

# Understanding Individual and Contextual Factors for Development of a Behavior Change Communication Campaign for Trachoma Prevention In Busoga and Karamoja Regions, Uganda



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**JOHNS HOPKINS UNIVERSITY  
BLOOMBERG SCHOOL OF PUBLIC HEALTH  
CENTRE FOR COMMUNICATION PROGRAMS**

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**UNDERSTANDING INDIVIDUAL AND CONTEXTUAL  
FACTORS FOR DEVELOPMENT OF A BEHAVIOR  
CHANGE COMMUNICATION CAMPAIGN FOR  
TRACHOMA PREVENTION IN BUSOGA AND  
KARAMOJA REGIONS, UGANDA**

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## EXECUTIVE SUMMARY

Trachoma is a neglected tropical disease that affects about eighty million people worldwide with the majority of cases found in poor rural communities). Trachoma is prevalent in communities that have inadequate water supplies, poor infrastructure for sanitation and limited health services. Poor personal hygiene behaviors and dirty faces among children are also important factors in the transmission pathway. Infection and transmission of Trachoma can be reduced by implementation of the World Health Organization SAFE strategy which aims to eliminate Trachoma as a public health problem by the year 2020. Trachoma is endemic in 34 districts in Uganda causing blindness in about 47,000 people in the country. An estimated 700,000 children below the age of 10 years have active disease and about 7 million people are at risk of being infected. This research focused on two Regions in Uganda with high Trachoma prevalence, specifically, Busoga and Karamoja, to take full advantage of Trachoma-related experiences in different geographical and environmental terrains.

Formative research was conducted in selected communities in Moroto and Iganga Districts of Karamoja and Busoga Regions respectively, to identify and understand the contextual and behavioral factors that influenced the transmission and prevention of Trachoma infection. The study also characterized the factors influencing community members' ability to implement the Facial Cleanliness ('F') and Environmental Change ('E') components of the WHO SAFE strategy for preventing Trachoma. The study was conducted to provide information about Trachoma that was contextually relevant to the lived experiences of the target population, and that also would support the development of a behavior change communication campaign for preventing Trachoma.

The research used a cross-sectional design and multiple data collection methods to explore and understand how different hierarchies of context may influence risk of and efficacy to prevent Trachoma. 104 households from eight communities that were stratified by Trachoma prevalence and availability of water and sanitation resources were purposefully selected to participate in the research. Data was collected via a descriptive household demographic survey, two eight-hour days of non-participatory observations of caretaking activities regarding the use and non-use of water, and a total of forty-eight semi-structured key-informant interviews about knowledge, beliefs and factors relevant to Trachoma transmission, treatment and prevention in the community

The following key themes emerged from the data.

### **Knowledge**

Community leaders and health workers demonstrated more knowledge of the causes of Trachoma and how to prevent infection than caretakers and other community members. There was good knowledge about the symptoms and consequences of Trachoma and similarly good insight into the consequences of untreated Trachoma infection; however knowledge of causes, the transmission pathway and prevention of Trachoma was poor. Respondents were aware that Trachoma infection could spread within a family did not discriminate among family members and when untreated, the symptoms of Trachoma were persistent and progressive. Trachoma was perceived to have physical painful effects, social effects including alienation and isolation that were driven by fear, and long-term consequences of disability, blindness, dependency and decreased productivity all contributing to an altered quality of life. Causes of Trachoma were believed to include dirt, other illnesses such as malaria, yellow fever and measles, hereditary factors, airborne eye irritants, evil spirits and witchcraft, or the good will of a higher power.

### **Culture**

The lifestyle of respondents and work-related hazards they encountered during their day-to-day activities were the main factors perceived to influence the occurrence of Trachoma. Relationship with livestock, kraals, “manyattas” (communal living), and the social and hospitality behaviors of the community were identified as the main factors influencing Trachoma. The ‘cattle culture’ of the Karamojong increased interactions with animals and also increased the proximity of animals and their dung to homesteads and living areas. Dwelling patterns that were characterized by *Manyattas*, kraals, and communal living practices were also believed to increase proximity and interactions with others including animals and facilitate the transmission of illnesses. Specific activities related to livelihoods and daily work were perceived to influence Trachoma. Smoke from “tadooba” (paraffin candles) and wood fires used for cooking, powder from milling grain, coffee and tubers, and dust from farming during the dry season produced airborne particles that irritated the eyes and started the cascade of symptoms that led to Trachoma. Hospitality behaviors that encouraged close social interaction, mingling and hand shaking were also believed to increase one’s risk for Trachoma.

### **Community**

Community level factors identified in relation to Trachoma infection included the status of water resources, facilities for waste disposal, and fly densities. Safe water sources were not available, situated a long distance from homesteads or perceived to be insufficient in number relative to the numbers they served. In addition, inoperable or intermittently functioning boreholes led to high user ratios and long wait times at the few functioning water sites; these influenced decisions regarding using other non-protected and natural sources of water. Rationing of household water was often done by caretakers to limit frequent trips to water sources. The status of water in the community (good versus poor) was significantly related to the prevalence of eye and nasal discharge and also to observed face washing activities.

The lack of community-based facilities for disposal of waste was another community-level factor perceived to influence Trachoma: None of the study sites had community-based facilities for waste disposal and the majority disposed of their household waste and animal dung in backyards/gardens. Several sources of attraction for flies were identified including residues of sweet fruit such as mangoes, jackfruit and sugarcane thrown in the environment and on individuals who did not wash up after consuming them. Animal dung and human excreta also increased the fly population in the community. Very few respondents perceived that flies were attracted to the eye and nasal drainage of individuals.

## Household

Household factors that affected use and non-use of water included the lack of latrines, rationing of water, limited resources for obtaining and storing clean water, absent caretakers and proximity of animals. Lack of public latrines for the community or personal ones for households were cited as a factor that increased the practice of open defecation and also the presence of flies and Trachoma in the community. Significantly more households sampled in Moroto (50%) did not have latrines compared to those in Iganga (11.5%) ( $p=0.001$ ). While the effort in distance traveled and time spent to acquire clean water for the household was perceived to influence rationing of water, poverty, lack of facilities and resources to safely store water in amounts that were needed to meet the needs of the household and family members also influenced decisions about water use in the household.

Children were reported to often wake up in the morning to a home without adult caretakers and supervisors: there was often no-one to provide hygiene care and it was not unusual for children to have dirty faces throughout the day until the parents returned home. The practice of

sharing homesteads with animals or having them in close proximity to the living and communal areas of compounds was also believed to put individuals at risk of acquiring Trachoma.

### **Individual**

Individual behaviors that were perceived to influence Trachoma infection and transmission included poor hygiene including hand and face washing practices and techniques, negligent caretakers, cold food, open defecation, inappropriate use of latrines, health seeking behaviors. Overall, personal hygiene, especially hand washing, face washing, and complete baths were perceived to be rarely practiced, and when these behaviors did occur, they were usually not done with correct technique. Hand washing was observed to occur in 7.6% of eye discharge episodes and 4.8% of nasal drainage episodes. Of note is that substantially more hand washing occurred in response to animal care, handling trash and using latrines, than for eye discharge and nasal drainage. Similarly, face washing occurred in only 9.5% of all observed episodes of nasal discharge. Correct technique for both behaviors was also extremely low (less than 1%) although it occurred with more frequency in communities with low Trachoma prevalence.

Some community members did not keep themselves, their children, and their homesteads clean. The parents of children who were usually observed to be dirty were described as “negligent”, “irresponsible”, “lazy”. “dirty” and uncaring. The practice of providing cold food to children influenced fly density and consequently Trachoma, in their communities. Open defecation was thought to be compounded by non-acceptance of latrines and inappropriate use of the latrines by those who did use them. Closely related to a lack of and non-use of latrines was the practice of defecating in the bush and general environment (open defecation). This practice was cited as a problem in both Iganga and Moroto Districts but appeared to be a much more significant problem in Moroto District.

Poor health seeking behaviors in response to eye infection was identified as a reason for increased transmission of infection in the community. There was knowledge that the best way to treat Trachoma was to seek medical attention from formal health facilities but this was not practiced. Visits to the VHT to obtain medicines in lieu of going to a health centres occurred frequently however VHT members frequently did not have medicines. Traditional healers were used to treat Trachoma in both Districts. Other treatment options that were perceived to increase prevalence of Trachoma were to go to chemical and drug sellers for them to prescribe medication or for purposes of self-medication.

## **Risk Perception**

The perception of risk of getting Trachoma was high in all communities and was attributed more to the state of the environment than to specific individual practices that occurred in the household or to the use and non-use of water. Living in an environment that was littered with feces, solid waste, with no latrines or structures for proper waste management contributed to heightened feelings of susceptibility to Trachoma. Increased perceived risk of getting Trachoma was also related to beliefs that it had an airborne source and to observations that Trachoma did not appear to discriminate among who got infected. Risk of Trachoma was perceived to be high regardless of one's personal efforts to prevent getting Trachoma; personal prevention efforts were thwarted by the unhygienic actions of others in the community.

## **Self Efficacy**

Fatalistic attitudes were strongly apparent throughout the data and especially regarding individual efficacy to prevent Trachoma. Descriptions about self efficacy to prevent getting Trachoma were laden with words and phrases like "*inevitable*", "*no guarantee*", "*hard to prevent*", and "*nothing much you can do*". Incorrect knowledge about Trachoma, specifically beliefs attributing Trachoma to external spiritual forces and a ubiquitous characteristic of the environment rather than to behavioural factors in the domain of the individual were common. These beliefs fostered an external locus of control within the individual that did not empower individuals with the ability to protect self and their families from getting Trachoma.

Community members also were not equipped to implement Trachoma prevention strategies. There was a lack of interest in Trachoma, low motivation and involvement in Trachoma prevention programs, poor attitudes towards behavior change, and lack of support from the community for prevention strategies.

## **Summary and Conclusion**

Overall, the study results showed limited knowledge about the cause of Trachoma and the strategies to prevent it. There also were specific cultural-, community-, household- and individual-level factors that increased perception of risk of Trachoma and decreased self efficacy to prevent infection with Trachoma. The main themes derived from the study are consistent with the key water, sanitation and hygiene (WASH) activities to prevent Trachoma

that are outlined in the Global Manual for WASH implementers (2013). In addition, new understandings underlying attitudes and behaviors of local populations that increased risk of Trachoma were identified and provided deeper insights into antecedents to behavior change. These new findings also demonstrated how different levels of influence factors in the environment intersect to influence the use and non-use of water and the behaviors related to sanitation that are deemed critical to the successful elimination of Trachoma.

## INTRODUCTION

### Background

Trachoma, a neglected tropical disease, is endemic in fifty-five countries and affects about eighty million people worldwide with the majority of cases found in poor rural communities (Rog et. al., 2011). Trachoma is prevalent in communities that have inadequate water supplies, poor infrastructure for sanitation and limited health services. Poor personal hygiene behaviors and dirty faces among children are important factors in the transmission pathway (Taylor, 2008). Blindness results when Trachoma is untreated, however the infection and transmission of the disease can be reduced by implementation of the World Health Organization (WHO) SAFE strategy which aims to eliminate Trachoma as a public health problem by the year 2020. The SAFE strategy involves the use of surgery (S), antibiotics (A), facial cleanliness (F) and environmental change (E) interventions (World Health Assembly, 1998; Mariotti and Pruijs, 2001) to decrease Trachoma infection. Previous studies have assessed the effects of face washing only, environmental change only and a combination of these strategic approaches to prevent Trachoma.

### ***Face washing and Trachoma prevention***

A study in Egypt (Rubinstein et al., 2006) showed that there was 33% lower risk for active Trachoma when a face-washing strategy was implemented, and a study in Tanzania showed that face washing, or clean faces, among preschool-aged children in Tanzania was associated with a significant decrease in risk for Trachoma [Rog, et. al., 2011]. Poor access or longer distance to water, and inadequate water for washing in the household have also been associated with increased risk of Trachoma infection (Polack, et. al., 2006]. Studies on predictors for washing among children under the age of five years demonstrated that water supply alone did not explain face washing habits among households. Individual perceptions and societal impediments, such as mothers' belief that it takes one liter of water to wash a child's face along with the thought that there are more important uses for water have also been shown to influence both the decisions and the ability to keep children clean (Rog, et. al., 2011).

### ***Environmental change and Trachoma prevention***

Empiric data on the influence of environmental improvements on the prevention of Trachoma are sparse and what is available has shown mixed results. A systematic review of six

studies on environmental sanitary interventions was conducted by Rabiou et al. (2012). The review showed that two trials on latrine provision for fly control did not show a significant reduction in Trachoma (Emerson et al., 2004 [The Gambia]; Stoller et al., 2011 [Ethiopia]); a health education study in Mali showed a significant reduction in Trachoma (Resnikoff et al., 1995) but not in another study in Niger (Abdou et al.); use of Insecticide spray to reduce the fly population was beneficial in reducing active Trachoma in The Gambia ( Emmerson et al., 1999) however a reduction in Trachoma was not found in a similar study conducted in Tanzania (West et al., 2004).

### ***Combination of face washing and environmental change, and Trachoma prevention***

Most of the literature on combination studies emphasized medical and surgical treatment options (i.e., the ‘S’ and ‘A’ components of the WHO SAFE strategy for Trachoma prevention) and not socio-behavioral prevention strategies. Two studies by Ngondi et al. (2008 [Southern Sudan]; 2010 [Ethiopia]) that examined the effect of interventions addressing the ‘AFE’ components of the WHO SAFE strategy showed a reduction in Trachoma. In the study conducted in Ethiopia (2010), each component of ‘AFE’ showed independent protective effects against active Trachoma: The F and E components increased frequency of face washing (two or more times a day compared with none) and owning a pit latrine both resulted in a reduction in the odds of active Trachoma, 50 and 40 percent respectively. A study by Edwards et al. (2006) in Ethiopia that delivered health education about Trachoma showed a statistically significant increase in the awareness of Trachoma, but the reduction in prevalence of Trachoma and adoption of prevention behaviors were not significant. The authors concluded that health education on its own was unlikely to reduce the prevalence of Trachoma.

A study by Khandekar et al. (2006) evaluated an intervention in Vietnam that included creating awareness about face washing and its role in the prevention of Trachoma, and improved water access through well and latrine construction and installation of water tanks. One village received all SAFE components and another only the SA components. The prevalence of Trachoma rate was significantly reduced in both villages; the F & E strategy was responsible for 58.7% of the decline at all ages and 37.4% of decline in children under 15yrs of age. There was an improvement in knowledge of prevention, but not in the attitudes towards, or the behaviors that prevented Trachoma, the latter being an important precursor to sustained behavior change. Although it may appear that hand washing may be associated with face washing and having a clean face, a literature search for this evidence yielded no significant results.

There is a lack of strategic and nationally coordinated communication responses for face washing in many Trachoma endemic countries. There has also been decreased emphasis on the 'F' and 'E' components of the WHO SAFE strategy and a consolidated information repository for facial cleanliness and environmental change materials, strategies, publications, tools and products is not available. Evidence also suggests that many health workers, including environmental and sanitation workers often lack the knowledge about socio-behavioral communication change activities that are most effective in influencing activities associated with 'Facial cleanliness' and 'Environmental change' for the WHO's SAFE strategy.

The results of this research will be useful for the development of a consolidated and comprehensive knowledge management repository of tools and guides for developing, implementing, monitoring and evaluating a behavior change campaign to prevent Trachoma infection. The results can also provide guidance for the development of audience specific and contextually relevant behavior change communication campaign messages for prevention of Trachoma. Study results will also yield community-level data and recommendations of interest and use to the Uganda health authorities.

