, and other male relatives to appreciate the need for women



A pediatric trichiasis patient prepares for surgery.

to get surgery. This is particularly important for younger women who suffer from blinding trachoma.

Furthermore, education of caretakers and male relatives will reinforce the counseling provided to the patient. Although a woman may understand how to care for herself after surgery, she may not live in a household where she is empowered to improve her own hygiene and access to sanitation, or even follow the recommendations for postoperative care provided by a surgeon. It is crucial that male relatives and caretakers receive counseling and education so that they do the following:

- Understand that their wives and daughters will benefit from the surgery, be free of pain, and able to resume their usual duties
- Recognize the importance of postoperative care
- Encourage women to promote positive hygiene behaviors for the benefit of the whole family

- Provide access to sanitation
- Are able to recognize signs of recurrence or other abnormalities and know where to seek treatment
- Understand how to prevent trachoma
- Adopt SAFE strategy interventions for the benefit of the whole family

Health workers and surgeons should be reminded that children require special attention and require more effort than would be invested in an older person. If a child receives good quality surgery, counseling and postoperative care, he or she can have 50 or more additional years of socially meaningful and economically productive life, unlike an older adult. If a child with trichiasis does not receive surgery, he or she will continue to be a burden on the family and will risk a lifetime of social isolation and extreme poverty.

## Follow-up of Trichiasis Surgery

In some, but not all, endemic countries there is a suggestion that the incidence of trichiasis recurrence can be different for men and women. Because routine monitoring of recurrence is rare, it is not possible to assess differences in recurrence among men and women in most settings.

Regardless, it is important for programs to have a plan for surgical follow-up. Because women are less likely to have the opportunity to leave their communities for additional medical care, how can programs build routine follow-up into existing surgical delivery?

Routine follow-up can be improved by:

- Providing good preoperative and postoperative counseling
- Linking patients to a specific eye care worker who is accountable for follow-up or to a facility
- Employing routinely supervised record-keeping systems
- Visiting a random sample of patients selected from surgical registers to observe recurrence patterns

Where it is not possible for the program to follow up all individual cases, a simple random sample of patients can be obtained from surgical registers. These patients can

Box 2.4 Steps for Measuring Recurrence



An Ethiopian woman is evaluated for visual acuity before trichiasis surgery.

- 1. Choose an intervention unit (e.g., district).
- 2. From surgical records, compile a list of all trichiasis patients who received surgery during a specified time period (e.g., 12 to 18 months ago).
- 3. Use the list to select a simple random sample of 200 patients.
- 4. Visit the selected patients at home.
- 5. Examine and interview the selected trichiasis surgical recipients:
  - Count the number of trichiatic lashes and record on a standard form.
  - Use a standard interview form to evaluate the outcome of surgery.
- 6. Refer recurrent cases for surgical treatment.

Sample follow-up forms are included in Appendix A at the end of this book.

be traced by the program using their names and village identification. A simple questionnaire can be administered to compare a patient's visual acuity and severity of trichiasis from the time of surgery to the time of follow-up. Recurrent cases can be identified and referred for additional care. Box 2.4 shows the follow-up procedure in Ethiopia.

Programs should think critically about how to reach women. When follow-up of surgery is conducted, the data can be used to generalize rates of trichiasis recurrence, and follow-up visits should help identify potential operational or cultural reasons for poor outcomes. If the data indicate higher recurrence rates

#### Table 2.3 Trichiasis Surgery Follow-up Evaluation Questions

Surgical Quality and Recurrence	Indicators	Possible Solutions
Are women more likely to be operated on by less- experienced surgeons?	Look at each surgeon's register and compare the number of men and women operated on.	Encourage less-experienced surgeons to work under the supervision of more seasoned surgeons.
		Train surgeons on the importance of surgery for women and children.
		Establish quotas for surgical output by gender.
Do women receive adequate counseling?	During follow-up assessments or surveys, ask patients to describe	Implement counseling training during surgeon training.
	their postoperative care at home.	Conduct counseling practice sessions with staff before surgical campaigns (role playing).
Are women more likely to have recurrent trichiasis?	Compare visual acuity and severity of trichiasis among former patients.	Improve health education targeted to male family members and other caretakers.
	Is there a difference between men and women?	Identify cultural practices or other risk factors that reintroduce infection or encourage trichiasis.
Are women actively seeking follow-up care?	Ask women during follow-up if they know where to find additional	Inform patient at time of follow-up on service availability.
services and whether they are able to leave the community for care.	Use community mobilization and health education to reach men and decision-makers to permit women to travel to seek follow-up care.	
		Educate local health workers on how to manage recurrent cases.

# Table 2.4Example Calculations of Setting Targets for Surgery

	Ghana (2008 Data)	Egypt (2001 Data)
Intervention Area	Northern Region	Menofiya Governorate
Estimated Population	1.8 million	2.75 million (363,000 age 50+)
Survey Population, by Sex	48.2% Male	49% Male (age 50+)
	51.8% Female	51% Female (age 50+)
Estimated Total Adult Population, by Gender	867,600 Men	177,870 Men (age 50+)
	932,400 Women	185,130 Women (age 50+)
TT Rate in Men	0.20%	5.0%
TT Rate in Women	0.39%	7.7%
Backlog	1,735 Men	8,893 Men
	3,636 Women	14,255 Women

**Note**. Using this example, if the trachoma control program in Ghana sought to eliminate this backlog in three years, the program would need to operate on 578 men and 1,121 women each year.

among women, the program should evaluate the surgical delivery system. In Table 2.3, evaluation questions with indicators are presented alongside possible solutions to improve patient outcome.

# Monitoring and Evaluating Surgical Program: Setting Targets

Before initiating a surgical program, program managers should evaluate existing data to set annual and ultimate intervention goals (UIGs). If baseline data are not available, a prevalence survey is needed to measure the extent of the disease, including an analysis of the prevalence of trichiasis cases by gender and age.

To calculate intervention targets program managers need to do the following:

- Estimate total adult female and male population
- Estimate surgical backlog by sex
- Multiply adult population by sex-specific TT rates
- Note that the surgical backlog is the ultimate intervention goal (UIG)

Determine annual intervention goals (AIGs) by dividing sex-specific backlog by number of years planned for program implementation

See Table 2.4 for examples of these calculations.

# **Guidelines for Monitoring**

The establishment of monitoring and evaluation guidelines at the start of a program enables partners to collect uniform data on sex-specific indicators. Surgical output data can be sent from the facility or campaign site to the local, regional, and national health departments. These data will encourage programs to assess progress toward elimination goals, in addition to ensuring that women and children are adequately served in proportion to their share of trichiasis cases. The proportion of women who receive surgery should correspond to the prevalence of trichiasis among them if the intervention goals are to be reached. Failure to reach all target groups will mean that the overall program cannot reach its elimination targets.

#### **Guidelines for Record Keeping**

The following tools should be used for collecting and analyzing patient data:

Patient Registration Form. Each surgeon at a surgical facility or campaign will complete a registration form for the patient. Registration should include adequate tracing data so that the patient can be followed up if required. Adequate tracing data usually includes name, family name, age, district, village, subvillage or location, and compound. Adding the question, "How did you hear about our trichiasis surgical service?" to a registration form can help identify how men and women learned about the service.

#### Personal Story: Mare and Enatnesh Alegegn

After living with trichiasis for 15 years, Mare Alehegn received trichiasis surgery in 2005. Divorced by her husband after she became visually impaired and could not complete routine tasks such as cooking and farm work, Mare and her daughter, Enatnesh, struggled for 10 years, depending on the help of other families and neighbors. The pain of trichiasis made it impossible for her to cook over an open fire, tend animals, cultivate fields, and travel for firewood or water. According to Mare, "If I get my health back, it means everything. I'll be able to work and support my family."

Three years after her surgery, Mare does not have trichiasis, is not epilating, and shows no corneal damage. Her bilateral TT has been completely reversed by surgery. Although she still lives in poverty with Enatnesh, she is extremely upbeat. She is now able to till by hand half of her own plot. She cannot farm her whole plot because she has neither oxen nor donkeys for plowing, but she is able to gather wild cotton for sale and her vision has improved to the point that she is able to weave baskets from sweet grasses gathered from the riverside. Mare described the surgery as being like a "second birth," and as "an end to the isolation of trichiasis." People used to be cruel and disregard her "since she couldn't even look after her family." Mare has a modest income now; she provides for her family and can pay small expenses such as school fees. In doing so, she has earned back respect from her neighbors. She now lives with extraordinary optimism for her future and for Enatnesh.



Enatnesh (left) and her mother, Mare, describe how life has improved as a result of trichiasis surgery.

- Facility Summary Register. Patient registration forms are summarized using a facility summary register. Data from the patient registration forms are recorded as a summary and submitted to the district level each month. In particular, this report indicates the number of patients receiving surgery, the number of men receiving surgery, the number of women receiving surgery, and the proportion given postoperative azithromycin. The total number of men and women receiving surgery should be included in each summary.
- District Summary Register. Each district office should record the monthly totals for each facility. Each month, the total number of surgeries performed at all sites can be calculated.
- **Regional Summary Register**. Each region records the monthly totals for each district.
- National Summary Register. The national program compiles all output data for each region.

This information should be stored in a computer database or paper record system at either the regional or national level so that the national program can respond to the performance of both individual surgical facilities and national and regional progress toward reaching targets. Sample distribution registers and summary forms are included in Appendix A at the back of the book.

## **Suggested Reading**

Bowman RJ, Faal H, Jatta B, et al. Longitudinal study of trachomatous trichiasis in The Gambia: barriers to acceptance of surgery. *Investigative Ophthalmology and Visual Science*. 2002;43:936-940. This paper explores various reasons why trichiasis cases are unable to access surgery for trichiasis.

Ngondi J, Ole-Sempele F, Onsarigo A, et al. Blinding trachoma in postconflict southern Sudan. *PLoS Medicine*. 2006;3:e478. *This paper uses baseline survey data to identify target areas for SAFE implementation and calculates surgical backlog. The paper also describes the high prevalence of trichiasis in children*.

