Maasai Response to Mass Drug Administration for Trachoma in a Changing Political Economy in Tanzania

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Declaration of Originality

I, Tara Beth Mtuy, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

Delivery of global health interventions tackling NTDs are often socially complex. The ‘neglect’ in NTDs is a social dimension and the communities in which the diseases persist are often historically, politically and/or socially marginalized. Trachoma, the commonest infection causing blindness worldwide, is endemic among the Maasai, a historically marginalized tribe in Tanzania. Lack of health facilities and schools in their communities, and the different views about their “development” have impacted on their experiences of health services more generally. Recent incidents in Maasai communities, continue to drive a sense of political subjugation, marginalization and cultural discrimination which fosters distrust in government led activities.

This thesis aims to explore insights and experiences from the Maasai perspective on how trachoma control, specifically MDA, was implemented in relation to their livelihoods. This work draws upon a political-economic approach and the influence of power and authority. This research engaged issues of development and cultural relevancy, within the context of historical power relations. Ethnographic fieldwork was carried out in a Maasai community over 16 months and utilized qualitative methods to explore Maasai’s perceptions and experiences of trachoma; the lived experiences of a Maasai community during a round of MDA; other encounters with health services and development programmes.

This research describes why a ‘one size fits’ all approach is ineffective for a ‘hard to reach community’. Understanding indigenous knowledge may initially help guide control programmes and address local beliefs. Complex social, economic, and environmental barriers to programme implementation are ignored to meet programme goals. Power relations that emerged from colonial and post-colonial political systems in Tanzania and systems of dominance have transcended health care delivery. In light of these findings, this thesis suggests trachoma control programmes and health care delivery more

broadly, utilize a more tailored approach to sustainably reach programme targets and meet community needs.

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List of Acronyms

BCD	Behaviour Centered Design
CDD	Community Drug Distributor
COSTECH	Tanzania Commission for Science and Technology
DOT	Directly Observed Treatment
FAME	Foundation for African Medicine and Education
GET 2020	Global Elimination of Trachoma by 2020
ICH GCP	International Conference on Harmonization Good Clinical Practice
ITI	International Trachoma Initiative
KCCO	Kilimanjaro Centre for Community Ophthalmology
KCMC	Kilimanjaro Christian Medical Centre
KCMUCo	Kilimanjaro Christian Medical University College
MDA	Mass Drug Administration
NGO	Non-Governmental Organization
NIMR	Tanzania National Institute for Medical Research
NTD	Neglected Tropical Disease
RTI	Research Triangle Institute
SAFE	Surgery for trichiasis, Antibiotics, Facial cleanliness, Environmental improvement
SDGs	Sustainable Development Goals
SHOWeD	What do you See here?, What is really Happening here?, How does this relate to Our lives?, Why does this situation concern of strength exist?, What can we Do about it?; approach in photovoice methodology to describing photos
TB	Tuberculosis
TEO	Tetracycline Eye Ointment
TF	Trachomatous inflammation-follicular
TS	Trachomatous conjunctival scarring
TT	Trachomatous trichiasis
WASH	Water, sanitation, and hygiene
WMA	Wildlife Management Authority
WHO	World Health Organization

Glossary:

Maa terms

alaigwanani (s) / ilaigwanak (pl)	Maasai cultural leader
alpayan (s)/ ilpayiani (pl)	married men, junior elders age set, approximately 30-50 years
altasat (s) / ildasat (pl)	male elders
anya ilomo	‘sharing the news’; Maasai cultural way of engaging in conversation
enaoji	condition of the eye associated with irritation specific to the eyelid
eng’oki (s) / ing’ok (pl)	offences
engolon	divine power
enkai	God; sky
enkang	Maasai homestead (‘boma’ in Kiswahili)
enkeeya naitukui	‘the disease that is washed away’; a type of skin ailment
enkituak (s) / inkituak (pl)	married women
enkojonani	mosquito; malaria
esiangikin (s) / isiangikin (pl)	circumcised, unmarried girls
olmurrani (s) / ilmuran (pl)	warriors age set, approximately 15-30 years
indunda naado	‘that red pill’
inok	cultural offence
koko	grandmother; elder woman
manyatta	an encampment of young warriors
olchani (sing) / ilkeek (pl)	medicine; trees/shrubs
oldeket	a curse
olmarei	family, refers to a married man, his wife (wives), dependent children (including own and fostered and any other dependent relatives
olng’eher	ceremony for Maasai rite of passage from a warrior to a junior elder age set
oloiboni (sing) / iloibonok (pl)	healers, ritual experts, and diviners
olputet	U-shaped iron used for epilation of eye lashes

ormeek (sing)/ irmeek (pl)	non-Maasai, others
orpul	healing retreat to maintain health and vigor
papa	father
ronjo	temporary homestead used during migration
sarkin	taboo

Kiswahili terms

balozi	leader of a ten cell (the lowest level of administrative structure in Tanzania)
boma	Maasai homestead
dawa	medicine
maji	water
mganga	healer
mtendaji	village executive official
mwenyekiti	village chairman
mzungu (s)/ wazungu (pl)	derived from Bantu meaning ‘wanderer’; used to refer to white people
shuka	a large piece of cloth typically worn by people
uchawi	witchcraft
ugali	stiff maize flour porridge
uganga	traditional healing
vitongoji	sub village leaders
mlizi (s)/ walinzi (pl)	watchmen; security guards

Chapter 1: Introduction

This thesis focuses on mass drug administration (MDA), one of several strategies to control and eliminate trachoma, a neglected tropical disease (NTD). Through ethnographic fieldwork in Maasai communities in northern Tanzania, I explore the complex ways in which this government led programme is delivered without consideration of the livelihoods of a hard-to-reach community. Considering the historical context of the Maasai in Tanzania and the continued political subjugation, a political economy framework guides the arguments in this thesis. This perspective attempts to unravel the complex factors contributing toward inequities among Maasai and how they influence responses to MDA and health services more broadly.

This chapter draws on literature from a range of sources including sociology, anthropology, development, biomedicine, epidemiology, public health, and policy. It provides an overview of the Maasai tribe in Tanzania, medicine in Tanzania, trachoma, and control programmes, foregrounding the way in which Maasai people respond to public health programmes, specifically MDA for trachoma in Tanzania. The chapter concludes with the study aim and objectives and an overview of the thesis structure.

Maasai in Tanzania

> *"The most picturesque people in East Africa are those of a tribe which has changed little of its ways since the advent of the White Man- the Masai. The tourist, when he spots a Masai herding his beloved cattle, or leaning gracefully on the haft of his long-bladed spear, cannot but feel the spirt of Africa of yesterday."* (Kilusu, 1956 as cited in Hodgson, 1999)

History of cultural and political-economic tensions

Maasai, thought to have descended from the Nilotic people, migrated south to East Africa from present day Sudan and the Nile Valley during the first millennium AD (Table 1) (Homewood, Kristjanson, et al., 2009; Peers, 2011; Spear & Waller, 1993). Originally agro-pastoralists, Maa-speaking peoples were divided into farmers in the highlands, hunter-gathers inhabiting the forests on the edges of the plains and pastoralists for those in the plains. The latter is what is today known as the Maasai tribe. The above quote evokes a romanticized picture of the Maasai, which is contrary to the current fate of this marginalized tribe.

Table 1. Summary of Maasai historical timelines

1000-0 BC		Cushitic-speaking farming and herding groups spread as far as Southern Rift. Nilotic groups differentiating into Plains and Highland Nilotic language groups.
0-1500 AD		Livestock herding groups across East Africa interact with incoming Bantu and adopt iron. Maasaians differentiate within ancestral Plains Nilotes. Emergence of specialized pastoralism versus mixed farming/herding economy. Maasaians spread southward through Kenya 1000-1500 AD.
c. 1700's	Maasai expansion	Maa-speaking groups extend from Lake Turkana in Northern Kenya throughout Rift Valley and Maasai steppe in Tanzania.
1880's- 90's	*Emutai*[1]	Rinderpest pandemic, epidemics, livestock losses and social disruption. Loss of pastoralist political and military dominance.
1890- 1964	Colonial rule	Germany colony from 1890-1915, followed by British rule until independence.
	Maasai moves	Areas designated for settlement and Maasai initially removed
1940's- 1960	Protected areas made in Maasailand	1959- Serengeti National Park, Ngorongoro Conservation Area; Manyara and Tarangire National Parks, Mkomazi Game Reserve
1964- 1980's	Independence	President Nyerere: all Tanzanian citizens have the right to live anywhere in Tanzania: extinguishes customary rights
1980's	Economic liberalization	Communal lands can be sold by central agencies with minimal consultation of users.
2000- present	Land issues	Wildlife management areas legislation threatens land tenure and village/household revenues from wild-life based enterprises

Source: adapted from Homewood, Trench, et al. (2009)

Historical accounts of the mid to late 1800's portray encounters with Maasai as aggressive and hostile. Arabs, Europeans and Swahili were competing for ivory

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[1] *Emutai,* meaning to wipe out, was used to reference the period from 1884-94 when outbreaks of bovine disease wiped out cattle in East Africa Waller, R. (2019). Emutai: crisis and response in Maasailand 1883–1902. In *The ecology of survival* (pp. 73-112). Routledge.

trade, exploring west toward Lakes Tanganyika and Victoria and later colonization (Hodgson, 2001; Peers, 2011; Waller, 1976). The famous journalist-explorer Henry Morton Stanley declared in 1878 that Maasai were a “tribe… that specially delights in blood” (Rigby, 1981, p.111). Stories of these encounters seem to vary from travellers provoking Maasai to allow them to loot Maasai villages and interfere with their women to Maasai *ilmuran* engaging in cattle raids (Peers, 2011; Rigby, 1981; Waller, 2010). According to their beliefs the Maasai God, *Enkai,* gave all the cattle in the world to Maasai. Therefore it may be seen as religious responsibility to take back cattle that belonged to their people over centuries (Peers, 2011; Talle, 1998; Wagner-Glenn, 1992).

Over a period of ten years from 1884, *Emutai* wiped out 95% of cattle in East Africa (Homewood, Trench, et al., 2009; Waller, 1976; Waller, 2019). Furthermore, introduced diseases including smallpox and leishmaniasis coupled with famine wiped out two thirds of the Maasai population (Waller, 2019). Tanganyika[2] was colonized initially by the Germans which was formalized in 1890 by the Anglo-German Agreement. The German administration were confronted with the aftermath of draught and epidemics, turning blame onto the Maasai. They imposed direct rule and established a system of monitoring and controlling Maasai raiding and movement (Hodgson, 1999). Germans allied with the Maasai’s neighbouring tribe of Kilimanjaro, the Chagga, to defend against Maasai raids of Chagga settlements for their cattle. The German administration formed a Maasai Reserve to consolidate the ethnic group to make way for European settlement and cutting them off from important trade opportunities and critical grazing areas (Hodgson, 1999; Waller, 1976). European missionaries did nothing to prevent or assist Maasai with the loss of land and water. By the end of the nineteenth century, Maasai had created connections between capitalist penetration, colonial political domination and missionaries’ evangelical activities (Rigby, 1981). In fact, Sorrenson in (Rigby, 1981, p.123) said most missionaries “welcomed European settlement in the belief that settlers, by introducing improved methods of cultivation and employed labour, would assist in the civilizing process.”

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[2] Tanganyika is the name given to mainland Tanzania pre-independence.

The British took over Tanganyika informally in 1915 and formally in 1920 under a League of Nations mandate. The British set up a system of indirect rule of the Maasai, reshaping gender and age relations within their communities. Seen as a threat to control and order, British tightened up the Maasai reserve, some of the driest and desolate land in Tanganyika. Colonial interventions such as water development, veterinary control and education were created to restrict Maasai to pastoralism and to their confined space, eventually benefiting from their revenue (Hodgson, 2000). Veterinary policies implemented under British colonial rule included a permit system for the Maasai's movement of cattle within and outside of the reserve, quarantines for cattle to be inoculated, and systems to 'improve' Maasai animal husbandry practices. Such livestock restrictions were a form of control over the pastoralists' lifestyle and their strong social relations (Hodgson, 1999). The Provincial Commissioner remarked in 1927, "Masai District has been constituted as an ethnological and economic sanctuary; rigidly closed to outside influence and to trade, it has remained for 11 years a stagnant island set in the midst of the most progressive areas of the Territory" (Hodgson, 2001, p.132).

This system of government extended authority to men, particularly elder men, to hold new rights and responsibilities including collecting taxes, enforcing livestock decisions, and codifying customary law. Gendered spaces of 'political' and 'domestic' were partly attributed to the gendered nature of the British administration itself. Shifts in the gender balance among the Maasai have been largely attributed to the change from a system of informal trade and bartering to a British colonial instituted system of money exchange (Hodgson, 1999; Talle, 1998). Pre-colonialism, husbands and wives were more autonomous and particularly around their most valued possession, livestock. They conferred and agreed on trade and slaughtering of cattle. Women were the traders of hides and milk for food, beads, cloth, or other materials. This changed when cattle were forced to be a commodity resulting from a new gendered tax system, making adult men the taxpayer. Taxes were inflicted on men including a 'plural wives tax', livestock tax and a hut tax (traditionally built by and belonging to women). This removed women from being the dominant trader to a male dominated cash economy (Hodgson, 1999) and contributed to a shift in Maasai gender roles.

Such colonial practices created norms of oppression that were carried over by the Tanzanian government into independence from 1964 and shaped the power imbalances between the Maasai and the state (Hodgson, 1999). With a post-colonialism focus on development, fingers were pointed at Maasai for not living up to this new agenda. State led development programmes were aimed to modernize land management, settle communities, and manage resources through an introduction of villagisation, ranches and Wildlife Management Areas (Benjaminsen et al., 2013; Homewood, 1995; Lankester & Davis, 2016; Sulle & Banka, 2017). The legacy of the colonial past and neo-colonial present has shaped the stereotype of Maasai as noble savages, defiantly persisting on their traditions despite modernization happening around them and as being backwards.

More recent incidents at the start of this field work, indicated a continued sense of political subjugation, marginalization, and cultural discrimination of the Maasai. Reports include the burning of a tourist camp over a dispute over cattle grazing (Mjema, 2014). This occurred in a village that the LSHTM/ KCMC Trachoma Project was working in. A text message from the project field coordinator read:

> *“The work in Mitimirefu was a bit difficult today, women were angry due to the incidence of [tourist camp], some of men and women are in lockup, now they are claiming of their parents being not around…”.*

Only a few months after this incident, a Maasai market in Arusha was burned down where Maasai sell crafts and art to tourists (Magubira, 2014). Ongoing evictions from parts of the Serengeti National Park to create a hunting reserve for the Dubai royal family continues to leave Maasai powerless ("Loliondo land saga in new controversy," 2022; Oluoch, 2022; Smith, 2014).

A changing livelihood

Today, over-population, restricted land-use, climate change and a changing political-economy have resulted in a semi-nomadic form of pastoralism and even agriculturally based lifestyle. Reliance on pastoralism is not as economically viable, forcing alternative forms of income. Men are migrating for work some as far as the island of Zanzibar. Many work as security guards, *walizi*, mining and selling traditional medicines. Women are taking on more economic responsibilities that have followed from family diversification and higher levels of male outmigration. In addition to their domestic responsibilities, women are raising chickens and making crafts for tourists.

Change is inevitable, yet as a result of a history of being supressed and decisions on livelihoods dictated by outsiders, *ormeek*, Maasai want change to happen at their pace. In Hodgson's discussions with Maasai men about this changing political economy, they blame the colonial period for rejecting education, farming, and involvement with the state. They use the term, *emodai*, to mean stupid in a way that is "ignorant of the languages and practices of the nation-state; it is unable to operate in the world of hospitals, courtrooms, banks and politicians". They talk about the "wisdom of the past" being worthless and a need to gain the "wisdom of the present" (Hodgson, 2001, p.140). Yet with this growing appreciation for education as the hope for their future, Maasai are having to manage a shift in the home dynamics. Children are not available to help with grazing cattle, to fetch water and firewood, placing greater demands on women while men find additional income to support school fees. These socio-economic changes including rural-urban migration and adopting more formal religion, have implications on polygamy and hence the number of children that men have (Coast, 2006). Not all Maasai are comfortable with these changes to their livelihoods. Some Maasai I have spoken to are less eager to change and express concern that younger men lack respect, are too individualistic, and materialism has led to selfishness. This modern/traditional dichotomy is a difficult balance that Maasai are grappling with.

Despite the negative stereotypes of Maasai, the new nation state recognized the role of Maasai in tourism. A typical tourist's safari includes a visit to a Maasai boma to engage in dancing, singing, taking photos, and buying women's crafts. Government land and resource management programmes aim to empower communities to manage and benefit from tourism activities on those lands. Yet the reality is Maasai communities in these areas are often side-lined in decision making and negotiating revenue sharing (Benjaminsen et al., 2013; Homewood, Trench, et al., 2009; Sulle & Banka, 2017). Prioritization of water in Ngorongoro is to the tourist lodges, "when tanks and swimming pools are full, water is diverted to villages for livestock and human beings to use" (Melubo and Lovelock, 2019, p. 8).

The number of development projects in Maasai communities increased considerably during the 1980's. Many of these organizations were led by "liberal" Westerners (Hodgson, 2011b) with specific visions of modernity and progress, seeking input only from educated junior elders, *ilpayiani,* in a traditional society structure where decision making includes the elders, *ildasat*. Often the work of NGOs alters and/or supresses the local communities' self-reliant movements of change. NGOs are seen to come with their agendas and resolutions to the issue and with "top down" approach rather than being advised by and supporting the local community in their efforts for change. Today many international NGOs are focused on stopping the practice of female genital mutilation (FGM), and early child marriage.

Relationships with medicine

Colonial power and the control of medicine

Pre-colonial forms of "public health" involved healers mobilizing medicine to manage social kinship, the control of the rains, times for planting and harvesting and healing illness. Biomedicine was introduced to Tanganyika by colonialists and missionaries to enhance their political and social control (Turshen, 1977; Wilkens, 2011). They restricted biomedicine to medical research and disease control programmes (Hoppe, 2003), rather than a social concern for the people of Tanzania.

During the Maji Maji rebellion from 1905-7, medicine was utilised by rebels in an act of resistance against German colonial forces. Medicinal water, *maji*, was created and sprinkled on African warriors throughout the southern part of the country, bringing men of different ethnic groups together to fight the German forces. The *maji* was said to dissolve bullets and protect the people from European weaponry. Eventually the Germans crushed the Maji Maji Rebellion. Yet the power of solidarity that the medicinal water had, led colonial officials to rethink the control needed in Tanganyika. When the British came into rule a decade later, their reflection on the Maji Maji Rebellion rationalized their fears of traditional medicine (Langwick, 2008).