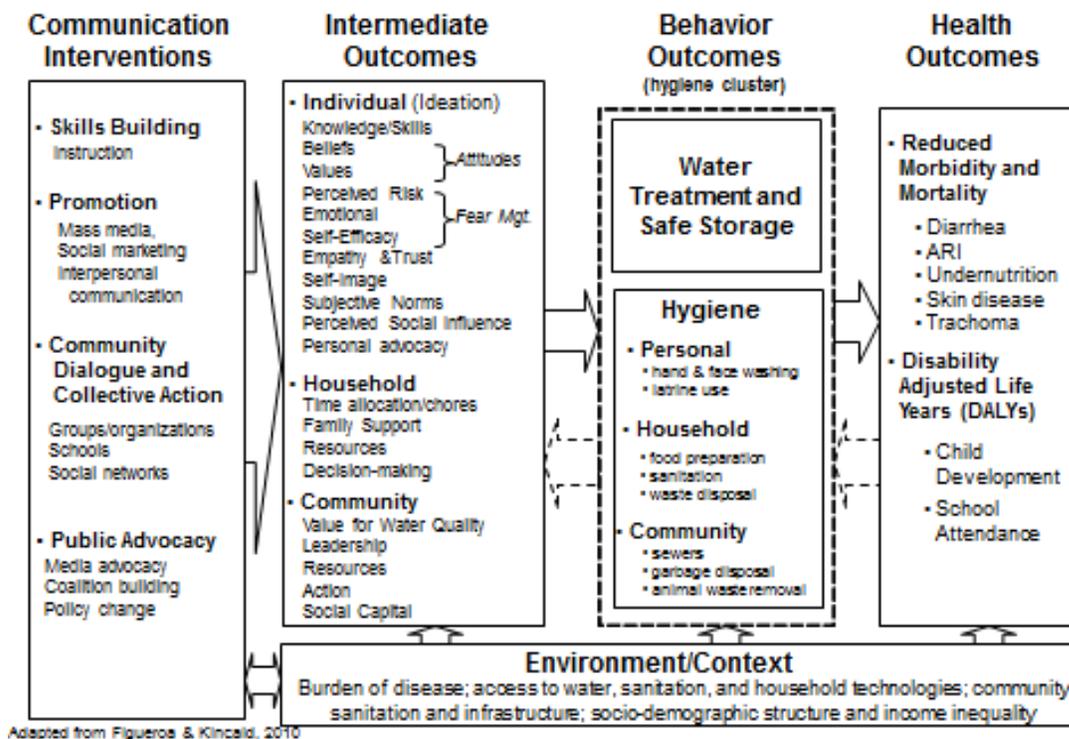
## **Conceptual Framework**

The underlying theory supporting the research is the Risk Perception Attitude Framework (RPA), adapted from the Extended Parallel Process Model (EPPM) (Rimal and Real, 2003; Witte, 1992). The EPPM has been used successfully to explain the moderating role of self-efficacy in the relationship between risk and behaviors. Specifically, the model postulates that when risk perception is low, efficacy will have little impact on behavior, but when both risk perception and perceived self-efficacy are high, stronger positive behaviors will result. The RPA framework is based on four attitudinal groups formed by the intersections of risk and efficacy, specifically responsive, avoidance, proactive and indifference. The framework posits that these groups differ in their self-protective motivation and prevention behaviors and allows programs to target each group with interventions that are specific to their needs. This approach is useful for a global strategy that provides a standardized approach yet maximizes the effect of health and behavior change messages by taking advantage of the differences in individuals and environments at the country, district, and community level. It facilitates audience segmentation and the derivation of different strategic messages for different characteristics of the audience. Combined, this theory-based approach to BCC program design will promote the use and scale-

up of best practices, lead to better health outcomes, and improve country-level advocacy for Trachoma prevention.

The 'F' and 'E' components of the WHO SAFE strategy focus on change at the level of the individual and the environment and both perception of risk and contextual factors in the environment will be important for an effective Trachoma prevention strategy. Thus, an approach that acknowledges attitudes and behaviors related to perceived risk and efficacy as they intersect with both the individual and the social-cultural and physical environment will provide strong basis for interventions to promote and diffuse positive Trachoma prevention behaviors among the majority within a community. The water and hygiene framework described below provided such an approach and the guidance for tool development.

**Fig. 1. Communication for Water Treatment and Hygiene**



The communication for Water Treatment and Hygiene Framework (Figueroa and Kincaid, 2010) in Figure 1, above is a predictive model developed to guide the design and evaluation of interventions to promote good water, sanitation, and hygiene behaviors, It provides guidance to both research and program efforts and links outcomes evidence to specific health communication strategies. This framework provides appropriate guidance to this study as both

the framework and the study focus on using research to inform the development of a context-appropriate communication campaign. The model can be applied to two approaches: It can be used to guide the evaluation of the effects of a communication campaign (i.e., assessing health communication impact on a specific health problem) and it can also be used to inform the development of an evidence-based communication campaign (i.e., using the framework constructs to collect the information needed to identify relevant communication strategies).

The model shows the importance of ideation in the behavior change continuum. Ideation factors are the antecedents to behavior change. Ideation is shaped by knowledge, attitudes, beliefs, efficacy, emotion and fear to name but a few, all of which are important concepts to this study. These factors influence behavioral intention and eventually action in the form of desired behavior change. The specific data collection methods and the questions of interest in the research were developed using this framework. The questions included in the in-depth interviews were in part derived from the “intermediate outcomes” section of the model: the study explored how these factors were related to Trachoma and how they could inform a behavior change campaign. The components of the observation checklist were informed by the “hygiene” component of the “behavior outcomes” section. The household survey also included questions to better understand the factors discussed in the “environment/context” section.

## **Trachoma in Uganda**

Trachoma is endemic in 34 districts in Uganda causing blindness in about 47,000 people in the country. An estimated 700,000 children below the age of 10 years have active disease and about 7 million people are at risk of being infected. Results from a survey conducted by Sight Savers and Aid Norway (Uganda MOH, 2006) showed that prevalence of active and non-active Trachoma in all the surveyed districts was >20% and >4% respectively, and Trachoma remains uncontrolled in areas of high prevalence. Trachoma elimination through mass treatment with Zithromax began in 2007 and to-date, over 12.8 million people have received this treatment. The other components of the SAFE Strategy being implemented include surgery, face washing in schools and improvements in environmental sanitation. This research focused on two Regions in Uganda with high Trachoma prevalence, specifically Busoga and Karamoja.

Karamoja Region: Karamoja Region extends over 27,900 square kilometers and has a population of 1,107,308 with about half of the population less than 18 years of age (Knaute and Kagan, 2008). The region is mostly a semi-arid plain with harsh climate and low annual rainfall.

Karamoja has the worst socio-economic indicators in Uganda and lags in indicators for health, education and infrastructure development. Literacy rate is 21% compared to the national average of 68% (UBOS, 2004) and about 82% of the population live in poverty; less than half (46%) have access to safe drinking water, and 8% have access to sanitation facilities. Prevalence of Trachoma Follicular (TF) in the Region is 65.7% (MoH, 2006).

Busoga Region: Located in South-Eastern Uganda this Region and extends over an area of 17,815.9 square kilometers, and has a predominantly agrarian population of 3, 211, 0101 (UBOS, 2009). The area has a lot of migration due to economic hardships and food shortages fueled by poor crop yields. Studies estimate the prevalence of TF in the Region at 20.1% to 33.6% (Busoga CES Evaluation Report, 2009; MoH, 2006).

## METHODS

### Study Sites and Sampling

The study was conducted in the Karamoja and Busoga Regions of Uganda to take full advantage of Trachoma-related experiences in different geographical and environmental terrains. Within these two Regions, Moroto District and Iganga District were purposively selected with input from the Uganda Ministry of Health<sup>1</sup>. Data from Uganda Ministry of Health on prevalence of Trachoma (characterized as high or low prevalence) and on availability of water and sanitation resources by percent water throughout the year and percent with toilet (characterized as good or poor availability) that were available at the Parish level were used to stratify Parishes into four groups. See Table 1 below. Within each of these four groups, one sub-county was randomly selected for inclusion in the study, and then one LC-1 (Local Council-1) level village was selected from the sub-county for a total of four villages per District (and eight per study). This constituted the communities of interest.

**Table 1: Selection Matrix**

Level	Criteria	Moroto District				Iganga District			
		+ Water + Toilet		--Water -- Toilet		+ Water + Toilet		--Water -- Toilet	
Parish	*Water/Sanitation								
	**Prevalence	High	Low	High	Low	High	Low	High	Low
Village		1	1	1	1	1	1	1	1
<b>TOTAL SAMPLE (8)</b>		1	1	1	1	1	1	1	1

\*Parishes were considered to have + water/toilet if both indicators (percent water and percent with toilet) were above average and – water/toilet if both indicators were below average

\*\* High /low designations were based on the average Trachoma prevalence for each Region (High- above average, Low- below average)

District Health Officers assisted with the selection of the following villages for inclusion in the study:

**Table 2: Study Sites**

Region/District	Parish	Village	TF Prevalence	Water/Sanitation
	Acholi Inn	Rupa	Low	Poor
	Goli	Police Barracks	Low	Good
	Kadilakeny	Lobuneit	High	Poor

<sup>1</sup> After approved study design, some of the communities selected for Karamoja Region were found to be re-zoned into the new Napak District. For purposes of the study, we analyzed those communities under Moroto District, Karamoja Region.

Region/District	Parish	Village	TF Prevalence	Water/Sanitation
Karamoja/Moroto	Loroketo Nasike	Nasike South	High	Good
	Bugono	Nabinyonyi	Low	Poor
Busoga/Iganga	Bunyama	Bunyama Village	Low	Good
	Kigulamo	Kigulamo Village	High	Poor
	Bulumwaki	Nsinze	High	Good

## Sampling and Sample Size

Participants were key informants and members of households (adults and children) from the eight communities.

### In-depth Interviews

Six key informant interviews were conducted in each selected community for a total of 48 interviews (6 interviews X 8 communities). In qualitative research, five to eight individuals per subgroup is recommended as a guideline for sample size using stratified purposeful sampling (Crabtree & Miller, 1999), so six interviews was appropriate to achieve saturation of themes for a domain of interest, and provided a sufficient amount of data to compare across countries and settings.

### Non-participant Observations

#### *Household Observations*

Households were purposefully selected in collaboration with the chairman of the Local LC-1 and the Village Health Team (VHT). Households were selected based on two criteria: 1) presence of children in the house and 2) the primary caretaker would be home and available for two days of observation. The unit of analysis for household observations that was used to estimate sample size was behavioral actions relevant to the use, and non-use of water. These actions were chosen as the primary units for observation as they have a key influence on transmission of Trachoma (Mariotti and Pruis, 2001). A literature search did not provide information on average numbers of actions related to water use and environmental sanitation among households in Uganda, consequently we use maximum variability ( $p=0.5$ ) for prevalence of relevant actions to obtain the largest sample size; the variances of indicators measured as proportions are maximized as they approach .50.

**Sample Size Formula:**

$$n = \frac{t^2 \times p \times (1-p)}{m^2}$$

Where:

n = required study sample size

t = confidence level at 95% (standard value of 1.96)

p = estimated prevalence of relevant actions in each household

m = margin of error at 5% (standard value of 0.05)

The sample size calculation yielded a sample of 384 relevant actions per community. Sampling literature (Israel, 1992; Sudman, 1976) recommends a minimum of 100 elements (i.e., relevant actions related to water use) for each major sub-group (such as males or females) and 20-50 elements for each minor subgroup (such as communities), in the sample. We anticipated exceeding this requirement for the overall and for sub-groups during the eight hour observation activity per household. We included a design factor to correct for sampling inefficiency related to the cluster sampling design (as randomized selection will only occur at the village and household level). The design factor also corrected for any correlations that may have existed at the community level between households sharing the same environment, and also at the household level between individuals within the same household. This increased the number of relevant actions to 768 per community. This well exceeds the minimum number of observed actions required to show major and minor sub-group differences between and within communities.

To determine the number of households to observe within each community, we conservatively estimated the number of relevant actions observed per day-long (eight hours) observation at 30 (personal communication with MoH and local Program Officer). This expectation resulted in about 26 observations to be enumerated per village (768/30 relevant actions), and a total of 208 households (26 households X 8 villages). We conducted two days of observations per household, thus the sample size is 104 households (208/2). This translated to 13 households per village community (104 / 8 = ~13).

*Community Observations Mapping*

All eight communities participated in the community observations and mapping activity.

## Study Procedures

### Data Collection Tools and Process

The formative research was based on a cross sectional design and the data were collected using qualitative and quantitative research methods, specifically semi-structured in-depth interviews, a household survey, structured non-participatory observations of household activities, and a community mapping activity. Informed consent was obtained from all study participants prior to the start of data collection.

**In-depth Interviews:** Interviews with community members and stakeholders were conducted to understand the norms, perceptions and attitudes influencing behaviors around Trachoma treatment, prevention, and control. Key informants were purposefully selected to create diversity in the interviewee pool, and also on the basis of their familiarity with the culture and community, and their ability to articulate in detail, the challenges operating at different levels of the system. Selection of informants was done in collaboration with the local research team and Chair of the village VHT. Informants included:

- Healthcare workers from the selected communities including but not limited to health inspectors responsible for water and sanitation activities in the community and health center III in-charges;
- Political and local leaders such as local council leaders and Parish chiefs with knowledge of local culture;
- Community members with local influence including traditional healers, teachers, community elders with specialized knowledge of the community and culture, VHT Chairs and members;
- Trachoma patients including those who had vision loss, were in the process of receiving treated, or had successfully completed treatment;
- Mothers and other caretakers of young children;
- Religious leaders who routinely disseminate messages to community members.

The key informant interviews were conducted using semi-structured field guides developed for each category of informant as discussion aides. The guides included questions on attitudes, norms, and environmental factors impacting the transmission and prevention of Trachoma infection. Other categories of information included in the guides were perceptions about for Trachoma

**Household Demographic Survey:**

After consent was obtained, and prior to starting the first observation, the consenting adult in the household completed a brief *quantitative household questionnaire* regarding demographic and descriptive characteristics of the household such as the number of adults and children, presence of illness, ownership of the radio, toilet facilities, access to and use of water, disposal of human, household and animal waste, and other environmental factors.

**Non-Participatory Observations:** Non-participatory observations were conducted of the activities in households and of the community environment to provide information about the usual and routine behaviors and practices related to childcare, domestic hygiene and environmental sanitation. The observations occurred on two levels: 1) two day-long (eight hours) observations of individuals (caretakers, mothers) in the home, and, 2) a community walk-through and visual assessment of the environment with community mapping.

*Household Observations:* The households for observation were randomly selected just prior to the start of observations. The observer was a trained member of the research team, and, to promote an unbiased observation, was not from the community. Participants were informed that observers were interested in learning about the daily routine and activities carried out in the households such as behaviors related to cooking, cleaning, and child care. Household observations were conducted for two days, each over a period of eight hours, in each selected household. The primary female caretaker in the household who was responsible for carrying out the activities of interest such as childcare, compound cleaning, washing, cooking, obtaining water etc was the focal point of the observation. However, all members of consenting households who interacted with the primary caretaker during the observation period were included in the observation.

Observations were passive and not intrusive, and the observer did not interact with, interrupt, or question observed behaviors during the observation. Observers paid attention to the condition of faces of adults and children, personal and domestic hygiene (specifically face cleaning, face washing, food and water hygiene), water use, animal care and disposal of waste. Relevant actions related to use and non-use of water, and environmental sanitation toddlers and young children were observed being bathed and cleaned. An observation checklist was used to document the use and non-use of water for the following items of interest to the study:

- time of the observed behavior (or lack of behavior) took place;
- individual performing the behavior (actor);
- whether the action was performed on themselves or on a child (acting on);
- the observed factor that did, or should have, result(ed) in hand or face washing (impetus);
- individual's action related to the impetus (observed response);
- details about the technique of any observed hand and face washing (technique).

Observers were trained to minimize bias, and also to respect the privacy of those being observed as they performed personal hygiene activities such as taking a bath and using the toilet. Personal hygiene actions for household members who were age-dependent on caretakers for their care such as infants and very young children were observed freely.

*Environmental Observations and Mapping:* A community walk-through was conducted to observe and map the following environmental characteristics:

- community water sources (type, distance, and access)
- sources of water for animals
- sanitation (including latrines, latrine location/proximity, garbage disposal, and open sewage drains)
- cleanliness of compounds
- recreational areas for children/where children were observed playing
- location of animals and animal dung in relation to household compounds
- fly density
- dirty faces
- open sewage and waste water drainage

A pictorial map of each village was produced that identified geographic locations of key structures considered relevant to Trachoma infection transmission, control and prevention.