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. This study uses a population-based survey to calculate the gender distribution of trichiasis cases in trachoma communities in Vietnam and Tanzania. The gender distribution of these cases is analyzed to determine whether women are using surgical services proportional to their needs.

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urrently, where the prevalence of clinical signs of trachoma (grade TF) exceeds 10 percent among children ages 1 to 9 years, WHO recommends annual mass treatment with antibiotic to the total eligible population for at least three years. Most people are treated with a single oral dose of azithromycin, donated by Pfizer Inc., while children under 6 months of age receive topical tetracycline eye ointment. Mass administration of antibiotic treats individual cases and is believed to reduce transmission of C. trachomatis within a community. When combined with health education and environmental improvement, the use of antibiotics can lead to sustainable trachoma control.



Sudanese distribution workers prepare for the day's activities.

Because children are the main reservoir of trachoma infection,

it is imperative that antibiotic distribution programs intentionally target children and their caretakers, because they are at an increased risk of multiple infections, which often lead to conjunctival scarring and trichiasis 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 an 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 control programs need to think beyond monitoring the total quantity of drug distributed. They should create a strategic plan to target women, children, and other groups who are at the highest risk of infection and blinding trachoma.

#### **Setting Targets**

Programs calculate antibiotic distribution forecasts using estimated population data for targeted areas. This can be taken a step further to calculate gender-specific targets in a similar fashion.

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

- Estimate the total population in at risk areas, minus 1.5% (or 2% in some countries) for children younger than 6 months of age = Total eligible population
- Calculate the percentage of men, percentage of women, and percentage of children within the total eligible population to determine the annual treatment objective (ATO) for each subgroup.

See Table 3.1 for sample calculations for annual treatment objectives in Mali and Niger.

#### Table 3.1

Sample Calculations for Azithromycin for Mass Drug Administration

	Niger (2008)	Mali (2008)
1. Total Population in Endemic Areas	7,641,583	7,579,990
<b>2. Subtract 2%</b> (for those younger than 6 months of age)	- 152,831	- 151,600
3. Total Population at Risk	= 7,488,751	= 7,428,390
<b>4. Total Adult Population</b> (15 years or older)	Multiply by 45.8% = 3,429,848 Adults	Multiply by 51.0% = 3,865,795 Adults
	M	en
5. Annual Requirement (ATO) (% women x total adult eligible population)	51.9% Adult Men = 1,780,091 Men	49.5% Adult Men = 1,913,568 Men
6. Minimum Total Requirement (3-year distribution total)	= 5,340,273 Doses	= 5,740,704 Doses
	Women	
7. Annual Requirement (ATO) (% children x total eligible population of children)	49.1% Adult Women = 1,684,055 Women	50.5% Adult Women = 1,952,226 Women
8. Minimum Total Requirement (3-year distribution total)	= 5,052,165 Doses	= 5,856,678 Doses
	Children	
9. Annual Requirement (ATO) (% children x total eligible population of children)	54.2% Children = 4,058,903 Children	49.0% Children = 3,714,195 Children
10. Minimum Total Requirement (3-year distribution total)	= 12,176,709 Doses	= 11,142,585 Doses

Note: Data are from the 2008 Carter Center Trachoma Control Program Review and the Niger and Mali Demographic and Health Surveys.

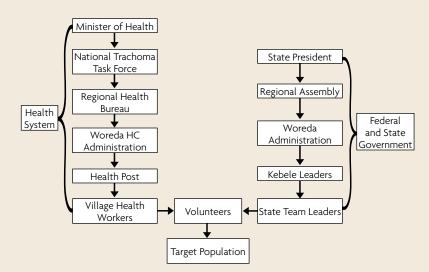
## **Community Mobilization**

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. Failure to acquire information; often men and women define reliable sources of information differently. Frequently, men and women 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 select the programming. In this case, if it is known that male heads of households listen to the radio regularly, it would be best to target

secure support among community leaders could lead to low uptake of the distribution among the general population. Educating leaders and decision makers will limit the spread of inaccurate information, skepticism, and rumors about the drug.

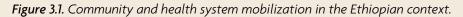
The method of community mobilization should also be considered strategically. Many programs use megaphones, radio announcements, or other modes of communication to inform communities of scheduled distribution activities. It is essential to choose a medium to which the target population has access. Generally, multiple media are required. It is important to consider how men and women

This flow chart shows the parallel system of mobilization used to engage both the health sector and local government to participate in antibiotic distribution.





Community health workers use megaphones to announce antibiotic distribution activities.



information about the distribution to them, informing men of the benefits of participation for their wives and children, and find an alternative method to reach women directly. Using the Ethiopia program structure, Figure 3.1 shows how government and the health system can be simultaneously mobilized to ensure support for antibiotic distribution.

# **Training of Distribution Teams**

Program managers are responsible for overseeing the preparatory activities preceding distributions, but the onthe-ground success of a mass administration campaign is dependent on well-trained and supervised distributors. Before each mass drug administration, 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, the distributor can be trained to target women and children in particular.

Where possible, employing both male and female distributors for each team will ensure access to femaleheaded 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 the public health system. Programs should use their best judgement to assemble distribution teams with the appropriate personnel for the local cultural context.

# **Antibiotic Distribution and Pregnancy**

Pregnancy is a very important time for women and their partners and there is considerable mystique associated with it. There is currently no evidence to suggest negative pregnancy outcomes are associated with taking azithromycin for trachoma control. Indeed, the data available suggest that women taking azithromycin during pregnancy have better outcomes than those who do not. Pregnancy should not exclude a woman from azithromycin distribution; however, if an individual expresses concern, she can be given topical tetracycline eye ointment.

# 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 household to household. Distribution campaigns typically identify fixed sites and rely on



Height-based dosing for azithromycin.

community mobilization to attract participants from nearby communities. The advantage of this approach is that the communities are involved in the selection of the distribution sites and the time and day of the distribution. This helps overcome logistic barriers such as lack of transport for the distribution teams, poor accessibility, and limited staff. Record keeping and stock management also become easier. Household-level distribution requires training distribution teams from local communities to administer drug and monitor stock. Although individual uptake of the drug may be higher if offered at the household or community level versus a centralized site, this method requires a large investment of time and resources, both on behalf of the program and the distributors. Accurate record keeping requires a degree of literacy that these distributors may not have, and stock management is harder—drugs can be allocated to many distributors and collecting any unused portion may be difficult. Case Study 3.1 discusses distribution challenges in one community in Egypt.

## **Distribution Delivery**

Depending on the delivery strategy, distribution teams should consider the following guidelines for distribution.

#### **Central-Site Distribution**

- Sites should be staffed with at least three distributors: one conducts health education, another registers recipients, and a third administers the drug.
- If the program has the resources to employ additional personnel at the distribution site, an additional person, or a community volunteer, could be used to assist in mixing POS solution, measuring for heightbased dosing, or managing crowds of people.
- Regardless of the size of the distribution team, administration of azithromycin should be conducted to maximize the productivity of each team so that recipients, especially women with small children, do not have to wait a long time.

Case Study 3.2 provides the perspective of a health worker during an antibiotic distribution campaign.

#### House to House

- A team of two or three distributors can be employed to conduct house-to-house distribution.
- Teams should include at least one female distributor so that households where only women are present will permit the distributor to enter. (This applies only if it is culturally appropriate for a female distributor to travel with a distribution team.)

### Case Study 3.1 Antibiotic Distribution in Tokh Tanbesha, Egypt

Initiating antibiotic distribution in a trachoma-endemic setting offers unique challenges for program staff. Few communities in developing countries have experience with the concept of mass distribution of a medicine to treat a condition that affects only some members of the community. Why should all members of a community take a medicine when not all of them are "sick"? Misunderstandings, political shenanigans, and rumors have wrecked havoc on antibiotic distribution efforts in a number of settings. In most cases, the end result varies according to social and political divisions within communities — these divisions are often based upon gender roles and responsibilities.

The first antibiotic distribution carried out in Egypt is a good example. Several weeks before the planned distribution, team members carried out promotion in Tokh Tanbesha (population 20,000) through a variety of methods. Meetings and trainings were held with local political leaders, religious leaders, health workers, and schoolteachers. This was supplemented with door-to-door promotion at the time of household enumeration, when it was recognized that local groups had not reached many households. Although evidence of significant trachoma prevalence was noted through a number of surveys, there was still little understanding of trachoma by government officials, local health staff, and the population. There was no recognition of a link between trichiasis in adults, which was quite common, and the "red eye" of childhood.

Right before the distribution was to start, rumors erupted among villagers suggesting that the drug was going to blind people within three days and that deaths occurred in other villages—when, in fact, this was to be the first distribution. The distribution ended with 62 percent coverage, almost identical for preschool children, school-age children, and adult women (all 69 percent) but much less for adult men (48 percent). Refusals were generally family based rather than person based. Many men were away in the fields or working elsewhere when the teams were doing door-to-door distribution, and some women were unwilling to accept treatment without the agreement of the male head of household. When one family refused, this information spread quickly, and nearby families also refused. Subsequent rounds focused on changing the time of distribution to make sure that men were present when teams visited. The second round of distribution succeeded in increasing coverage; however, coverage among adult men never reached more than 65 percent. The importance of understanding community perceptions and the role that gender plays in adoption of new technologies such as mass distribution cannot be underestimated.



An Egyptian family.



A young girl waits in line for antibiotics.

### Case Study 3.2 Antibiotic Distribution Through the Eyes of a Health Worker

In November 2008, the Amhara Regional Health Bureau in Ethiopia organized an integrated malaria and trachoma health education and antibiotic distribution campaign in west Amhara. Over the course of "Maltra" week, the trachoma control program distributed approximately 4.8 million doses of antibiotic through fixed-site delivery. Well-planned coordination of the health system and thorough mobilization of local communities enabled Maltra week to reach its intervention targets.