As a form of social control, the British colonialists, seeing the political and social power of medicine created the 1928 Witchcraft Ordinance, prohibiting divination and distribution of medicine to entire communities. What constituted medicine or healing was not well understood. Concepts of healing were not easily separated from witchcraft and its associated political and social power. This effort to separate witchcraft *(uchawi)* from healing *(uganga)* was a result of European interpretation of medicine in Tanzania and was revised with subsequent acts, the current being of 2002 (Langwick, 2008; Mesaki, 2009).

Traditional medicine and biomedicine

Traditional medicine refers to health practices, approaches, knowledge and beliefs incorporating plant, animal and mineral based medicines, spiritual therapies, manual techniques and exercises, applied singularly or in combination to treat, diagnose and prevent illnesses or maintain well-being (WHO, 2003). Explanations for illness and approaches to healing in Tanzania differ between traditional medicine and biomedicine. Belief in traditional medicine combines religion, sorcery, interpersonal conflict and health. Scientific explanations of disease do not fulfil people's questions around illness (Gessler et al., 1995). Traditional healers in Tanzania typically consider illness to have a natural cause and/or a supernatural cause brought about by witchcraft and spirits. The most frequently reported conditions treated by traditional healers include malaria, infertility, headache, abdominal problems, mental confusion, epilepsy, paralysis, fever, sexually transmitted disease and ulcers (Gessler et al., 1995).

Gessler et al. (1995) discuss the commonest reasons for dissatisfaction with biomedical health services in Tanzania including long waiting times; only brief encounters with medical staff; feelings of confusion and being alone in an unfamiliar environment; no opportunity to express concerns; and prescribed medication with no explanation of the cause of illness. Consequently this may contribute towards a level of distrust in biomedical systems (Wilkens, 2011). Alternatively, traditional medicine is commonly incorporated into healing in Tanzania. A study on the use of traditional medicine in the Kilimanjaro Region including various ethnic groups (Chagga, Pare, Maasai, Sambaa and others), found that 56% reported using traditional medicine in the past year with no difference between those living in urban or rural settings. The study reported the following major determinants for use of traditional medicine: disease understanding, biomedical health care delivery, credibility of traditional practices, health status, and strong cultural identities (Stanifer et al., 2015).

Decisions to seek traditional medicine and biomedicine in Tanzania are based on the type of symptoms or ailments, and cultural interpretations of such, a preference for biomedicine for diagnostics and traditional medicine for treatment, and cultural beliefs (Stanifer et al., 2015). Considered an important source of advice on medical decisions, Tanzanian elders reported that ancestors did not have hospitals and used traditional medicine while today people go to hospitals and at the same time "diseases have erupted". Respondents associated biomedicine with a "foreignness" with concerns of biomedicine ranging from side effects to associations with being colonized. In a survey of 655 adults from the Kilimanjaro community, 45% of respondents said they use traditional medicine because of their perceived effectiveness compared with biomedicine (Stanifer et al., 2015).

The Tanzanian government recognizes traditional medicine and is in the process of incorporating this form of medicine into the national health care system. In 1991 the Institute of Traditional Medicine in Tanzania was established for research and development of plant based medicine (Strangeland et al., 2008). Despite government support for traditional medicine, there is a disconnect between traditional healers and the formal health system. In a study of healers in Tanzania, 28 of 31 healers reported referring patients to hospital but they felt blamed by hospital staff for treating patients and sending them to the hospital late in the course of their illness (Gessler et al., 1995). The Traditional and Alternative Medicine Act of 2002 encourages cooperation between bio-medical doctors and traditional healers.

Medicine among the Maasai

Traditional medicine is still widely practiced among the Maasai possibly due to isolation from centres of development (Sindiga, 1994) and a strong cultural identity (Kiringe, 2005). A study conducted with the Maasai of Southern Kenya, found in 2006 that 73% of participants indicated traditional medicine was their preferred form of treatment (Kiringe, 2006). However traditional medicine is not the sole form of medical treatment as 98% indicated they also seek medical attention from local dispensaries and clinics (Kiringe, 2006). At the same study site, use of traditional medicine seems unrelated to age, gender, education or Christianity (Kiringe, 2005). This is in contrast to Sindiga (1995a), reporting that Christian Maasai are moving away from or opposed to some traditional practices and beliefs including the use of traditional medicine. Maasai preferences for traditional medicine are contributed by beliefs that it is more superior than biomedicine, inadequate health facilities (poorly equipped, lack of medicines and understaffed) and higher costs of biomedicine (Kiringe, 2006; Sindiga, 1995b).

Traditional medicine includes trees, shrubs, and plants, which are of important symbolic meaning to the Maasai. Trees are considered a link between earth and heaven or God as well as analogous to human beings (Olsson, 1988). The Maa terms for trees and shrubs, *olchani* (pl. *ilkeek)* is also the term for medicine including biomedicine. In most cases the bark, roots or leaves are prepared either by boiling or soaking in water and then ingested in tea, soup, or milk. Some medicines are chewed or sap swallowed directly (Kiringe, 2006). Maasai believe polluting substances that impede digestion and blood circulation causes many illnesses. Therefore, many traditional medicines cause vomiting and diarrhoea as a means of cleansing the body.

The intergenerational transfer of knowledge on traditional medicine is done orally among Maasai. In the study by Kiringe (2005), 87% of Maasai in the community reported they had plans or were already teaching their children aspects of traditional medicine. *Iloibonok*, Maasai healers, have a more vast knowledge of local medicine and this role along with the knowledge is passed on through kinship (Fratkin, 1996; Kiringe, 2005).

Epistemological dimensions of disease among the Maasai are based on complementarity, described as “double causality”, including an observable event, a ‘cause’ and an unobservable element, ‘guiding cause’. An observable event or physical dimension is based on empirical observation and common sense reasoning (Olsson, 1988). This is similar to Evans-Pritchard’s (1976) observations of the Azande in Sudan. Witchcraft among the Azande is deeply rooted and intertwined in daily life and activities and provides the missing link to why something did not take its usual or expected course. Evans-Pritchard uses the example of a boy who knocked his foot on a stump of wood and the wound festered and did not heal well. Azande did not believe witchcraft had anything to do with the wood in the path but that being bewitched would explain why he did not see the stump in the path and why the wound did not heal. As early as 1904 it was documented that for the Maasai malaria is carried by mosquitos and indicated by the Maa term for mosquito, *enkojonani*, which carries the meaning of malaria (Merker, 1904; Olsson, 1988). For the Maasai a ‘guiding cause’ of illness or misfortune can be the agency of divine power of a curse, *oldeket*, or cultural offence, *inok*, such as breaking a marriage taboo, *sarkin*. Such guiding causes are believed to originate from God, *enkai,* (Fratkin, 1996; Olsson, 1988). While traditional medicine in many parts of Tanzania has historically included spirits (Langwick, 2011), the Maasai view spirits as being outside their culture. Unlike many indigenous African belief systems, the Maasai do not worship their ancestors (Fratkin, 1996) but rather offer penitential sacrifices to *enkai*. Maasai philosophy around beliefs of health, illness and medicine and their existence are based on instrumentality, in that events and objects receive an instrumental quality of being employed by God through which he exerts his power. Amulets and rituals are used in the metaphysical aspects of Maasai healing. An instrument of *enkai*’s divine power, *engolon*, amulets protect the owner although are not specific to certain diseases (Olsson, 1988).

Syncretism of medical traditions may be the direction medicine is moving among the Maasai. The impact of modernity may impact these traditional medical beliefs and practices. Kiringe (2006) discusses the threat to traditional medicine due to reduced and changing land use particularly with an increase in agriculture; use of trees and shrubs for firewood and construction (deforestation); increasing population; overuse and commercial sale of medicinal plants.

Trachoma: a neglected disease among neglected communities

Biomedical understanding of trachoma

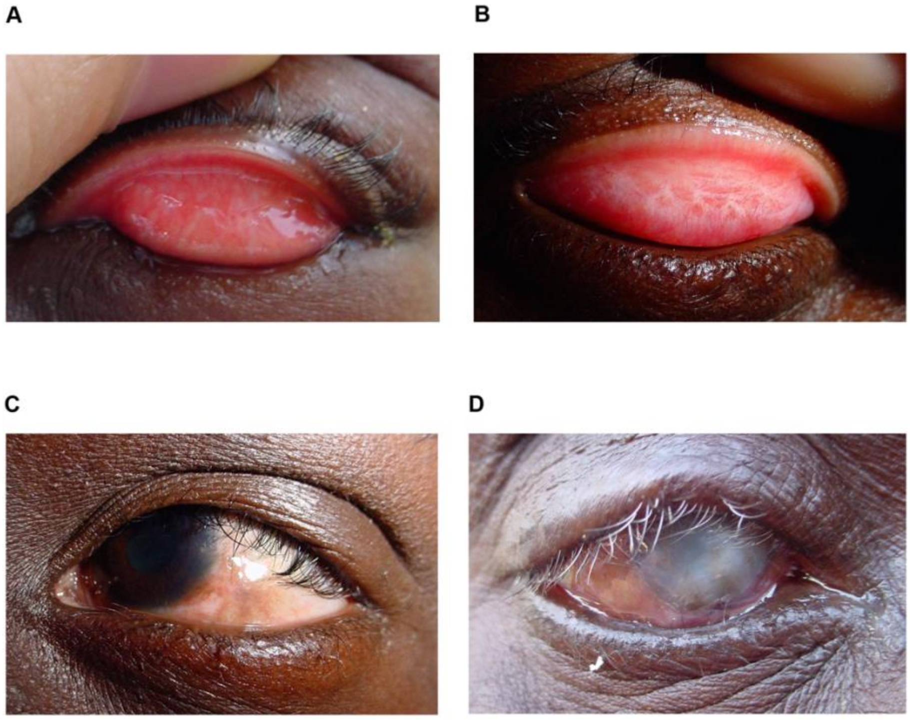
Trachoma is the commonest infectious cause of blindness worldwide (Baneke, 2012); it is caused by the bacterium *chlamydia trachomatis.* This infection is thought to have been around as early as 27th century BC in China (Al-Rifai, 1988). As crowded living conditions and poor hygiene became more common, outbreaks of chlamydial infections increased reinfection. Trachoma was common in Europe and North America but as living standards and hygiene improved in the twentieth century the burden decreased (Harman, 1930; Mabey et al., 2003). With the introduction of antibiotics trachoma was completely eliminated from more developed countries with the exception of indigenous populations in Australia (Landers et al., 2005). Today trachoma remains endemic and disproportionality affects marginalized populations in poor, rural communities in low-income countries (WHO, 2022).

Trachoma is caused by recurrent infection with C. *trachomatis* leading to scarring. The clinical features of trachoma are divided into those related to ‘active’ disease which characterizes episodes of infection and are most common in children under five years; and those associated with scarring (Figure 1). The disease process begins with infection of the conjunctiva (clear membrane that covers the inner eyelid and the front surface of the eye) with C. *trachomatis*. Early stages of trachoma are characterised by follicles and inflammation in the inverted upper eyelid. ‘Trachoma’ comes from Greek meaning ‘a roughness’, in reference to the conjunctival surface (Harman, 1930). Patients are often asymptomatic or have mild symptoms of irritation in this slowly progressing disease. Contraction of scar tissue causes the eyelids to turn inward, entropion. Trichiasis occurs when eyelashes make contact with the eye. At this stage, it is often quite painful as a person blinks and the eyelash scratches the front of the eye. Eventually a number of factors including corneal trauma and secondary infection can lead to blindness (Hu et al., 2010). Trichiasis typically does not occur until middle to late age.

The WHO simplified grading system (Table 2) is used to assess the prevalence and severity of trachoma. Screening for active trachoma (TF and TI) is done in children under ten while adults are screened for trichiasis (TT).

Chlamydia trachomatis is found to cluster in families or households (Bailey et al., 1989). While rates of active trachoma are fairly similar between the sexes, women tend to have more scarring and loss of vision likely due to more exposure to infection from caring for young children (Solomon et al., 2022). Frequent reinfection tends to occur in endemic areas, possibly due to a critical prevalence of infection in the population and the length of time spent in closed and proximate environments (Taylor et al., 2014).

Figure 1. Clinical features of trachoma



(A) active trachoma in a child, characterized by a mixed papillary (TI) and follicular response (TF); **(B)** tarsal conjunctival scarring (TS); **(C)** Entropion and trichiasis (TT); **(D)** blinding corneal opacification (CO) with entropion and trichiasis (TT)

Source: provided by Matthew Burton

Table 2. 1987 WHO simplified trachoma grading

Grade	Abbreviation	Description
Trachomatous inflammation-follicular	TF	The presence of five or more follicles (>0.5mm) in the upper tarsal conjunctiva
Trachomatous inflammation-intense	TI	Pronounced inflammatory thickening of the tarsal conjunctiva that obscures more than half of the deep normal vessels
Trachomatous scarring	TS	The presence of scarring in the tarsal conjunctiva
Trachomatous trichiasis	TT	At least one last rubs on the eyeball
Corneal opacity	CO	Easily visible corneal opacity over the pupil

Trachoma, classified by WHO as one of 20 neglected tropical diseases (NTDs), is endemic in 44 countries across Africa, Asia, Australia and the Middle East and is responsible for blindness or visual impairment of approximately 1.9 million people (WHO, 2022). In 2021, it was estimated that 136 million people live in endemic regions, which require control programmes. The African continent has the highest burden of trachoma (WHO, 2022). As of March 2022, WHO has validated 14 countries to having eliminated trachoma as a public health problem[3] (WHO, 2022).

Public health approaches to trachoma

SAFE strategy

Risk factors for trachoma span environmental, socio-economic, and behavioural factors. Risk factors include limited access and use of water (Bailey et al., 1991); limited face washing (Schemann et al., 2002; West et al., 1995; West et al., 1991); poor sanitation (probably through promotion of fly populations) (Emerson et al., 2004; Schemann et al., 2003); and crowding (Bailey et al., 1989). Yet, public health rhetoric on risk factors overshadows the complexities of their interactions and being situated within a broader political economy of health (Gupta-Wright, 2019).

Control of trachoma is based on the SAFE strategy, adopted by WHO in 1993. SAFE includes four public health interventions: Surgery for trachomatous trichiasis; Antibiotic treatment to eliminate the infection; Facial cleanliness promoting hygiene and Environmental improvement which includes management of animal and human faeces (use of latrines), living standards that reduce ocular promiscuity and crowding and access to water to reduce transmission (WHO, 2012). This multipronged strategy of control measures is aimed at different phases of the disease spectrum.

"S"

Surgery to treat TT in people aims to relieve discomfort and reduce the risk of blindness. Tarsal rotation surgery is performed to correct in-turned eye lashes. This surgery is performed by trained surgeons based on WHO training manual (WHO, 2015). Trichiasis surgery is done at static sites as well as via outreach camps within endemic communities to increase accessibility and uptake of surgery.

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[3] Elimination of trachoma as a public health problem is defined as: (i) a prevalence of trachomatous trichiasis "unknown to the health system" of <0.2% in adults aged ≥15 years (approximately 1 case per 1000 total population), and (ii) a prevalence of trachomatous inflammation—follicular in children aged 1–9 years of <5%, sustained for at least two years in the absence of ongoing antibiotic mass treatment, in each formerly endemic district; plus (iii) the existence of a system able to identify and manage incident trachomatous trichiasis cases, using defined strategies, with evidence of appropriate financial resources to implement those strategies WHO. (2022). *Trachoma Factsheet*. Retrieved September 14, 2022 from https://www.who.int/news-room/fact-sheets/detail/trachoma

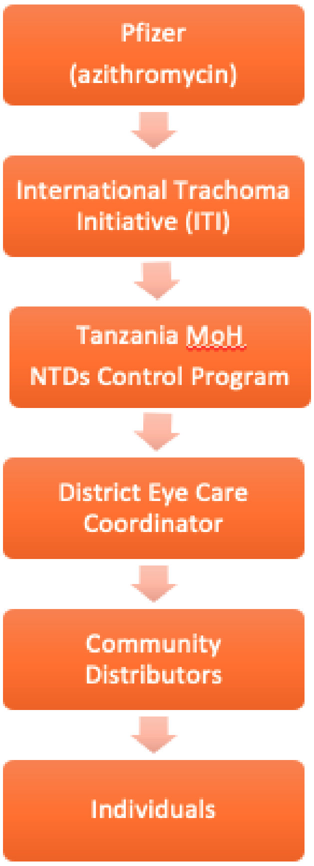
“A”

Antibiotic treatment aims to kill the bacteria, *C trachomatis* in individuals with active disease, and to reduce the burden of transmission and infection in communities. Azithromycin is provided via mass drug administration (MDA) in trachoma endemic communities with transnational support. Implementing annual MDA in endemic districts was based on evidence that MDA of single dose azithromycin reduced active trachoma for 12 months (Evans et al., 2019). A single dose of azithromycin from 20 mg/kg up to 1 gm (tablet or syrup) is recommended for all residents over one year of age. Infants less than one year are treated with topical tetracycline eye ointment (TEO). In a study in The Gambia, after six months of MDA, trachoma resolved in 78% of participants (Bailey et al., 1993) and in another study done in Egypt, The Gambia and Tanzania, after one year, trachoma ranged from 64-93% lower from baseline (Schachter et al., 1999).

For communities with a prevalence ≥ 10%, MDA should be conducted annually for three years and those with a starting prevalence ≥ 30% conduct five years of MDA before doing an outcome survey (WHO, 2010). For desired population level effect, recommended minimum coverage for each round of MDA is 80% (Solomon et al., 2022). MDA should be completed within about a three-week period in a community. As the population in remote communities is highly mobile, completing treatment within this timeframe will minimize the likelihood of re-infection and achieve higher population coverage.

In addition to reducing trachoma infection and disease, when given as part of MDA, azithromycin has shown to have benefits to communities including reduced short term respiratory infections, impetigo, diarrheal disease, malaria, yaws, and overall mortality in children (Coles et al., 2012; Coles et al., 2011; Fry et al., 2002; Keenan et al., 2018; Marks et al., 2015; Porco et al., 2009).

Figure 2. Top-down approach of MDA



The national control programmes for trachoma endemic countries receives donated azithromycin free of charge through a programme with Pfizer Inc., the makers of azithromycin, and the International Trachoma Initiative (ITI). ITI was created in 1997 to manage the distribution of donated azithromycin from Pfizer and reporting of prevalence data for trachoma control. This top-down approach to move azithromycin from the pharmaceutical company to individuals in endemic communities in Tanzania is shown in Figure 2.