## **Analysis**

**In-depth Interviews:** Recorded data and handwritten notes were translated, transcribed and typed into a word processing program. A preliminary codebook of *a priori* codes was developed based on the study aims and concepts of interest to the study that were outlined in

the interview field guides to facilitate consistency in the coding process. Data were coded using the coding structure in the codebook to identify themes in the data, and the codebook was expanded and refined as data analyses progressed and new themes emerged from the data. Codes were used to conceptually name the data and reduce it to manageable units of information that cover shared broad and general categories.

The coded data was organized into a hierarchy of themes that were meaningfully linked to each other to show patterns, relationships and explanations. In conjunction with the coding process, memos were used to develop conceptual categories and themes and to track emerging insights and interpretations. Analysis entailed comparing responses across the two Regions, as well as across the village stratifications. Where possible, the views of different participant categories were also compared.

**Non- Participatory Observations:** The household demographic and observation data were linked and entered into a quantitative database for analysis using analytic software. Numerical counts of relevant actions sub-aggregated by region, TF prevalence category, community, and availability of water and toilet facilities were tabulated and comparisons made by bi-variate and multi-variate analysis. Analysis was also conducted by exploring relationships between household characteristics and observed behaviors.

Triangulation across the methods (in-depth interviews and observations) was done to increase the validity of study findings and offer opportunities for deeper explanatory insights into the concepts under study (Patton, 2002). Results from the observations were also used to strengthen themes identified through key informant data. The community mapping products were visually analyzed to provide further understanding of structural issues that may influence perceptions and key behaviors of community members.

## **Human Subjects Research and Ethics**

Approval for the research was obtained from Johns Hopkins Bloomberg School of Public Health and locally from the School Of Health Sciences Research And Ethics Committee, College Of Health Sciences at Makerere University as well as from the Uganda National Council for Science and Technology in Kampala. The rights of Human Subjects in research were respected and incorporated into the study protocol. Investigators (PI, Co-I) on the study were

certified in research ethics, and training in ethical issues for field research was included in the training workshop content for the local research team.

### **Training Workshop**

The JHU-CCP research team conducted a two-day training workshop for the local research team in Kampala (data collectors, team leaders, quality control officers and supervisors) prior to data collection. Training content included information on research ethics in the field, rights of human subjects during research, research methodology and protocol, sampling procedures, informed consent, interpretation and use of the collection tools, and data management, security, and quality. The workshop also included practical sessions for team members to practice their interviewing techniques and using the different data collection tools.

## RESULTS

In this section we describe and collate the results of in-depth interviews, the household survey, non-participatory observations, and community mapping to explore factors that relate to the transmission and prevention of Trachoma. Participants' knowledge of Trachoma, factors influencing the prevalence of Trachoma and perceived ability of community members to prevent Trachoma are presented.

### Knowledge and Beliefs about Trachoma

Participants' knowledge about Trachoma, specifically the symptoms, causes and consequences of infection varied depending on the type of informant, with female caretakers of children demonstrating less knowledge about Trachoma than community leaders and village health workers. Community member perceptions of Trachoma were also shaped by individual and family experiences with Trachoma as well as personal observations of and interactions with community members who had infection.

#### ***Knowledge of symptoms***

The local terms used to describe Trachoma, “*Lochiir*” (muddy eyes or eye discharge) and “*Loboroch*” (disease of the eye lashes) in Moroto and “*Amayisor Amalole*” (watery dirty eyes) in Iganga were suggestive of knowledge of the symptoms of Trachoma that were rooted in personal experiences and observations. Study participants from both Regions and across sites that were characterized as high and low Trachoma prevalence communities reported being aware of most of the symptoms of Trachoma. A majority of respondents mentioned having “swollen eyes”, “reddening of eyes”, “whitish eye discharge”, “itchy eyes:”, “itchy eye lashes that eventually drop off”, and “dry eyes” that make blinking painful as the symptoms of Trachoma. The following excerpts of respondent experiences illustrate these points:

*“Yes, I have ever had Trachoma. The eyes first got dry with no lubrication and it was hard to blink. Then later they started itching. If it starts like at midday and no treatment has been administered, you wake up then you cannot see, you are like blindfolded. Even, my family members got infected with Trachoma; my mother and the children. For my mother, the eyes started by itching her and later started to pain and produce discharge”. (Community Member, Bunyama, Iganga).*

*“Trachoma to me is a disease that affects people’s eyes. Both young and old persons who have that disease always have discharge around their eyes, the eyes are red and teary all the time”. (Community Leader, Goli, Moroto).*

These illustrations show that respondents were aware that Trachoma infection could spread within a family, did not discriminate among family members and that untreated symptoms of Trachoma were persistent and progressive. Respondents described how chronic infection could cause permanent reddening of the eyes and made reference to a community where Trachoma infection had been rampant for so long that its community members were known as the ‘red-eye people’ by the local populace.

Some respondents also described how individuals with Trachoma had difficulty opening their eyes when they woke up in the morning and difficulty keeping them open in bright sunlight. They explained that the latter photophobia occurred with advanced stages of Trachoma, and when individuals were observed covering themselves with cloth to avoid direct sunlight; it became obvious to community members that these individuals were suffering from Trachoma. A few respondents mentioned headache as a symptom of Trachoma but did not clarify if this was radiating pain from the eyes.

### ***Knowledge of consequences of Trachoma***

Overall, respondents demonstrated good knowledge about the consequences of untreated Trachoma. Consequences of Trachoma ranged from changes in physical appearance such as “chronic redness” and eyes that look “dull”, “not clear” and “are not sharp looking”, to losing one’s sight from infection or by removal of the infected eye. The majority of respondents from both Districts mentioned impaired or deteriorating sight and eventual blindness as the long-term consequences of infection with Trachoma. As observed with knowledge of the symptoms of Trachoma, respondents’ knowledge of the consequences of infection was related to personal experiences with Trachoma as shown in the following illustrations:

*“I have ever suffered from Trachoma and I got some defect from it because right now I am short sighted... In the community, we have one man who eventually lost his sight”.*  
(Community Member, Kigulamo, Iganga).

*“Yes; I have Trachoma and it started way back when I was about 10 years old. It kept on reoccurring by itself until I got blind”* (Community Member, Bugono, Iganga).

*“Trachoma if not treated, one can lose sight, will not be able to see. It can also lead to the eye being removed”* (Community Leader, Acholi Inn, Moroto).

Perhaps, the most telling statement made by community members about the impact of Trachoma on their lives had to do with their recognition of effects beyond the physical manifestation of infection. Some respondents discussed how the long-term effect of Trachoma transcended beyond the physical deterioration of sight to a much wider effect on the quality of one’s life. Community members stated that untreated Trachoma impacted their livelihood, their economic and household productivity, and their ability to look after their families as seen in the illustration below from a community member from Iganga:

*“If one is suffering from Trachoma at home, it will be hard to do any work because one gets disabled after losing sight with no work done and eventually poverty comes in as one becomes unproductive....”* (Community Member, Kigulamo, Iganga).

The impact of Trachoma was not limited to the individual with the infection; community members recognized that other family and household members were impacted by their having to provide long-term support to the member who could no longer function effectively.

*“If a member of my family gets Trachoma... it affects every member of the household because this person becomes disabled and needs continuous support”.* (Community Member, Kigulamo, Iganga).

Respondents also described stigma and social isolation as consequences of infection with Trachoma, and described how community members with Trachoma were often shunned by others in the community. Fear of infection often led community members to exclude those with Trachoma from activities including simple social acts such as “shaking hands” or acknowledging them by direct eye-contact: a respondent from Iganga included that *“some people think that one can get Trachoma by looking at eyes of a patient with Trachoma”* which resulted in behaviors that further alienated those with Trachoma. Infected individuals were oftentimes not encouraged to mingle with others in the community and many were restricted to their homes to prevent them

from spreading the disease to others. A community member from Bunyama Village in Iganga likened the alienation from Trachoma to “staying confined for a long time the way prisoners do”.

*“The worst experience with this infection in this community is that you are alienated... by the people of the community for fear of getting infected”.* (Community Leader, Bunyama, Iganga).

The pain from sunlight and the inability to function independently which was characteristic of advanced cases also contributed to the confinement and isolation of individuals to their homes. Respondents perceived the isolation to be especially emotionally difficult for children when their attendance at school was interrupted and also because they could not fully understand why they were prevented from socializing with their peers.

In general, the respondents demonstrated good knowledge of the immediate and chronic symptoms of Trachoma. They also had insight about the impact of Trachoma on the lives of individuals as well as families that were beyond the physical symptoms of infection.

### ***Perceived causes of Trachoma***

Respondents had varied perceptions about the causes of Trachoma and cited multiple interrelated factors including dirt, environmental sanitation, spiritual forces, foreign particles and other illnesses. Other perceptions were that Trachoma was hereditary, ubiquitous, or caused by unknown factors.

#### **Dirt, Dust and Refuse**

Dirty individuals and dirty communities were described as a problem in both Moroto and Iganga Districts and Trachoma infection was commonly perceived by community leaders and health workers to be linked to the dirt on children and adults as well as to dirt in their households and community environment.

*“It is also due to dust and in most cases; children get it after playing with dust”.* (Community Leader, Bunyama, Iganga).

A community leader from Bugono in Iganga stressed *“the people in the community do not see Trachoma the way I see it because they do not connect it to dirt”*. Sources of dirt and dust

that were described included poor hygiene behaviors, poor household and environmental sanitation, and dust common during the dry season.

Dirt on hands, faces, and clothes as well as personal tools and household appliances were perceived as sources of Trachoma infection in both Districts. A community member from Bugono, Iganga, advised that as a way to stop the Trachoma infection "*we should keep our bodies and clothes clean not to attract flies, and avoid dirt of all kinds*" and a leader from Goli in Moroto District reiterated that "*a child with a clean face is free from common diseases like Trachoma ... whereas a dirty child is normally sickly*".

"Even if the eyes are normal, they eventually get infected because of dirt. That child will get Trachoma for what I know is that it is due to dirt." (*Community Leader, Bulumwaki, Iganga*).

"The dirty children are at a high risk of being attacked by disease like Trachoma and other diseases". (*Community Member, Kadilakeny, Moroto*).

Another statement referenced below showed that community members believed that even patients treated successfully for Trachoma were at risk of re-infection if they did not keep themselves clean:

"It's believed that once you suffered Trachoma you still stand a risk of getting re-infected if you don't keep proper hygiene" (*Community Leader, Goli, Moroto*).

In addition to dirty individuals, a dirty household and community environment was also believed to cause Trachoma. A health worker from Moroto stressed that Trachoma was "caused by living in a dirty place and also that "the community must keep the environment clean otherwise there can be an outbreak [of Trachoma]".

"One can influence getting Trachoma when the environment and homesteads is very dirty". (*Health Worker, Kadilakeny, Moroto*).

"Litter[ing] the compound / environment with rubbish is another leading cause of Trachoma." (*Community Member, Goli, Moroto*).

While community members were knowledgeable that poor hygiene and sanitation influenced the occurrence of Trachoma they had little knowledge of the causative agent and poor understanding of the factors in the transmission pathway for infection.

The dusty environment of the dry season was also perceived to be a cause of Trachoma in both Moroto and Iganga Districts for, as a community member explained, “eyes are susceptible to dust”. This belief is illustrated in the following excerpts:

*“Yes, we are at risk of getting infected with Trachoma because it is a dry season”.*  
(Community Member, Kigulamo, Iganga).

*“You see at times Trachoma comes during the dry season when there is dust. So we try to caution children from playing in dust”.* (Community Member, Bugono, Iganga).

*“Through air is another way someone can get Trachoma when the dry winds blow dirty dust into your face; you are at risk of getting Trachoma”.* (Community Leader, Goli, Moroto).

By these illustrations, some community members linked Trachoma to environmental factors, believing that the cause of Trachoma infection is within the dust that children play in and also that blows in one’s face during the dry season. Of note, also, is that dust of the dry season is qualified as being “dirty dust” with the implication that there is something different about this dust that enables it to cause Trachoma. Nevertheless, few respondents further qualified the properties of “dirty dust” or linked it to contamination with human and animal waste. This finding is elaborated on in greater detail in the section ‘Airborne Causes of Trachoma’ further on in the document.

### **Spiritual Causes**

Spiritual factors were perceived by the majority of respondents to be the main cause of Trachoma, and both good and evil forces were linked to the eye infection. Substantial numbers of respondents, more so in Iganga than in Moroto, believed that Trachoma was either the result of witchcraft and curses or the will of a higher spiritual power, specifically God’s plan for the individual with Trachoma. The following quotations are examples of these perceptions:

*“There are people who think they are bewitched forgetting it is their dirty environment that makes them sick”.* (Health Worker, Bunyama, Iganga).

*“Another says you are bewitched”.* (Community Member, Loroketo, Moroto).

*“It is God’s plan for one to have Trachoma; therefore one can get it at any time”.*

(Community Member, Kigulamo, Iganga)

In this respect the cause of Trachoma is perceived not to be a result of human behaviors but rather viewed as one’s destiny, consequently the solution is perceived to be out of the realm of human effort. This concept is discussed in more detail in the subsections on treatment and self-efficacy.

**Related to Other Illnesses:** Measles, Yellow Fever and Malaria

Some respondents associated Trachoma with illnesses that presented with ocular symptoms such as measles (respondents from Iganga), yellow fever (respondents from Moroto) and malaria. Some respondents recalled they got Trachoma shortly after they had had malaria or measles, and therefore associated the preceding illness as being in the causal pathway for Trachoma.

*“When I got Trachoma, I had just had malaria. ....what I know is that Trachoma comes with malaria and measles”* (Community Member, Bugono, Iganga).

*“I just guess because when it comes you think it is Trachoma then maybe it is measles. You continue guessing”* (Community Member, Kigulamo, Iganga).

Nevertheless, a few respondents were able to distinguish that yellow fever caused a yellowing, and Trachoma a reddening, of the eyes, and in addition Trachoma spread easily within the household compared to eye infections seen with measles and yellow fever. Respondents failed to make a possible link between poor facial and eye hygiene during the preceding illness and later Trachoma infection. Others also believed that Trachoma is as a result of jiggers and high blood pressure.

*“A person with jiggers can get Trachoma because jiggers consume a lot of human blood, weakening his/her body immunity hence leading to Trachoma”.* (Community Leader, Bulumwaki, Iganga).

While the relationship between jiggers and Trachoma may be a rare insight from a few respondents, as with other causes, the link between the presence of jiggers and poor hygiene and environmental sanitation was not evident.

### **Hereditary Factors**

Many respondents attributed hereditary causes to Trachoma infection. The feeling conveyed was if one came from a family with members who had suffered from or currently had Trachoma, then chances were high that you and other members of your family would also eventually get Trachoma.

*“Especially when this disease goes to the chronic state and that is when they start saying that its some kind of inheritance making statements like my grandmother also used to have the same disease before, not knowing it’s actually a complication of Trachoma”. (Health Worker, Goli, Moroto).*

*“So some people in this community take a person who has Trachoma as inheritance or genetic”. (Community Member, Loroketo, Moroto).*

These statements show that knowledge about the connection between shared environments and the infective potential and transmissibility of Trachoma between family members are lacking among community members.

### **Unknown Origin**

While some respondents identified specific airborne particles that started the infection pathway, a few had no knowledge of what caused Trachoma. There were others who, while believing that Trachoma was from airborne particles, also perceived the causative agent was invisible, and ubiquitous in the air. These respondents perceived that Trachoma was so widespread and pervasive in their communities and very difficult to understand and identify a cause. Therefore, it had to be all around individuals and communities, and consequently, from the air. They explained that they observed that no one was immune to Trachoma and it did not discriminate among community members; the rich, poor, adults, children, and the aged were all prone to infection. Consequently, they were sure Trachoma had to have a ubiquitous or airborne source.

*“I do not know what to do about Trachoma because you cannot tell how it comes. So it is very hard to prevent. I have only my grandson but he also doesn’t know what to do”. (Community Member, Bugono, Iganga).*

*“Some people say that Trachoma is due to poor sanitation, but even those from good families also get it, so it’s an airborne disease” (Trachoma Patient, Bugono, Iganga).*

Last, some elders in Busoga believed that Trachoma came from Bulamogi in Kaliro district. Among such people, Trachoma was regarded as a permanent and persistent disease because it has been there for as long as anyone could remember.