"I am one of the community health extension workers recently posted in Fogera *woreda*. Our usual activities are with the communities, and I spend a lot of time going from house to house talking with people and promoting hygiene, sanitation, HIV awareness, and malaria control. Sometimes the communities want more from us than just advice, and that is one of the reasons I enjoyed the Maltra week. In my team, there were three other people: a volunteer to measure the children, a second volunteer to organize the families as they presented for treatment, and an official from the *kebele* 



A distribution worker passes out azithromycin.

administration who was very useful filling in the logbooks. My part was to provide the actual treatments and dispense the azithromycin and tetracycline, conduct malaria diagnostic tests for people with fever, and provide malaria treatment, too.

"This was our second year of distribution so all the logbooks were already filled, one page per family, and the after the sensitization, my little team waited at the crossroads in the community and treated families as they came to us. After three days of sitting in the busiest parts of the village, we then opened the logbooks again and moved from house to house, visiting those who had not come to us. Between us, we knew everybody in the logbooks, and we had a target of 1,226 people to treat during the week. When a group assembles at the distribution point, I stop what I'm doing and use it as an opportunity to provide health education for trachoma and malaria. The people listen and respect me because I am a health worker, but I think they've heard most of it before and are just coming to see me for the drug. The people have noticed that there are several beneficial effects of azithromycin. Although they seldom talk of their eyes

feeling better, they mention skin diseases, stomach problems, and chest complaints all disappearing. Others have told me that the drug gives them diarrhea and precipitates their hemorrhoids, but these effects can't be too bad because most people come and seek the drug. There's very little work to be done to convince people of the benefit.

"After being posted to this *kebele*, my colleague and I have not received frequent refresher training. We really enjoyed not only being a part of the training for the Maltra week, but also being given financial resources to train some of the community members to assist us. It's nice to be part of something big and provide something useful for the communities."

- Distribution activities should be scheduled to occur at a time when family members are likely to be at home—meal times, evenings, or early mornings. Because house-to-house distribution allows the distribution team access to families within their own homes, the opportunity for tailored health education is available if distributors are adequately trained to do it.
- Teams should record a full census for each household, indicating the members who received drug and who did not for any reason. It is not necessary to include full names, but age and sex information will enable program staff to determine whether the same proportion of men and women are being treated.

Case Study 3.3 discusses house-to-house distribution in Niger.

### Case Study 3.3 House-to-House Distribution in Niger

Moussa and Issoufou – both respected men in their village - were selected to be distributors for their community's first round of azithromycin treatment. In addition to treating all the families in their own village, they were assigned 10 other communities to visit. Because most families were busy with farming during the day, Moussa and Issoufou would wait to finish their meal at dusk and then begin their distribution. Each evening for two weeks, Moussa and Issoufou rode their horses to neighboring villages, carrying azithromycin and tetracycline, register books, measuring sticks, and oil lanterns. Working by the light of their oil lanterns, the team would register households and treat eligible family members. When questions arose, they took the time to explain the purpose of the drug and the importance of preventing trachoma. Some women seemed nervous about the presence of strangers in their home, but Moussa and Issoufou made sure to greet the women's husbands and explain the nature of the visit. Although large Nigerien families could take up to 30 minutes each to treat, Moussa and Issoufou left the communities with a better understanding of trachoma prevention and community support for future treatments.

### Households with Absent Men

In several African countries, there is a substantial minority of households where male heads of household are absent. These households emerge from a number of different contexts, often due to male migration, death of men in conflict, adolescent fertility, and divorce. A female-headed household can assume many forms:

- Women who are divorced or widowed, have not remarried, and have their own dwelling
- Women who live with extended family members in a shared compound or dwelling but are not perceived as part of that immediate family
- Single women who live with another household as a domestic worker, indentured servant, or other longterm economic relationship
- Married women who live alone for a portion of the year because their husband is away due to an extended absence such as migrant labor or military service

Local census data or prevalence survey findings should enable the program to estimate the proportion of households that do not have a male head of household present. In Africa, the proportion of these households varies from 11 percent in Egypt to as high as 25 percent in Tanzania. Women and children who reside in these households may not be able to travel to visit a distribution site. Although a program selects a delivery method based on what is most appropriate for the local context, there should be a mechanism to include this subset of the population. In many cases, female-headed households have fewer assets and less access to resources such as land, livestock, credit, education, health care, and extension services. Box 3.1 shows methods for reaching both male- and female-headed households.

### **Monitoring for Gender-Specific Coverage**

A follow-up assessment of distribution coverage immediately after mass drug administration can be

performed using distribution registers and tally sheets or by using a population-based survey to estimate 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.

Programs need to look at coverage by sex and types of household. If there is no way to measure which groups are being reached, how will the program identify groups or geographical areas where delivery needs to be intensified? The program may report an 80 percent coverage rate but who are the 20 percent not covered? Delivery methods, mobilization, and health

### Box 3.1 Equitable Delivery of SAFE Among Diverse Households

### Male-headed households

Use health education to convince men to allow their wives and children to 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 where culturally appropriate. Explain to community leaders the need to follow-up with these households. education could systematically exclude specific subgroups such as female-headed households, nomadic groups, and other minority members of a community.

### **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, sex, 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 gender-specific data from registers allows the district, regional, and national staff to monitor antibiotic distribution progress in terms of men, women, and children reached. A sample distribution register and summary table are included in Appendix B at the end of this book.
- Staff can determine population coverage by dividing the total number of doses distributed by the population of the total intervention area.

### **Coverage Survey**

Reliance on distribution records alone to measure coverage can be risky. These records can be unreliable because registers are sometimes incomplete, missing, or forged. 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.

To conduct a coverage survey, program staff should do the following:

- Randomly select 10 villages (clusters) from a list of all villages that participated in the distribution
- Use the "map and segment" method to choose 10 households
- Interview the head of the household
- Record participation among all members of household on a census form
- Enter all data into an analysis program such as Epi Info or Epi Data
- Calculate the frequency of participation

The findings from a coverage assessment should be incorporated into the regular monitoring database for antibiotic distribution. If it appears that either men or women are less likely to present for drug, the program should follow up in these areas with additional health education, community mobilization, and possibly additional distribution "mop-up." The program can use distribution registers and coverage survey results to estimate the proportion of men and women who are receiving azithromycin, and then apply that to the annual targets. For example, if the program estimates that 60 percent of drug is consumed by women, then the program can report progress made in reaching this critical demographic. These data are not only relevant for planning purposes, but can be used for advocacy to raise funds for distribution activities.

### Personal Story: Azithromycin as Part of the Full SAFE Strategy

Since the introduction of trachoma control interventions in their district, the Yemane family of Fogera *woreda* in the Amhara region of Ethiopia has embraced the full SAFE strategy. Not only has the family participated in all three annual rounds of azithromycin distribution, but it routinely participates in the other interventions offered within the community. The family was first introduced to trachoma

control when father Yemane participated in latrine construction training. The two children attend the local primary school where trachoma control has been integrated into the standard health education curriculum, and they are required to practice face washing and other improved hygiene behaviors. A new health extension worker was



introduced to the community last year. After a few health education sessions, Yemane's wife, Tigist, began to see the connection between antibiotic distribution and the overall SAFE strategy. When the family participates in the other aspects of SAFE, the antibiotic therapy is complementary. She remarked, "Antibiotic distribution happens just once a year, but we practice SAFE all the time."



### **Suggested Reading**

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.

O'Laughlin B. Missing Men? The Debate over Rural Poverty and Women-Headed Households in Southern Africa [Working Papers Series No. 252]. The Hauge, 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. World Health Organization. Trachoma Control: A Guide for Program Managers [NLM classification WW 215]. Geneva; 2007. 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.

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 drug in a community in Tanzania.

## BEHAVIOR CHANGE AND GENDER

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. 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. Although different theories assign various weights to individual factors, such as 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, intending to practice. 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." The goals of health education for behavior change are presented in Box 4.1.

### **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.

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 relate successes and failures. They also will be able to identify areas

### Box 4.1 Goals of Health Education and Behavior Change for Trachoma Control

### Education

With adequate and appropriate information, communities and individuals will understand the cause of trachoma, how it is transmitted, how the disease progresses, and the purpose of the SAFE strategy interventions. Communities will understand that they do not have to live with blinding trachoma.

### Health Education

Health education is the process by which a target group is informed about health risks, methods of prevention, and availability of health services. Providing health education does not automatically result in behavior change.

### Health Education Media and Materials

The media used to conduct health education are the means of sharing information. These include print media (e.g., posters, leaflets, manuals, books), nonprint media (e.g., radio shows, skits, songs, videos), and materials to support health education (e.g., t-shirts, printed cloths, musical instruments, hats).

### **Behavior Change**

As a result of a strategic communication strategy, individuals and communities will choose to adopt better health behaviors to reduce the transmission of trachoma.

### Behavior Change Campaign

A behavior change campaign is a comprehensive program aimed at increasing the practice of certain positive behaviors. A behavior change campaign is like an umbrella — it covers many different behaviors and generally many different strategies to seek behavioral change.

### **Community Mobilization**

A comprehensive, culturally appropriate health education program will ensure support for SAFE strategy interventions on the part of individuals, communities, and local leadership. 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, staff should conduct communitybased interviews to generate information about cultural practices and attitudes regarding trachoma control. These do not need to be formal interviews or complicated surveys; staff can visit several different communities and speak with the target audience and other influential community members (key informants). These interviews will elicit information about participants' attitudes toward certain types of behaviors, their motivation for changing their behavior, and the sources of information they find trustworthy. Interviewers should probe for more detail when a participant mentions something new. Discussion guides can be helpful to facilitate this information-gathering activity. The guide serves as a reminder for the interviewer, listing the key questions to ask and suggested topics for discussion. A sample is included in Appendix C at the end of the book.

There is no fixed number of interviews to conduct. Staff should continue questioning different members of the target audience until new information is no longer conveyed. Staff should take notes during the interviews to remember the key points; notes should also include observations on the community and a few households. For example, the interviewer should record observations about patterns of behavior as they relate to sanitation, food preparation, and household water use. Identify practices that might be unique to the cultural group. When the interviews are complete, staff should review their notes and record each new theme that emerges on a list for that subgroup. After all the notes are reviewed, the program will have a list of themes, ideas, and concepts that correspond to each subgroup of the target population (e.g., a different list for men, women, the elderly). The program should then identify what these groups have in common and how they differ, paying particular attention to similarities and differences among men and women. These interviews can be used to identify positive behaviors that are already practiced by members of the target audience. Case Study 4.1 describes information gathered during interviews in Southern Sudan.