“F” and “E”

Facial cleanliness and environmental improvement interventions aim to suppress transmission of C *trachomatis.* Ocular and nasal secretions are potential sources of infection and promotion of clean faces (absence of these discharges) could reduce transmission (Kuper et al., 2003). *Musca sorbens* flies are a known vector for the bacteria being attracted to facial discharge (Emerson, Bailey, et al., 2000). The flies breed and are found in areas of poor sanitation- food waste, animal and human faeces and other trash. Therefore, improving cleanliness of living spaces and regular face washing require education and behaviour change interventions. Interventions have focused on improved access and use of water and latrines, reducing overcrowding, and proximity to livestock. These aspects of SAFE are viewed as more complex than the “S” and “A”, lacking a “magic bullet” (Emerson, Cairncross, et al., 2000), and therefore fewer resources have been allocated and less implementation.

Global policy

In 1997 WHO established the Global Alliance for the Elimination of Blinding Trachoma by the year 2020 (GET 2020). The early 2000’s saw greater efforts from various global actors to make diseases less ‘neglected’ in the global health landscape. This was driven by policies addressing global inequality and poverty. GET 2020 leveraged pharmaceutical support, public-private partnerships creating and strengthening national control programmes. This included the implementation of the SAFE strategy and strengthened capacity through epidemiological surveys, monitors, surveillance, evaluation and resource mobilization (WHO, 2012). Yet emphasis has been on biological aspects of disease and little attention on the social constructs and livelihoods of communities affected.

Since the target of elimination was not achievable by 2020, the alliance reset the target date to 2030 as outlined in the Roadmap for Neglected Tropical Diseases 2021-2030. The revised strategy aligns with the Sustainable Development Goals and shifts from disease specific approaches to a holistic approach of cross-cutting activities that intersect multiple diseases. The road map is based on three pillars to support global efforts to control, eliminate and eradicate NTDs, (1) accelerate programmatic action, (2) intensify cross-cutting approaches, and (3) change operating models and culture to facilitate country ownership (WHO, 2021).

Review of challenges of MDA delivery for NTDs

MDA is carried out for several NTDs including trachoma, schistosomiasis, lymphatic filariasis, soil-transmitted helminths and onchocerciasis. The concept is that if coverage of MDA is high and repeated on a yearly basis, the disease will eventually be eliminated. It is suggested that in a number of countries, for example Morocco, the provision of azithromycin for MDA through the ITI, coupled with the other components of the SAFE strategy, has led to a marked reduction in the prevalence of disease (International Trachoma Initiative, 2022). However, studies have shown that distribution comes with challenges including reaching community members that live in physical and social isolation, conflict situations, distributor motivation, rumours, non-biomedical beliefs of medicine and cause of disease, and migrancy.

Local conflict

In some settings social divisions have been shown to affect distribution. In a study of MDA for lymphatic filariasis in Tanzania a rift between Christian and Muslims influenced distributors in registering or not some residents (Parker & Allen, 2013). Some dismissed Christians as “refugees” or were considered “not real people”. Other conflicts, which affected acceptance of the distribution programme, have resulted from social, political, and economic hierarchies, which result in poor relations between people of Panyimur in North- West Uganda and the Ministry of

Health (Parker et al., 2008). Rates of active trachoma in post-conflict South Sudan was 63.3% with an estimate of over 5,344 persons needing trichiasis surgery (Jeremiah. Ngondi et al., 2006). A 21-year civil war made this area inaccessible for SAFE to be implemented.

Physical and social isolation

MDA for control of lymphatic filariasis conducted in Muheza and Pangani Districts, Tanzania, included remote villages that required crossing a river to access the villages. Such travel can be technical, long and expensive and affect motivation of volunteer distributors to cover such villages (Parker & Allen, 2013). A case control study was conducted following two rounds of MDA for trachoma in 2008 and 2009 in 28 Tanzanian communities (Ssemanda et al., 2012). Cases were households with at least one child that did not participate in MDA and controls were households where all children participated in both MDAs. Parents with a decreased social reliance were associated with non-participation. This is probably due to lack of social networks: there is an association between strong social networks and a positive well-being in low-income countries (Tungaraza, 1993). Household factors associated with child non-participation included having multiple children in the household. In these rounds of MDA, drugs were distributed from a central location site in which case the logistics of bringing multiple children to a distribution point can be logistically and financially burdensome. Yet distributors in some cases were distributing at the homes of residents. Travel time for community distributors and the community members non-familiarity with the community volunteers were also associated with non-compliance. Travel time is likely to be as a result of the volunteers not traveling to distant households and, with subsequent rounds of distribution, motivation to cover remote areas (that likely have poor uptake anyway), decreases.

Migrancy

A study conducted in Kongwe, Tanzania looked at the risk of infection with *Chlamydia trachomatis* in migrant children to communities undergoing MDA for trachoma. Migrant children were more likely to be infected than those children resident in the community. Settlements where the children migrated to were more likely to have infections than settlements with no migrants. This was more significant following the third round of MDA (West et al., 2015). A study done in The Gambia, looked at the effects of MDA in 14 villages. There was a reduction in infection in 12 of the villages while in two villages infection rates increased after two months. This was attributed to an annual pilgrimage to a festival in Senegal where rates of active trachoma are higher than in The Gambia (Burton et al., 2005).

Side effects

Several studies have reported concern about side effects including death, fear of infertility and miscarriage (Astale et al., 2019; Babu & Kar, 2004; Cabral et al., 2017; Hastings, 2016; Mulugeta et al., 2018; Parker et al., 2008). In a community in Kilimanjaro Region, Tanzania, 32% of questionnaire respondents reported side effects of azithromycin including diarrhoea, stomach-ache, and nausea. Reports of these side effects spread, affecting uptake of the drug (Desmond et al., 2005). On the other hand, some participants in the same study by Desmond et al. (2005) viewed side effects as a sign that the drug was working, "*At the beginning I didn't know if it was working, but once I got the side effects I felt that this was a sign it was working well*." (p. 660). Dosing of drug is based on weight of the individual, yet due to logistics heights are used to estimate weights and hence dosage. Concern for over-dosing in that use of height, rather than weight, leads to incorrect dosing of drugs (Parker et al., 2008).

Trust in authorities

With several authorities involved in distribution programmes, trust in parts of or the entire labour chain can affect the community's acceptance of the drug. Use of volunteer distributers of drug has varied effects on uptake with some stating that they could only take the drug if someone from the village was part of the distribution. While others question the trustworthiness of the local volunteer distributors due to a perceived lack of knowledge in medicine. In some cases, there was evident confusion among the distribution team regarding eligibility for drug including eligibility of those consuming alcohol. Inconsistent treatment in the community created confusion and mistrust. Personnel from outside the village were perceived as doctors and hence possessing biomedical knowledge and therefore uptake was related to 'trust in the doctors' (Desmond et al., 2005). Perceptions of inappropriate drug handling had a negative effect on acceptability. Some who refused the drug, reported that they saw the drugs exposed to the elements (sun and dust) making the drug ineffective or causing harm (Desmond et al., 2005).

Trust in local and national government varies by setting affecting acceptance of MDA. In two Tanzania based studies, many respondents in the study by Desmond et al. (2005) placed trust in local *balozi* leaders and even national government while respondents in the study by Parker et al. (2008) reported poor relations and trust in national government and uptake was as low as 31.3%.

Rumours

The origin of rumours around health interventions can be complex. On one hand rumours can arise due to misinformation. While on the other hand rumours may have historical or political origin or result from cultural beliefs. Rumour arose that the Ugandan government was using MDA and similar interventions to weaken the population in Northern Uganda, and that the US government was assisting Uganda in population control (Parker et al., 2008).

Rumours of health interventions causing sterility or containing contraceptives has been documented since the 1920s in Africa including vaccinations, malaria treatment and vitamin supplementation. Rumours can be related to alterations of individual bodies through either depletion of vital energies or removal of some body part which have a strong historical basis, often predating colonial rule (Kaler, 2009). Rumours of blood-stealing and organ or limb-selling are not uncommon in African settings. The act of passing on rumours may not be related to whether the person passing it on believes the rumour (Geissler & Pool, 2006) but rather a response to someone’s mistrust or uncertainty in something.

Rumours around infertility are common during health interventions and part of a broad category of bodily harm rumours. Rumours of drug-induced sterility as well as cancer were reported in MDA for trachoma in Tanzania (Desmond et al., 2005). Infertility rumours are unique as they speak of effects extending into the future. Kaler (2009) discusses a theory of sterility rumours resulting from four socio-political forces: (1) asymmetries of power, (2) collective survival, (3) bio politics and (4) reproductive bodies.

It is critical that rumours be recognized, analysed, and addressed, rather than seeing them as impediments to a health campaign. In a 2003 polio vaccination programme in Nigeria, political and religious leaders in Muslim states in the North spread rumours that the polio immunization was contaminated with contraceptive agents.

They claimed that the vaccine was “America’s revenge for 9/11”. Health authorities compromised by agreeing to source the vaccines only from companies in Islamic countries and they would test the vaccine for the presence of contraceptives and other toxins. The campaign resumed in 2004 with advocacy and public support in Muslim communities (Kaler, 2009).

Traditional beliefs in medicine

Belief in and use of traditional healers is common in Tanzania. Local healers often instruct community members not to mix local medicine and healing with western medicine (Langwick, 2011). This may contribute toward refusal of MDA for trachoma although use of traditional healers was not associated with uptake of MDA in a study in Tanzania (Ssemanda et al., 2012). Parker and Allen (2013) in their research on the coast of Tanzania of MDA for lymphatic filariasis, noted the members of the community used traditional healers for treatment which include use of medicines derived from locally found natural substances, spiritual healing, *uchawi*, a type of witchcraft, or any combination of these forms of local treatment. Traditional medicine can impact biomedical understanding of disease, prevention, and uptake of MDA. Experiences with Swahili spirit possession cults contribute significantly to beliefs about interpersonal and spiritual causes of disease and suffering (Giles, 1997; Parker & Allen, 2013).

Poor knowledge of disease and treatment

Effectiveness of an MDA programme often depends on sensitization and education done in the communities. Local understandings of the disease, causes and treatment may vary and are influenced by local beliefs. Parker et al. (2008) reported that health education regarding treatment and prevention of schistosomiasis in Uganda was approached from a biomedical perspective and not incorporating local understanding, beliefs around illness and local healers. Local understandings of schistosomiasis were two-fold: (1) symptoms are a sign of witchcraft or locally defined illness rather than resulting from a parasitic infection. A witch inflicts the illness on a person, resulting from envy. It is thought that only witchdoctors or local healers can heal the individual while biomedical treatment is considered dangerous and can even lead to death. (2) symptoms associated with a general term for worms, *okudi*, which is not the same biomedical understanding of *S. mansoni* (one of the main types of schistosomiasis). It is thought to be due to drinking or bathing in contaminated water but with little understanding of the lifecycle of *S. mansoni*.

In the study of azithromycin distribution in Tanzania (Desmond et al., 2005), sensitization prior to distribution was poor with only 170 of 305 (56%) treated questionnaire respondents reported being satisfied with the amount of information they received. Knowledge on trachoma and azithromycin and its role in trachoma prevention was low and thus related to uptake of azithromycin. Community members questioned the effectiveness of an oral drug for eye disease. Some individuals with trachoma had used tetracycline eye ointment and therefore did not trust and refused the oral pill. An injection was perceived as more effective than oral medicine for prevention of disease, "*injections reach more of the body quickly, because they spread through the blood, and are therefore more useful in prevention*" (p. 659). Community members reported use of specific drugs varied by individual; effective for some, not others or even harmful; based on an individual's belief in their own 'type of body' and 'type of blood'. Disease discourse in this community affected uptake. Swollen eyelids and ocular discharge in children with active trachoma were not seen as a disease process but as a normal phenomenon.

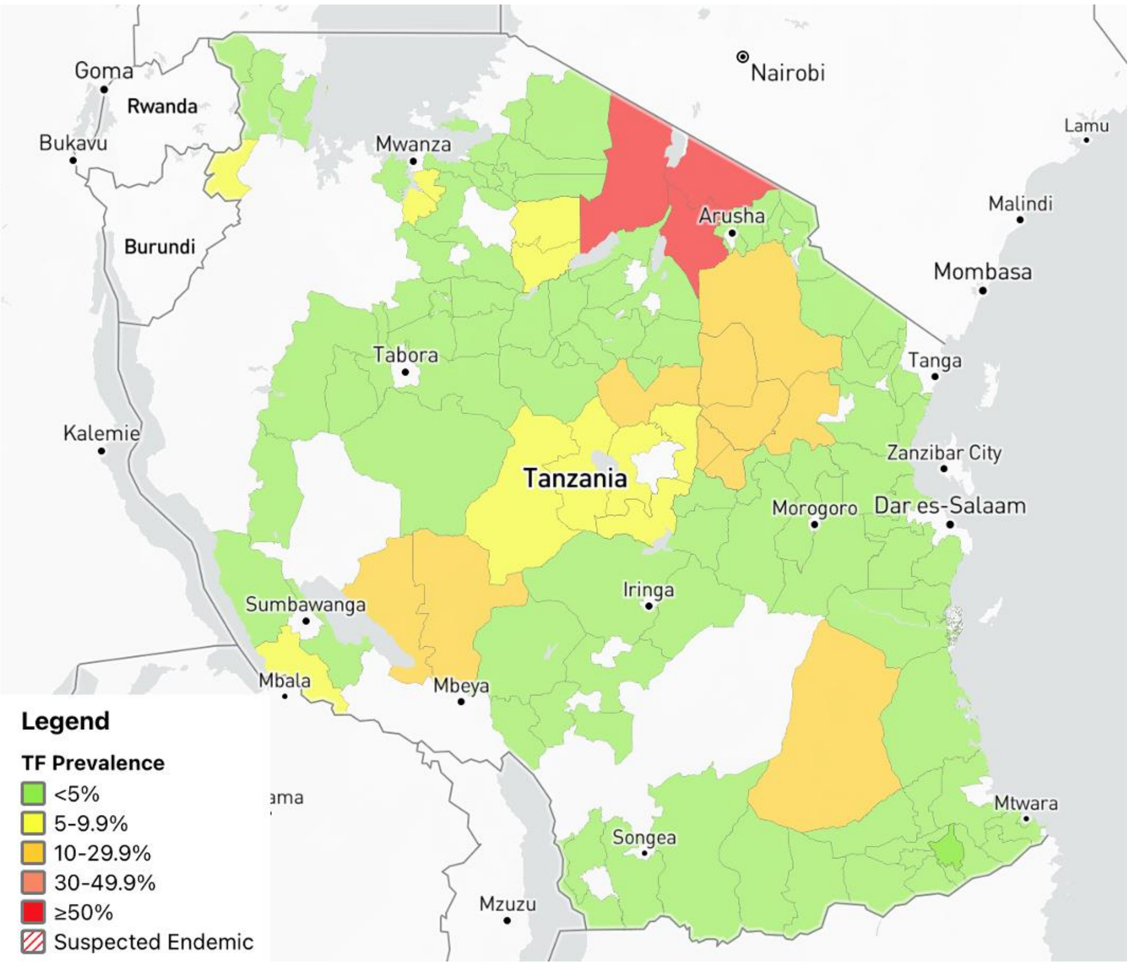
A common belief in the community, and often for volunteer distributors as well, is that if one is feeling well or healthy then they are not ill and hence no need for treatment (Parker et al., 2008; Ssemanda et al., 2012). Medicine is for sick people and being sick is related to exhibiting symptoms. "*I am not suffering from eye disease and I don't have any reason to treat them*," (Desmond et al., 2005).

Trachoma among Maasai districts in Tanzania

In 2017, trachoma was estimated to affect 17% of the population of Tanzania (WHO, 2017). Yet, the majority of trachoma endemic districts in Tanzania are predominantly Maasai communities including Longido, Monduli and Ngorongoro. In 2016 prevalence of trachoma was >50% in these three districts (Figure 3). The baseline prevalence of trachomatous inflammation-follicular (TF) in Longido District was greater than 50% in 2004 (Masesa et al., 2007; Mwingira et al., 2016). Longido use to be part of Monduli District and was split in 2007 when they became their own districts. Monduli has had five rounds of MDA- 2005, 2007, 2008, 2009 and 2010. Uptake of MDA during those rounds was roughly 78%, 65%, 30%, 50% and 10%

respectively. In 2015, Longido District was part of the identified districts by Tanzania National NTD Control Programme and the ITI as being a hyper-endemic area, greater than 30%, and therefore eligible for MDA. Longido District received several rounds of MDA before undertaking trachoma impact surveys in 2018, that showed that TF had declined to 7.2%; however, MDA was continued as per WHO guidelines. Prior to 2015, MDA coverage was patchy. Following concerted efforts to improve by the Tanzania NTD Control Programme and partners, coverage improved gradually: 43% in 2015, 66% in 2016, 76% in 2017, 87% in 2018 and 94% in 2019.

Figure 3. Prevalence of trachoma in Tanzania (2016)

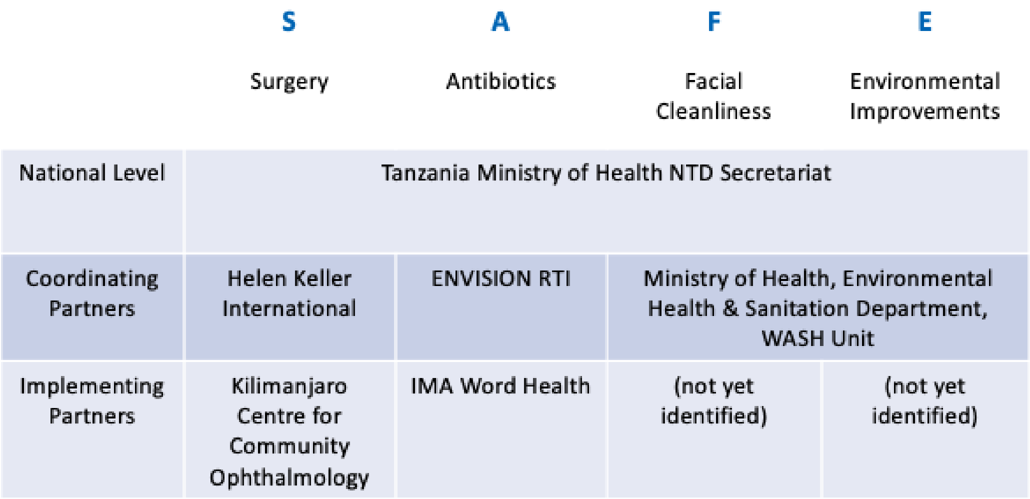


Source: ITI, Global Atlas of Trachoma 2016

Tanzania National Control Programme

The Tanzania Ministry of Health NTD Control Programme coordinates all SAFE programmes in Tanzania working with several NGOs functioning as coordinating partners and implementing partners (Table 3). The National Control Programme hosts annual join planning meetings with all involved NGOs and stakeholders to discuss and plan activities, monitoring and evaluation of control programmes. In 2015, the first East Africa Trachoma/NTD Cross-Border Partnership Meeting was an effort of several national control programmes and NGOs to coordinate control efforts on national borders.