Overall, the data shows that lack of correct information about Trachoma is present among the majority of respondents but especially among community member groups who are responsible for managing the household and providing for the daily needs of children.

### **Recommendations for health communication messages.**

Health messages should:

- continue to promote knowledge about Trachoma and address the myths and cultural perceptions about the causes of Trachoma;
- include information about transmission pathways including the role of cultural practices, environment and individual behaviors in spreading infection;
- inform about the consequences of Trachoma and emphasize the long term consequences on family, productivity, and overall quality of life. A reverse message that relates preventing Trachoma and maintaining or improving quality of live may be well accepted;
- also focus on returning control over their destiny to individuals. Message content should emphasize that Trachoma is preventable and individuals have the power or ability to prevent Trachoma within them.

### **Factors Influencing Trachoma**

In this section, results are presented regarding respondents’ perceptions about the factors that enabled Trachoma within the community. The factors influencing prevalence of Trachoma are organized from broader macro level influences such as culture, to more specific meso level factors such environment and community, further narrowed to micro level influences such as household factors and individual perceptions and behaviors. This ecological and systems approach to understanding the results better conceptualizes how over-arching contextual issues

may shape individual and family day-to-day experiences and decisions regarding the use and non-use of water. Factors identified complemented the ecological framework underlying the study and were classified into the following categories of information: culture, community/environmental, household and individual/behavioral.

## **Culture and Livelihood Factors**

### ***Cattle, kraals, and manyattas***

The lifestyle of respondents and work-related hazards they encountered during their day-to-day activities were the main factors perceived to influence the occurrence of Trachoma. Factors related to culture and lifestyle were more pertinent to respondents in Moroto District but were still prevalent for all respondents. Relationship with livestock, kraals, “manyattas” (communal living), and social practices were identified as the main factors that influenced Trachoma, and were related to lifestyle. The ‘cattle culture’ of the Karamojong was perceived by respondents to increase their risk of Trachoma. Cattle are not just a source of livelihood, to the Karamojong; they are also regarded as a key part of their social life and their social fabric. Respondents from Moroto reported that because animals are kept close to the homesteads, especially at night, the homesteads are often littered with cow dung which attracts flies and increases their risk for Trachoma.

Manyattas which describe the practice of communal living that is common in Moroto District was identified as another cultural practice that increased one’s risk of Trachoma. Although it was not widely acknowledged as a risk factor, a few community leaders in Karamoja perceived this dwelling pattern characterised by several families settled together in one large homestead, the *manyatta*, as a factor that facilitated the transmission of Trachoma between individuals. There is close knit interaction, including play among children of the *manyatta* which provides ample opportunity for illnesses to be passed from one to another. The kraal setting for roaming shepherds and livestock herders also was perceived to facilitate the transmission of Trachoma. Animals and their herders were found in congested settings and living in very close proximity in this setting. Milk, which is also found in abundance at the kraals also attracts an abundance of flies that spread illnesses like Trachoma.

### ***Eye irritants***

Several routine activities that are related to the livelihood and daily activities of respondents were also cited as factors that influenced the occurrence of Trachoma. These factors were akin to work-related hazards that increased one's predisposition for getting Trachoma. The majority of community members perceived Trachoma to be linked to eye irritants specifically smoke from "tadooba" (paraffin candles) and wood fires used for cooking, powder from milling grain, coffee and tubers, and dust from farming during the dry season. These activities produced airborne particles that were eye-irritants that started the cascade of symptoms that led to Trachoma. Maize and coffee mills in the community, and the winnowing of milled products was observed by respondents to irritate the eyes and lead to Trachoma

*"Another cause of Trachoma are the factories [maize and coffee] around, which eject fumes, dust and other particles which affect our eyes and cause Trachoma".* {Community Member, Bulumwaki, Iganga).

Airborne dust and earth from traffic on the untarred roads during the dry season also irritated the eyes and led to Trachoma. Individuals who lived along transport routes were considered at risk for Trachoma as illustrated in the quote below:

*"With things about the environment, for instance in our place here, we are on the road side. The road is not tarmac [tarred]. So as vehicles pass they raise a lot of dust, which we believe to be one of the causes of Trachoma".* (Community Leader, Bunyama, Iganga).

*You may find someone traveling in a taxi also experiencing dust on the way. Such a person may also get that problem [Trachoma]".* (Community Member, Bugono, Iganga).

Respondents perceived Trachoma was also associated with farming activity during the dry season. Digging up dry earth on farmland during the dry season, specifically during the months of January and August, was considered to put one at increased risk of contracting Trachoma due to the dust raised during digging that irritates the eyes.

*"The adults as they dig in the gardens during the dry season are also affected by the dust. You see eyes are susceptible to dust".* (Community Member, Kigulamo, Iganga).

*“Even us adults, not that we play in dust, but because we raise dust as we dig in the gardens, it may go into our eyes and we get such white discharge in our eyes. You may find someone traveling in a taxi also experiencing dust on the way. Such a person may also get that problem [Trachoma]”.* (Community Member, Bugono, Iganga).

An important omission in all these descriptions from respondents is their inability to connect the role of human behavior when contaminated hands or cloths are used to clean irritated eyes as being relevant to the occurrence of Trachoma.

### ***Values around hygiene and cleanliness***

Perhaps most important to the prevalence and transmission of Trachoma infection were informant views on hygiene and cleanliness of children. Respondents, specifically those from Moroto District, perceived that practicing good hygiene in the morning and routine face washing was not a cultural norm for their communities. This point is made through the following quotations:

*“Very few people here consider cleanliness as a very important issue even if your children are clean, they don’t bother about it, others think it is time wasting washing the child’s faces all the time, since they take it as a cultural norm to have a dirty face”.* (Community Member, Acholi Inn, Moroto).

*“Hygiene is not a priority. They think it is normal to have a dirty face so don’t bother wasting time cleaning the face. Need to change community norms about how people view hygiene”.* (Community Leader, Acholi Inn, Moroto).

While some respondents believed that poor hygiene was a reflection of cultural norms in the community, others felt that the decreased emphasis on hygiene was simply because it was not a priority in the larger scheme of things. Hygiene, including face and hand washing was not linked to dirt but rather to the routine activity of eating: washing was not a priority, but food was.

*“When children wake up in the morning, the first thing is to wash the face of a child, but in our community mothers don’t bother on child’s face. What they do first is to look at what to eat in the morning and when they come back at late times they even give children food without washing the face then maybe after eating then they will wash their faces”.* (Health Worker, Goli, Moroto).

*“So face washing in this community seems not to be important including even the hand washing and a child and only be washed when it is time for food only”.* (Community Leader, Acholi Inn, Moroto).

While these behaviors may be influenced by the chronic scarcity of water in most of the communities in Moroto District, the statements made by respondents were not in the context of the availability of water but rather what is considered normative behavior by community members.

### **Recommendations for health communication messages.**

Health messages should:

- promote messages that develop a positive value system around personal hygiene;
- promote cleanliness in the home and compound and among children as a new norm;
- promote attention to physical cleanliness as an attractive behavior and for instance, encourage face washing in the mornings for all children and not just school-going children;
- discuss efficient use of water as scarcity and rationing was mentioned as an issue;
- discuss simple ways to protect the eyes from airborne irritants encountered on dusty roads and at milling stations.

Introduction of other options for obtaining water for household activities should be considered, such as rain water harvesting and homestead cistern approaches.

### ***Social interaction and ‘mingling’***

Respondents described the local culture as a sociable and hospitable one with a lot of human interaction and close knit family ties. Handshaking as a cultural form of greeting in Busoga was perceived to be one way through which Trachoma was spread, especially in a cultural environment where hand and face washing was not routine. Respondents also mentioned sharing handkerchiefs, clothes, and the towels of an infected person as ways the infection was spread through contact with the discharge from the eyes of the infected person. One respondent described how Trachoma spreads from one person to the other in the following ways:

*“When you go greeting people, who have been affected by Trachoma, you end up catching it because you may touch your eyes with the dirt from somebody’s hands. If you also share a handkerchief or any clothes that has been used by an affected person, you automatically get Trachoma. People here in police village, through mixing with sick people end up getting Trachoma”. (Community Leader, Goli, Moroto).*

*“Yah, people shaking hands. I may be suffering from Trachoma and find a friend with whom I shake hands. One finds an infected person and we shake hands. Eventually one touches his/her own eyes and gets infected”. (Health Worker, Bunyama, Iganga).*

Social interaction in playgroups and in school settings was also mentioned as a reason for increased infection among children. A few respondents noted that a lot of nasal and eye infection was transmitted during play activities to children who are kept clean by those who were not clean. They explained that allowing children to mingle and play together was a cultural norm and thus they perceived that there was not much to be done to prevent transmission of infection.

*“However much you keep your child clean, he may get the disease from the playmates. All in all, people have nothing much they can do to prevent child interaction because in our place here, mingling is cultural. You cannot prevent one from coming to your home”. (Community member, Bunyama, Iganga).*

By these illustrations, respondents described their perceptions that social interaction and handshaking contribute to the spread of Trachoma among community members and especially among children. Community members specifically cited touching the face with dirty hands as one of the ways that Trachoma is acquired indicating that the hands had a role in the causal pathway for Trachoma.

### ***Low acceptance of latrines***

Few households in the study, especially in Moroto District, had latrines, and where latrines were present, respondents stated that cultural beliefs interfered with the community’s acceptance of latrines and their willingness to use them. Examples of local myths that prevented use of latrines included beliefs that pregnant women may drop their unborn babies into the latrine and that women of childbearing age will not be able to get pregnant if they used the

latrine. Children were also not supposed to use latrines but the reasoning behind this was not clear from the data. In Iganga, respondents stated that community members believed that women were not supposed to share a latrine with their father in-laws as this was a sign of disrespect to a senior family member.

This information from respondents shows that the even if there were currently latrines or if a program supported the provision of latrines it did not necessarily mean that they would be used by the community members.

### **Recommendations for health communication messages.**

Health messages should:

- teach school-age children about hand and face washing behaviours, and encourage children to be change agents both at home and at school;
- address local myths and fears about latrine use and encourage the acceptance and use of shared or community latrines;
- introduce the installation and use of improved latrines as a status symbol for households and families and an act of love for the family;
- promote hand washing after using the latrine or toilet-cleaning dependent children.

### **Community-Level Factors**

Several community level factors were mentioned by respondents in relation to Trachoma infection, specifically the status of water resources, facilities for waste disposal, and fly densities.

#### ***Availability and Access to Clean Potable Water***

Some respondents identified the lack of clean and potable water sources in the community as one of the factors influencing Trachoma. A community member from Moroto District aptly summarizes the important role water plays in preventing illnesses by stating “*it’s a big challenge because without water no hygiene can be possible*”. This seems to contradict perceptions by some respondents that practicing good hygiene behaviors was not valued or prioritized by members in their communities, however it is the link to the availability of water that makes their perception sound. Safe water sources were not available, situated a long distance from

homesteads or perceived to be insufficient in number relative to the numbers they served. A respondent from Iganga explained the risk for Trachoma as:

*“The risk may be due to lack of or limited water sources, because we only have two boreholes, yet in our village we are many”.* (Community member, Kigulamo, Iganga).

Although 82.5 % of households surveyed in Iganga and 100% of households surveyed in Moroto reported they used a borehole for their main source of water, many of the boreholes functioned intermittently or not at all. In some communities classified as good water resources, only one borehole was functioning. The community mapping also showed that in some good water communities, there could be three boreholes clustered geographically on one side of the community and community members from other sections of the community had to walk long distances across the community. This was true in both districts but mostly so for Moroto.

*“Secondly, we lack water; the boreholes are very far, which makes people not to have access to water for use.”* (Community Member, Kadilakeny, Moroto).

A common complaint from community members about water sources was that bore holes servicing their communities were frequently non-functioning or operated intermittently causing a ‘shortage’ of safe water sources. Respondents perceived that this led to a high user-ratio for each water source in turn resulting in long queues and waiting times to obtain water for the home. These also influenced some community members to knowingly resort to the use of other non-protected sources of water, including sources that were shared with cattle and they knew was contaminated. It was not a choice, it was out of need.

*“When you go for water in the morning, you come back late in the afternoon due to the long queues at the water source. The only alternative to this is water from the stream, which is dirty”.* (Community leader, Bunyama, Iganga).

*“We mostly use unsafe water from the wells and most of our bread winners cannot afford buying soap all the time. We do not have enough boreholes to access safe water ‘.* (Community leader, Kigulamo, Iganga).

The amount of time it took to get to safe and clean water sources influenced the decisions that some community members made regarding the use of water in their homes, and especially use related to cleaning children. Almost two-thirds of the respondents from Iganga District

(63.5%) and more than three-quarters of those from Moroto District (78.8%) reported that it took them one hour or less to get to their usual water source, and this was not a significant difference ( $p = .188$ ). Long distances to the water source, long queues, and lengthy waiting times at the few available or working water sources was perceived to be responsible for the rationing of water and judicious decision-making by caretakers and homemakers about when to use water within the household. Respondents from Moroto described this in the excerpt below:

*“The water sources are too far and that is why people don’t even bother to wash children’s faces very early in the morning since they are trying to save the little water available”.*  
(Health Worker, Kadilekeny, Moroto).

*The water usage here is also poor, most people here don’t use much water, all the time they use very little water for clearing themselves generally”.* (Community member, Loroketo, Moroto).

Analysis of the observation data from good versus poor water resourced communities provides some support for the aforementioned perceptions about water use. The prevalence of eye discharge in communities classified as having poor water resources (7.0%) was significantly higher than in communities classified as having good water resources (4.8%) ( $p = 0.001$ ). Similarly, the prevalence of nasal discharge in communities classified as having poor water resources (24.9%) was significantly higher than in communities classified as having good water resources (20.6%) ( $p = 0.001$ ). There was also significantly more face washing in response to nasal discharge observed in communities with good water resources (11.6%) compared to communities with poor water resources (8.1%) ( $p = 0.001$ ). However, rates for hand washing after nasal drainage occurred in equal proportions (4.8%) in both good and poor water communities. In addition, the communities classified as low Trachoma prevalence and good water resources had significantly higher prevalence of hand washing (51.4%) compared to communities classified as high Trachoma prevalence and having poor water resources (26.8%) ( $p = 0.001$ ). The same was true for face washing behaviors; communities classified as low Trachoma prevalence and having good water resources had significantly higher prevalence of face washing behaviors (30.3%) compared to communities classified as high Trachoma prevalence and having poor water resources (26.8%) ( $p = 0.001$ ).

### **Recommendations for health communication messages.**

Health messages should:

- inform on what a protected and unprotected source of water is, the dangers of using water from unprotected sources, and using water sources that are shared with animals;
- encourage obtaining water from protected sources;
- encourage the installation, maintenance, and use of water/hand washing stations and tippy taps to conserve water.

### ***Lack of community-based facilities for disposal of waste***

Many respondents lamented the state of their community environments and related the unsanitary conditions to the prevalence of vectors, specifically flies that transmitted Trachoma. None of the study sites had community-based facilities for waste disposal and community members had no formal structures for disposing of household waste. A community leader from Iganga summarized the problem as a lack of garbage collection points that resulted in households not *“managing their wastes very well”*. Respondents made the connection between a dirty environment and dirty children

*“Throwing rubbish around the area also contributes to making the children dirty as they play all the time with the rubbish. Littering feces all over the village can also make it hard to keep the children’s faces clean, because of many flies”*. (Community Leader, Loroketo, Moroto District).

and also between a dirty environment and eye infection:

*“In this community here we dispose of garbage anyhow, for example maize cobs, jack fruit refuse. Inevitably, we touch those dirty things and by mistake touch our eyes before washing our hands.”* (Community Member, Bulumwaki, Iganga District).

Waste disposal practices in the community were also linked by respondents to illness and Trachoma infection. The majority of community members stated that they disposed of their household waste in their backyards, and predominantly in the area where their farms were, while those with latrines stated that they usually disposed of feces from young children in the pit latrines. Survey data showed that significantly more respondents from Iganga reported that they dumped their household waste (86.5%) and animal dung (80.8%) in the backyard compared to Moroto District where fewer respondents reported disposing of household waste

(40.4%) and animal dung (26.9%) in the backyards ( $p=0.001$ ). Of note, the wandering nature of the communities in Moroto affords less opportunity to have household and animal waste lying about defined compound areas. In addition, significantly more respondents from Iganga (88.5%) reported disposing of human waste in pit latrines compared to 17.5% from Moroto ( $p=0.001$ ); compounding this dismal statistic from Moroto is that only about a third of respondents (32.7%) also stated that they buried human waste. (The limited use of pit latrines among respondents from Moroto District is discussed in more detail in the section on Individual Factors Influencing Trachoma further in the document).