### Case Study 4.1 Interviews in Southern Sudan

A team from the Eastern Equatoria Trachoma Control Program conducted community-based interviews with these different target groups: heads of households, women with children younger than 5 years of age, and youth ages 11–16. These interviews were conducted to gather information on the attitudes and behaviors toward sanitation and hygiene practices of three target groups. The discussion yielded the following information:

- Adults and older children defecate away from their compounds.
- The young, elderly, and sick defecate in the compound, and it is disposed of by family members.
- Women described defecation as a shameful act requiring privacy so that others do not know that the women are going to defecate.
- Mothers identified children who are 3 years of age or older as mature enough to wash their own faces. They stressed the fact that they wash their children's faces in the morning; however, they did not mention another time during the day during which they wash the children's faces.



A health worker visits a household in Southern Sudan to learn more about local practices.

- Parents of both genders placed great importance on keeping their children's faces clean in order to reduce the likelihood of them getting diseases and to be attractive to others.
- Having a clean environment and being physically clean are important to community members, and group members are interested in building and using pit latrines.
- Participants enjoy singing and dancing and prefer health education tools that pictorially represent their community.



A mother in Ghana washes her child's face.

### **Survey of Information Sources**

To know how best to promote behavior change messages to target communities, it is important to know the most common, preferred, and influential methods of receiving information among men and women. Before initiating a health education or mass media campaign, trachoma control programs can identify how information is spread using a survey 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.

The following are the steps for conducting a populationbased survey of information sources:

- 1. Define the target groups of interest (e.g., men, women, 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.

### Case Study 4.2 Survey of Information Sources in Southern Sudan

A questionnaire was used to determine the types of information sources individuals could access, how they currently communicate, and their preferred means of communication. The study examined both contemporary forms (e.g., radio, cassettes, television, movies, print media, signage) and traditional forms (e.g., traditional entertainment) of communication and systems for receiving information.

Because the program was interested in understanding the media habits of men, women with children, and youth, structured interviews were conducted with heads of households, women with children under 5 years of age, and youth ages 11–16 from 49 randomly selected villages in Kapoeta South County. Participants were allowed to self-identify their groups and one standard survey was administered to all groups.

The survey revealed the following information about access to media:

- Watch TV or video shows: men 26%, women 20%, youth 19%
- Like to watch TV or video shows: men 97%, women 96%, youth 96%
- Listen to radio every day: men 47%, women 24%, youth 32%
- Listen to cassettes: men 86%, women 49%, youth 54%
- Attend traditional entertainment: men: 93%, women 96%, youth 93%

This survey highlighted the importance of understanding the media habits and preferences of community members when designing a health promotion campaign. The data show that there are differences in the access to information and media among men, women, and youth. These three groups need to be targeted differently. Men are more likely to be reached by radio, whereas all three groups can be reached through traditional entertainment. Cassettes are popular among all groups, but do not have the same popularity as traditional entertainment. If the program had assumed that these groups could all be reached via the same method, it would have missed entire segments of the target audience.

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 such as Epi Info or Epi Data. Both programs are available free in English and French (see Suggested Reading at the end of the chapter). The responses then can be analyzed to calculate frequencies of responses among the different target groups.

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 what sources of information are available to the target population, and, of these, which sources are considered credible and trustworthy. Case Study 4.2 provides survey results for a county in Southern Sudan.

### **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 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. Figure 4.1 shows how to implement the positive deviance model.

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 also can 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. Additional messages can be developed to complement the main health education message, encouraging the audience to appreciate the advantages of positive behaviors. Regardless, the focus should be fixed on simple, "do-able" messages from information sources people trust. Conversely, the health education program

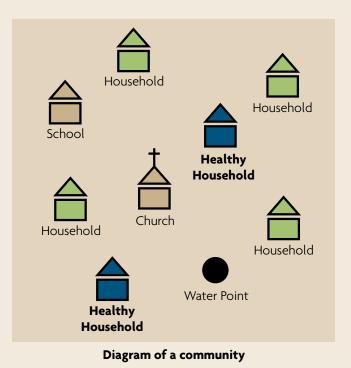


Figure 4.1. Positive deviance framework.

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 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.

### Box 4.2 Examples of "Do-able" Messages

"Wash your children's faces in the morning, after meals, and before they go to sleep."

"Sweep your compound every day."

"Bury human feces away from the compound."



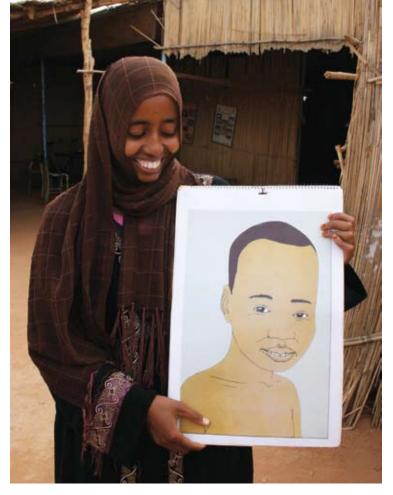
A health education session in Nigeria.

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 Box 4.2.

### Reaching Men to Encourage Behavior Change Among Women

It is important to recognize that a variety of people influence behavior. These include heads of households, community and religious leaders, 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 a disproportionate control over the household, they are also vulnerable. Men in resource-poor settings experience social stresses such as the following:

- Poor economic conditions
- Little to no formal education
- Heavy physical workload



A Sudanese health worker uses flip charts to facilitate sensitization.

- 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 community expectations that men 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 with disabilities such as trichiasis are at an increased disadvantage. Given these pressures, men 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. Men are sensitive to community perception and group approval and are unlikely to adopt behaviors that will contradict their definition of masculine behavior or status within the community. Box 4.3 provides examples of messages that may resonate with men.

### Box 43 Use Men to Reach Women

To tailor messages that are meaningful to men, program managers should identify the traditional model of masculinity in the target community:

- What health behaviors do men identify as positive? Negative?
- How does decision making among women affect male identity?
- How are household finances and resources managed differently between men and women? education strategies, even if

Health education can

be used to provide an



The male audience should be incorporated into health the primary target audience is women.

alternative model to empower men. Example positive messages include the following:

- "Using my spare money to pay for my wife's travel to have trichiasis 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."

Successful programs will understand the cultural and traditional model of masculinity in their target communities.

### **Development 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 prefer nonprint media while others consider text-based media to be more valid. There is no one-size-fits-all approach to health education.

### **Identifying Subgroups**

Within a trachoma-endemic district, there are many different groups of people, yet all may be affected by trachoma. However, 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.

Audience segmentation allows a behavior change program to target different audiences concurrently. If interviews with key informants reveal that men and women respond to different forms of media, then individual health education tools should be developed to reflect those differences. Table 4.1 shows how messages can be tailored to specific audiences.

### Table 4.1

Example Health Education Messages, Separated by Audience and Possible Media

Message	Audience Segment	Media
"Construct a latrine"	Male head of household	Radio
"Wash your child's face"	Mothers	Religious leader
"Have your wife/mother get surgery"	Men, young adult boys	Health worker education session
"Participate in azithromycin distribution"	Men, women, children	Community leader meetings, radio
"Seek trichiasis surgery"	Elderly adults, adult caretakers	Health worker home visits, radio

### **Designing Health Education Materials**

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

- 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 trichiasis cases).
- 3. Determine what 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 community health workers. Women and men may need to be targeted individually.

- 4. Produce a draft of the material.
- 5. Pretest the material with the target audience.
- 6. Modify the material based on the target audience's response.
- 7. Pilot-test the final version with 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

### Box 4.4

### 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 women are tested by women. For example, 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:

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



Pretesting health education materials in Southern Sudan.

### Case Study 4.3 Pretesting Shirts in Sudan

The Sudan national trachoma control program developed the "JMAL" Arabic acronym to translate SAFE. *Jmal* is the Arabic word for beauty. A local artist was hired to render the four components of SAFE into images that would appeal to women and children. When these images were pretested with groups of women to ensure they were appropriate for distribution, the program discovered that women did not wear t-shirts, the original idea for use of the images. As a result, the artwork was printed on long shopping bags instead, which were more appropriate for women in rural communities to wear. 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 his or her ability to create accurate representations of the target population. See Box 4.4 and Case Study 4.3 for more specific instructions and an example of pretesting.

### Box 4.5 Planning Education Around Calendars

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

Men	
Mosque, prayer	Religious leader after prayer
At home, eating breakfast, preparing for day's work	Radio broadcast
In field, planting, harvesting	_
At home or at neighbor's home, socializing	Radio broadcast, meeting with community leaders
Women	
Making breakfast, helping children prepare for school	Radio broadcast (if women have access to radio)
At home, cleaning compound, fetching water and firewood	
Cooking, pounding grain, looking after other children	Informal women's groups, discussions during chores
Washing children, preparing dinner, sometimes at neighbor's, socializing	Radio broadcast directed at male head of household
	Mosque, prayer         At home, eating breakfast, preparing for day's work         In field, planting, harvesting         At home or at neighbor's home, socializing         Women         Making breakfast, helping children prepare for school         At home, cleaning compound, fetching water and firewood         Cooking, pounding grain, looking after other children         Washing children, preparing dinner,

Seasonal calendars should also be developed to determine the best times of year to reach different groups. Program managers should consider how seasonal labor changes for men, women, the elderly, nomadic groups, and children. This will affect the timing of the delivery of the health education program.

### Case Study 4.4 Targeted Health Education in Vietnam

International Development Enterprises (IDE) decided to promote hand and face washing through a campaign focused primarily on children but also on mothers. Because of the focus on children, IDE developed a central character for



the campaign — a "funny-haired" boy modeled on the Vietnamese folktale about the Buffalo Boy, who has a lot of adventures and is well regarded among children. This character became the campaign logo and was incorporated into all materials. The primary slogan of the campaign was incorporated into the logo. It reads, "Clean eyes—healthy eyes" above the boy and "a bright future" below him.