Table 3. Partners of SAFE implementation in Longido District, 2016-18



	S Surgery	A Antibiotics	F Facial Cleanliness	E Environmental Improvements
National Level	Tanzania Ministry of Health NTD Secretariat			
Coordinating Partners	Helen Keller International	ENVISION RTI	Ministry of Health, Environmental Health & Sanitation Department, WASH Unit	
Implementing Partners	Kilimanjaro Centre for Community Ophthalmology	IMA Word Health	(not yet identified)	(not yet identified)

Together with the Tanzania National Control Programme, NGOs divide up their work geographically, each being assigned to coordinate or implement measures in different districts. In Longido District, Kilimanjaro Centre for Community Ophthalmology (KCCO) conducted trichiasis surgery. MDA is orchestrated by several international and local actors. In a very much top-down approach, RTI as the coordinating partner and IMA World Health, the implementing partner, working in partnership with the National NTD Control Programme, provide training and antibiotics to the district level NTD Coordinators and Eye Coordinators. Azithromycin is then distributed house to house by community drug distributors.

The Tanzania Ministry of Health Environmental Health and Sanitation Department has a WASH unit responsible for the “F” and “E” components, although an implementing organization was not yet identified at the time of this field work and therefore no programmes were being implemented.

The ‘end game’

Progress in the control of NTDs and specifically trachoma is evident. In 2017, a 10-year progress report of NTD control and elimination reported a 50% decrease in global trachoma prevalence and deemed elimination a realistic goal (Hotez & Aksoy, 2017). Trachoma has been eliminated as a public health problem in 11 countries (WHO, 2021). Provision of MDA coupled with other components of SAFE has led to a marked reduction in prevalence of disease in Tanzania. Baseline prevalence surveys conducted in mainland Tanzania in 2004-6, estimated 12.5 million people were at risk and 71 districts were considered endemic for trachoma. As of 2018, only eight districts require MDA for trachoma (Tanzania Ministry of Health Neglected Tropical Disease Control Programme, 2018).

With progress in delivering programmes and lowering disease burden, there is shift in thinking from control to elimination. This ‘last mile’ toward elimination has also been termed as the ‘end game’, the final stages of elimination campaigns where disease is still present at reduced levels (Klepac et al., 2013). Several strategies are being considered or implemented to achieve elimination beyond preventive chemotherapy, including improved diagnostics, immunological studies, integration with other diseases, and health system strengthening including sustainable surveillance and treatment (Hatherell et al., 2021; Macpherson et al., 2015).

Yet there remain hard-to-reach communities with high burdens of disease. These communities are geographically isolated or afflicted with conflict but furthermore are marginalized communities that require a critical understanding of their social, political, and economic context. Control of diseases in neglected communities often leads to tensions between local cultural demands and national targets. The same socio-political factors that drive NTD transmission in marginalized communities pose challenges in control efforts. Bardosh (2014) discusses three main challenges: (1) efficacy of tools and operational issues in hard-to-reach communities, (2) reliance on preventative chemotherapeutic treatment with little education and behaviour change and (3) moving interventions from international partners into socio-economically and politically marginalized communities.

The literature use terms such as ‘resistance’, ‘refusal’, ‘non-compliance’, ‘non-adherer’ and ‘non-participation’ to label individuals in communities with low uptake of MDA. There is a need to shift this blame from the community and reflect more on the nature of the programme strategies (Bardosh, 2014) and the wider political-economy of health. The end game requires a shift toward a more person-centred approach to programme delivery. “Appreciating the relevance of local specificities and variabilities, and the prioritisation of a deeper connection with local people, could yield significant benefits for tackling such public health concerns” (Gupta-Wright 2019, p.217). In her work on trachoma elimination in Malawi, Gupta-Wright draws on the concept of a ‘slow research’ (Adams et al., 2014) to suggest a ‘slow’ public health practice in the approach to trachoma. Such an approach “would interrogate assumptions of biomedicine, take care to listen to those least powerful; and acknowledge the structural roots of a health problem, their depths, and the ways in which they construct inequalities today” (Gupta-Wright 2019, p.218).

As Tanzania moves into the end game, the remaining foci of C *trachomatis* infection are districts of predominantly Maasai residents, requiring a more thoughtful, tailored and ‘slow’ approach. A critical understanding of Maasai livelihoods and responses to MDA will inform a control strategy that is relevant and effective in these hard-to-reach communities.

Thesis summary, aims and objectives

The idea for this dissertation has emerged from reports and my own observations of the low uptake of MDA of azithromycin for prevention of trachoma in Northern Tanzania by the Maasai population. My insights into the livelihoods and health experiences of a few Maasai communities where I assisted with MDA led me to believe reasons for low uptake were multifaceted.

Little research has been done to understand the impact on MDA and possible reinfection into Maasai communities. Yet the challenges in these communities require an investigation into the context from a socio-cultural point of view. There have been efforts to understand the context of MDA and the community response for NTDs (Babu & Kar, 2004; Cavalli et al., 2010; Desmond et al., 2005; Hastings, 2013;

Parker & Allen, 2013; Parker et al., 2008), although limited for trachoma (Desmond et al., 2005). Following my initial observations, I decided to do an in-depth study of the reasons for poor uptake including the social, political, and historical experience of the Tanzanian Maasai, and specifically how perceptions, experiences, and responses to health programmes, specifically MDA for trachoma, are impacted by the changing political and economic landscape of the Maasai.

The overall aim of this thesis is to investigate the responses to mass drug administration of azithromycin for trachoma and how these are situated in the current political, economic, and social context of the Maasai in Tanzania.

The broad research questions are as follows:

1. What is the Maasai interpretation of MDA for trachoma?
2. How do the Maasai respond to MDA?
3. How does the changing political economy of the Maasai influence the MDA programme?

The specific objectives are as follows:

1. To investigate Maasai knowledge of trachoma including pathology, progression of disease, risk factors and treatment.
2. To explore how Maasai prioritize prevention of trachoma against the backdrop of social, economic, and political challenges.
3. To explore the context of uptake of MDA.
4. To compare the experience of MDA in adherers and non-adherers.
5. To investigate the effects of migration in the community on uptake of MDA including the patterns of migration, characteristics of migrants and their experiences with MDA.
6. To describe decision-making around health issues, particularly eye health, among household members.
7. To explore Maasai response to MDA within their cultural perceptions and practices of biomedicine and traditional medicine.
8. To explore the Maasai’s access and response to health services more broadly.

9. To design and deliver a contextual appropriate public engagement intervention informed by this ethnographic research.

This research is grounded in some overarching assumptions. The past and current political situation of the Maasai affects their relations with ‘outsiders’. As development problematizes the culture of the Maasai, issues of power and resistance are of concern. Therefore, their decision about uptake of azithromycin is tied to this agency.

The Maasai responses to health programmes are shaped by their historical and political situation. MDA specifically may be perceived as a form of public health that does not conform to their socio-cultural norms.

Thesis overview

This thesis includes four academic papers, each having its own chapter (chapters 3 to 6). As detailed in the research paper cover sheets, three of the papers have been published and one has been accepted/ in press. Each of these chapters has an overview summarizing the rational and linking the papers to facilitate a cohesive body of work.

Chapter two discusses the theoretical framework to the research. It also provides a description of the research setting and the methods of data collection. The broad approaches to data analysis are provided but details for analyses for each paper are provided in the respective chapters. This chapter concludes with positionality and reflexivity.

Chapter three is a research paper that describes Maasai’s discourse of trachoma and more specifically their understanding and perspectives of pathology, progression of disease, risk factors, treatment, and prevention. This explores the systems of meaning around trachoma within the wider socio-cultural context of a Maasai community.

Chapter four is a research paper that describes the experiences and responses to a trachoma control programme of mass drug administration. This uses a socio-anthropological framework (Bardosh, 2018) to assess the effectiveness of MDA.

Five domains describe factors influencing participation and delivery of the programme.

Chapter five is a research paper that uses a framework of cultural safety and ethical space, used with indigenous populations, to understand the Maasai experiences with health care in a post-colonial discourse. It details research on perspectives and challenges of health care access and uptake and the relevant historical and political perspectives of Maasai people. This chapter is useful for thinking about how delivery of trachoma control programmes such as MDA might be better understood in light of these broader observations.

Chapter six is a paper that describes a public engagement activity to disseminate information about trachoma to the research community. This project, co-produced with Maasai, uses photo voice as a method for evaluation and discusses its impact on empowerment of women.

Chapter seven concludes the thesis by discussing how the overall findings from each of the research papers contribute more broadly to the literature on tailoring approaches to control of disease for marginalized populations. It details recommendations for policy and future research to engage Maasai communities more effectively in health programmes.

Appendices include ethical and local approvals, informed consent documents, data collection tools, and disseminated work including poster and oral presentations at conferences.

Chapter 2: Methodology

This chapter outlines the study design, its epistemological influences, and the theoretical approach to this research. The aim is to describe the process from theory to practice in exploring and interpreting Maasai's lived experiences. I describe the research setting including geographical context as well as specific locations that significantly contributed to this research and the ways in which data was generated. I conclude with reflections on my positionality as a way to be transparent of the influences I had on this research and to allow for a personal account of my experience with the research community.

Study Design

This was a qualitative prospective observational ethnographic study conducted in Sinya of Longido District in northern Tanzania, a trachoma hyperendemic community. Qualitative methods are used to provide more meaningful explanations, to understand the what, how and why of a phenomenon (Green & Thorogood, 2009). Qualitative research builds on quantitative and descriptive findings in the development of new concepts and theories (Britten, 2011). In global health, qualitative research can clarify values, language and meanings attributed to different actors in communities and organizations. It is a means of giving voice to those rarely heard or with relatively little power in society (Sofaer, 1999).

Ethnographic research is people-centred, locally contextualized and its iterative nature cultivates an insider understanding of the people, and perspectives and interpretations they articulate of their social worlds (Biehl, 2016). Prentice (2010) points out four main principles of ethnographic research in global health: it uses fieldwork to build theory, it emphasizes meanings, it explores the negotiated nature of reality, and it emphasizes the role of context both immediate and broad scale systems of political economy. Thus using ethnography can serve as an 'empirical lantern within global health' (Biehl, 2016). It can challenge our view of the world and our place in it. Through ethnography, this research aims to uncover that interventions are "complex and messy: a social arena where histories, politics and social conflicts are inevitable" (Bardosh, 2018).

Epistemological Influences

Epistemology is the theory of knowledge or more specifically the study of the sources and production of knowledge to understand the world. It underpins how knowledge will be constructed and interpreted thereby influencing research approaches and practice. Humanist, Wilhelm Dilthey (1989), describes human beings as living in a web of meanings that they spin themselves. To understand those meanings, a non-positivist approach must be employed. This study used constructivist inquiry to examine experiences of a Maasai community. In this non-positivist line of inquiry, it is assumed that it is meaningful to make sense of realities, specifically social constructs. The emphasis is on introspective-investigator accounts of social contexts, examining and interpreting the forces that shape and influence behaviours (Denzin, 1971).

Epistemological approach to this research

It is critical to acknowledge that the ‘neglect’ in neglected tropical diseases is a social dimension (Parker et al., 2016) and the communities where NTDs persist are often marginalized (Allotey et al., 2010). Here the focus is on trachoma, an endemic NTD among the Maasai, a historically marginalized or ‘neglected’ tribe. Constructivist inquiry was used to explore how the Maasai interpret their social worlds and gain a more in-depth meaning of the response to MDA for trachoma in the context of a changing political, social, and economic landscape in Tanzania. This approach provides critical insight from within the community into potential barriers to carrying out effective trachoma control programmes, namely knowledge, decision making structure, beliefs, and practices around medicine. Recipients of interventions are often ignored and are depicted as having meaningless contribution or as unreceptive (Biehl, 2016). This research aimed to explore insights and experiences from the Maasai perspective on how trachoma control was implemented in relation to their livelihoods.

Theoretical Framework

My approach in framing this research stems from my experience and observations of an often-narrow perspective underpinning global health interventions. All too often approaches are conceived as a ‘one size fits all’ and fail to consider the role of social relations in health and illness (Farmer et al., 2013; Goodman & Leatherman, 2010). Further, health interventions such as MDA for trachoma are political. They involve global actors working with national programmes implementing interventions in historically, politically and/or socially marginalized communities. Social theories remind us that interventions can have unintended consequences, are socially constructed, bound in complex social suffering and involve power dynamics (Kleinman, 2010). I have drawn upon a political-economic approach and a focus on the influence of power and authority, as a lens to which to frame, analyse and interpret my research.

Political-economy theory

A political-economy analysis approach, focused on livelihoods, aims to understand political, economic, social, and cultural influences on livelihoods and how they affect power and vulnerability, or powerlessness. The approach encompasses the historical, and geographical context explaining why power and vulnerability change over time (Collinson, 2003). A political-economy perspective attempts to unravel the complex web of factors contributing toward inequities. Further to this, Ferguson (2006) points out the importance of recognizing that inequities are not only attributed to political-economy but also effects of power.

Whilst ‘culture’ is complex and often poorly defined concept (Baldwin et al., 2006; Jahoda, 2012; Mironenko & Sorokin, 2018), a recent and more clear definition of culture is “a multidimensional phenomenon that encompasses processes, products and results of human activity, material and spiritual, transmitted from generation to generation in a non-biological way” (Mironenko & Sorokin, 2018, p. 8). Alongside this, external and internal realities have been used to define how culture manifests itself. External realities are in the form of artefacts, localities and forms of social organization and institutions. Internal is the notion of culture as an inner psychic phenomenon. Thus, a focus on culture as only external, aside from distinct dress, language, and ways of living, indexes membership into unequal social groups (Jahoda, 2012; Mironenko & Sorokin, 2018). Further to this, for the Maasai, culture is negatively deployed to accuse the Maasai of being “primitive”, “backwards” or “different”. To understand the Maasai, then, a more complex understanding of culture is drawn on to acknowledge social and economic subjection in marginalized communities.

In global health, policy and practices implemented by organizations, corporations, or governments embed power and authority in their practices, often reinforcing the very inequities they intend to overcome (Biehl, 2016). Max Weber (1947 as cited in Farmer et al., 2013) describes three levels of authority - traditional, charismatic and rational-legal. Traditional authority is derived from history, customs, and traditions, that is passed by generation by for example royalty or tribal leaders. Charismatic authority is held by extraordinary leaders that they are able to hold over a society or group because of specific personal qualities. It may include political or religious leaders as well as leaders of social or moral movements. Rational-legal authority is derived from modern law and based on a belief in abiding by society's rules and in the right of leaders to act under these rules. This modern authority functions in the context of bureaucracy, having a hierarchical structure of subordination. Rational-legal authority is given to a particular position within an institution that an individual fills, rather than an individual. When an individual leaves that office or position they transfer the authority to next individual in that institution. "Bureaucracies at times function like an 'iron cage' in which rules trump common sense, creative innovation, and human decency" (Farmer et al., 2013). Understanding the dangers of such authority and power is essential to critiquing global health programmes.

A further application of power is the concept of biopower, that Foucault (1982) explains as control exerted by authority on the health and social welfare of populations. The concept goes beyond 'having' and 'using' power to that concerned with structural relationships, institutions and techniques (Lukes, 2004). Foucault (1982) describes two poles of biopower: (1) regulation of biological processes at the population level and (2) the effect of power on populations on the level of individuals and their actions. This concept of two poles was evident on the African continent throughout colonial periods. In Rwanda for example, the Belgians branded the Tutsi tribe as being more superior to the majority tribe, Hutus. This favouritism later fuelled the 1994 Rwanda genocide (Mamdani, 2020).

In much of Africa, there is an awareness of national governments' inability to manage the countries macroeconomics and the needs of the people at the local level. In addition, there are transnational bodies including financial institutions, development agencies, mission groups and NGOs, that are "shadow governing" African nations. It is important to explore these powerful transnational institutions which according to Ferguson (2006) often ineffectively control many aspects of African economy and society. There is a need for “re-moralization” of political discourse and how best to serve the public good at national level. While civil society organizations are an attempt to be the middle ground and bring a balance of state and the communities, they are still “top-down” and frequently foreign-based organizations. NGOs in a sense take over the powers of the state and leaves the question of how non-governmental they are. In many cases NGO’s are a means of development to manoeuvre difficult national governments (Ferguson, 2006). The downside, the NGOs are acting as ‘individuals’ and not integrated into the national institutions.

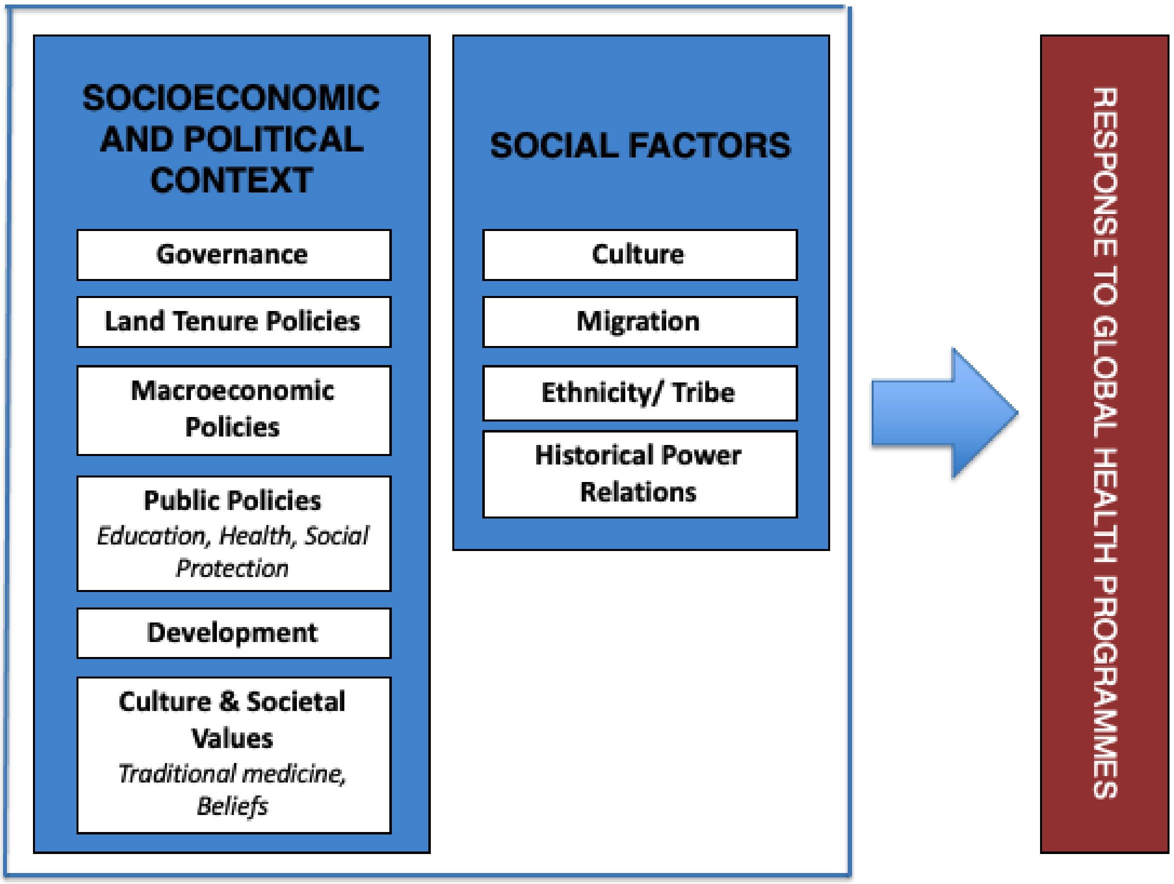
The political economy of health framework extends political economy theory to incorporate the structural and social production or determinants of health and how those may affect health related decision-making. The social elements incorporated in political economy of health offer a critical historical and interdisciplinary perspective which examines the political, economic, and social context within which health and illness are defined, treated, and managed.