An interesting observation during the study was that the waste and possibly feces-contaminated earth from the backyard farms was usually trekked back into the home and homestead area through farm dust on clothes, feet, hands and the body of female caretakers when they returned home from farming. This increases the risk for contaminating the face and eyes of self or others when the hands were not washed or clothes were not changed when individuals returned from working on the farm.

A few respondents perceived that a dirty environment put all community members at risk of Trachoma including those who maintained clean homes.

*“The risk [of Trachoma] is possibly high because the condition in which most people in the community are is of dirty environment, which puts even the clean homes at risk”.*

(Community Leader, Bulumwaki, Iganga).

*“I am not confident enough because I do not confine myself at home. I visit other homes and other people visit me. So, the risk is still high.”* (Community Leader, Bugono, Iganga).

By these statements some respondents described how an individual’s risk for Trachoma may be increased by the actions of others in the community (versus their own) and secondarily, how one’s self-efficacy to prevent infection by, for example, keeping a clean home, can be reduced by the risk increasing behaviors of others in the community.

### **Recommendations for health communication messages.**

Health messages should:

- promote the attractiveness of a clean community as a new shared norm;

- inform on the health hazards of a dirty community environment;
- inform on appropriate ways to safely dispose of different types of waste;
- encourage communities to develop community waste disposal systems;
- encourage community members to bury or burn household waste;
- encourage hand washing after handling waste.

### ***Fly Density***

A few respondents linked flies in their environment to both dirty environments and to infection with Trachoma. They demonstrated remarkable insight into some of the behaviors practiced that might increase the fly population in their communities. Respondents perceived ocular and nasal drainage, and littering of sugary fruits such as jackfruit, sugarcane and mangoes, as well as human feces and animal dung to support increased fly density in their communities.

Many households in the study communities also reported having members, especially infants and children with nasal discharge at the time of data collection. There were significantly more reports of nasal drainage in the high Trachoma prevalence communities (26.9%) compared to the low Trachoma prevalence communities (17.8%) ( $p=0.001$ ). A similar finding was present for eye discharge reported in high Trachoma prevalence communities (6.9%) compared to the communities classified as having low Trachoma prevalence (4.9%) ( $p= 0.001$ ). A community leader observed during data collection:

*“Many of the children in front of us are dirty as you can see they have nose drains [nasal drainage], see even the eyes are full of discharge. It makes the children look very dirty. All of them need washing”.* (Community Leader, Kadilakeny, Moroto).

The residuals of sweet fruits that were staples in the community were also identified as factors that increased the fly population when they were not disposed of appropriately.

*“What causes these children to be dirty, during the mango season; children eat and smear all the bodies and clothes with the fruit sugars attracting flies. They play in soil, eat it and also play in dust and mud. Even a washed child eating mangoes in a disorganized manner can attract flies”.* (Community Member, Bugono, Iganga).

*“Among the things that may make children dirty, in such young stages, a child can eat sugarcane and remain with sugar on their bodies which attract flies the whole day”.* (Health Worker, Bunyama, Iganga).

Of importance is that many respondents perceived the flies in the community to be attracted to the residue from sweet fruits that were left on human bodies (including hands and the face) and that also were disposed of inappropriately in the living and community environment. There were very few comments that flies were attracted to the ocular and nasal drainage on the face.

The aforementioned lack of community-based facilities for the proper disposal of household, human, and animal waste in many of the study communities also compounded the littering that supported fly populations.

*“Dirty compounds, all this invites flies to come around, most especially lack of latrines and dumping rubbish anywhere. This therefore applies to both community and environment”.* (Community Member, Loroketo, Moroto).

Overall, community member perceptions about flies in the environment were predominantly linked to unsanitary environmental conditions and unhygienic behavioural practices than about their role in the transmission of Trachoma.

### **Recommendations for health communication messages.**

#### **Health messages should:**

- include similar recommendations as with the management of waste- messages should stress the importance of environmental cleanliness and bring it back to how it reflects well on the entire family and community;
- make a connection between a clean environment and clean children;
- promote hand and face washing for/by young children after they finish eating;
- educate on the role of flies in transmitting Trachoma and how to decrease sources of flies in the community including correct use and maintenance of latrines, clean faces, and household and community waste disposal systems.

## Household Factors

There were many factors at the level of the household that affected respondents' use and non-use of water and consequently the risk of infection with Trachoma. Factors discussed included lack of latrines, rationing of water, limited resources for obtaining and storing clean water, absent caretakers and proximity of animals.

### ***No / few latrines***

Lack of public latrines for the community or personal ones for households were cited as a factor that increased the practice of open defecation and also the presence of flies and Trachoma in the community. Significantly more households sampled in Moroto (50%) did not have latrines compared to those in Iganga (11.5%) ( $p=0.001$ ). One respondent mentioned that there was only one community latrine where he lived and the mapping of a community in Moroto showed one latrine per 40 households. Myths and misinformation about latrine use (introduced earlier in document) influenced minimal sharing of latrines between different households and families; for the few instances where latrine sharing was reported it occurred between households whose members were related.

### ***Rationing of household water***

While the effort in distance traveled and time spent to acquire clean water for the household was perceived to influence rationing of water in the household, respondents also believed that poverty, lack of facilities and resources to safely store water in amounts that were needed to meet the needs of the household and family members also influenced decisions about water use in the household. A respondent described how the lack of appropriate storage containers and the means to acquire more, limited the amount of water available and increased risk of Trachoma.

*“Poverty is a very important factor because with it, there is failure to buy soap for washing, buy water containers, causing shortage in water storage and failure to buy basins, resulting into sharing with the infected persons”.* (Community Member, Bunyama, Iganga)

However there were other respondents who commented that there were some households that had resources to buy such items yet their children were observed to be dirty and community members referred to such parents as being “lazy” and “negligent”.

## **Recommendations for health communication messages.**

Health messages are:

- already addressed above with rationing of water. Possibly providing ideas of how to do so effectively.

### ***Absent caretakers***

Respondents from both Districts characterized the majority of the households in their communities as having absent adult caretakers for most of the day on a routine basis. Individuals may only wash their faces once in the morning while children's faces may often not be washed at all because parents leave the children at home when they go to the gardens to farm or to attend to other tasks. Children were reported to often wake up in the morning to a home without adult caretakers and supervisors: when children woke up in the morning, there was often no-one to provide hygiene care and it was not unusual for them to have dirty faces throughout the day until the parents returned home. Respondent from both Moroto and Iganga Districts elaborated on this point:

*“Children are mostly at a risk because they are not being taken care of by the caretakers/ mothers, they are left alone all day over till evening. So in the process the children play all over dirt, and nobody even bothers to clean or wash their hands”. (Community Member, Kadilakeny, Moroto).*

*“In the community here, people spend most of the time in the garden. They wake up very early in the morning before sunrise, leaving their children in bed. By the time she [mother] comes back the child has already woken up with nobody at home to wash his face. It is too late because this child has picked cold food to eat without washing the face and hands, and has eaten dirt” (Community leader, Bunyama, Iganga).*

The caretaker's absence from the home and from care giving activities occurred frequently and for an extended period of time each day. The lack of appropriate supervision of children in the home when the primary caretaker was absent increased the risk of children getting dirty, and being in contact with dirt and feces in the compound.

## **Recommendations for health communication messages.**

Health messages should:

- educate caretakers about teaching their children about the importance of washing their face when they wake up. Possibly suggest leaving water out for the children in the morning before heading to the farm so that they have a reminder to wash their face.

### ***Animals in close proximity***

Some of the community leaders and health workers in Moroto believed that the practice of sharing homesteads with animals or having them in close proximity to the living and communal areas of compounds put individuals at risk of acquiring Trachoma. They explained that the dung from cows and goats attracted flies which were responsible for transmitting Trachoma.

Community walk-throughs showed that this was behaviour also was present in the communities in Iganga. A community member stated:

*“Also having the animals likes the goats / sheep tied on the verandah of the house, makes it difficult to keep the child clean, since flies will be all over the dropping of goats, which spread Trachoma”.* (Community Member, Loroketo, Moroto).

*“Some families also stay near the animals and as a result cow dung is all over their homes, which attracts flies, which spread Trachoma:”* (Health Care Worker, Acholi Inn, Moroto).

### **Recommendations for health communication messages.**

Health messages should:

- emphasize the importance of keeping animal dung cleaned up around the house to avoid attracting flies;
- securing animals in areas of the compound where children do not play;
- promote hand washing after handling animal waste.

### **Individual Behavioral Influences**

Several individual level behaviors predominantly among caregivers of children were identified relevant to the presence of Trachoma in the community, with many behaviors being influenced by cultural, community and household level factors described earlier in the report.

Individual behaviors that were perceived to influence Trachoma infection and transmission included poor hygiene including hand and face washing practices and techniques, negligent caretakers, cold food, open defecation, inappropriate use of latrines, health seeking behaviors

### ***Poor face and hand washing behaviors***

Overall, personal hygiene, especially hand washing, face washing, and complete baths were perceived to be rarely practiced, and when these behaviors did occur, they were usually not done with correct technique. Respondents stated that individuals usually washed their face once in the morning while children's faces (and their bodies also) were often not washed because care giving parents were frequently out of the house when children woke up in the morning.

*"People here do not mind about washing children's faces. What they do [is] they make sure they leave cold food for them to eat as they wake up and then take off to the gardens. There are few who wash their children in the morning. It is only in exception cases of Moslems who can tell their children to wash their private parts and faces as a ritual, before they are given anything to eat".* (Community Member, Bunyama, Iganga).

The implication is that some groups such as Moslems may practice more ritual face washing and hygiene behaviors as part of religious tenets than for the specific purpose of preventing illnesses like Trachoma. Extremely few community members elaborated more on their perceptions about the link between poor hygiene and Trachoma; they perceived that flies were attracted to dirty children and this increased the child's risk of Trachoma. This link between poor hygiene, flies and Trachoma is summarized in the illustration below:

*"Someone can easily get Trachoma through poor hygiene, that is when you don't have frequent bathing and washing the face, yet you cannot know where the flies have been visiting, then later they bring or carry germs to your eyes".* (Community Member, Loroketo, Moroto).

Some respondents linked dirty hands to contamination of the eyes however, hand washing was described as an "uncommon" behavior. Observation data validated that the prevalence of both hand and face washing was low for situations when they were indicated, and more so for Iganga than in Moroto District. In addition, more face washing occurred with eye discharge than

with nasal discharge. Table 3 below is a summary of prevalence of different behaviors observed in households that required the use of water.

**Table 3: Prevalence of Hand and Face Washing Behaviors in Iganga and Moroto Districts**

Impetus	Hand Washing % Yes			Face Washing % Yes		
	Iganga	Moroto	Total	Iganga	Moroto	Total
Eye Discharge	3.6*	9.7*	7.6*	32.1*	46.6*	41.4*
Nasal Drainage	2.7*	6.5*	4.8*	7.2*	11.3*	9.5*
Animal Care	26.2	41.9*	29.7			
Trash Disposal	22.3*	45.9*	36.7			
Toilet Use	33.2	42.2	38.9*			

\* p-value < .05

Hand washing was observed to occur in 7.6% of eye discharge episodes and 4.8% of nasal drainage episodes. Of note is that substantially more hand washing occurred in response to animal care, handling trash and using latrines, than for eye discharge and nasal drainage. Similarly, face washing occurred in only 9.5% of all observed episodes of nasal discharge.

Respondents were also careful to explain that when hand washing did occur it was usually not done correctly.

*“Generally, in this community we don’t know how to wash children’s faces because at times one can just wet the hands and pass them in the child’s face”.* (Community Leader, Bunyama, Iganga).

*“There are those who just wet their hands to pass into the children’s face and claim they have washed”.* (Community Leader, Bugono, Iganga).

Observation data showed that a mere one percent of all the observed hand washing was done correctly (used soap, correct technique, adequate water, dried with a clean cloth) and there were no statistical differences by District (0.9% in Iganga and 1.0% in Moroto) or by status of water resources (1.1% in poor water and 0.8% in good water communities). However, there was a significant difference in correct technique for hand washing when assessed by prevalence of Trachoma: 70.5% of correct hand washing occurred in communities with low Trachoma

prevalence compared to 29.5% of correct hand washing that occurred in communities with high Trachoma prevalence ( $p=0.001$ ).

Similarly, one percent of all the observed face washing being done correctly – used soap, correct technique, cleaned eyes, cleaned nose, adequate water, dried with a clean cloth. Significantly more correct face washing occurred in Iganga (71.4%) than in Moroto (28.6%) ( $p=0.004$ ), and significantly more correct face washing technique was done in Iganga (1.7%) compared to Moroto (0.5%) ( $p=0.004$ ). More than four-fifths (85.7%) of all correct face washing was observed to occur in low Trachoma prevalence communities compared to 14.3% that occurred in high Trachoma prevalence communities ( $p=0.001$ ). Only 2.2 % of all the face washing observed in the low Trachoma prevalence communities was done correctly; this was significantly more than all the correct face washing that occurred in the high Trachoma prevalence communities (0.2%) ( $p=0.001$ ).

Hand washing was also not routinely done after using the latrines. A respondent stated:

*“People here do not have the culture of washing hands after defecation and also they clean the nose drains using their hands, yet they don’t wash after”. (Community Member, Loroketo, Moroto).*

Observation data showed that hand washing occurred after slightly more than a third (38.9%) of all observed episodes of toilet use, and significantly more hand washing occurred after toilet use in Moroto District (42.2%) than in Iganga District (33.2%) ( $p=0.43$ ). In addition:

- Significantly more hand washing in response to toilet use was observed in communities with good water resources (49.2%) compared to those with poor water resources (29.7%) ( $p=0.43$ );
- Significantly more hand washing in response to toilet use was observed in communities with low Trachoma prevalence (43.5%) compared to communities with high Trachoma prevalence (34.7%) ( $p=0.43$ ); and,
- Hand washing after toilet use was observed to occur significantly less in communities with poor water resources and high Trachoma prevalence (28.1%) versus communities with low Trachoma prevalence and good water resources (60.4%) ( $p=0.43$ ).

These data introduce the important role that available water in communities and households may play in influencing hand washing behaviors. Tippy taps and hand washing stations have been established as usually effective strategies for dispensing minimal but adequate amounts of water to effectively clean hands after using latrines. Observation data from the study showed that the majority of the latrines did not have water stations, and almost all of the very few tippy taps seen outside of latrines were non-functioning or empty of water. A few tippy taps were found broken on the ground, were being used as a toy by children and one was observed to have a bird nesting in it.

The observation data showed a relationship between the presence of eye and nasal discharge and the intersection of water resources and Trachoma prevalence.

- Communities classified as low Trachoma prevalence and having good water resources had significantly lower prevalence of eye discharge (3.8%) while communities classified as high Trachoma prevalence and having poor water resources had the highest prevalence of eye discharge (8.1%) ( $p=0.001$ ).
- Communities classified as low Trachoma prevalence with good water resources had significantly lower prevalence of nasal discharge (13.9%) than communities classified as high Trachoma prevalence with poor water resources (28.8%) ( $p=0.001$ ).
- Face washing after cleaning nasal drainage was observed to occur significantly less in communities with poor water resources and high Trachoma prevalence (7.0%) compared to communities with low Trachoma prevalence and good water resources (17.0%) ( $p=0.001$ ).
- Hand washing after cleaning nasal drainage was observed to occur significantly more (5.7%) in communities classified as having low Trachoma prevalence and good water resources compared to communities with high Trachoma prevalence and good water resources (4.4%) ( $p=0.001$ ).

Overall, the prevalence of hand and face washing was very low in participating communities from both Districts. Correct technique for both behaviors is even lower although it occurs with more frequency in communities with low Trachoma prevalence.