The channels used to reach the children included school, television, and commune loudspeakers. The communication materials developed included video spots broadcast to children in school and on television, a song taught in schools focusing on how having clean and healthy eyes results in success in school and happiness for the whole family, and school exercise book covers that read, "Have you washed your face?" "Wash your hands and clean your face with your own towel." IDE designed a cartoon based on the campaign logo that showed the funny-haired boy waking up, washing his face with his own towel, and happily going to school. No words are spoken, trachoma is not mentioned, but the background music is the trachoma song. IDE also developed a video slot targeted to boys. In this video, a boy is watching television and sees a football star washing his face and talking about the importance of hygiene. This boy decides to wash his face before playing football with his friends. He goes on to score a goal and is lifted into the air by the other boys.

### **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 mass drug administration 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 men, it should not do so during the hours of the day when men are not near their homes, nor should it attempt to conduct education during months of frequent migration for seasonal labor. 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. Box 4.5 discusses planning around community calendars and Case Study 4.4 presents an example of health education materials from Vietnam.

### Radio

Radio is a hugely 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 will not likely reach those who do not have access to a radio or have control over the programming selection.

In many trachoma-endemic communities, women and girls do not have the same degree of mobility that men and older boys usually enjoy. Lower rates of literacy, less economic independence, and a reliance on male providers place women in a precarious situation — they do not always have access to the information they want or need. While radio is an effective tool for communicating health to a large audience, understanding radio-listening habits of target communities is essential to ensuring the messages reach the intended audience. Even though there may be a working radio in a household, this does not mean that all members have equal access to decide on what content is played, what time of day it is used, or with whom it is shared.

The survey to measure information sources described in this chapter outlines ways to assess patterns of radio use within a household (see Appendix C). 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 about how their families will do better if they protect them from trachoma.

Some trachoma control programs have used wind-up radio sets to form radio listening clubs and other women's groups. These clubs are effective ways to involve women in trachoma control programming, ensuring that they have access to radios and are able to discuss the health topics with their peers. Where radio donations are not available, women's groups are still an effective forum for women to discuss their health concerns and develop local solutions. Women's groups in Mali are discussed in Case Study 4.5.

### Case Study 4.5 Mali Women's Groups

Although women's groups are common in traditional rural Malian society, the use of these groups to promote trachoma control and overall health improvements has encouraged the development of female leadership. To maintain progress toward trachoma elimination, the Mali national trachoma control program has trained women's groups to ensure uptake of the F and E components of the SAFE strategy for trachoma control. Women and children are typically the primary target groups for trachoma control intervention. However, they often are not reached by existing channels of health education because of inadequate training of community health workers and the bulk of messages with which they are confronted.

In late 2007, the National Blindness Prevention Program (PNLC) targeted already existing women's groups in nine health districts in Segou and Mopti regions for training related to trachoma control. The training program focused on the fundamentals of behavior change for hygiene and sanitation improvement, implementation of the SAFE strategy, and support for how to incorporate trachoma activities with existing community-based interventions. Upon completing training, each group received a trachoma flip chart, a radio cassette player, and a trachoma cassette.

The women's group training project ensured that improved hygiene and sanitation practices are integrated into the regular activities of rural women and their families. In addition, the involvement of trained women leading trachoma control activities complements the ongoing activities of community health workers. The women's groups include radiolistening clubs to ensure that trachoma messages are reaching other women. These radio clubs provide women structured access to radio messages that does not interfere with their husband's or father's listening habits.



A leaky tin for hand washing in Ethiopia.

### **Suggested Reading**

Roberts A, Pareja R, Shaw W, et al. Tool Box for Building Health Communication Capacity. Washington, DC: Academy for Educational Development; 1995. http://www. globalhealthcommunication.org/tools/29. This publication provides guidelines for developing health communication programs, designing health education materials, and implementing culturally appropriate and programmatically viable communication programs to encourage behavior change.

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://www.hcpartnership.org/Publications/Field\_ Guides/Mobilize/htmlDocs/cac.htm. 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.

Family Health International. Behavior Change Communication for HIV/AIDS: A Strategic Framework. Arlington, VA: Author; 2002. 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.

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.

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 hygienepromotion 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\_education/index.html.

Epi Info available for download: http://www.cdc.gov/epiinfo/ downloads.htm

Epi Data available for download: http://www.epidata.dk/ download.php

# 5 ACHIEVING EQUITY



rachoma 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 limited decision-making authority of women in most trachoma-endemic communities, they can begin to design interventions and health education messages that empower and support women to meet the hygiene and environmental needs of their families.

Facial cleanliness and environmental change activities include hygiene promotion through targeted health education, school-based trachoma education, latrine construction, and water provision. Although the F and E interventions will not be discussed individually in this manual, this chapter provides trachoma control programs with tools to encourage the uptake of hygiene promotion among 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 and E activities and ensure equitable access to improved sanitation among all persons at risk of trachoma.

### **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, other 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 responsible for the hygiene of their children, 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 even more limited in areas or times of scarcity. Gender also informs the division of labor and household tasks, which affects exposure to trachoma. Table 5.1 presents household tasks and the corresponding risk factors to which adult men and women are exposed. Possible F and E interventions are also listed, showing that not all community members are at the same risk of trachoma.

### Table 5.1 Ways that Gender Roles Can Affect Risk for Trachoma Infection

Individual	Gender Roles	Trachoma Risk Factors	How to Address with F and E
Men	Building Digging Physical 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

### **Cultural Practices: Taboos and Rituals**

Individual behaviors arise from community norms. These unwritten rules govern how 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 their own particular specific preferences for how members should behave and interact with others. 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 traditional beliefs may be inaccurate in light of current knowledge of infectious diseases, but they are 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 traditional beliefs may be based on local superstitions or animist 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 taboos inform behavior and find creative ways to implement the program while respecting local culture.

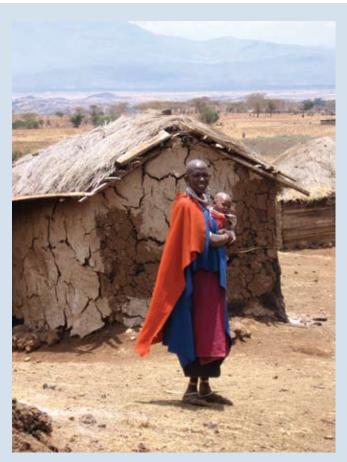
Most trachoma program managers are probably aware that changing community norms and behavior is

### Case Study 5.1 Masai Cultural Taboos

Trachoma has likely been prevalent among the Masai and other pastoral tribes of eastern Africa for a number of generations and possibly hundreds of years. Attempts to reduce transmission have focused largely on hygiene and sanitation for a number of reasons. There are unique cultural taboos among the Masai that have limited adoption of use of latrines; foremost among these is the patriarchal notion that after undergoing their coming-ofage ceremony, men no longer need to defecate. While this might seem preposterous to most people, the cultural explanation for this is that gods do not need to defecate and, in traditional patriarchal Masai society, men make virtually all of the decisions and are "like gods."

As a consequence of this cultural perception, it is taboo for women or children to observe men defecating or even entering a latrine. One or two generations ago, men would leave the *boma* (homestead) early in the morning, spending the entire day outside the *boma* herding cattle. The men defecated in the bush. Attempts to convince the Masai to build latrines generally failed, and latrines constructed by outside organizations often ended up as storage rooms. Around the *boma*, women disposed of human waste in the animal waste, collected in a central fenced-off stockade surrounded by the *boma*.

In the past 50 years, a reduction in grazing lands and other social and political shifts have resulted in a more sedentary lifestyle for most Masai, men included. The concentration of animal and human waste has increased in many villages. At the same time, men remain hesitant to invest in the construction of latrines. Women may desire latrines, but this requires efforts by the men to construct them. Additionally, due to other existing taboos, two



A Masai woman and her child.

latrines are required: one for women and children and one for men. The gradual integration of the Masai into the broader society in Kenya and Tanzania will likely improve acceptance of use of latrines, but cultural taboos do not change quickly. a difficult and lengthy process. Understanding the perceptions a community holds about gender, hygiene, and sanitation is key to designing successful sanitation interventions. See Case Study 5.1 for an example of a taboo in the Masai culture that affects trachoma control.

### **Cultural Divisions of Labor**

Most cultures have some form of gender-specific division of labor. For example, in sub-Saharan Africa, women are generally responsible for domestic tasks such as child care, cooking, and cleaning, whereas men are 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 genders 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.

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 uptake 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. Achieving high coverage with sanitation interventions requires programs to understand gender roles and to encourage men and women to work in cooperation so that all members of the community can participate.

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); this will ensure the highest rate of uptake.

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



A Ghanaian girl laughs during a health education sketch.

- 1. Know the community. Ask questions during information gathering and baseline 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 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 culturally appropriate gender roles.
- 4. Make a list of barriers individuals might encounter. Consider how gender roles limit participation. Do not forget about other minority groups such as poorer households, nomadic groups, and polygamous households.



A mason builds a latrine slab in Nigeria.

### Case Study 5.2 Gender Roles in Nigerian Latrine Construction

In Plateau and Nasarawa states in Nigeria, household latrine promotion is supported by the national trachoma control program. However, all beneficiaries are required to contribute to the construction of their own latrines. The trachoma control program supports the training of local masons to prepare cement slabs to cover the latrine. Each community receives one set of equipment for making the latrine slab mold. In each community, between one and three masons are trained, depending on the need and the rate of mason attrition. The mason compensation varies from community to community and even household to household because it is agreed upon by the head of household and the mason. The amount ranges between 100–1000 Naira (1–8 USD), though it can also be a donation of grain, or even done for free as an expression of community solidarity. Cement is allocated by the national program to the village. The head of household is responsible for providing the sand and gravel and for constructing the latrine superstructure. Latrine superstructures can be made of anything from grass, palm leaves, mud bricks, zinc sheets, and cement bricks.