Application of political-economy theory to research with the Maasai

The political economy of health framework extends analysis at the macro level of the impacts of external structures and environment on health-related behaviours and decisions. In the context of Maasai in Tanzania, political economy is the complex historical relations of tribe, culture, and hegemony resulting from complex colonial and socialist transitions through to a more recent neoliberal agenda.

This broader approach of political economy of health is a useful framework to conduct research with Maasai (Figure 4). The factors in this framework are linked in a complex way ultimately influencing Maasai responses to health programmes. Considering an unequal distribution of resources, wealth, and power, the framework helps with the understanding of the realities of historically marginalized populations such as the Maasai, and health related behaviours beyond the typical focus of individuals or communities.

Figure 4. Political economy of health framework for Maasai response to health programmes



Application of this theory to the Maasai context, requires a critical understanding of their historical, political, and social context. Pre-colonial, Maasai kinship was based on a strong network of dependence; a social system which provided a valued social position. In Tanzania, colonialism and capitalism shifted this dependency among Maasai. Up through the early twentieth century, people bartered one product for another, but colonialism brought forced commodity production and hence social division of labour leading to wage labour (Hodgson, 1999). In the last 30 years, Maasai men have travelled across Tanzania to work as watchmen, *walinzi,* at private homes and businesses including in the tourism industry (Hooli, 2017). Several instances of forced relocation and isolation of Maasai during colonialism that continues today has also impacted Maasai relationships with colonial authorities and state to that of subordinate and dependent status (Benjaminsen et al., 2013; Brockington, 2004, Hodgson, 1999; Homewood, 1995; Homewood et al., 1987; Lankester & Davis, 2016; Sulle & Banka, 2017).

Since colonialism, there is a legacy of mistrust which remains today with international health programmes which have strong political, economic, and cultural ties. In developing countries, medical personnel and programmes are viewed with economic and political power, while many international health programmes view these marginalized populations as being ‘backwards’ or uncooperative or unwilling to change. Such tension and resentment make delivery of health to those most in need increasingly challenging. A person’s health status may be associated with complex social and cultural dimensions that often alienate them from biomedicine. This politics of blame on disease exists on some level among the Maasai. When trachoma education is provided, some Maasai respond with, “you are telling us we are dirty.” According to Farmer (2003), public health authorities are guilty of a social framing of disease by which suffering is attributed to culture rather than diseases of poverty. Structural drivers of disease have both increased marginalized populations risk of disease and response to health policies and programmes. This two-way resentment is self-perpetuating with a harsh judgement on the developing world’s ability to take responsibility and care for themselves. This ignites the resentment of neo-colonialism and mistrust in development among marginalized populations (Keller, 2006).

Power applied to indigenous populations in contemporary times and specifically the Maasai of Tanzania is multifaceted from relationships with government, international development organizations, and the consequences of hegemony over the past century. From the first interactions with ‘outsiders’, power has been a central theme in social relations with the Maasai from relocation from their land, restricted movement, and agricultural policies. It could be argued that historically power has shaped medicine in general in Tanzania as well as the culture of the Maasai, so has it influenced decision-making and responses to health programmes in the Maasai.

Thus, in framing this research, there was consideration of how politics and power relations have created a subaltern voice and its cultural, economic, and social effect on uptake of public health programmes, specifically MDA for trachoma. The framework considers the structural and social factors of responses and decisions to public health programmes, specifically MDA for trachoma, among the Maasai. This approach focuses on production at the societal level and less on individual agency.

This research engaged issues of development, and cultural relevancy within the context of historical power relations.

Setting

The section describes my reflections on the field work settings including the geographical location as well as key spaces that my research was conducted at including homes, health facilities and shared community spaces. Descriptions are based on observations, field notes and grey literature.

Entry to the Research Community

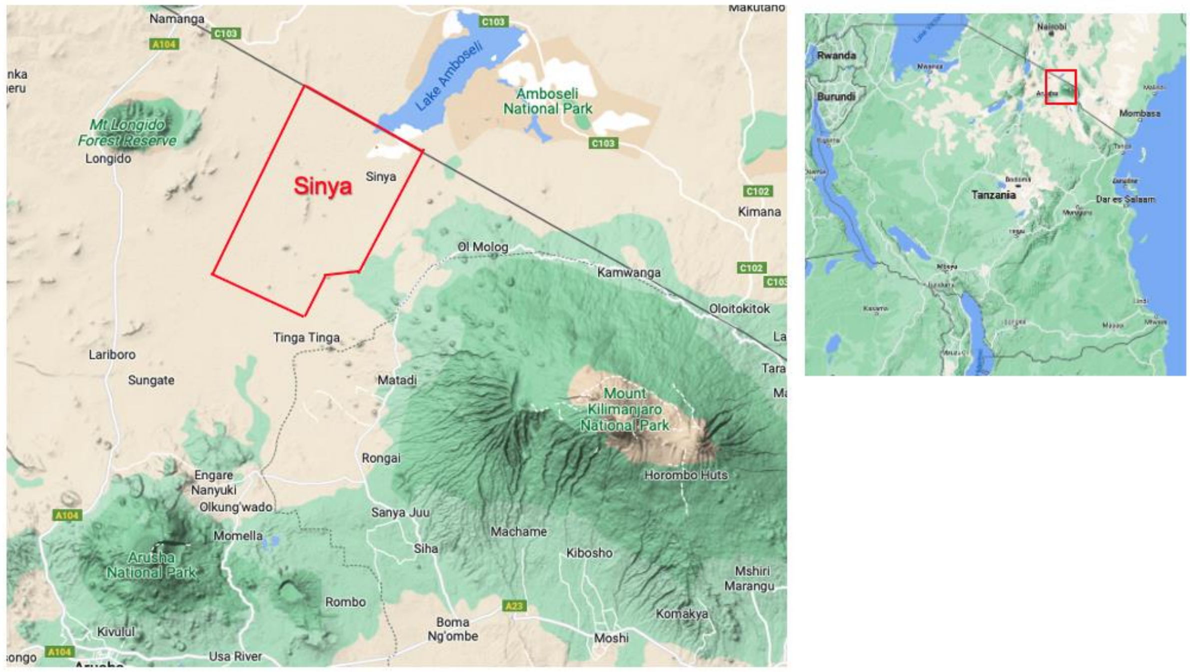
During the initial phase of preparing for field work, I met with local authorities including regional and district medical officers, eye coordinators, and village chairmen. In September 2016, I organized accommodation for myself and my research assistants in the town centre of Sinya. We conducted village meetings to introduce the research. Attendees included village executive officials (*mtendaje*), village chairmen (*mwenekiti*), sub village leaders (*vitongoji*), ten cell (*balozi*) leaders, Maasai cultural leaders (*ilaigwanak*), local health clinic staff and school representative.

Sinya

The geographical starting point of this study is the area of Sinya in Longido District, Arusha Region of Northern Tanzania (Figure 5). Sinya is located 60 km from the district capital, Longido. Longido is situated on the main road from the city of Arusha to the border town of Namanga (on the border with Kenya). Sinya is in the plains between Mt Kilimanjaro and Mt Meru, bordering Amboseli National Park in Kenya and is part of a wildlife corridor between Amboseli, Kilimanjaro and Arusha National Parks. It is within the Enduimet Wildlife Management Area (WMA)- a Tanzania government authority that manages wildlife resources and conservation outside the national park system. There is no public transport to Longido and dangerous wildlife in the vicinity make the journey by foot hazardous.

Sinya is comprised of three villages; Ildonyo, Leremeta, and Endonyoemali; covering 223 km^2 and had a total population of 4,285 in 2015. The three villages have a total of 10 sub-villages. Sinya contains two government dispensaries, a government primary boarding school, a large market and four churches (Lutheran, Catholic, and Pentecostal). The community is nearly all Maasai, most of whom have permanent homesteads in the villages. Electricity was brought to Sinya in 2016 but only serving the trading centre. In 2017 three borehole were constructed but prior to then there was only one serving all of Sinya. There are a few non-Maasai, *irmeek* staying in Sinya for the purpose of government work in the schools and dispensaries. The main source of livelihood has been traditional livestock production.

Figure 5. Map of study area



Source: https://www.google.com/maps/@-6.1143824,37.8812351,6z/data=!5m1!1e4 (accessed 24 October 2022)

This community was purposefully selected for this research for the following reasons: (1) a trachoma-hyperendemic community, (2) majority Maasai population, (3) cooperation of village leaders, and (4) reasonably accessible to my hometown, Moshi, 110 km or two-hour drive.

Enkang

Homesteads or households, *enkang* (in Maa) and *boma* (in Swahili), in Maasai communities, are male-headed households composed of their wives (a traditionally polygamous culture), children and his parents. Some large *enkang* may be comprised of multiple brothers and their wives and elders. A patriarchal society, each *enkang* has an elder man in charge. In 2015, there were 107 *enkang* in Sinya.

An *enkang* is an enclosed space surrounded by bushes and branches to protect again invasion of predator wildlife. It is comprised of several houses or huts each occupied by an individual wife and her young children with a large shared central paddock for cows, and smaller separate paddocks for smaller livestock (goats and sheep), calves and sick livestock. The population of *enkang* vary but with a changing political economy the number of homes within an *enkang* is decreasing. In 1998 an *enkang* in Tanzania comprised of four huts compared with seven to nine in the 1960's (Coast, 2001). The women build their own house, traditionally made from wood and a mix of mud and cow dung with a thatched grass roof. Today some Maasai are using tin roofs and brick walls although this is not common in Sinya. The *enkang* is divided into the right side, established by the first wife, and the left side, established by the second wife. Each subsequent wife builds their house on alternating sides. The design of the houses incorporates separate beds made of animal skin for men, and women with their small children; a space for small livestock; and a hearth. While an *enkang* serves a functional role for cooperative decision-making over pastoralist activities (Coast, 2001), it carries strong cultural meaning. Specific spaces within the enkang are used for traditional events such as rites of passage, burials, birthing, healing, blessings, and family meetings (Ayubu et al., 2019).

Figure 6. Landscape of Sinya with an *enkang* in the background

Interviews were carried out in participants' *enkang*, typically under a tree. *Enkang* are spread apart and the distance between two neighbouring *enkang* can be up to 500m apart (Figure 6).

> *We drove up to the enkang which had several entrances, but Jeremiah knew which entrance we were to use. We walked through the entrance and only a few meters inside when we stopped to wait to be seen and welcomed. Young women greeted us, bowing their heads to the senior men accompanying me who then touched the top of their heads. The women then said 'takwenya' to me (greeting to women) and I responded 'iko'. We walked to some men gathered under a tree, anticipating our arrival, where we were offered short wooden stools or a log to sit on and then we 'shared the news'. Sharing the news is where the head of the household or man in charge starts by sharing what is happening in their lives including how the cattle are, the children and grazing. And then we were given an opportunity to share our news about ourselves and the research we were there for.* [field notes]

Health Facilities

Sinya has two government dispensaries, primary health facilities- in Ildonyo and Endonyoemali villages (Figure 7). Each was staffed by one clinical officer and one nurse. Research in a few health facilities frequented by the Maasai expanded to other areas outside of Sinya. These included NGO-based health centres in Longido and Ngorongoro Districts and Kilimanjaro Christian Medical Centre (KCMC), a referral hospital serving northern Tanzania based in Kilimanjaro Region.

Figure 7. Photos of health facilities in Sinya

Community

Part of this ethnographic research included time spent in community spaces to attend to my own needs of living in Sinya (ie. buying food and collecting water) but also to engage in the community's everyday lived experiences. I needed to fetch water for my own needs from the community borehole, situated in the town centre.

The borehole is operated by a village appointed person and runs off a diesel generator during designated times of the day. I would drive to the borehole with three to four 20-litre jerry cans that either of my research assistants would fill with water and load into the Land Rover. I would often encounter many women who would travel by foot and with donkeys to collect water for their homes. Men passed by with cattle. If the borehole was busy or not functioning, I would collect water from the primary school which had piped water from a large water tank.

The weekly market day was on Tuesdays. Vendors would come from outside Sinya to sell produce, grains, housewares, shoes, and material for clothing. It was also a place for buying and selling cattle as well as purchasing fresh meat. Apart from a place to purchase goods, most only available on market day, it was a place for socializing. Only men are allowed in the areas where meat is slaughtered and sold. Women would purchase large sacs of dried maze and take it to a grinding machine in the town centre to make corn flour used to cook *ugali* (stiff maize porridge). Men would purchase *mandazi (*donuts) as treats to bring home to young children. I would often arrange an interview a long distance from the town centre in the late afternoon on market days so that I can assist with driving some people back from market.

Over the course of my fieldwork in Sinya, I was honoured to have been invited to community and cultural events. There was a community meeting in October 2016 with the Regional Commissioner to discuss the community's needs and concerns including water, roads, financial support, child health, education, price of cattle and government representation. I was invited to *olng'eher*, the 'graduation' of the *ilmuran* age group, in June 2017. This celebration happens once every seven years as the culmination of warriorhood and initiation as junior elders. I attended a wedding celebration, when the bride had already been taken to the man's family and staying with the in-laws while men and young girls danced (Figure 8).

Figure 8. Photos of the context of field work in Sinya

(A) community borehole **(B)** providing transport on market day **(C)** *olng'eher* celebration (*ilmuran* graduation) **(D)** decorated home of a groom's family for a wedding celebration

Translation and interpretation

Kiswahili is the official language of Tanzania, but the Maasai tribe predominantly speak Maa, a language spoken by a few tribes of Tanzania and Kenya. As a resident of Tanzania since 2004, I had a good working knowledge of Kiswahili. I took Maa lessons in the six months prior to moving to Sinya, which included language and cultural understanding, but my communication was still limited, thus the support of a Maa-speaking research assistant was essential to carry out this research.

Two Maasai research assistants were recruited to assist with access to communities, interpret and facilitate interviews. Both research assistants were not from Sinya but were living in Longido town, the capital of Longido District.

I advertised the research assistant post in July 2016, looking for applicants with the following qualifications:

- Experience with qualitative research methodologies
- Proficiency in spoken and written English, Kiswahili, and Maa
- Experience with transcription of digital recordings
- Experience with written and verbal translation from Maa and Kiswahili to English
- Experience in community social development/working with rural communities is an advantage
- Experience that demonstrates excellent organization skills and ability to complete tasks and assignments on time and at a high-level of quality
- Excellent command of Microsoft Office packages

Six applicants applied, 4 men and 2 women ranging in age from 26-34 years. I interviewed all applicants along with a colleague at KCMC, a female, Maasai ophthalmologist. In addition to the interview, applicants were given practical tasks that included translating text from English to Maa and Maa to English, answering some questions on ethics and field work scenarios and observed computer skills. My colleague and I discussed pros and cons of working in the field with each gender. We felt it best to have a male research assistant to allow for more smoother relations with the male dominated leadership in Maasai communities. Yet, I was nervous about how I would be perceived and treated as a female and specifically around not having my voice always heard as the lead researcher. This was where my female Maasai colleague's opinions of the candidates were invaluable. I looked to her as an insider to help me decide who is best suited to accompany me in the field. As a result of her consultation and based on his communication skills, experience, practical skills and our 'gut feeling', I hired Jeremiah in August 2016. Jeremiah assisted with initial entry into the community, continued supporting me to the end of the field work and with ongoing analysis and interpretation of findings. From our initial meetings with leaders Jeremiah was well respected, welcomed and was instrumental is maintaining a very positive relationship with the community and leaders.

The second Maasai research assistant, Joseph, was hired when we were preparing for household interviews and more intense observations. We met Joseph when he had come to Sinya collecting data for an environmental research project. He had already been introduced to community leaders and established a rapport with the community. As the research unfolded, his previous research in Sinya proved helpful in our relations with participants and his knowledge and advice of working there. Initially Joseph’s main role was for simultaneous translations of interviews which was effective, efficient, and less disruptive. Furthermore, having an additional perspective to interpret our experiences and data from someone else who knew the people, culture, and the research was invaluable.

Additionally, my research had day-to-day support from two key community members whose relationship with myself, Jeremiah, and Joseph grew organically. Samson was a respected community member who over time become a local leader and later a ranger at the WMA. Daudi, was a local leader, who lived next to Sinya Primary School since his wife was a teacher. He was on the boards for the school and the dispensary and invited to key village meetings. Either Samson or Daudi accompanied my research assistants and myself on all visits to people and places within Sinya. We would plan together for people or households we wanted to visit, and they would call ahead to arrange the required logistics. They were the familiar, respected faces that introduced us at each visit and contributed to the co-creation of meaning around the data.

Data generation

I used a variety of methods for generating data in this ethnographic research (Table 4). For the purpose of describing the methodology, the more commonly used term in English and Swahili, ‘boma’, is used when talking about *enkang.* A boma is considered a household since decisions are made by the male head of the boma. A boma also physically acts as a household in that it is a fenced in enclosure of all homes of an extended family.

Table 4. Methods for data generation

Method		**Sample**	**Sample size**	**Sampling method**	**Date of data collection**
Observations		Sinya community, health care facilities, outreach health programmes	NA	NA	September 2016- December 2017
Individual Interviews		men and women over 18 years residing in Sinya	men- 13 women-15	random	October- December 2016
Household Interviews	round 1	all households in Sinya	20	random	March- July 2017
	round 2		20		August- September 2017
Oral History		women aged approximately 90+ years residing in Sinya	5	purposeful	9 November 2016
NGO Interviews		NGOs working with Maasai communities in Tanzania	12	purposeful	February 2017- March 2019
Public Engagement	Workshop	women residing in Sinya	20	purposeful	September 2017
	Photovoice				September- October 2017

Observations

Observational methods were used to provide a thick description of the social structure and local culture; allowing me to produce a more authentic account of responses to trachoma control measures among the Maasai. Through observation we can witness the aspects of daily lives that may be considered mundane or neglected information by participants in interviews or focus groups (Green & Thorogood, 2009). It allows the researcher to get a sense of the context of people's lives in the community. Observations included field observations to become better acquainted with the context of the lives of the people of Sinya. This included visits to the market, community borehole, primary school, village offices, and homes of community members. Observations included unstructured interviews with people or groups of people I came in frequent contact with during my observations. A lot of my understanding of this Maasai community came from talks with research assistants, community members and leaders over meals, walks through the town centre, and drives around the community.