### **Recommendations for health communication messages.**

Health messages should:

- instruct on the correct technique for both hand and face washing and the appropriate times to do so.

### ***Negligent caretakers***

Respondents described some community members who did not keep themselves, their children, and their homesteads clean. The parents of children who were usually observed to be dirty were described by respondents as “negligent”, “irresponsible”, “lazy”. “dirty” and uncaring.

*“Irresponsible parents just tell those children to bathe themselves. In some extreme cases some parents do not wash them at all. They do not care whether the children have washed themselves clean or not”. (VHT Chair, Nsinze, Iganga).*

*“But for those with children of dirty faces, people comment on them and refer to them as lazy parents. They cannot even wash their children’s faces!” (Health Worker, Bunyama, Iganga).*

*“For those whose children are always dirty, the community members degrade them and even hate to associate with them because they consider such parents to be dirty and lazy”. (Community Member, Kigulamo, Iganga).*

Others believed that some children were dirty because their parents were also dirty and therefore such parents do not value cleanliness.

*“Definitely a child with mucus and discharge on the eyes needs to be cleaned. Some mothers are dirty themselves, that they don’t bother to clean their children regularly”. (Health Worker, Acholi Inn, Moroto).*

Community members believed that when care givers let their children be dirty, the state of being kept constantly dirty in turn caused children to engage further in unhygienic behaviors that increased their risk of Trachoma. Clean children will behave in ways to remain clean while dirty children will engage in acts that make them dirtier. A community leader explained this concept below:

*“A clean child is conscious of dirt, does not sit on bare ground, does not eat anything without washing hands. Such a child washes hands every time he visits and leaves the latrine. A dirty child on the other hand, sits anywhere, just eats anything without washing hands. The eyes of such a child are dirty with marks of dry saliva on the mouth and also with dry nasal drainage. Such a child uses his shirt or dress to blow or clean the nose. The clean child will always be careful with what he does, but a dirty child will sit anywhere in soil and get anything within there to eat”. (Community Leader, Bugono, Iganga).*

However some caretakers explain that the perceived negligence on their part is not always what it appears to be as explained in the following statement:

*“In this community, we actually get shortage of clean water, so we find difficulty in keeping our children’s hygiene and mostly the faces because of shortage of water since they sometimes just use any stagnant water from the streams or neighbouring rivers”. (Community Member, Kadilakeny, Moroto).*

*“The water sources are too far and that is why people don’t even bother to wash children’s faces very early in the morning since they are trying to save the little water available”. (Health Worker, Kadilkeny, Moroto).*

These statements show that while there may be some cases where children’s hygiene needs may be wilfully neglected, there are also multiple interrelated issues underlying caretaker decisions regarding the use of water and when to wash children. The effort to obtain the water, the source of the available water (whether it was a clean source or not), and the amount of water in the home may influence the caretaker’s conscious decision to not use it on the face, hands, or body.

### **Recommendations for health communication messages.**

Health messages should:

- develop a new value system around having clean children.

### ***Cold food***

Several respondents also linked the practice of providing cold food to children with an increased prevalence of flies, and consequently Trachoma, in their communities. The belief was that cold food attracted flies as shown in the illustration below:

*“Unfortunately; they still follow the ways of the olden days of giving children cold food which attracts flies. So even if the child’s face has been washed, the cold foods like potatoes, millet bread and the like attract flies”.* (Community Leader, Bugono, Iganga).

*“The unwashed eyes and cold food will attract flies which will eventually fall into their eyes and infect them with Trachoma”.* (Community Member, Bulumwaki, Iganga).

This practice was linked to caretakers being absent from the home and leaving food out for their children while they were gone. Alternate practices such as covering food were not suggested by the respondents. Although it was not clearly articulated in their responses to questions about what caused Trachoma, these statements also showed that some community members were aware that flies had a role to play in the transmission of Trachoma.

### **Recommendations for health communication messages.**

Health messages should:

- instruct on the importance of covering any food that is left out in order to prevent attracting flies.

### ***Non-use and inappropriate use of latrines***

Open defecation was thought to be compounded by non-acceptance of latrines and inappropriate use of the latrines by those who did use them.

*“The people here have still not stopped open defecation, and feces are all over the place, which has attracted flies. Currently we have one-community toilet, which is not even being used properly as people still defecate outside the pit”.* (Health Worker, Loloketo, Moroto).

*“Yes the people around Acholi Inn fear that they are at a great risk, since the hygiene here is so poor. Looking around the area, there is a lot of human feces due to open defecation,*

*people here have not yet embraced use of latrines, so this makes flies spread the disease very easily". (Health Worker, Acholi Inn, Moroto).*

### **Recommendations for health communication messages.**

Health messages should:

- dispel myths associated with latrines and encourage the use of latrines.

### ***Open defecation***

Closely related to a lack of and non-use of latrines was the practice of defecating in the bush and general environment (open defecation). This practice was cited as a problem by respondents in both Iganga and Moroto Districts but appeared to be a much more significant problem in Moroto District. Nevertheless, community mapping showed that there were profuse amounts of feces in the backyards, pathways, and homestead compounds in almost all the participating communities. For some of the communities in both Districts, feces were openly visible every few steps along established walking paths and common areas and not hidden in the bushes to reduce the risk of individuals coming into contact with it. Respondents attributed community member practice of open defecation to cultural norms, a lack of latrines and poor acceptance of latrines in Moroto and predominantly to a lack of latrines in Iganga. In Moroto, community members recognized that feces were a breeding site for flies and put others who did not practice it at risk for Trachoma:

*"The community here is not prepared in the flight against Trachoma, simply because, they still practice a lot of open defecation other than use of latrines which are even not there". (Health Worker, Kadilakeny, Moroto).*

*"To me, am not at great risk though I may get it anyway, because the children here and even the adults still go defecate in the open areas even near the manyattas (homes). Since the flies like smelly things, they get attracted to it and yet the same flies can come and land on our faces and food, which makes it possible for someone to get Trachoma any time". (Community Member, Acholi Inn, Moroto).*

*"I think if the people can stop defecating in the open, the Trachoma diseases can be stopped". (Community Member, Kadilakeny, Moroto).*

### ***Health seeking behaviors***

Community member responses to Trachoma infection specifically the health seeking behaviors of those with infection were identified as reasons for increased transmission of infection in the community. Most study participants knew that the best way to treat Trachoma was to seek medical attention from formal health facilities and some respondents mentioned that they visited the VHT to obtain medicines in lieu of going to a health centres however VHT members frequently did not have medicines. The actions taken by many community members in response to initial symptoms of eye infection were perceived by community leaders and health workers to influence the rapid spread of infection within the community. The use of traditional healers, Jaijas (wise older community members), self-medicating, or not responding to symptoms were cited as reasons for persistent infection in communities.

### **Traditional healers and “Jaijas”**

Traditional healers were used to treat Trachoma in both Districts. Several reasons emerged from the data supporting community member decisions to use traditional healers to treat Trachoma. What community members believed to be the cause of their infection with Trachoma influenced how they responded to the initial symptoms of infection. Many community members believed that spiritual attacks were best combated by retaliatory spiritual warfare and consequently the traditional healer was the first course of action for those believing they had been cursed or bewitched with Trachoma.

Some community members reported that the nearest health facility to be too far to access and felt their only option was to resort to traditional medicine. Others approached “Jaijas”, older and grandmotherly individuals in the community known to have special knowledge about local herbs used for the treatment of illness including Trachoma. “Jaijas” were reported to prepare mixes for those with infection to use to wash their face. Respondents from Moroto talked about using traditional medicine, mainly herbs to wash the face of an infected individual, and later going for treatment in hospitals, if the herbs did not work.

*“The challenge is that, the people here are so primitive in that when one someone is suffering from Trachoma, instead of taking him to the hospital, they prefer taking him to the local herbalists who do not know even how to treat it and the end result they go blind and all the blame is put on God that it is his wish“.* (Health care worker, Kadilakeny, Moroto District).

*“The reason these Trachoma infections persist is that people do not get treatment. There is no nearby health facility where patients can access treatment, and we move long distances to access health services”. (Community Leader, Kigulamo, Iganga).*

*...there are no Trachoma drugs because even when you go there they just prescribe for you to buy (Community leader, Bunyama, Iganga).*

Negative prior experiences with the health system, fear of treatment from formal health institutions, and the inability to afford medical care were other reasons identified by respondents for the use of traditional healers to treat Trachoma.

*“I know it is good [to seek treatment], but I am not empowered enough to go to hospital due to poverty. I cannot go alone I need support, which I do not have”. (Community Member with Trachoma, Bugono, Iganga).*

### **Chemical sellers and self-medicating**

Another treatment response identified by respondents that increased prevalence of Trachoma was to go to chemical and drug sellers for them to prescribe medication or for purposes of self-medication. Community member decisions to self medicate their symptoms were rooted in fear related to the health care services as one community member from Bugono in Iganga stated *“people fear to go to hospital and go for self medication”* however, the reasons for these fears were not elaborated on in the data. Other respondents stated that self-medicating behaviors stemmed from prior negative experiences at the point of care specifically, an absence of health personnel to provide services, no medication, and ineffective treatment (many reported being given eye drops that did not work) rather than poor interpersonal interactions with health care providers. In addition, many respondents who had personal experiences with Trachoma reported that they were given a prescription to purchase drugs that they could not afford elsewhere. A Village Health Team member explains some of the thoughts about self medicating in the excerpt below:

*“Those who go are just given eye drops which are no longer effective. So some people go and buy medicines from small drug shops for self-medication. They mix antibiotics (Pen V) with Vaseline to apply to the eyes, but they eventually complain that they do not see properly”. (VHT, Bulumwaki, Iganga).*

Community members felt that it was better to take matters into their own hands and self-medicate their symptoms rather than walk a long distance to a health facility for nothing.

Regardless of health seeking behaviors some members were aware of the consequences of inappropriate treatment of Trachoma. The data showed that infections were either exacerbated, persistent, or recurred due to partial treatment.

*“There are those who continue applying herbal medicines which may not give complete recovery from Trachoma. These are likely to get the infection again”.* (Community Leader, Bugono, Iganga).

### **No Treatment**

When observed infection with Trachoma was not responsive to local treatment modalities, it fueled community member perceptions that it was untreatable, hereditary, or the will of a higher power. Perceived self-efficacy to prevent infection would be influenced by these perceptions and consequently, there were some respondents who stated that they, their family or relatives with Trachoma infection did nothing to treat it because Trachoma was inevitable, there was nothing one could do about it, and it was best to let nature take its course or the gods have their way.

*“...other people think Trachoma is hereditary and do not care to keep themselves clean or bother to get treatment”.* (Community Member, Bulumwaki, Iganga)

A few respondents believed Trachoma infection was self-limiting and could heal on its own without any treatment while others believed there was no cure once you were infected.

### **Recommendations for health communication messages.**

Health messages should:

- encourage the use of modern health services including information on where to go to get medical help;
- educate on the different treatment options for Trachoma;

- educate that Trachoma is both a preventable and a treatable condition. Messages should also increase awareness of the potential complications and consequences of delaying and self-treating eye infections.

### **Perceived Risk for Trachoma**

Many respondents perceived that they were at high risk of getting Trachoma and attributed this more to the state of their community environment than to specific individual practices occurring in the household or to the use and non-use of water. Respondents explained that living in an environment that was littered with feces, solid waste, with no latrines or structures for proper waste management all contributed to heightened feelings of susceptibility to Trachoma among community members:

*“Yes the people are at great risk because most people here are not observing clean environment when you move around you will find human feces all over the place, which makes it easy to get Trachoma. ... You cannot avoid getting re-infected with Trachoma once you have already suffered as long as you don’t maintain proper hygiene”.* (Community Leader, Loroketo, Moroto).

Of note in the above illustration is that risk was also increased for those who had been treated for Trachoma in the past implying that post-treatment education to prevent re-infection may be inadequate.

Increased perceived risk of getting Trachoma was also related to respondent beliefs that it had an airborne source and their observations that Trachoma did not appear to discriminate among who got infected whether they were aged, young, rich or poor. This perception could possibly be reinforced by the high number of cases encountered in some of the communities. In Iganga, when asked about the burden of Trachoma in the community, a VHT Chair responded that “at least one person in every household” and took the research team to her home where her father was blind and two brothers had symptoms similar to Trachoma. The following quotation describes the community-wide susceptibility to infection perceived by community members:

*“Because it is abrupt and an airborne disease which means that we are all vulnerable to get it”.* (Community Member, Bugono, Iganga).

From the above illustration infection occurs “abruptly” or without warning with the implication that it cannot be controlled and one is at the mercy of the disease.

Risk of Trachoma was perceived to be high regardless of one’s personal efforts to prevent getting Trachoma. A highly sociable culture and the poor hygiene behaviors of others were perceived to put others in the community at risk. Respondents considered children to be high transmitters of infection that they frequently acquired from those they played with, including in the school setting.

*“However much you keep your child clean, he may get the disease from the playmates. All in all, people have nothing much they can do to prevent child interaction because in our place here, mingling is cultural”. (Community member, Bunyama, Iganga).*

*“You see it is inevitable. ...I may also go to visit or sympathize with a patient somewhere and get it because there is no guarantee that I will not get it. With the Kisoga cultural practice, if am ill, people will have to check on me and they will not fail to come with their children. It is really inevitable”. (Female Community Member, Bugono, Iganga).*

From the above, the implication is one’s actions to prevent Trachoma were futile as individual efforts were thwarted by the actions of others in the community.

### **Recommendations for health communication messages.**

Health messages should:

- emphasize that each person has the power to prevent Trachoma;
- the ability to prevent Trachoma is in their hands (literally and figuratively).
- encourage people that they have the resources to prevent Trachoma and show easy steps to do so such as cleaning up environment, burying or burning trash, using water wisely. (these messages also apply to the section below)

## **Perceived Self Efficacy to Prevent Trachoma**

### **Individual Efficacy**

A strong theme related to fatalistic attitudes was apparent throughout the data regarding perceptions about individual efficacy to prevent Trachoma. Respondents descriptions about

their self efficacy to prevent getting Trachoma were laden with words and phrases like “*inevitable*”, “*no guarantee*”, “*hard to prevent*”, and “*nothing much you can do*”. Some respondents verbalized resignation to eventual infection including those who did not think they had behavioral risk factors.

*“To me, am not at great risk though I may get it anyway, because the children here and even the adults still go defecate in the open areas even near the manyattas (homes).*  
(Community Member, Acholi Inn, Moroto).

Perceived efficacy to prevent Trachoma was hampered by a lack of knowledge, skills and personal and structural resources to effectively implement appropriate Trachoma prevention strategies. Knowledge, specifically, lack of knowledge and incorrect knowledge regarding the causes of Trachoma, were the two main factors underlying respondents’ low perceived self efficacy to prevent getting Trachoma infection. The lack of knowledge about the causes of Trachoma among some respondents was responsible for feelings of apathy regarding what they could do to protect themselves from getting Trachoma. The statement below from a community member in Iganga is an example of how knowledge relates to prevention and action:

*“I do not know what to do about Trachoma because you cannot tell how it comes. So it is very hard to prevent. I have only my grandson but he also doesn’t know what to do”.*  
(Community Member, Bugono, Iganga).

Nevertheless, some respondents verbalized interest in wanting to know more about what caused Trachoma and to learn about what they could do to prevent it. However, a few also believed that community members would respond better to information from outsiders “because the community believes more in outsiders than they do with their own people”.

*“We would like the health educators to come and give us information on several ways of preventing Trachoma in our area, and what the major causes of Trachoma are”.* (Community Member, Acholi Inn, Moroto).

*“I would like to know more about infection and prevention of Trachoma for complete management of the disease”.* (Community Leader, Bunyama, Iganga)

Respondents also noted that education on its own may not be sufficient and that individual efficacy to prevent Trachoma could be increased when people are also shown how to do the desired activities:

“But if the people are just advised without showing an example, nobody will take up the advice”. (Community Member, Acholi Inn, Moroto)

Incorrect knowledge about Trachoma, specifically beliefs attributing Trachoma to external spiritual forces and a ubiquitous characteristic of the environment rather than to behavioural factors in the domain of the individual are common. These beliefs foster an external locus of control within the individual that does not empower them to believe that they have the ability to protect self and their families from getting Trachoma. Respondents explained that if a disease is caused and determined by God, then it is part of God's plan that the individual should have the disease and there is little a human could do to overturn a spiritual determination. For these individuals, self-efficacy to prevent infection is low.