The flexibility of community payment and contribution enables the mason to provide his service to households based on their ability to contribute. In Nigeria, manual tasks such as digging pits, building superstructures, and laying the cement slab are performed by men. Women are able to bring water to construction sites and collect leaves and branches or other light materials; their contribution should not be discounted.

### **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 also serve to provide women with institutionalized leadership roles that may not exist elsewhere in local leadership structures. See Case Study 5.2 for a discussion of latrine building in Nigeria and Case Study 5.3 for a discussion of water in Ethiopia.

### Children as Agents of Change: School Health

Because children are not directly reachable through radio, primary-school programming is a viable alternative to targeted health education. In areas where school attendance is high among children, school health programs can make a significant impact.

In most resource-poor countries, ministries of health and ministries of education work together to develop health education curricula for primary-school students. Primaryschool health programs use the existing educational

### Case Study 5.3 Water and Women in Ethiopia

In July 2006, the sub-*kebele* of Fek Ayil, situated in the highlands of the Amhara region of Ethiopia, began collecting water from its first protected water source. Living a two-hour walk from the nearest paved road, the 21 households in this small community had never before had access to a clean, regular, and protected water source.

Living in the household adjacent to the water point is Simegn Alem, member of the community management committee and volunteer guardian. When asked why she was chosen to be the water-point guardian, she replied, "I live in the household nearest to the well, so it is no problem for me to open the gate when asked. I sometimes get discouraged by the responsibility, but I am willing to continue serving in this role because it is important," she said. "Without a guardian, the pump could get damaged or water would be wasted," she added. The small community contributed all the labor for the water pump, including digging the 18 meter well and carrying construction equipment by hand from the road to the village. The community selected five members to serve on a management committee. This group collects 1 Birr (about .11 USD) per month from each household, which is deposited in a local savings account in the district capital. The community is able to use these savings to make loans and finance regular maintenance on the water pump. The committee includes two other women who help Simegn maintain the pump and keep track of family contributions. Their involvement in the committee has allowed them to serve as village leaders for the first time in their lives.



Simegn Alem, water-point custodian.

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 and face- and hand-washing areas and the integration of trachoma lessons into the standard curriculum to encourage students to continue these practices at home. Case Study 5.4 discusses this topic in the Nepal context and Box 5.1 discusses the components of a school program.

### Case Study 5.4 A Teacher's Perspective in Nepal

### Yagya Raj Bahtta, a teacher at the Janata Lower Secondary School in Kanchangpur, Nepal:

"I was one of two teachers from my school who were selected for training under the Helen Keller International program. The other teachers were clamoring to be included because there are few opportunities for training in this remote province. The training was very good, but I felt that it was too short. Afterward, I felt ready to deliver the program immediately, and I give one class per week to each of the standard three to five classes, but I have not been able to integrate the trachoma lessons into the existing curriculum except sometimes in science class.

"I do not see the additional curriculum as a burden because the materials we were trained on were ready to be used, and the notebooks and storybooks were nicely printed, and the pupils found them very attractive. They like them so much that they take them home and like to keep their copies. It's difficult for me to get them back; I realize this is not sustainable in the long term because the supply of books may not be reprinted.

"In my school, I have started a 'team against trachoma.' We clean the school compound and classrooms, keep the area around the school well and latrines tidy, and have prepared a drama presentation that we have given to the whole school and at open days for the community. The children are proud to participate in the presentations and are very good at answering questions raised by the audience. The students have an opportunity to participate in interschool quizzes, where they have a chance to win prizes such as t-shirts, pens, or other promotional items.

"As a result of the lessons, I have seen an overall improvement in the personal hygiene of my students. They also report having told their parents and other friends about trachoma, which I hope will increase the awareness of the disease and encourage improvements in sanitation and hygiene among the community."



Nepalese students read about trachoma.

### Box 5.1 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 children as agents of change and sources of health information.
- 2. Create a healthy school environment. Install handwashing stations and latrines on school grounds and enforce use. 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 instructors understand the importance of trachoma control and introduce participatory teaching methods.
- 4. Schedule regular health education sessions. Encourage educators to conduct hygiene checks each morning and hold lessons at least once a week.

School-based health education in a Ghanaian primary school.

Create sanitation clubs, drama groups, hand-washing leaders, and school-cleaning groups to encourage participation and practice of hygiene behaviors.

5. Encourage students to debate the health and hygiene situation of their communities. During health lessons, instructors should involve students in a discussion about the health problems in their communities. Explore causes and solutions.



### Personal Story: Soap Making in Niger

As part of the F (facial cleanliness) component of the SAFE strategy for trachoma control, the national trachoma control program in Niger assists health districts in training women in the preparation of traditional soap. Through other health education channels, women are educated about the importance of washing children's faces regularly to reduce transmission of trachoma.

Aisha Oumarou lives in the village of Adorihi, in the Matameye district of Zinder region. She was trained in the preparation of traditional soap in 2003. Since then, of her own initiative, she has trained 20 other women from her village and in neighboring villages. She sells her homemade balls of soap for 50 CFA francs each (about 10 cents), and can sell between \$4–8 worth of soap per week in the village.

"When the health district was looking for women to be trained in traditional soap making, I volunteered immediately. I know the importance of soap in keeping clean, and I knew it would be a useful skill to have. During the training, I realized the process is simple to learn. It's also easy because all of the ingredients I have at hand here in the village. The only obstacle sometimes is finding water to use.

"For me, making soap has several benefits. People like my soap and appreciate how it keeps them and their children clean. They say it keeps their skin healthy and keeps clothes clean. I also like having a useful skill that brings me some income. I've made a bag full of soap for my friend who will give birth soon. I know it will be important for her to have soap for cleaning clothes and for keeping the baby clean."



With local materials, Nigerien women can produce their own soap.

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, have been successful in getting students to be enthusiastic about trachoma control. 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.

### **Suggested Reading**

Emerson P, Frost L, Bailey R, et al. Implementing the SAFE Strategy for Trachoma Control: A Toolbox of Interventions for Promoting Facial Cleanliness and Environmental Change. Atlanta, GA: The Carter Center; 2006. This manual describes the various interventions available for the F and E components of SAFE and outlines how to conduct a community assessment to determine appropriate interventions.

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.

Lewallen A, Massae P, Tharaney M, et al. Evaluating a school-based trachoma curriculum in Tanzania. *Health Education Research.* 2008;23:1068–1073. *This article* reports an evaluation of a school-based trachoma curriculum in Tanzania. The authors found that there was a disparity between the health education messages (which were viewed positively by teachers) and environmental capabilities for implementing these messages. There were no wells at the schools and minimal latrine facilities at the school and at homes. Jenkins MW, Curtis V. Achieving the 'good life': why some people want latrines in rural Benin. Social Science and Medicine. 2005;61:2446–2459. A qualitative study using in-depth interviews was conducted to determine the motivation for installing household latrines in rural Benin. The respondents reported non–health-related reasons such as status, privacy, and convenience. The authors argue that these motivations should be used when promoting sanitation interventions.



## APPENDICES

SAMPLE FORMS FOR A MONITORING SURGERY

### Patient Surgery Card

Patient's serial number		Surgeon's name	
Patient's full name		Assistant's name	
Patient's age			
Patient's sex	Male □	<b>Fem</b>	ale 🗆
Patient's village			

		Right	Left
Clinical status of patient before surgery	Visual acuity		
	<b>Corneal opacity</b> Mark position of any opacity		
	Severity of trichiasis Number of lashes touching the globe	0□ 1-5□ 5-10□ 10+□	0□ 1-5□ 5-10□ 10+□
	Draw any lashes touching the globe		

Date of surgery	/ /		
Informed consent		irgery will not restore my	
	sight but help to sustain n	ny current sight.	
			Signature
		Right eye	Left eye
Surgical procedure	Type of operation		
performed	Type of suture		
	Operative		
	complications		

PO follow-up		Right eye	Left eye
Day 1	Post operative		
	complications		

Follow-up	/ /		
		Right eye	Left eye
PO after 10 days	Visual acuity		
	Removal of sutures		
	Complications/		
	comments		

Sample Summary Register: Facility Register

Name of Facility or Campaign:\_\_

Month/Year:

Date																										
Azithromycin Given?																										
Procedure																										
Surgeon																										
Village																										atient register.
Sex																										ividual p
Age																										nd to ind
Name																										Note. Serial number (SN) should correspond to individual patient register.
SN	1	2	3	4	٢	9	2	8	6	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	Note.

Total Men Receiving Surgery\_\_\_\_

Total Women Receiving Surgery\_\_\_

Total Men Given Azithromycin\_

Total Women Given Azithromycin\_

# Sample Summary Register: District Level

District:

Month/Year:

u																											
Total # Azith. Treatments Women																											u
Total # Azith. Treatments Men																										Total Men Given Azithromycin_	Total Women Given Azithromycin.
Total # Women Receiving Surgery																										Total Men G	Total Wome
Total # Men Receiving Surgery																										y	gery
Name of Facility																										District Total Men Receiving Surgery_	District Total Women Receiving Surgery.
SN	1	2	3	4	5	9	2	8	6	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	Distr	Distr

Sample Summary Register: Regional Level

Region:

Month/Year:

		Total # Men Receiving	Total # Women	Total # Azith. Treatments	Total # Azith.
SN	Name of District	Surgery	Receiving Surgery	Men	Treatments Women
1					
2					
3					
4					
5					
9					
7					
8					
6					
10					
11					
12					
13					
14					
15					
16					
17					
18					
19					
20					
21					
22					
23					
24					
25					
Regior	Regional Total Men Receiving Surgery_	ry	Total Men Given Azithromycin_	1 Azithromycin	
Region	Regional Total Women Receiving Surgery.	rgery	Total Women Gi	Total Women Given Azithromycin	

# Sample Summary Register: National Level

Month/Year:\_

Total Women Given Azithromycin\_ l otal Men Given Azithromycin\_ National Total Women Receiving Surgery\_ National Total Men Receiving Surgery\_