I conducted observations during a round of MDA to document the interaction of MDA and the community including uptake, interactions with CDDs and community reactions. I attended and observed community sensitization prior to MDA. This included a meeting with village leaders and a training for CDDs. During these meetings, community reactions, responses and interactions were documented to provide information on community level decision-making. The actual distribution of azithromycin to the community of Sinya took place over five days in July 2017.

I also conducted observations at a variety of health care settings to take a closer look at response to other health care settings and programmes. Health facilities and programmes included the two government dispensaries in Sinya, Olmoti and Foundation for African Medicine and Education (FAME) health centres, district, and national referral hospitals, trichiasis surgery outreach, and vaccination programmes. I carried out participant observation with married women (*inkituak*) to explore how traditional medicine is incorporated into daily lives and potentially influence decisions to seek biomedical assistance.

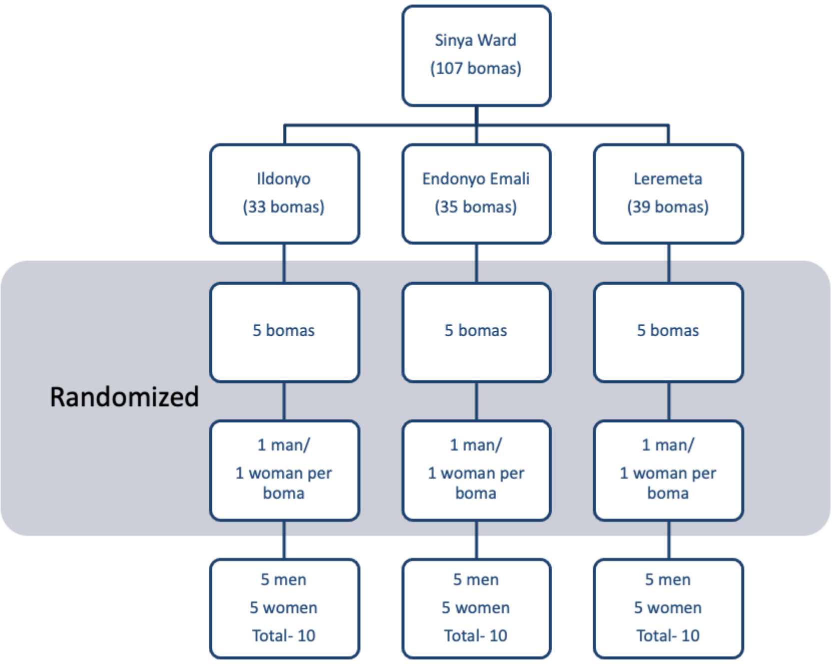
I kept in-depth fieldnotes through the field work. In some settings, it was inappropriate to take notes with pen and paper. In such situations I tried to jot points on my phone. Regardless of what was possible to capture, daily I debriefed with my research assistants, reviewing any notes taken and adding additional information and preliminary interpretations.

Individual Interviews

Semi-structured interviews were conducted with 30 adult Maasai, 15 with women and 15 with men, to obtain information on knowledge, experience, and understanding of the nature of trachoma including pathology, progression of disease, risk factors, prevention, treatment and blindness. These interviews also informed additional topics to be explored through household in-depth interviews. It was expected that in this traditional, isolated, Maasai community with little variation in lifestyles, 30 participants representing all three villages and different bomas would be a representative sample of the larger community.

We used a random sample distributed between the three villages of Sinya based on village census data (Figure 9). Census data of bomas and residents of each boma were obtained from village and sub village leaders. Five bomas from each village were separately randomly selected using Research Randomizer (https://www.randomizer.org). One set of randomized numbers was done for each of the three village with five numbers per set based on the number of bomas per village as per census data. We visited each boma and together with the male head of the boma documented a list of all people ages 18-50 residing at the boma. Using the census data, one woman and one man aged 18-50 years were randomly selected to be interviewed from each of the 15 bomas. If the first randomly selected person was not available, the next person in the randomization list was approached to participate. Since we had conducted the census at each boma, most selected participants were familiar with the researchers and a rapport was established.

Figure 9. In-depth interview sampling



Semi-structured interviews were conducted from October to December 2016 with participants in Maa by the Maa speaking research assistants in a conversation-like manner. Interviews were conducted in a private setting, typically under a tree, at the participants home with only the participant, interviewer and myself present. The interview guide (Appendix 3) consisted of socio-demographic information, and open-ended questions on experiences, knowledge and understanding of the nature of trachoma. Interviews were audio recorded and later transcribed and translated from Maa to English.

Participants were asked about local treatments used for trachoma. A list of common plants in Maa was compiled. Along with my Maasai research assistants and a village leader, we identified and photographed the plants. The list of Maa plant names together with photographs were used by a botanist from the Tanzania Ministry of Agriculture, Livestock and Fisheries to identify the botanical names.

Household interviews

In-depth household interviews provided me with accounts, or narratives of experiences of development and community health programmes, with an emphasis on MDA for trachoma. Interviews provide more in-depth insights on knowledge, beliefs, and interpretations of a phenomenon. Using an unstructured approach gives the interviewees some freedom for their views and interpretation of the matter at hand.

I conducted a total of 40 in-depth household interviews within Sinya. Twenty bomas were included and two rounds of interviews were done per boma. The first round of interviews, conducted from March to July 2017, explored experiences and responses to other community health programmes and general development programmes, including vaccination programmes and any other government or NGO health promotion programmes that have come to the community (including SAFE). It covered inquiry about non-public health related programmes such as WMA activities, community-based tourism from two tourist camps located in Sinya, and other programmes that arose in conversations. The second round of interviews were conducted one-month post-MDA from August to September 2017. These interviews provided information on experiences of MDA, how prevention of trachoma is prioritized, perceptions of and treatment of trachoma including practices of biomedicine and traditional medicine and how migration in and out of the community effects participation in MDA.

A random sample of 20 bomas was selected from the list of 107 bomas already obtained from the village executive offices. Random sampling of bomas was used to allow for transparency in the selection process within the community. I aimed to reduce perceptions of favouritism in a society in which decision-making is based on fairness. There are 10 sub villages across the three villages of Sinya. The internet-based sample builder (https://www.randomizer.org) was used to randomly select two bomas from each sub-village, giving a total of 20 bomas. If the first randomly selected boma was not available, the next boma in the randomization list was approached to participate.

The interview guides (Appendix 3) consisted of open-ended questions on their experiences and perceptions of health and non-health related programmes in the community. Interviews were conducted at the bomas with both men and women present. As our field team had been living among the community for six months at that time, most residents of the selected bomas were already familiar with myself and my field team and rapport had been established. Household interviews were conducted in Maa by a Maasai research assistant in a conversation-like manner, with myself present for all interviews with another Maa speaking research assistant for simultaneous translation. The discussions were audio recorded and later transcribed and translated from Maa to English.

Oral history

Group oral histories or witness seminars involved a group of participants that have been involved in a set of historical events. Together participants discuss the events and the interactions between the group often allows more information to emerge by individuals prompting with events and emotions (Durand & Chantler, 2014). Documented historical accounts of medicine in the Maasai are limited. Therefore, although the reliability of oral histories may be limited and the potential for recall bias exists, it gives an account of the social history of medicine as seen by Maasai today.

A group oral history was conducted with five Maasai women elders to learn how biomedicine may have changed over time and investigate links any changes may have to political, social, cultural, and economic realities. The small group helped to promote discussions within the group around historical events. Their stories helped in elucidating what has and is happening with biomedicine in Maasai culture. I explored significant events such as colonization, nationalization, missionization, epidemics, famines, and the introduction of new diseases over time.

Purposive sampling technique was used initially followed by a snowball sampling to assure inclusion of women estimated to be older than ninety years to allow for a richer history of medicine among Maasai.

The discussion was guided by a topic guide (Appendix 3) consisting of significant historical time points and the impact on health and medicine in the Maasai context. The venue for the discussion was under a tree near the market on a non-market day. The discussion was conducted in Maa by a Maasai research assistant, in a conversation-like manner, with myself present with another Maa speaking research assistant for simultaneous translation. The session was audio recorded and later transcribed and translated from Maa to English.

Local leaders and community members identified those they believed to be over 90 years of age based on events they were around for, although none of the women knew their age nor the year they were born. All five women did not receive any education. Four women were raised in Longido district and one in the bordering district of Siha yet all five married men in Sinya and have spent their entire adult lives in Sinya.

NGO interviews

To explore the political, economic, and cultural issues facing the Maasai community, in-depth interviews were conducted with NGOs that work with Maasai communities. The aim of the interviews was to (1) explore the current political issues facing the Maasai on a larger scale and their response to the issues, (2) compare experiences and challenges of various programmes conducted in Maasai communities and (3) understanding public health assistance for the Maasai and their experiences. Purposive sampling technique was used initially followed by a snowball sampling technique.

Interviews were conducted with five organizations with diverse areas of focus. Table 5 summarizes the interviews. The interview guide (Appendix 3) consisted of open-ended questions on their experiences and perceptions of health and non-health related programmes in the community. Interviews were conducted in English and detailed notes were taken. Only one agreed to be audio recorded. Interviews were conducted at the organizations office except one was conducted at a café in Arusha.

Table 5. NGO interviews

ID	Interview date	Organization’s area of focus	Position
101	09 February 2017	land use, environmental	Director
102	23 February 2017	nutrition	Nutrition Project Officer
103	03 March 2017	health services	Programme Coordinator
104	07 March 2017	education, women’s rights, land rights	Programme Manager
105	13 March 2017	female genital mutilation	Programme Coordinator

Public Engagement

Participatory workshop

A public engagement participatory workshop was carried out in September 2017 with women in Sinya. The aim of the workshop was to deliver accurate and contextually appropriate information on trachoma. Women were trained as trachoma control ambassadors. In this role as ambassadors, it was hoped that women would share their knowledge from the workshop with other women in their village and facilitate discussions on control measures within their socio-cultural context.

Together with Maasai research assistants, I designed the curriculum of the participatory workshop using the local understandings of the disease as a foundation gained from the analysis of individual interviews. The workshop was approximately 3½ hours and covered basic information on causes and pathology, transmission, signs and symptoms, treatment, and prevention.

The participants were 20 Maasai women coming from the three villages of Sinya: Il Donyo, Leremeta, and Endonyoemali. The three village chairmen selected two women in each sub-village (total of 10 sub-villages) to participate in the workshop and contacted them directly. The workshop was conducted at the Il Donyo village office. Women were given transport allowance and all who were invited attended the workshop. The workshop was delivered in Maa by two Maasai research assistants, supported by myself, all whom had established a rapport with leaders and community members during the course of the fieldwork pre-empting this public engagement workshop.

The following participatory methods were used in the workshop.

Giant fly models: Giant stuffed, *M. sorbens,* were used to show transmission of chlamydia trachomatis. Baby powder, representing chlamydia trachomatis, was put around the eyes of women. It was demonstrated that when the giant fly landed on their eye it got some baby powder on its feet and then flew off and landed on another woman’s eye and left some baby powder on her eye.

Story telling: Issues around trachoma infection and treatment were conveyed through a story telling session, which used an adapted version of the story of

Kokwana from the book “a Village Struggles for Eye Health” (Sutter et al., 1989) translated into Maa.

Video demonstration: a short video, “Leaky Tin: A Simple Solution”, was shown and simultaneously translated in Maa to show a simple and effective way to wash faces and hands using minimal amounts of water. This demonstrates the use of a container with a hole poked into the bottom. When filled with water hand and face washing can be done with the water slowly trickling down. The hole can be plugged with a thorn when not in use. Since the video was of Maasai from Kenya it was thought to have more of an impact with members of their own community addressing trachoma prevention than seeing people outside their community on the video (Freudenthal et al., 2006).

Discussion groups: Women were asked to go back to their villages as ambassadors for trachoma control by sharing knowledge from the workshop with other women in their village and facilitating discussions on control measures within their socio-cultural context. Through small discussion groups, women planned ways of disseminating knowledge from the workshop to other women in their village.

Photovoice

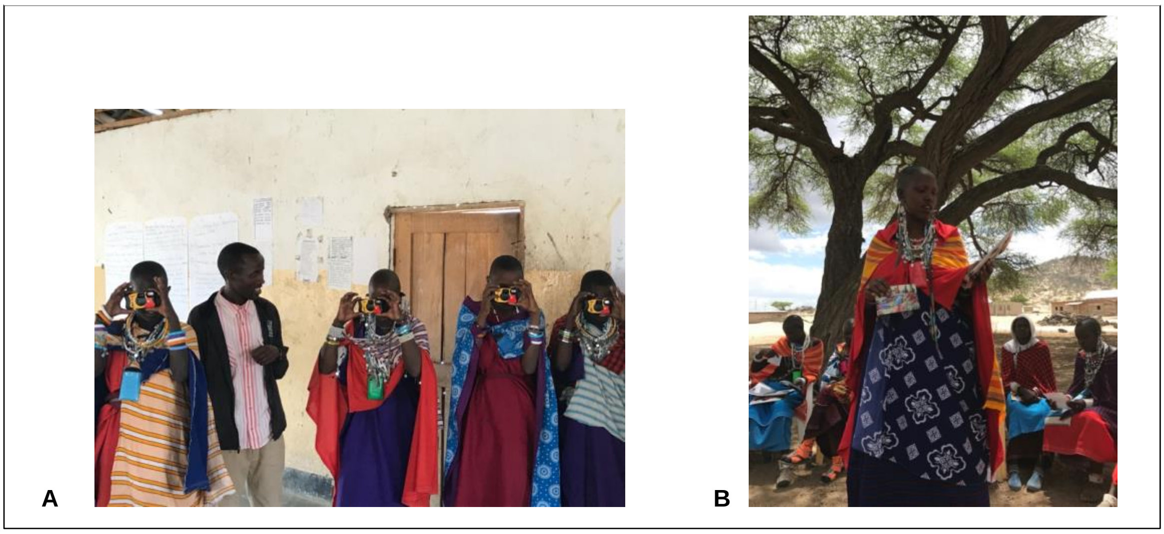
Photovoice is a method increasingly being used in research of marginalized populations to explore and address health inequities (Christensen, 2018; Mamary et al., 2007; Packard, 2008; Thomas et al., 2015) and inform policy. Photovoice is a means of generating knowledge as a needs assessment tool to provide researchers or development programmes with “the possibility of perceiving the world from the viewpoint of the people who lead lives that are different from those traditionally in control of the means for imaging the world” (Ruby, 1991). This brings forth the concerns from the community themselves rather than what the researcher or programmes think is important. Photovoice was used as a method to visually document the outcomes of the trachoma workshop conduced with women; their efforts as ambassadors, and the challenges raised around trachoma control.

At the participatory workshop conducted in September 2017, the twenty women participants were given disposable cameras. They were taught how to use the disposable cameras, what types of images they can capture, and the ethics of photography. Women were asked to photograph people, activities and things that can convey their efforts as ambassadors for trachoma control including successes and challenges. The women were encouraged to consider the confidentiality of people and places being photographed by taking metaphorical photos, aimed at using creative ways to depict a situation symbolically (Ponic & Jategaonkar, 2012).

The ethics of photography was discussed in the workshop, including respecting people’s requests not to have their picture taken. It was noted at the workshop to take metaphorical photos; photos did not need to include people or show their faces in order to display their efforts as ambassadors or the successes and challenges around trachoma control.

A week after the workshop, the research assistants and I visited each woman to make sure they were comfortable using the cameras. Women were asked to return the cameras to the research team two weeks later, on market day. All 20 cameras were returned. The cameras were sent to the United Kingdom for film development.

Figure 10. Photos of public engagement



(A) Participants learning to use cameras at the participatory workshop **(B)** Participant sharing a photo based on SHOWeD

Five weeks post-workshop, we held a follow up meeting with the women. Each woman received their set of photographs to keep. The women were asked to select two photos to discuss with the group- ideally one showing a success and one a challenge in their efforts as ambassadors for trachoma control. In a group discussion each woman individually shared their photos with the group. Woman described their two photos and all women engaged in discussions related to the photos based on SHOWeD (C. C. Wang, 1999): What do you **S**ee here?, What is really **H**appening here?, How does this relate to **O**ur lives?, **W**hy does this situation concern of strength **e**xist?, What can we **D**o about it?

Data management and analysis

Data management

With permission from participants, interviews were audio-recorded. All audio recordings were directly translated and transcribed into English for analysis by a Maasai research assistant. I went through the transcriptions with my research assistant in order to combine quality control with an additional opportunity to learn the meanings of central terms and phrases of the local language. Some transcripts were corrected to ensure more understandable English while assuring meaning was not changed. Detailed field notes of observations and interactions were mainly recorded in a hard copy notebook although in some instances in my phone. All field notes were transcribed into Microsoft Word and stored on my laptop.

Individual projects were set up in using QSR- Nvivo 11 software (QSR International, Australia) and English transcripts and field notes relevant to that analysis were included in the project. The internal memo function was used for ongoing reflections and interpretations. All data including transcripts, audio-recordings and NVIVO projects were maintained on a secure, password protected laptop and backed up regularly. To assure confidentiality, names and identifiers were removed from transcripts. Unique participant codes were used for audio recordings and transcripts. Hard copies of field notes, informed consent forms and a link-log which links the names of the participants on the informed consent forms and their study codes were maintained in a locked cabinet of my office to maintain participant confidentiality.

Analysis

Analysis of individual and household interviews aimed to identify shared ideas and experiences of trachoma, biomedicine and specifically MDA for trachoma. Drawing from my observations I aimed to understand how biomedicine and particularly MDA for trachoma is situated in the daily lives of the people of Sinya. Observations at different health facilities and one round of household interviews provided insight into provision of health care and how MDA is situated in health seeking behaviour among the Maasai. Through analysis of oral histories and interviews with NGO's the aim was to uncover the web of historical and current political influences on Maasai culture and society and its impact on responses to health programmes. Based on these steps, and drawing from other sources of data, the core of the analysis revolved around creating links with the political economy of the Maasai and low uptake of MDA for trachoma.

Throughout the entire data collection process, I continuously reviewed my findings against the original assumptions and objectives of my research. This on-going process included constant notetaking, reviewing notes, and experiences, and considering and documenting emerging themes. This iterative process, informed subsequent data collection with new lines of inquiry by refining interview guides, reconsidering the order of data collection, and informing some observations.