In addition to the influence of knowledge, perceived efficacy to prevent Trachoma was also affected by a lack of community and personal resources to support increased water use and increased hand and face washing. There was not enough water to continually wash hands and faces and no waste disposal systems to support desired behaviors around environmental cleanliness. Respondents stated that they did not have the means to acquire sufficient water storage vessels to ensure they had enough water in the home, build a latrine, and purchase soap for hand washing for example. This lack was related to their inability to effectively implement Trachoma prevention strategies.

*“Poverty is a very important factor because with it, there is failure to buy soap [and also clean basins, clean towels] for washing, buy water containers, causing shortage in water storage and failure to buy basins, resulting into sharing with the infected persons”.*  
(Community Member, Bunyama, Iganga).

*“I am not confident [about keeping safe from Trachoma] because in our village we don't have latrines ...and feces are spread all over the community”.*..(Community Member, Kadilekeny, Moroto).

*“In this community, we actually get shortage of clean water, so we find difficulty in keeping our children’s hygiene and mostly the faces because of shortage of water...”.* (Community Member, Kadilakeny, Moroto)

Not having the resources to implement Trachoma prevention behaviors eroded the confidence respondents had in their ability to effectively prevent Trachoma.

### **Collective Efficacy**

Respondents perceived that community members were not equipped to implement Trachoma prevention strategies in their communities. They stated there was a lack of interest in Trachoma, low motivation and involvement in Trachoma prevention programs, poor attitudes towards behavior change, and lack of support from the community for prevention strategies.

Some respondents described a general lack of interest in Trachoma in their communities. Community leaders reported that they encountered low motivation among community members regarding involvement in Trachoma prevention programs. Some respondents noted that although some community members were aware of the importance of hygiene in preventing illness they did not practice the good hygiene behaviours. It was reported that even when community cleaning exercises are arranged – as had been attempted in parts of Moroto – community attendance was poor. Some attributed the low motivation to the lack of knowledge about Trachoma

*“They are not very involved in our community because they are not much informed on Trachoma transmission and prevention”.* (Health Worker, Acholi Inn, Moroto).

Others attributed the low level of community involvement in Trachoma prevention programs to poor attitudes among community members. They stated that when treatment advice was given it was sometimes regarded as interference.

*“I usually advise people to clean their eyes and also go to hospital citing my experience for an example. The few who take my word have appreciated, but others say that I do it because I have money and time to waste. Such people do not heed to any advice as they consider you interfering with their life”.* (Community Member, Nsinze, Iganga).

Respondents described a few campaigns to stop the practice of open defecation that were implemented in Moroto District. Health worker respondents from Moroto also reported that they continually educated and encouraged community members to adopt good hygiene and environmental sanitation behaviors, however, little change was evident at the household and community level.

*“There is very little being done here to prevent Trachoma, very few educators come to our area on health issues. The local leaders do try including the few VHTs but little is achieved on the fight against Trachoma”.* (Community Member, Acholi Inn, Moroto).

There were no reports from respondents in Iganga about Trachoma prevention programs being implemented in their communities and a community member in Iganga stated that *“there is no support offered by the community in preventing Trachoma”*. A health worker respondent stated that drugs had been in short supply and occasionally they could not treat cases that presented for treatment.

*“We also give them tablets when we have them in stock, but of late we have not been getting drugs and instead we advise those infected to go to hospital for medical help. When the medicines are available we give these tablets once. It is not a daily supply that whenever someone gets the problem we give the treatment, no”.* (Health Worker, Bunyama, Iganga)

Community leaders and health workers in Iganga felt that that the community as a whole would be more responsive to treatment of eye infection if VHTs were supplied with the drugs they needed to treat Trachoma and they did not have to go to a health facility that could not help them as shown in the excerpts below:

*“There should be full stock of medicines with the VHTs because lack of medicines in health facilities where we advise the community members to go will not encourage people to [be] involved in community programs”.* (Community Leader, Bunyama, Iganga)

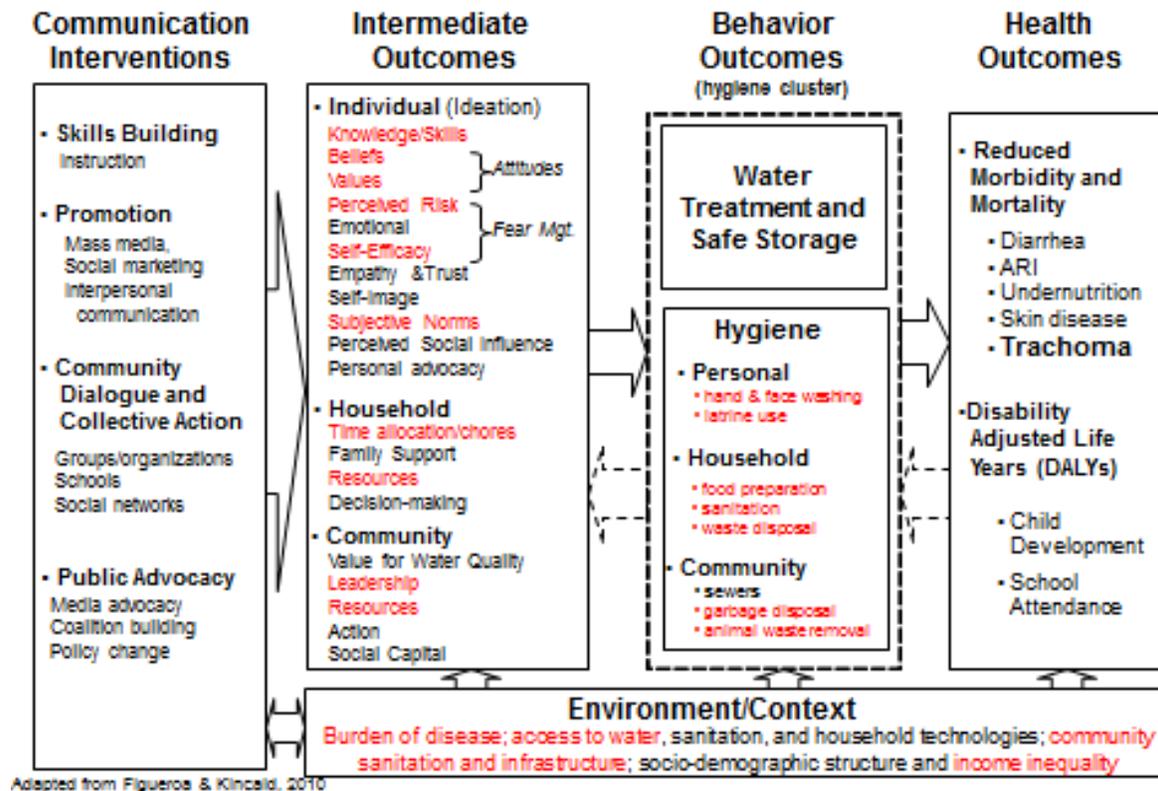
*“If more medicines could be supplied and availed to the VHTs for constant stocking, because this will encourage community members to come for the drugs when they are sure they will be served”.* (Health Worker, Bunyama, Iganga).

Overall, both individual and collective efficacy to prevent Trachoma were low. Perceived causes of Trachoma, lack of structural and personal resources and low levels of individual

motivation and community engagement influenced perceptions about ability to protect self from Trachoma.

The study results are well represented in the constructs of the communication for water and hygiene framework (Figueroa and Kincaid, 2010) that guided the research approach and the design of data collection instruments. In the framework below, the main findings of

**Fig. 1. Communication for Water Treatment and Hygiene**



the study, the intermediate and behaviour outcomes, are highlighted. Several intermediate ideation factors were apparent from the data as were individual, household and community hygiene factors. These factors represent target areas for health communication messages and interventions for effective change.

## DISCUSSION

Formative research was conducted in selected communities in Moroto and Iganga Districts of Karamoja and Busoga Regions of Uganda respectively, to identify and understand the contextual and behavioral factors that influenced the transmission and prevention of Trachoma infection. The study also characterized the factors influencing community members' ability to implement the Facial Cleanliness ('F') and Environmental Change ('E') components of the WHO SAFE strategy for preventing Trachoma. The study was conducted to provide information about Trachoma that was contextually relevant to the lived experiences of the target population, and that also would support the development of a behavior change communication campaign for preventing Trachoma.

Overall, the study results showed that respondents had limited knowledge about the cause of Trachoma and the strategies to prevent it. There also were specific cultural-, community-, household- and individual-level factors that increased perception of risk of Trachoma and decreased self efficacy to prevent infection with Trachoma. The main themes derived from the study are consistent with the key water, sanitation and hygiene (WASH) activities to prevent Trachoma that are outlined in the Global Manual for WASH implementers (2013). In addition, new understandings underlying attitudes and behaviors of local populations that increased risk of Trachoma were identified and provided deeper insights into antecedents to behavior change. These new findings also demonstrated how different levels of influence factors in the environment intersect to influence the use and non-use of water and the behaviors related to sanitation that are deemed critical to the successful elimination of Trachoma.

### Knowledge

Knowledge of Trachoma was variable among the target population with community leaders and health workers demonstrating more knowledge of Trachoma than community members who were caretakers of children and managers of the household. There was good knowledge about the symptoms and consequences of Trachoma and similarly good insight into the consequences of untreated Trachoma infection; however knowledge of causes, transmission and prevention of Trachoma was poor. While a few community members believed that Trachoma was connected to feces and the flies that were attracted to it, they had no knowledge about what specifically caused Trachoma. The belief that Trachoma originated from dust in compounds was widespread and while this perception may be to some extent true, respondents

did not discuss belief in relation to feces contaminated dirt or dist. Likewise, the belief that Trachoma had an airborne source was not linked to vectors in the air but to different eye irritants. A similar formative study in Kenya also demonstrated a lack of clarity regarding how Trachoma was spread among study participants; informants knew it was an eye disease that was spread by flies but not about what caused specifically caused infection. In the Kenya study, Trachoma was linked to the rainy season and to milk that attracted flies, while in Uganda the dry season and sugary fruits including sugar cane, jack fruit and mangoes were perceived to play an important role. These differences emphasize the important contributions a contextual assessment makes to understanding the underlying knowledge and perceptions (or lack of them) that influence behavior.

The attribution of Trachoma by some respondents to non-human causes indicated a lack of understanding of the role of human behavior in perpetuating and transmitting infection. In addition, there was also strong indication of a lack of understanding regarding the transmission pathway for Trachoma: this was evident in the belief that eye irritants from various sources (roadside dust, milling dust, farm dust etc) caused Trachoma. While eye irritants may be a part of the transmission pathway for these communities, all the respondents who believed Trachoma started with an airborne eye irritant failed to make a connection with the role that dirty hands, or contaminated hands such as when used to clean a child's nose, may have in causing Trachoma when they are used to rub or wipe such irritated eyes. On the other hand, there were a few references to dirty (feces- and discharge-contaminated hands) having a role in the spread of Trachoma within the community which introduces discussion about whether it is possible to maintain a clean face when the hands are dirty. Hand washing is not formally included in the personal hygiene behavior strategies that are promoted to prevent Trachoma, however, frequent contact between hands and face as may be seen with the mouthing behaviors of young children, using hands to soothe an irritated eye, wiping sweat from brows and the like, warrants further exploration about a secondary role hand washing may have in preventing Trachoma infection and causing a 'dirty' face.

Lack of, and misconstrued knowledge regarding how to prevent Trachoma was linked to respondents heightened perceptions of personal risk for infection. Misconceptions that Trachoma was hereditary, ubiquitous, or caused by witchcraft influenced beliefs that all were at risk of infection regardless of efforts to protect ones' self. The resultant resignation to one's impending fate also relates to the low levels of self efficacy seen among respondents. There was a general unwillingness among community members to intervene in a matter that they perceived they had no power over, to do something to alter the expected course of events.

While knowledge in itself has been shown to usually not be sufficient to effect behavior change, it is an important antecedent to behavior change. Correct understanding of the transmission pathway is key to community members' understanding of the role their current behavior has in perpetuating Trachoma in the community. For instance, it is important for community members to understand the role of eye discharge, nasal drainage, and feces in Trachoma infection as a precursor to their understanding of why hand and face washing is important to Trachoma prevention efforts. Knowledge of the transmission pathway will also help community members to identify the change required for multiple behaviors at the individual-, household- and community-level to successfully interrupt the transmission pathway.

### **Culture**

Cattle culture was identified as an important factor for environmental sanitation. Over 90% of the population in the Karamoja Region depend on pastoralism and agro-pastoralism (UNFPA/MGLSD, 2009; Stites and Akabwai, 2009). Although the Karamojong rear cattle, goats and sheep, they are well known for cattle-keeping which is their main economic activity and source of livelihood. The Karamojong are known to treasure their cattle so much that some are prepared to die for them. The relationship that the people in Karamoja Region have with their cattle is a social as well as economic one and will be difficult to change. As the flies responsible for Trachoma predominantly are attracted to human feces versus animal dung, more may be accomplished by focusing on strategies to keep individuals in contact with animals clean rather than on strategies that may be perceived to put distance between individuals and their animals.

A new theme from the data was the culture of hygiene and how it was perceived by the target population. Hygiene and specifically bathing and cleaning children were reportedly not considered to be priorities and consequently hand and face washing were not routinely practiced. However, the cultural expectation of hand shaking was believed to be linked to the transmission of Trachoma. Cleanliness and a dirty face were also perceived to be normal and usual occurrences by some respondents in Moroto District. While some community leaders railed against caretakers whom they described as neglectful and lazy for leaving their children dirty (implying that keeping children clean was an expected behavior), other respondents stated that it was not a priority or an unusual expectation within their community. The reasoning behind these thoughts was not clearly articulated in the data; thoughts may be influenced by the dry pastoral terrain and the agrarian-based activities that expose one to a lot of dirt, or influenced by the drought and chronic shortages of water in some areas of the District that result in judicious use of whatever little water is available. The harsh realities of poverty or the lack of

structural resources for easy access to water and sanitation disposal facilities may also influence these attitudes towards hygiene. Regardless, in an environment where knowledge of the causes of Trachoma is also limited, there is also limited understanding about the relationship between Trachoma prevention and good personal hygiene which when present may possibly foster better attitudes towards cleanliness. Admittedly, understanding community perceptions about hygiene is a complex one and most likely it will be the intersection of multiple strategies that will work together to improve prevailing attitudes about hygiene.

Cultural beliefs also had a strong influence on the use of pit latrines. While open defecation was linked to a structural lack of latrines in some of the communities, it was also linked to non-acceptance and non-use of latrines in communities that did have pit latrines in Moroto District. There were many cultural myths around the use of latrines that discouraged their use by community members and influencing the practice of open defecation. The data show that provision of latrines as a response to open defecation may not necessarily curb the practice or increase the use of latrines. The underlying issues influencing open defecation behaviors must be addressed to in-turn increase the demand for and the use of resources for sanitation. Assessing for, and addressing any cultural myths and fears related to using latrines must be conducted alongside the strategies implemented to increase access to latrines for improving environmental sanitation.

Of note, the nomadic lifestyle of some communities such as that seen among the inhabitants of Moroto District may result in inconsistent use for the usual structural interventions and resources including latrines and wells implemented to improve personal hygiene behaviors and environmental sanitation to prevent Trachoma. Interventions for nomadic populations will probably be more accepted and probably also utilized more when they are designed to fit into the migratory lifestyles germane to this group. Appropriate strategies might include capitalizing on resourcing the migratory route and kraals rather than developing fixed resources that become irrelevant and inaccessible as families continue with their pastoralist behaviors. Strategies such as burning and burying human waste may also be explored as alternatives to latrines in other communities.

Given this information, some cultural practices specifically social mingling and hand shaking, along with open defecation contributed to perceptions of risk for Trachoma among respondents.