### Assessment of Trichiasis Recurrence

Patient code Dis	trict	Village	
Name of follow-up surgeon		Date	
Surgeon code	Operating su	rgeon: left-handed c	or right-handed
Presenting Trichiasis		Right Eye	Left Eye
No. of eyelashes touching the	e globe		
Location of in-turned eyelash	es		
(Temporal/Middle/Nasal)/Th	MN (Circle all that apply)	T M N	T M N

No.	Questions	Reponses – Codes	Skip to Question
Q1	Age of respondent in completed years	years	
Q2	Sex of respondent	Male 1 Female 2	
Q3	Were you practicing epilation for your trichiasis before the surgery?	Yes 1 No 2	<b>→</b> 5
Q4	What was the frequency of epilation before surgery (in day's interval)?	days	
Q5	Who advised you to go for surgery?	Trachoma volunteer 1 Health worker 2 Family member 3 Beneficiary of surgery 4 Other (Specify) 9	
Q6	Did your surgery improve your condition?	Yes 1 No 2 No response 3	
Q7	Why do you think the condition has not improved? (Circle all that apply)	Recurrence 1 Tissue growth at wound site (granuloma) 2 Pain 3 Decreased vision 4 Disfigured eyelid 5 Other(Specify)9	
Q8	What are you doing now for your trichiasis? (Circle all that apply)	Nothing 0 Surgery 1 Epilation 2 Local healer 3 Ointment 4 Other (Specify) 9	
Q9	Why do you say your condition has improved? (Circle all that apply)	Trichiasis corrected 1 Pain relieved 2 Improved vision 3 Other (Specify) 9	

### (Continued)

No.	Questions			Skip to Questior					
Q10	If you needed it, would you have the surgery again?								
Q11	After your operation, have you ever advised other patients for the surgical treatment?		1 2 3						
Q12	Have you heard of any negative aspects of surgical treatment for trichiasis?		1 2	<b>→</b> 14					
Q13	What negative things have you heard? (Circle all that apply)	Other							
Q14	Which eye/s was/were operated?					I	ght Left oth	1 2 3	
Exam		ŀ	Right ey	9					
	No. of eyelashes touching the globe Location of in-turned eyelashes (Temporal/Middle/Nasal)/ TMN (Circle all that apply) Granuloma (Yes/No) Lid closure defect (Yes/No) Overcorrection (Yes/No) Lid notching (Yes/No) Corneal opacity (Yes/No) (Temporal/Middle/Nasal)	T Yes 1 Yes 1 Yes 1 Yes 1 Yes 1 Yes 1 T	No No	N 5 2 5 2 5 2 5 2 5 2 5 2 5 2 N	T Yes 1 Yes 1 Yes 1 Yes 1 Yes 1 T		No No No No	2 2 2	

# $B_{\rm ANTIBIOTIC \ DISTRIBUTION}^{\rm SAMPLE \ FORMS \ FOR}$

		TEO (no. of tubes)																										
Distribution Register: Station Daily Registration Distribution Register: Distribution Statio	Distribution Station	Quantity	Syrup (ML)																									
			Tablets (no.)																									
		Sex																										
		Age																										
			Village	-				~	~	~	~	~		~				-										
Date	Region		No.	1	2	3	4	5	6	2	8	6	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	Total

Form for use in central-site distribution approach at the distribution site. Record the village, age, and sex for each recipient.

Report
Summary
istribution

	y	TEO (no. of tubes)																										
Report Date	Total Quantity	Syrup (ML)																										
		Tablets (no.)																										
District		Total Females																										
		Total Males																										
		Station																										
Region		No.	1	2	3	4	5	9	2	8	6	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	Total

Form for use in central-site distribution approach. Record the total doses distributed by site to calculate summary data for the district at the end of the distribution.

**Regional Summary Form for Antibiotic Distribution** 

ort Date	Total Females     Tablets (no.)     Syrup (ML)     of tubes)																										
Report Date_	Total Males Total Fer																										
Region	No. District	1	2	3	4	5	6	2	8	6	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	Total

At the regional level, list each district with the total summary data. The district data are summarized to give a regional total for the entire distribution.

# National Summary Form for Antibiotic Distribution

ar	
Yea	
nth/	•
lon	
$\geq$	

					Total Quantity	
No.	Region	Total Males	Total Females	Tablets (no.)	Syrup (ML)	TEO (no. of tubes)
1						
2						
3						
4						
5						
9						
2						
8						
6						
10						
11						
12						
13						
14						
15						
16						
17						
18						
19						
20						
21						
22						
23						
24						
25						
Total						

National summary of antibiotic distribution. List each region with the total summary data. The regional data are summarized to calculate the total of antibiotics distributed nationally.

# Sample Guide for Key-Informant Interviews

# Questions for Head of Households and Mothers with Children Under 5 Years of Age

# Water Use and Face Washing

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 flipcharts. 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?)

# Questionnaire to Identify Information Sources and Media Habits

0.1	NT 1		E 5	
Serial	Number	Data Entry 1	Entry Dat	te
		(initial)		
State /	County / District	Data Entry 2	Entry Dat	te
		(initial)		
Villag	e			
	-			
Date	f interview DD/MMM/YYYY			
Dateo				
~ 1	~			
Obser	ver/Interviewer name			
Inform	ned consent given? Initial and date			
	-			
	Γ	Demographics		
01	Description of respondent		ad of Household=1	
Q1	Description of respondent			
		Mother with child		
		Youth	ages 11-16 years=3	
Q2	Gender of respondent		Male=0	
			Female=1	
Q3	How old are you?			
			(write in age)	
Q4	What is the highest level of school you have		None=1	
~.	attended?		Religious=2	
	attended.		Some primary=3	
	(If "none," ask "have you had any nonformal		Some secondary=4	
	education (NFE)?")			
	education (NFE): )		All secondary=5	
			More=7	
		-	NFE=8	
Q5	What is your main occupation?		Youth=1	
			Student=2	
			Farmer=3	
			Trader=4	
			Employed=5	
			Cattle herder=6	
			Military=7	
			Housewife=8	
		Other (write in)_	=99	
Q6	What is your religion?		Christian=1	
$\times^{0}$	w nat is your religion:		Islam=2	
			Animist=3	
		$O_{1}$		
07		Other (write in)	=99	
Q7	What is your ethnicity?	(insert appro	opriate response)=1	
			=2	
			=3	
			=4	
			=5	
		Other (write in)_	=99	
		Radio		
R1	Do you own a radio?		No=0	
			Yes=1	
R2	Do you ever listen to the radio?		No=0	→R13
IX2	Do you ever listen to the ladio:			×1(1)
1			Yes=1	

<b>D</b> 2			
R3	How often do you listen to the radio?	Daily=1	
		Every few days=2 Weekly=3	
		Less than weekly=4	
R4	Where do you listen to the radio?	Home=1	
КŢ	(List all that apply)	Friend's Home=2	
	(List an that apply)	Farm=3	
		Market=4	
		While Cattle Grazing=5	
		Outside with Friends=6	
		Other (write in)=99	
R5	Which of these is your favorite place to listen to the	Home=1	
	radio?	Friend's home=2	
		Farm=3	
		Market=4	
		While cattle grazing=5	
		Outside with friends=6	
		Other (write in)=99	
R6	At what time of day do you listen to the radio?	Morning=1	
	(List all that apply)	Afternoon=2	
		Evening=3	
R7	What type of programs do you usually listen to?	All day=4 Whatever is on=1	
Κ <i>ί</i>	(List all that apply)	w hatever is on=1 News=2	
	(List an that apply)	Sports=3	
		Religious=4	
		Drama=5	
		Music=6	
		Other (write in)=99	
R8	Who selects the station you listen to?	Self=1	
110	who solecto the station you noter tov	Head of household=2	
		Owner of radio=3	
		Other (write in) =99	
R9	What radio stations do you listen to the most?	BBC=1	
	(List all that apply)	VOA=2	
		(insert appropriate response)=3	
		=4	
		=5	
		=6	
		Non-specific music=7	
		Do not know= $77$	
R10	What is your favorite radio station?	Other (write in)=99 BBC=1	
KIU	w hat is your lavorite radio station:	VOA=2	
		(insert appropriate response)=3	
		=4	
		=5	
		=5	
		Non-specific music=6	
		Do not know=77	
		Other (write in)=99	

R11	What languages do you like to listen to on the radio?	(insert appropriate response)=1 =2	
	(List all that apply)	=3	
		=4	
		No preference/Do not know=77 Other (write in)=99	
		Other (write in)=99	
R12	Do you ever listen to cassettes?	No=0	→TV1
D 1 2		Yes=1	
R13	What types of cassettes do you listen to? (List all that apply)	Music=1 Speeches=2	
	(Eist an that apply)	Public Announcements=3	
		Do not know=77	
		Other (write in)=99	
773.74		and Movies	N TTV /1 2
TV1	Do you have a television set at your home?	No=0 Yes=1	→TV13
TV2	How often do you watch TV at home?	At least daily=1	
		Every few days=2	
		Weekly=3	
		Less than weekly=4	
TV3	At what time of day do you watch TV?	Morning=1 Afternoon=2	
	(List all that apply)	Evening=3	
		All day=4	
TV4	At which of these times is your favorite to watch	Morning=1	
	TV?	Afternoon=2	
		Evening=3	
		All day=4	
TV5	How many channels can you choose from?		
		(umite in)	
TV6	What types of programs do you like to watch?	(write in) Whatever is on=1	
1.00	(List all that apply)	News=2	
		Sports=3	
		Religious=4	
		Drama=5	
		Soap operas=6	
		Other (write in) =99	
TV7	Who selects what you watch on TV?	Self=1	
		Head of household=2	
		Owner of TV=3 Other (write in)99	
TV8	What TV stations do you watch the most?	=99	
	(List all that apply)		
		(write in)	
TV9	Which TV station do you prefer?		
		(write in)	