Initial interpretation included data immersion with repeated review of transcripts prior to coding. Using a thematic content approach, data were first coded by myself and verified by a supervisor. Impressions and interpretation of the themes were discussed with the Maa-speaking research assistants. Narrative text was applied around the constructs and direct quotes presented in the papers are used to show dominant views of participants.

Ethical Considerations

Ethical approval was granted by the Ethics Committee of the London School of Hygiene and Tropical Medicine in UK and National Institute for Medical Research in Tanzania (NIMR). Additional permissions were obtained from Tanzania Commission for Science and Technology (COSTECH), Arusha regional office and Longido district office (appendix 1).

I provided training to the research assistants on research ethics including informed consent, privacy, confidentiality, and data management. In addition, we covered the ethics of working in a community including community engagement, building rapport and trust. As a coordinator for the research ethics module at Kilimanjaro Christian Medical University College (KCMUCo), I had presentations and materials to use and was well suited to guide them through it. In addition to trainings, we had ongoing discussions on the ethical challenges of field work and our positions as researchers in the community.

One of the purposes of informed consent is to assure autonomy in the research process. In a community with low education, low literacy, and different views on negotiation, it was most appropriate to read aloud informed consents in a discussion like manner. Additionally due to the anticipatory nature of informed consent, in ethnographic research it changes the nature of social relations between the researcher and the participants from exploratory, indeterminate and unpredictable to a ‘point of production’ from the researcher (Parker, 2007). Despite these challenges, research regulations were respected and abided to. Village leaders and the community were sensitized on the research and the purpose of informed consent documentation. An additional on-going confirmation of consent was confirmed by continued support and cooperation in the community.

Independent translators translated informed consent forms and information sheets from English into Kiswahili and Maa. Informed consent was obtained from study participants in line with international research practices (ICH GCP). Consenting in Sinya was done in Maa while NGO interviews were done in English. Individual informed consent was obtained for individual interviews, and oral history. Informed consent for household interviews were obtained from the male head of the boma. A witness was present for illiterate participants. Permission to digitally record interviews was obtained from individuals and for household interviews from the male head of the boma, all of whom gave permission. For NGO interviews, despite reassurance of confidentiality, all except one NGO did not consent to be audio recorded. Detailed notes of those interviews were taken.

Collecting data through observations does not allow for individual informed consent. Although it has been argued that observation should not be done of individuals who had not given their consent, it is a method that will advance knowledge and explanation that cannot be well understood utilizing other methods. Community consent for my participation in the daily lives of the people of Sinya and hence observations was granted at an initial meeting with Sinya leaders in September 2016.

It was advised by research assistants and village leaders not to obtain informed consent for the photovoice. The primary aim of the workshop and photovoice was for public engagement rather than research. It was suggested that by requesting consent to take photographs would raise suspicion and sever the community's trust in myself. Despite not consenting, we obtained layers of permissions including informing village leaders in a meeting of the workshop including use of cameras for selected women. I also gave village leaders the responsibility to identify women to participant. The day of and the following day of the workshop, the two Maasai research assistants, one village leader and myself visited the homes of each participant to meet their husband or the male elder of the boma to seek permission for woman to use cameras to document their experience as ambassadors for trachoma control. All agreed for them to use cameras.

Compensation of research participants was minimized to a fair token in exchange for their time and any expenses incurred. This was to minimize any sense of coercion and reporting bias. I provided individual interview and oral history participants with sugar and participants of household interviews with laundry soap. For any activities that required transportation from their home I either collected them at their homes myself or reimbursed for transport (ie. workshop).

Findings from this research were disseminated to the local communities, including village leaders, respected elders, women, and men in January 2018. Results have been shared with the ethical committees, Tanzania NTD Control Programme, RTI International and published in peer reviewed journals. Findings were presented at international conferences and via other media (ie. blogs) (Appendix 4).

Reflections on Positionality

Situating myself in the research

In beginning my reflection on my multiple positionalities in this field work, I became increasingly interested in how I as a white, American, woman, privileged with higher education shaped how I was seen and how I perceived and interpreted my experiences during and after fieldwork.

Prior to setting out to do this doctoral fieldwork in 2016, I had years of experience working and living in Tanzania. I moved to Tanzania in 2004 to begin what turned out to be long-standing research collaboration with KCMC in Moshi on the base of Mt Kilimanjaro. I initially worked in HIV prevention research with high-risk communities in the Kilimanjaro region. In 2011, I shifted to working on trachoma research conducted in predominantly Maasai communities. The trachoma research team were involved in a cohort study of children living in a trachoma endemic community to understand scarring progression. Since we were regularly visiting the community, we had agreed to assist the Tanzania NTD Control Programme with distribution of azithromycin as part of yearly MDA to the villages we were working in. The field team would return to the office sharing experiences of refusals of MDA that they were puzzled by since the community was agreeable and welcomed our research. For me it highlighted how internationally led biomedical programmes delivered at scale, disregard local context and problematize the communities (Lock & Nguyen, 2018).

Along with seeing the "big five"[4] most visitors to Tanzania are keen to see the Maasai, women adorned in beads and men posing with spears. I too was fascinated with the Maasai when I first came to Tanzania but more in understanding the historical land conflicts which brought me back home to similar socio-historical issues with Native Americans.

I married a Tanzanian from the Chagga tribe[5] in 2007 and we have two children growing up on the slopes of Kilimanjaro where we permanently reside. In Tanzanian society as soon as you have a child, your identify shifts away from the self to being seen as a mother, *"Mama Aiden"* [my first born], and no longer am I called by my first name. Furthermore, gender preferences are evident with praises of blessing the family with a son. They would say *"you have a boy now, so you don't need to worry."* If he was a girl, I'd have the pressure to continue to have children until I could bless

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[4] The big five is a term used to refer to the five African animals historically considered the most difficult and dangerous to hunt. This includes lion, rhinoceros, Cape buffalo, leopard, and elephant.
[5] The Chagga tribe are one of 120 tribes in Tanzania from the Kilimanjaro region. They are considered one of the more wealthy, well-educated, and industrious tribes of Tanzania.

the extended family with a boy. These shifts in identity and heightened awareness of gender differences helped ease the transition to a community in which these differences were further evident.

Over time I became self-conscious being married to a Chagga. Normally, I use that to my advantage in day-to-day life in Tanzania to show people I am with them, this is my home. Yet Maasai would call non-Maasai Tanzanians, ‘Swahili people’, a distinction between them and all other Tanzanian tribes. The meaning and emotion behind that distinction changed according to different interactions and contexts. Eventually I tucked away that identity to avoid being misinterpreted. On the contrary, being American seemed to be a ‘bonus’ in my research community, one of the more highly regarded *mzungu* nationalities. Maasai would tell me Americans were kind and did good things for the community. The ‘good’ often related to providing educational opportunities to their people. They seemed to have their own stereotypes seemingly based on internationally funded programmes. This distinction about people doing things ‘for’ or ‘with’ as opposed to doing things ‘to’ communities became more bound in my attempt at understanding the historical, social, and political context of the Maasai and their responses to development and health programmes.

I may have been seen as someone whom they have different expectations of, a clinician or a representative of the government or an NGO. Being an educated white person working on trachoma, it was assumed I was ‘qualified’ to provide medical advice and treatment. To manage expectations, my research assistants and I explained my position as a non-clinician researcher explicitly from the outset. Yet, conducting research on trachoma, I felt ethically responsible to assist any community members with any eye conditions. Although not qualified to examine eyes, when I identified potential cases of trichiasis I kept a list of cases and requested assistance from the implementing partner for trichiasis surgery in Arusha Region. Some community members approached me with general eye complaints of which most I advised to seek care from the local dispensary. The doctor in-charge was able to provide basic treatment or refer. There was one case with acute pain and irritation, and I drove him to KCMC, the large referral hospital, for treatment.

Despite efforts to avoid being seen as a clinician, I was called on to help on non-eye related medical issues. In a few cases, I was able to facilitate contact with hospitals or NGOs to assist and provided financial assistance to facilitate those follow-ups. Although not providing any clinical care confused some, most were extremely appreciative of the links and referrals I facilitated.

Many people working on eye related programmes came through Sinya at varying times. Some from NGOs doing trichiasis and cataract surgery. The government had conducted MDA and national surveys for trachoma and trichiasis. My colleagues at KCMC had been to Sinya to examine children at the primary boarding school who were enrolled in the cohort study. There were also other studies conducted where they moved from boma to boma doing eye exams. These different eye care actors were not easy to distinguish for the community although they did have varying opinions about some of the people they encountered. Initially I was seen as just another eye health person and I was categorized as working with a project or the government depending on my activities. Chapter 5 discusses in detail, how they were treated by these health related actors, influenced their response and opinions. My field team were often reminding and reemphasizing my positionality as an independent researcher, unattached to any of these actors for my doctoral work. At times, I was seen as a personal advocate for people who were not happy with their encounters with these eye care actors.

> *On Tuesday/ market day, the surgical outreach team came to the boma to collect koko and took her for TT surgery. Since it was market day, no one was home to be informed. Family came home from market to find koko with a bandaged eye. They are upset that no one was informed including koko who didn't realize they were actually doing surgery. They are asking me to inform the NGO they are upset and wish they were given proper information and informed leaders and family of the surgery. In addition, they want more information on TT, what is it, why it happens, what surgery involves and what to expect after surgery.* [field notes]

A training of international trachoma graders was conducted in Sinya in 2017. Part of the training was to examine children's eyes at a nursery school to practice grading. They came on a Tuesday, market day, which is not an ideal day for community leaders to inform the community and to accompany the visitors. Community leaders described the organizer of the training as 'pushy' and who insisted it be on a

Tuesday. In the end, parents were not informed their children were being used in this training. They asked me to explain to the organizer that the community leaders were not happy with how they approached the community. In such cases, my research assistants would voluntarily step in as my advocate or spokesperson. It was their way or protecting me as the obvious outsider but still feeling in a position of power to speak up being associated with the white researcher.

Figure 11. Photo of CDD training

During the weeks leading up to MDA and the week of MDA in July 2017, confusion on my role in all of it created uncertainty. The comings and goings of people, particularly of non-Maasai, were well noted in this very isolated community with nearly no vehicles. When the doctor in charge in Sinya was sent to Longido for training and later the district delivered azithromycin to Sinya, people started to question my role in all of this and who I was working with and why my interest in this week of MDA. The doctor in charge conducted MDA training for the CDDs and I attended as an observer (Figure 11). At the beginning of the training, my research assistant clarified our positions as independent researchers observing and we were not assessing anyone nor the training but simply there to learn. I had been told by many CDDs that in years past the CDD trainings, conducted outside of Sinya, were inadequate. Yet in this training, the doctor in charge was thorough in the topics covered and the content and at times he spoke in English. I couldn’t help but wonder if my presence led the trainer to do a quality training or were there other factors. Possibly it was attributed to the trainer; this doctor who is very good at his job and well respected in Sinya. Was he using English to make sure I understood he was delivering a quality training, or to show off to the CDDs? We would never know but my positionality effected the delivery of the CDD training.

Throughout fieldwork, I drove a white Land Rover Defender that belongs to the research project I work on at KCMC. The only vehicles in Sinya were the WMA rangers, vehicles delivering goods on market day, few safari vehicles from the two tourist camps in Sinya, and infrequent visitors for projects or government work. The Land Rover was well known and a cornerstone of my identity. At times it was used as an ambulance to bring sick people to the dispensary or to take new mothers and their babies back to their bomas after delivering at the dispensary. In the later scenario, one child was named after me for simply driving them home. The Land Rover often carried people, jerry cans of water, grains, and goats home on market day. Children would hear the engine in the distance and run out to greet me driving down the road. On a few occasions we would spot cheetah or lions while driving and report to village leaders to warn people of the wildlife. People wondered why I did not have a driver and were humoured by my all-male Maasai research team being driven by a white woman. During MDA we were driving from one village to another and encountered a group of *ilmuran* who heard and saw the Land Rover and ran very fast in the opposite direction. We stopped to ask someone why they were running and were told they thought it was a military Land Rover who periodically round up young men. Another time, cattle that were grazing in a neighbouring district were confiscated and the local government demanded a meeting on short notice with the owners of the cattle. Village leaders asked me to transport the cattle owners to the meeting in the Land Rover, an urgent opportunity to request their cattle be returned.

I am also aware that my interactions with key players in organizing and implementing MDA may have been viewed as threatening or of being critical of their work. This may be due to potentially poor organization of the distributions and fear of it being uncovered as seen in other studies of MDA for NTDs in Tanzania (Hastings, 2013; Parker & Allen, 2013). In one case, I contacted the District Eye Coordinator and District NTD Coordinator for details on the timing, methods, and contacts for MDA. The District NTD coordinator responded very positive to my request initially and provided requested details. Later that day she called to say she would happily escort me for part of the distribution and suggested a per diem amount. We had to make clear my research aims and my position as an independent researcher which would be biased if accompanied by her.

I met with the implementing partner for conducting trichiasis surgery in the district. They were very cooperative in arranging to get me contacts of their field person, timetables for surgery and background information. We accompanied them on some outreach visits and surgery. Yet later, when I noticed they were not following the schedule I had, I tried to contact them, but I received no reply to my calls or messages. Later, we would be told they were in Sinya conducting activities. There was a shift from cooperation to fear that my role was to police their activities.

Relationships shaping positionality and reflexivity

My field team was comprised of two research assistants and two village leaders- all Maasai men. It was important I employed research assistants seen as someone the community can trust. Their history and interactions in the community would influence the quality of the data collected. My initial discomfort with reliance on young male research assistants was multifold. Despite the amount of training provided on qualitative research, I was not convinced they would translate everything and what was deemed appropriate to translate was left for them to decide. Being a woman in a male-dominated traditional society, the power differential might affect the respect I was given as ‘the boss’. Gender would also affect their perspective and access to some information. I talk about my relationship with Naserian below as an attempt to overcome this. The two village leaders served the purpose of navigating logistics in Sinya- calling ahead to schedule visits, identify key people to involve in aspects of the research, provide insider information to personalities, community dynamics, and politics.

Although to some degree my concerns were legitimate, my relationship with these critical allies evolved based on trust. My research and personal intentions were perceived as genuine. Being a woman seemed to be trumped by being white and American. And probably what most won their loyalty was my ability to quickly adapt to the life in Sinya. I ate all meals with my research assistants and very often the two village leaders would join us. During meals and our drives around Sinya we would discuss the research, talk about politics, have a Q&A to further my understanding of the Maasai, share stories and laugh a lot. I came to realize the extent of their trust in me and willingness to be inclusive of me when they shared incidents of poaching, smuggling and corruption in the area. On the very few occasions, I was inappropriately asked by a community member to give money, any of these four men would navigate it smoothly on my behalf.

Naserian

I rented two rooms in a building that has four rooms- one for myself and one that acted as an office, place to eat and place to sleep for my research assistants. We had various neighbours over time in the other two rooms- a family of three, a ward leader and a ward education officer. We all shared one outhouse with no running water. It was located in the centre of Sinya where people frequented for shops, market day, charging phones, fetching water or socializing. Curious people would pass by especially in the early days of fieldwork. One woman welcomed me with one of her beaded necklaces she removed and placed around my head. She explained where her boma was and welcomed me to visit. We went to visit Naserian and turns out we had interviewed two of her family members, so we received warm welcomes back to the boma. Naserian invited us to her house where she prepared locally made tea- plant leaves and bark with fresh goat milk and sugar. Naserian was the youngest wife of an old man who passed away while she was in her 30’s. She had children and grandchildren but appeared less tied down to family obligations than the other wives. Naserian’s house was the only house in the boma that had a tin rough while the others had thatched rooves. She was a leader of the women’s microfinance group and was called upon by NGOs to visit other Maasai communities who were starting microfinance groups. We often talked about her idea of setting up a women’s boma- a boma managed by only women to bring separate income to women. Our friendship grew possibly because she was just a bit less traditional that others, had some more exposure and was comfortable to ask me questions. Naserian was my source of information about being Maasai, from a woman’s perspective. Areas of knowledge in Maasai society are very much gendered and she balanced out the knowledge sharing from my male research assistants.

Namelok

In one of my first few interviews conducted in November 2016, I came across a seven-year-old boy with vision problems named Namelok. The boy joined us and leaned up against the knee of his father who was being interviewed sitting on a stool. I was touched by the concern the father expressed about his son.

> *When I go outside of his mother’s house to stay with other men, he follows me like you see here now. And during the night when he wants to go back to his mother’s house, he asks me who will take him back because he can’t go alone. It is a big problem to the young boy like this to lose vision capacity at*

> *this age. Also is burden to us who are supposed to take care him. Like when I hear him on the other side of the boma he is crying and always I get scared because I worry that he gets [caught] in thorns. So, I will be happy when I see he is okay.* [Individual interview 03-1]

I extended support for him to be seen at the paediatric eye clinic at KCMC where he was diagnosed with a genetic degenerative eye condition that would eventually lead to full loss of vision. We discussed this with his parents, and they expressed concern for him being able to graze cattle and the burden and worry an active boy brought to the boma. I had already observed him leaving home to nursery school and he would quickly fall behind the group of running children. Once Namelok lost sight of the kids beyond the two meters he can see, he proceeded slowly to follow the sound while being cautious of not falling. I thought attending a school for the visually impaired was critical to Namelok having a more independent life. We enrolled him in a government boarding school in Longido town that has a programme of full inclusion of visually impaired children in the mainstream education system. I have continued to maintain contact and support to his family. This connection to this family early in my field work won me some support from community members. Yet I worried this would evoke assumptions of disposable wealth and sources of opportunity but rather it was the contrary. A woman asked me one day to help with her child's school fees and a community member overheard and sternly told her *"She is helping that boy from [boy's family name] boma. She can't be expected to help everyone."*

Nataana

Over lunch one afternoon, Kiserian, a respected village leader, told me about three girls that he arranged a room for them to stay at the primary school. When girls complete primary school, in Maasai society they are considered ready for marriage. The decision for them to be married off is between their father and potential husband. The fathers of the three girls were ready to arrange their marriages once they arrived at home despite the girls not being ready to marry and rather wanting to further their education. Providing shelter for the girls away from home is often the best solution to prevent early marriage arrangements from proceeding. Kiserian asked me if one of the girls, Nataana, could clean and cook for me for a small salary. I needed help with these tasks and was wanting to pay someone in Sinya to assist but was hesitant to be caught in-between a young girl and her father. I feared being seen as the reason why her father did not get the bride-price he was ready for. Despite encouragement from my field team to have her work for me, I said I would agree only if one of her parents gave permission. The next day, mama was at my room asking I provide her with opportunity to keep her from coming home too early and I was not to worry as she would talk to *Papa*. Nataana started work in my room the following day. Mama came to visit her at work every Tuesday on market day. I came to know Nataana well and she talked about her dream to be a veterinary officer in the district. Her progressive, feminist mentality was striking, and I wanted to encourage it. But I was also in a predicament of not getting too involved; that may be perceived as changing her 'Maasai-ness'. Nataana worked for me for four months when it was time to figure out her next steps or she go home. The school room was only a short-term solution and the other two girls had found opportunities to continue with their educations. So, my field team and I were invited to Nataana's family boma for a meeting. Emotions were high as it was the first time she was back to see family other than those that visited her on market day. *Papa* had arranged for sodas for everyone in the boma and then we were called into her mother's house by *Papa*. We discussed Nataana's dreams and further education. And then *Papa's* eyes got watery, and he explained his fear of what can happen if his daughter goes off to non-Maasai areas – she will not be around other Maasai to maintain traditions, speak her language, feel at home. He viewed places like Arusha has having a lot of bad influence on young girls and she may get pregnant. But in the end, he said if she wanted to continue education then he supported the idea. He sent us off with a goat as a gift. When my fieldwork finished in January 2018, Nataana went off to veterinary school 130 km from Sinya. She completed her first year in good standing but in the first semester of her second year, she got pregnant and returned to her family in Sinya. This was the exact reason *Papa* feared her leaving home. In Maasai society, a single mom rarely finds a husband.