## **Community**

Community resources for water and sanitation were lacking in all the communities participating in the study. Communities that were classified as having good water and sanitation

resources had few operational boreholes or the spatial distribution of the boreholes was not optimum and resulted in some community members having to trek a long distances within their community to access water. The WHO manual for Trachoma control program managers assesses water availability as a distance of one kilometer or a 15 minute walk each way to and from the nearest source of water in the dry season (Zondervan, M., et. al., 2006). The average time taken to get to water was reportedly one hour or less for the majority of respondents in both Iganga (63.5%) and Moroto (78.8%). High user ratios at water sources and the inconvenience of long waiting times were new findings that emerged from the data. Not only did these factors discourage use of protected sources and making frequent trips to safe water sources, but they also increased the likelihood that some community members would resort to the use of contaminated water acquired from natural and unprotected sources.

The most frequent impetus for water use in the study was cooking and eating and not hand or face washing which may be an indication of where the priorities for water use lie. Rationing of water occurred frequently in households directly as a result of the amount of time it took to get to a water source, and once there, to actually acquire water. The distance to water was not the only factor influencing access to water. The high user ratio at boreholes and wells resulted in long lines at the water source that caused longer delays to get water than it took to get to the water source in the first place.

The lack of water resources available to communities is a known risk factor for contracting Trachoma and also limits ability and efficacy of community member to have enough water in their household to perform recommended hygienic behaviors correctly and consistently.

## **Household**

The household factors related to the use and non-use of water and subsequently the possible transmission of Trachoma were the absence of caretakers, limited supply of water, proximity of animals to households and the disposal of household, human and animal waste. Absent caretakers in the household, especially first thing in the morning, meant that many children would spend the day with a dirty face, as they had no one to remind or help them with face washing and morning hygiene practices. Of note is that the children usually left unattended and uncared for in the home each day were the pre-schoolers, a sub-group known to have high rates of Trachoma infection. Pre-school aged children comprise a high-risk group that warrant targeted attention for hand and face washing behaviors. To elaborate, while school-aged children were expected to clean themselves in the morning before presenting themselves for inspection at school, the pre-schooler was not subject to such hygiene checks and was often

unwashed in the morning. In addition, some school-going child benefited from hygiene-related instruction at school while the pre-schooler at home was not taught about hygiene. Pre-school aged children need special attention in Trachoma prevention and control programs. However the caretakers of these children need to be included in the programs to teach these children when and how to wash hand and faces and help to keep the household compound environment clean. Specifically, caretakers will need to provide a supportive environment that enables the behaviors the children are taught. For instance, the caretakers who ration water will have to provide (or permit the children to use) sufficient water to wash their hands and faces.

The continued absence of caretakers during the day also led to unsupervised children playing with dirt and feces as there was no responsible adult to monitor their activities. In situations where caretakers were in the home in the morning, the limited supply of water in the household, and rationing of available water, made it difficult for consistent hygienic behavior to take place. Consequently, other activities such as cooking and cleaning often took priority over hand and face washing. The use of other strategies to obtain water such as rooftop rainwater catchment systems were not observed in the community any may be an affordable option for obtaining additional water for non-drinking purpose (other household activities and personal hygiene) especially during the wet season.

Finally, the close proximity of animals to the household, lack of or improper use of latrines, and constant household waste made it very difficult for community members to keep their compounds clean; cleaning of compounds was usually performed once in the morning and occasionally in the evening, and not continuously as the waste accumulated. Some community members disposed of waste, including animal and human feces, by burying it while others moved it to the backyard. Removing the waste to the backyard often attracted flies and the disposal often was not far enough from the house to prevent the waste from being tracked back into the compound by children playing around the dirty area.

Perception of risk for Trachoma was related to the dirty state of some of the household compounds. Respondents perceived that their risk for Trachoma was high because of the unsanitary conditions of neighboring environments. Children were also perceived to be at higher risk when not under the adult supervision necessary to protect them from engaging in behaviors that may cause illness and disease.

### **Individual**

Hand and face washing practices were barely existent in both Moroto and Iganga District, and when they were practiced, technique was poor. Community members rationalized their

poor hand and face washing behaviors by citing the lack of water, difficulty getting the water, and the unsanitary source of the water they had access. Although water from natural sources is considered appropriate for face washing, some community members were unaware of this knowledge and opted to not use water from unprotected sources to clean their children. Generally caretakers did not have the resources to consistently use water when it was indicated and had to prioritize the activities for which they would use their available water. In addition to providing more community water resources to households, there is a need for more water storage amenities and secondarily, a need for strategies for purifying some of the water that is used in the home.

Cleaning children was an activity that was perceived to be dependent on behaviors of the caretaker. The study showed that mothers who were negligent and not clean were perceived to have children who also appeared to be dirty. On the other hand, children in the household of a clean and responsible caretaker were also described as usually also being clean. The study in Kenya (2013) had similar results where bathing of children was dependent on the mother's hygiene behaviors. This finding suggests that perhaps primary caretakers of children may need to be targeted with behavior change interventions to promote cleanliness among children in their household. An additional important perception was that dirty children also engaged in behaviors that made them dirtier while clean children conducted themselves in a manner that kept them clean.

The study also showed that some respondents perceived that face washing was uncommon among non-school going children; those who did attend school were known to wash and clean themselves in the morning prior to leaving their homes. However, whether the pressure to clean one's self was to avoid punitive action or from a health promotion aspect was unclear. On the other hand, some respondents believed that social and play interactions in the school setting were responsible for the cases of Trachoma infection among children in the community. The implication that schools play a role in cleanliness and face washing behaviors among children is an important one. Hygiene promotion and education programs instituted in schools should emphasize responsive and proactive hand and face washing such as after play activities and in response to eye and nasal symptoms.

Absent and delayed health seeking behaviors of community members with symptoms of eye infection was a new theme that community members linked to the spread of the infection within the community. The beliefs about Trachoma influenced the response of community members to their symptoms of eye infection, and the usual first response was the use of traditional healers and 'Jaijas'. The services of chemical sellers and self-medication were other common choices

to treat their symptoms most often resulting in inappropriate and incomplete treatment that frequently worsened the infection. Negative experiences with health care system, specifically long waiting times, an absence of health personnel and drugs at the point of care, and provision of drugs that did not cure or relieve symptoms also influenced community member's decisions to access other treatment options. Many community members felt that drug treatment and prophylaxis must be brought to the community rather than having community members travel long distances for services that they are not provided, or unaffordable.

Risk for Trachoma at the individual level was more often linked by respondents to a dirty environment than to a lack of water to carry out specific Trachoma prevention behaviors. A lack of knowledge about correct technique coupled with limited finances to acquire resources such as soap, basins, and towels also hampered individual efficacy to complete recommended behaviors correctly. Risk of advanced stages of Trachoma was also related to current and somewhat inappropriate health-seeking behaviors leading to delayed medical treatment for initial symptoms and therefore potential for increased transmission of infection within communities.

A comprehensive Trachoma prevention program must include strategies to make both health education and treatment services easily accessible and available to the population. Implementing strategies for stilling confidence in health personnel and the treatment modalities for Trachoma will also be an important precursor to the early use of health services by community members to treat symptoms of Trachoma.

### **Self efficacy**

The data showed clearly that self efficacy to routinely implement hand and face washing was influenced by the status of water resources in the community and household, and also to financial resources. Decisions about water use in the home were related to the how easy it was to get the water and how much water could be stored in the household at a given time. Self efficacy to prevent Trachoma was also related to perceptions about what caused Trachoma. Many respondents in both communities attributed a spiritual cause to Trachoma or other non-behavioral causes including the air, the season, dirt, and hereditary factors. The locus of control for these factors is external to the community member, which in turn decreases one's perceived ability to take action to control the cause and change the course of events. Respondents believed they had no power to effect change and that their fate was in the hands of others in the community as well or in the spirit world. Resultant perceptions of impending doom and fatalism,

and the apathy that accompanies these perceptions also hinders individual and group level motivation, interest, and involvement in programs to prevent Trachoma.

In an environment characterized by such attitudes, the provision of structural resources to increase access to water for hand face washing may still not result in behavior change; there is a need to change the prevailing attitude of helplessness to one that empowers individuals with the belief that they have the power to prevent Trachoma infection among their and other families in the community. While structural resources are important to enable completion of intent to change behavior, strategies are also needed to foster the belief that preventing Trachoma is possible through changing current behaviors and that individuals have a successful role to play in breaking the cycle of transmission of infection.

The wealth of new information on factors influencing hand and face washing behaviors for Trachoma prevention derived from this study emphasizes the importance of researching and understanding context of the target community. Culture, attitudes and beliefs are intricately tied to the behaviors of local populations at-risk of Trachoma. The complex inter-relationships seen between the different levels of influence illustrate the importance of implementing a multi-faceted approach to Trachoma prevention in order to have acceptable interventions and realize sustainable results. Strategies to identify and understand these issues must be implemented in tandem with those implemented to provide improved structural water, sanitation and hygiene resources to communities in the fight to eliminate Trachoma.

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## APPENDICES

Table 4: Data Collection Outputs

Region	Household Survey	Households Observed	Key informant interviews	Community Maps
Karamoja	54	54	24	4
Busoga	54	54	26	4
<b>Total</b>	108	108*	50	8

\* Includes 6,360 total recorded observations

Table 5: Summary of Household and Respondent Demographics from Household Survey

<b>Demographics</b>	Iganga	Moroto
Avg. no. of children in HH	6.87	4.23
Avg. no of adults with eye drainage	.54	0.27
Avg. no of children with eye drainage	1.48	1.10
Avg. no of adults with nasal drainage	.79	.21
Avg. no of children with nasal drainage	3.50	1.73
	%	%
Caretakers who are homemakers	59.6	88.5
Caretakers who completed primary school	38.5	21.2
Homes with animals in HH compound	82.7	52.7
Homes with no toilet	11.5	50.0
Homes using borehole as main source of water	82.5	100.0
Homes using borehole water for washing hands, body and face	100.0	94.2
Homes that dump waste in backyard	86.5	40.4
Households with radio	63.5	19.2

Table 6: Demographics by Trachoma Prevalence and Water Availability

	<u>Low Trachoma</u>		<u>High Trachoma</u>	
	Low Water	High Water	Low Water	High Water
% with no toilet	34.6	7.7	53.8	26.9
% with latrine	65.4	53.8	46.2	69.2
% < 1 hour to walk to and from water source	69.2	88.5	73.1	53.8

## Summary of Observation Data

### 1. OVERALL

- **Water use**
  - Most common behaviors observed that required water included: eating (38.5%); nasal drainage (23%); cooking (8.7%); toilet use (8.6%), trash disposal and eye drainage (both 6.0%)
- **Hand washing**
  - Hand washing only occurred in 4.8% of observed nasal drainage episodes
  - 1% of all observed hand washing was done correctly – no differences by District or water resources.
  - There was a significant difference in correct technique for HW when assessed by prevalence of Trachoma. Low Trachoma communities had significantly higher proportions of correct HW technique compared to high Trachoma communities.
- **Face washing**
  - Face washing was done for only 9.5% of all observed episodes of nasal discharge.
  - Similar findings for FW. 1% of all observed FW were done correctly – used soap, correct technique, cleaned eyes, cleaned nose, adequate water, dried with a clean cloth.
  - Significantly more correct FW done in Iganga compared to Moroto
  - 2.2 % of FW in low Trachoma communities was done correctly compared to 0.2% of the FW in high Trachoma communities.
  - 85.7% of the correct FW behaviors were from HH or caretakers from low Trachoma prevalence communities compared to 14.3% of correct FW that were from high Trachoma prevalence communities

### 2. GOOD VERSUS POOR WATER RESOURCE COMMUNITIES

- **Eye and nasal discharge:**
  - Significantly higher prevalence of eye discharge (7%) and nasal discharge (24.9%) observed in communities classified as poor water compared to good water communities (4.8% and 20.6% respectively)
- **Face washing after nasal drainage**
  - More face washing in response to nasal discharge observed in communities with good water resources (11.6%) compared to communities with poor water resources (8.1%)
- **Hand washing after nasal drainage**
  - Occurred in equal proportions (4.8%) in both good and poor water communities

### 3. HIGH VERSUS LOW TRACHOMA PREVALENCE COMMUNITIES

- **Eye discharge:**
  - Significantly more eye discharge (6.9%) in high Trachoma communities compared to low Trachoma communities (4.9%)
- **Nasal discharge:**
  - Significantly more nasal drainage (26.9%) observed in high Trachoma compared to low Trachoma communities (17.8%)
- **Face washing after nasal drainage:**
  - Occurred more in low Trachoma communities (12.2%) than high Trachoma communities (8.2%)

- **Hand washing after nasal drainage:**
  - 5.2% in communities with low Trachoma prevalence and 4.6% in communities with high Trachoma prevalence

#### 4. CLASSIFICATION BY WATER AND TRACHOMA

- **Water use behaviors:**
  - Communities classified as low Trachoma and good water had significantly higher prevalence of hand and face washing behaviors
- **Eye Discharge:**
  - Low Trachoma and good water communities have lowest prevalence of eye discharge (3.8%) while high Trachoma and poor water have highest prevalence of eye discharge (8.1%). Significantly different
  - Good water with high Trachoma, and low Trachoma with poor water, had similar prevalence of eye discharge
- **Nasal discharge:**
  - Low Trachoma and good water communities had lowest prevalence of nasal discharge (13.9%) while high Trachoma and poor water communities had highest prevalence of nasal discharge (28.8%). Significantly different
  - Good water with high Trachoma had significantly higher prevalence of nasal discharge (24.8%) compared to low Trachoma with poor water communities (20.4%). [Possible influence of sanitation?]
- **Face washing after nasal drainage:**
  - Occurred least in communities with poor water resources and high Trachoma prevalence (7.0%) and occurred the most in communities with low Trachoma prevalence and good water resources (17.0%)
- **Hand washing after nasal drainage:**
  - Occurred most (5.7%) in communities classified as having low Trachoma prevalence and good water resources but occurred the least in communities with high Trachoma and good water resources (4.4%)

#### 5. HAND WASHING BY TRASH DISPOSAL

- **Overall**
  - Hand washing occurred with 36.7% of all observed episodes of trash disposal.
- **By District**
  - Hand washing after trash disposal was higher in Moroto (45.9%) than in Iganga (22.3%)
- **Classification by water and Trachoma**
  - Hand washing after trash disposal occurred least in communities with poor water resources and high Trachoma prevalence (25.2%) and occurred the most in communities with low Trachoma prevalence and good water resources (49.4%)
- **Good versus poor water resource communities**
  - More hand washing in response to trash disposal observed in communities with good water resources (42.3%) compared with communities with poor water resources (31.1%)
- **High versus low Trachoma prevalence communities**

- More hand washing in response to trash disposal observed in communities with low Trachoma prevalence (43.4%) compared with communities with high Trachoma prevalence (31.5%).

## 6. HAND WASHING BY ANIMAL CARE

- **Overall**
  - Hand washing occurred after only 29.7% of all observed episodes of animal care.
- **By District**
  - Hand washing after animal care was significantly higher in Moroto (41.9%) than in Iganga (26.2%)
- **Classification by water and Trachoma**
  - Occurred least in communities with poor water resources and low Trachoma prevalence (19.0%) and occurred the most in communities with high Trachoma prevalence and good water resources (39.2%)
- **Good versus poor water resource communities**
  - More hand washing in response to animal care observed in communities with good water resources (37.3%) compared with communities with poor water resources (22.5%)
- **High versus low Trachoma prevalence communities**
  - More hand washing in response to animal care observed in communities with high Trachoma prevalence (35.0%) compared with communities with low Trachoma prevalence (22.4%). *(Is it possible that the communities with high Trachoma have more animals and thus account for more handwashing?)*

## HAND WASHING BY TOILET USE

- **Overall**
  - Hand washing occurred after only 38.9% of all observed episodes of toilet use.
- **By District**
  - Hand washing after toilet use was higher in Moroto (42.2%) than in Iganga (33.2%)
- **Classification by water and Trachoma**
  - Occurred least in communities with poor water resources and high Trachoma prevalence (28.1%) and occurred the most in communities with low Trachoma prevalence and good water resources (60.4%)
- **Good versus poor water resource communities**
  - More hand washing in response to animal care observed in communities with good water resources (49.2%) compared with communities with poor water resources (29.7%)
- **High versus low Trachoma prevalence communities**
  - More hand washing in response to animal care observed in communities with low Trachoma prevalence (43.5%) compared with communities with high Trachoma prevalence (34.7%).