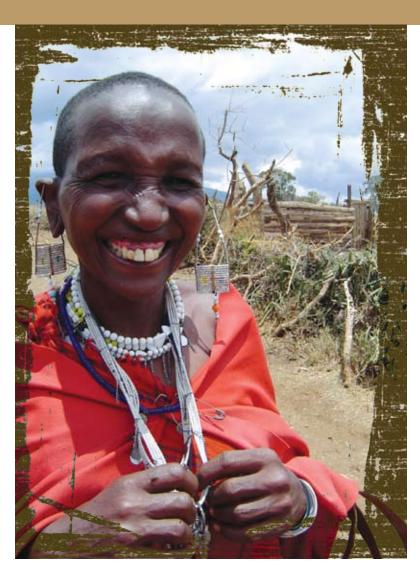
TV10	What languages do you like to hear used on the TV?	(insert appropriate response)=1	
	(List all that apply)	=2	
		=3	
		=4	
		No preference/Do not know=77	
		Other (write in)=99	
TV11	What is your favorite TV program?		
		(write in)	
TV12	Do you ever watch TV programs or movie shows	No=0	→ PM1
	outside your home?	Yes=1	
TV13	Where do you watch them?	Friend/Neighbor's Home=1	
	(List all that apply)	School=2	
		Shop=3	
		Bar=4	
		Movie house=5	
		Other public place=6	
		Other (write in)=99	
TV14	How often do you watch TV or movies outside your	Daily=1	
1,11	home?	Weekly=2	
	nome.	Monthly=3	
		Less=4	
TV15	Do you enjoy watching TV or going to see movies	No=0	
1 1 1 5	in public places like the market or a school	Yes=1	
	building?	105-1	
TV16	Is there a time of year that you are most likely to go	Anytime=1	
1 V 10	and see TV or movies outside your home?	Dry season=2	
	(List first answer only)	Rainy season=3	
	(List first answer offiy)	Harvest season=4	
		National days=5 Do not know=77	
		Other (write in)=99	
TV17			
1 V 1 /	Is there a day of the week that you are most likely to	No preference=1	
	go to see TV or movies outside your home?	Monday=2	
	(List all that apply)	Tuesday=3	
		Wednesday=4	
		Thursday=5	
		Friday=6	
		Saturday=7	
T1 11 0		Sunday=8	
TV18	What time of day do you like to see TV or movies	Anytime=1	
	outside your home?	Morning=2	
	(List all that apply)	Daytime=3	
		Evening=4	
		Night=5	
TV19	What type of TV programs or movies do you watch	American movies=1	
	outside your home?	(insert country name) movies=2	
	(List all that apply)	Martial arts/action=3	
		Whatever is on the TV=4	
		Music shows=5	
1		Educational=6	

TV20	What is your favorite type of program?	American movies=1	
	(Choose only one)	(insert country name) movies=2	
		Martial arts/action=3	
		Whatever is on the TV=4	
		Music shows=5	
		Educational=6	
		Other (write in)=99	
TV21	Do you usually have to pay to see TV or movies	No=0	
	outside your home?	Yes=1	
_		Sometimes=2	
DM1		Media	NDM9
PM1	Can you read in any language?	No=0 Yes=1	→PM8
PM2	Do you ever read newspapers or magazines?	No=0	→PM8
D) (2		Yes=1	
PM3	What newspaper/magazine do you usually read?	(insert appropriate response)=1	
	(List all that apply)	=2	
		=3	
		=4	
		Other (write in)=99	
PM4	Do you usually buy newspapers or magazines?	No=0 Yes=1	
PM5	What types of articles do you like to read in	National news=1	
1 1015	newspapers and magazines?	World news=2	
	newspapers and magazines.	Sports=3	
		Problem or advice pages=4	
		Editorials=5	
		Games/Jokes=6	
		Other (write in)=99	
PM6	In what languages are the newspapers and magazines	(insert appropriate response)=1	
	you read usually written?	=2	
	(List all that apply)	=3	
	(Dist all that apply)	=4	
		Other (write in)=99	
PM7	What is your favorite newspaper or magazine?	(insert appropriate response)=1	
	(List all that apply)	=2	
	(FF-))	=3	
		=4	
		Do not know=77	
		Other (write in)=99	
PM8	Do you ever look at newspapers or magazines?	No=0	→SB1
	,	Yes=1	
PM9	What newspaper/magazine do you usually look at?	(insert appropriate response)=1	
	(List all that apply)	=2	
		=3	
		=4	
		Do not know=77	
		Other (write in)=99	
PM10	What do you look at in the newspaper or magazine?	Photos=1	
	(List all that apply)	Comics=2	
		Advertisements=3	
		Other (write in)=99	

PM11	Do you generally understand what you see in	No=0	
	newspapers and magazines?	Yes=1	
		Do not know=77	
	Posters and	Sign Boards	•
SB1	Do you ever see posters?	No=0 Yes=1	→SB8
SB2	Where do you see the posters?	Market=1	
	(List all that apply)	Clinic=2	
		On houses=3	
		At school=4	
		Church=5	
		On stores=6	
		On tree=7	
		Other (write in)=99	
SB3	How often do you see posters?	Daily=1	
		Weekly=2	
		Monthly=3	
SB4	When you see a new poster do you go to look at it	Less than once a month=4 No=0	
3D <del>4</del>	more closely?	Yes=1	
	more crosery.	Sometimes=2	
		Do not know=77	
SB5	Do you generally understand the posters?	No=0	
	r i i i i i i i i i i i i i i i i i i i	Yes=1	
		Sometimes=2	
		Do not know =77	
SB6	If the poster is advertising something, does it make	No=0	
	you want to have it?	Yes=1	
		Sometimes=2	
0.0.5		Do not know=77	
SB7	If you wanted to hang a poster so everyone in the	Chief's house=1	
	community would see it, where would you put it?	Near water source=2	
	(List all that apply)	Health volunteer's house=3 Store=4	
		School=5	
		Tree=6	
		Do not know =77	
		Other (write in)=99	
SB8	Do you ever see large signboards/billboards?	No=0	→TE1
		Yes=1	
SB9	Where do you see the billboards?	Shops=1	
	(List all that apply)	Market=2	
		Large town=3	
		On the road=4	
		Near school=5 Other (write in) =99	
SB10	When you see a billboard, do you stop and take a	Other (write in)=99 No=0	
3010	closer look at what is on it?	No=0 Yes=1	
	CIOSCI IOUK AL WITAL IS OIT IL:	Sometimes=2	
		Do not know =77	

	Traditional Entartainman	to Theatma Drama Chains	
TE1	Do you ever attend traditional entertainment such	t: Theatre, Drama, Choirs No=0	→TS1
ILI	as theatre, drama, or choirs?	Yes=1	/101
TE2	At what time of year are traditional entertainment	Anytime=1	
1 22	shows usually performed?	Dry season=2	
	(List all that apply)	Wet season=3	
	(Diet all that apply)	Cattle herding season=4	
		National days=5	
		Do not know=77	
		Other (write in)=99	
TE3	Where do you normally see traditional	School=1	
	entertainment?	Market=2	
	(List all that apply)	Weddings=3	
		Circumcisions=4	
		Village center=5	
		Other (write in)=99	
TE4	Is there a day of the week that is best for traditional	No preference=1	
-	entertainment?	Monday=2	
	(List all that apply)	Tuesday=3	
		Wednesday=4	
		Thursday=5	
		Friday=6	
		Saturday=7	
		Sunday=8	
		Do not know=77	
TE5	What time of day do you usually go to see traditional	Anytime=1	
	entertainment?	Morning=2	
	(List all that apply)	Afternoon=3	
		Evening=4	
		Night=5	
TE6	Do you like traditional entertainment?	No=0	
		Yes=1	
		Sometimes=2	
		Do not know=77	
TE7	Do you believe the messages you see or hear in	No=0	
	traditional entertainment?	Yes=1	
		Do not know=77	
		r Receiving Information	
TS1	Where do you receive information from inside the	Market=1	
	village?	Family member=2	
	(List all that apply)	Friend=3	
		Elder=4	
		Child=5	
		Religious leader = $6$	
		Health worker=7	
TOO		Other (write in)=99	
TS2	Where do you receive information from outside the	NGO worker=1	
	village?	Government representative=2	
	(List all that apply)	General health worker=3	
		Public places=4	
		Friend/relative=5	
		Elder=6 Other (write in) =99	
		Other (write in)=99	

TS3	Is there a person in your village who gives	No=0	→C1
	trustworthy information?	Yes=1	
		Do not know=77	→C1
TS4	Who is the person that gives this information?	Cattle camp leader=1	
	(List all that apply)	Elder=2	
		Chief=3	
		Teacher=4	
		Religious leader=5	
		Health worker=6 Counselor=7	
		Other (write in)=99	
	Clas	thing	
C1	Do you ever see people in the community with	No=0	
CI	clothing or other items that have printed messages?	T-shirt=1	<b>→</b> C3
	clothing of other items that have printed messages:	Hat=2	
	If yes, what types of items are they?	Bag=3	
	(List all that apply)	Cloth=4	
	(Dist un that apply)	Do not know=77	
		Other (write in) =99	
C2	Do you ever see people in the community with T-	No=0	→End
	shirts that have printed messages?	Yes=1	
C3	Do you look at the pictures or messages more if they	Front=1	
	are printed on the front or back of the T-shirt?	Back=2	
	1	Does not matter=3	
C4	Do you think that messages on T-shirts affect how	No=0	
	you live your life?	Yes=1	
		Sometimes=2	
		Do not know=77	
C5	Do you own a T-shirt with large pictures or messages	No=0	<b>→</b> C7
	on it?	Yes=1	
C6	How often do you wear it?	Never=0	
		Every day=1	
		2–3 times per week=2	
		1 time per week=3	
		Sometimes, less than weekly=4	
C7	How do you identify health workers in your	T-shirt=1	
	community?	Cap=2	
	(List all that apply)	Other articles of clothing=3	
		Know the person=4	
		Badge=5	
		Cope=6 Other (write in) =99	
C8	If you see someone with a health education message	Other (write in)=99 Not at all=1	
	on his or her clothing, are you likely to go to that	Not at all=1 Sometimes=2	
	person if you have a health problem?	Always=3	
		Depends on health problem=4	
		Depends on health problem=4 Do not know=77	
		D0  HOU KHOW = 11	



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