This relationship with Nataana and her parents, forced me to step out of my feminist, American, educated body to embrace more of this beautiful culture. *Papa*'s fears for his daughter were real and he saw early marriage as a way to 'protect' his daughter, sticking to traditions and familiar connections. My fieldwork was finished by this time, but as I analysed my data I often paused, thinking of Nataana and *Papa*, before interpreting experiences from a white, American, educated, female perspective.

Reflecting on my positionality throughout fieldwork, has fulfilled the critical process of reflexivity and its effect on the data produced and its interpretation. At most times I was neither an insider nor an outsider but somewhere in-between. This sense of in-betweenness was multifaceted- white American but married to a Tanzanian, an outsider but able to live visibly comfortable among the community, working in public health but using a biosocial perspective, asked to intervene between community and health programmes- and yet dynamic, suiting different social spaces and constructing data specific to that time and place. This shifting in between inside to outside, including physically as I regularly moved in and out of the field, allowed me to constantly view and interpret with different lenses. I can only believe that this puts me in a position of contributing toward a more critical understanding of the Maasai's response to trachoma control.

Methodological Reflexivity

My presence and intentions for being in the community was known when I was conducting observations in Sinya. By seeking permission and support from community leaders, they in turn sensitized the community. This open communication between leaders and the community at large is part of Maasai culture. Although this provided me with a community level of acceptance, it may have altered how individuals behaved and responded to me.

My research assistants were more than translators; they were hired as experts on their culture and language to navigate situations and explaining nuances to me to allow for more locally appropriate and effective interviews. Simply by working in the field with me, my research assistants' awareness, and knowledge of the issues of trachoma and health in general for Maasai was naturally heightened. At times I was frustrated not to understand and sensed not everything was being translated. Yet, their sense of authority on health issues for Maasai may have allowed for more richer discussions during interviews.

Due to a history of mistrust in development and people outside their culture, I had assumed that my ability to draw on sensitive issues (such as land and human rights) may have been hindered. I came to realize that delving into such topics straight on was not appropriate nor how views of such issues are uncovered. I was advised by my Maasai research assistants that follow up on comments related to socio-political issues needed to be done carefully in part because it could lead to them questioning our intentions. I entrusted them to know when and how best to probe.

I realize that my presence during MDA, may have had some effects on the uptake of azithromycin- likely in obtaining higher coverage. As previously discussed, the selection and training of CDDs was more thorough than what was reported in previous years. This may have improved their knowledge of the drug, its side effects, and reasons for MDA thereby improving their explanations to the community during distribution. My presence during distribution may have led the CDDs to spend more time at each boma giving explanations and improved documentation in the registers. CDDs and community leaders reported there was more effort to locate community members who were not at home to improve coverage. I want to think that my ten months of residing in Sinya establishing trust, my research intentions known and a resulting heightened awareness and understanding of trachoma, may have improved people’s wiliness to take azithromycin.

My intention to collect information on the historical shift of biomedicine in the Maasai was dependent on oral histories. I was limited to only a few Maasai believed to be older than ninety years and able to recall events in their lifetime. I made the decision to use a group oral history so that the participants can trigger events and collectively recreate a history for my data. But this was limited as many did not recall or can attribute any shifts in medicine due to these historical events. The further back in history we went the fewer people who accessed formalized health care to be able to draw conclusions on effects of history on health care or perceptions of medicine among the Maasai.

Willingness to participate in interviews was lower than anticipated for NGOs working with Maasai communities. At the time of the fieldwork there were cases of land disputes for Maasai in Loliondo, rumours of evictions of Maasai and forced relocation of cattle from Ngorongoro. Yet the national political environment made such conversations challenging with fears of being critical of the government. Despite reassurance of anonymity and confidentiality, all but one NGO refused to be audio recorded. Yet this did not take away from participants sharing sensitive experiences and perspectives which still contributed richness to my data.

I conducted observations at the two health facilities in Sinya with support and reassurance of cooperation from the doctors. Transparency about my research, time to build trust and mutual respect facilitated this cooperation. Observations done at district and regional level facilities were more covert. Although not deliberately intending to disguise my role as a researcher, staff were too busy to take notice or question my presence. At Olmoti and FAME clinics, NGO based facilities, I had done more formal introductions of my research to those in-charge and sought permission to do participant observations. I was welcomed with tours and invited to talk to any staff which elicited further layers of data to my observations. Lastly, community health outreach programmes, both government and NGO, tended to be more suspicious of my presence. As I was always accompanied by at least one well-spoken research assistant and a community leader, I may have been perceived as being on the community's side. Many of these outreach programmes are funded and driven by numbers- coverage, number of visits, number of people seen, all the while losing focus on delivering thoughtful and appropriate services. My presence may have been seen as critical of them and the quality of services they provided.

Ethical reflexivity

While arguably differing in important ways, requirements, and guidelines of research practices in the social sciences is not as well defined or much attention given to compared with clinical research (Kleinman, 1999; Molyneux & Geissler, 2008; Parker, 2007). Having worked in clinical trials and having an acute awareness of good clinical practice, I used this as a basis of how to conduct myself and ultimately have respect for persons in my field work. Sensitivity to ethics was an on-going concern. Denzin (1968) specifies one consideration of observations; the method must not deliberately harm the credibility or reputation of the participants. This may require withholding sensitive information from publication and/or keeping it from authorities. Throughout this work, I have used pseudonyms for the people in the community that I talk about. The only identifiable names are for locations (ie. villages, districts) and the research assistants.

Although villages were carefully selected, rumours and misperceptions about my research or me could have potentially arisen. To help avoid this, I continuously discussed my experiences, observations, and interpretations with respected leaders in the communities not only to hear their opinions, but to maintain transparency.

The nature of this research involved exploring how potentially sensitive issues may affect Maasai responses to MDA for trachoma. Discussions and interactions elicited stories and examples of being marginalized, mistreated, or neglected. Attention to indigenous subaltern voices can also give false impressions or agenda to the participants and they may not have felt as free to provide information. From prior experience in interacting with Maasai communities, I knew that communication needed to be more thoughtful and direct questioning of their opinions on political issues would not be well received. The Maasai, a very insular society, are not easily forthcoming with sharing information with *irmeek*, non-Maasai. My field team were pivotal in navigating this on my behalf.

I encountered situations in which I observed hardship and suffering. This required me to consider my liminal position and distinguish that of which it is a part of their daily lives and that of which is more out of the ordinary. There were cases of female circumcision and early marriage of which I felt inappropriately positioned to manage. I was extremely lucky to have two village leaders assist, who unknowing to me when I met them, proactively fought against these issues in Sinya. I wondered if my association with them hindered interactions with community members who believed on the contrary, although no one ever refused participation. I was told Maasai confronted issues directly within their society and their personal matters would not be mixed with my research. After some interviews, the accompanying village leaders would use the time to discuss with the heads of the boma issues separate from the research such as truancy, and cases of female circumcision.

Sinya and its surrounding areas have a history of poaching and has drawn attention from wildlife conservationists and an increase in rangers patrolling for poachers. I did learn of incidents of poaching and unethical incidents while in the community. The tensions brought on by tourism both by the camps and tourists themselves were evident. An elder described, with anger, a tourist photographing him while he was bathing in a dam and the safari guide did not intervene. The extent of my actions in such situations was only to discuss first-hand information with the leaders I had established a positive report with.

Chapter 3: Maasai Perspectives and Experiences of Trachoma

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Surname/Family Name	Mtuy		
Thesis Title	Maasai response to mass drug administration for trachoma in a changing political economy in Tanzania		
Primary Supervisor	Dr. Shelley Lees		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

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Where was the work published?	PLOS Neglected Tropical Diseases		
When was the work published?	June 2019		
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SECTION E

Student Signature	Tara B. Mtuy
Date	13 May 2022

Supervisor Signature	Shelley Lees
Date	13 May 2022

Overview

When I first entered the research community, I aimed to engage with the community in a way that made my purpose known to them and allow people to interact directly with me in order to break down any barriers and preconceived notions. It was also critical to explore how the community understood and experienced trachoma in their everyday lives. The data analysed for this paper, served these purposes, and contributed to the following research objectives:

1- To investigate Maasai knowledge of trachoma including pathology, progression of disease, risk factors and treatment.
2- To explore how Maasai prioritize prevention of trachoma against the backdrop of social, economic and political challenges.
6- To describe decision-making around health issues, particularly eye health, among household members

In this chapter, I describe the experiences of trachoma among the Maasai. This includes their understanding of pathology, progression of disease, risk factors, treatment, and prevention. Understanding the systems of meaning around trachoma within the wider socio-cultural context of Maasai community, offers information to ground further exploration of the response to mass drug administration and more broadly the relationship with health services. This builds on the historical context of Maasai described in chapter 1.

In the paper, local understanding of trachoma and uses of traditional medicines for eye irritation are described and along with their historical, socio-political context may contribute toward the high prevalence of trachoma in Maasai communities. The findings demonstrate that whilst biomedical understanding of trachoma is poor amongst the Maasai, trachoma is an expressed health concern within the community.

Knowledge, perceptions and experiences of trachoma among Maasai in Tanzania: Implications for prevention and control

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Abstract

Background: The Alliance for the Global Elimination of Trachoma has set the target for eliminating trachoma as a public health problem by 2020. However, challenges remain, including socio-cultural issues. Districts in Northern Tanzania, predominantly inhabited by the Maasai ethnic group, remain endemic for trachoma. We explored socio-cultural factors that may impact the elimination of trachoma.

Methods/ Findings: This study was nested within a larger ethnographic study of trachoma among Maasai in Northern Tanzania. We used stratified random sampling and semi-structured interviews to examine knowledge and understanding. Interviews were conducted and recorded in Maa, by a native Maa speaking trained interviewer. Transcripts were translated into English. A framework method for a content analysis was used.

There was awareness of trachoma and basic symptoms. Yet understanding of etiology and prevention was poor. Trachoma was attributed to pollen, dust, and smoke. Water was recognized as beneficial but seen as treatment and not prevention. Traditional medicines were most often used for treating conjunctival inflammation, with the most common being a rough leaf used to scratch the inside of the eyelid until it bleeds. Knowledge of mass drug administration (MDA) was inconsistent, although many thought it helped the community, but it was perceived as only for children and the sick. Many participants reported not taking azithromycin and some had no recollection of MDA six months earlier. There was little connection between childhood infection, trichiasis and related blindness. Trichiasis was often seen as a problem of old women and treated locally by epilation.

Conclusion/ Significance: Understanding indigenous knowledge may help guide control programmes, tailor them to local contexts, address local beliefs and dispel misunderstandings. There is an essential need to understand the social, cultural and political context of the target community to deliver effective programmes. Despite limited knowledge, the community recognized trachoma as a public health problem. Results have implications for disease control programmes in other marginalized communities.

Introduction

Trachoma is the commonest infectious cause of blindness worldwide, caused by *chlamydia trachomatis* and remains a significant public health concern. This neglected tropical disease (NTD) tends to mostly impact poor and underdeveloped areas. Current estimates indicate about 182 million people live in trachoma endemic areas and is the cause of blindness or visual impairment of 1.9 million people in 42 countries (WHO, 2017).

The clinical features of trachoma are divided into those related to ‘active’ disease which characterizes episodes of infection and are most common in children under 10 years; and those associated with scarring. Early stages of trachoma are characterized by follicles and inflammation in the conjunctiva of the upper eyelid. Contraction of scar tissues causes eyelids to turn inward (entropion). Trichiasis occurs when eyelashes touch the eyeball. Eventually a number of factors including corneal trauma and secondary infection can lead to blindness (Hu et al., 2010). While prevalence of active trachoma is fairly similar across sexes; women tend to have more scarring, more trichiasis and subsequently more loss of vision likely due to greater life-time exposure to infection from young children (Taylor et al., 2014). There is a dearth of information related to trachoma among marginalized ethnic groups including the Maasai of Tanzania.

The Maasai are semi-nomadic pastoralists predominantly spanning the central border of Tanzania and Kenya. The traditional lifestyle of the Maasai is changing with reduced access to land for grazing and changes in weather leading to a more semi-nomadic or even agricultural based lifestyle. Maasai are facing challenges that may negatively impact health including increased drought, poor access to major roads and education, substandard health services and on-going land disputes (Goldman & Riosmena, 2013; Sikar & Hodgson, 2006; Sorensen & Vinding, 2016). Food insecurity was found to be severe and vaccination coverage the lowest among the Maasai when compared to five other tribes in Northern Tanzania (Lawson et al., 2014). For trachoma, baseline surveys in 2006, reported trachomatous inflammation-follicular (TF) prevalence of 57.6% in children aged 1-9 years (Masesa et al., 2007). More recent studies showed the prevalence of conjunctival follicles, papillary inflammation and scarring among a cohort of children aged 6-10 years in a predominantly Maasai community in northern Tanzania, was 33.6%, 31.6% and 28.5%, respectively (Ramadhani et al., 2017).

Risk factors for trachoma span environmental, socio-economic and behavioural factors. Risk factors for trachoma include limited access and use of water (Bailey et al., 1991); limited face washing (Schemann et al., 2002; West et al., 1995; West et al., 1991); poor sanitation (Emerson et al., 2004; Schemann et al., 2003); and crowding (Bailey et al., 1989). However, in marginalized communities such as the Maasai, communal living and poor economic, social and environmental conditions are a challenge to maintaining proper hygiene (McDonald et al., 2010). Control of trachoma is based on the SAFE Strategy, established by WHO in 1997 under the Alliance for the Global Elimination of Trachoma by 2020 (GET 2020). SAFE includes four public health interventions: Surgery for trachomatous trichiasis; Antibiotic treatment to eliminate the infection; Facial cleanliness promoting hygiene to reduce transmission; and Environmental change which includes management of human and animal feces, cleanliness to reduce flies, crowding and access to water (WHO, 2012).

SAFE has not been fully implemented in this context. Mass drug administration of azithromycin has been conducted in all high trachoma endemic Maasai districts in Tanzania in accordance with the National NTD Control Programme and WHO, although impact surveys are still ongoing. Surgical camps to reduce the backlog of trichiasis cases have been ongoing in Maasai districts with the support of several international implementing partners and the National NTD Control Programme. However, programmes addressing facial cleanliness and environmental change components of SAFE are limited particularly in Maasai communities.

Trachoma control interventions require community understanding of trachoma and behaviour change. Furthermore, it is important to consider the community's perspective to account for socio-cultural factors that may guide the design of effective control interventions and increase uptake of the SAFE strategy. The aim of this study was to explore the knowledge and understanding of the nature of trachoma including pathology, progression of disease, risk factors, prevention and treatment among a trachoma endemic Maasai community. These findings can help guide more effective public health approaches to implementation of the SAFE strategy in Maasai communities.

Methods

Setting/ Sampling

This study was conducted in Sinya Ward in Longido District, of Northern Tanzania. Sinya is located in the plains between Mt Kilimanjaro and Mt Meru. Sinya is comprised of three villages, Il Donyo, Leremeta, and Endonyoemali; with a total population of 4285. The community is nearly all Maasai most of whom have permanent bomas, in the village. A boma is a Maasai homestead headed by one male, consisting of houses for each of his wives and their children. A boma can range in size of 10- 70 people but on average is approximately 40 people. There are a few non-Maasai, *Ormeek*, staying in Sinya for the purpose of government work in the schools and dispensaries and for trade. The main source of livelihood has been traditional livestock production in this purely pastoralist community.

Of 107 bomas in Sinya, five bomas were randomly selected in each of the three villages to achieve a sample size of 30 participants. For the purpose of this study a boma was considered a household since decisions are made by the male head of the boma. A boma also physically acts as a household in that it is a fenced enclosure of all homes or huts of the wives which are systematically placed in order of marriage. It was expected that in this traditional, isolated, Maasai community with little variation in lifestyles, 30 participants representing all three villages and different bomas would be a representative sample of the larger community. Census data was collected by the lead author for the 15 selected bomas. Each boma was visited by the lead author and together with the male head of the boma a list of all people ages 18-50 residing at the boma was documented. Using the census data, one male and one female aged 18-50 years were randomly selected to be interviewed from each of the 15 bomas. An internet-based sample builder was used to randomly select five men and women from each boma (www.randomizer.org). If the first randomly selected person was not available, the next person in the randomization list was approached to participate. As the researchers had conducted the census at each boma, most selected participants were already familiar with the researchers and a rapport had been established.

Interviews

Semi-structured interviews were conducted from October to December 2016 with participants in Maa (Maasai language) by a native Maa speaking interviewer in a conversation-like manner. Interviews were conducted in a private setting, typically under a tree, at the participant's home with only the participant, interviewer and principal investigator present. The interview guide consisted of socio-demographic information and open-ended questions on experiences, knowledge and understanding of the nature of trachoma including pathology, progression of disease, risk factors, experiences, treatment, prevention and blindness. Interviews were audio recorded and later transcribed and translated from Maa to English.

Medicinal plant identification

Participants were asked about local treatment for trachoma and a list of plants in Maa was compiled. Two Maasai field assistants identified and photographed the plants in the field. The list of Maa plant names and photographs was used by a botanist to identify the botanical names.

Data management and analysis

Transcription was done directly from Maa to English; some transcripts were corrected to ensure more understandable English while assuring meaning was not changed. English transcripts were entered into NVIVO 11 Software. Initial interpretation included familiarization of the data and review of reflective notes. Data were coded by lead author, TM, using the interview guide as a framework and verified by author SL. A framework method for content analysis (Gale et al., 2013) was used and descriptive findings reported. Open coding was conducted on five transcripts to confirm there were no emerging codes to be included in the analysis. Codes were grouped into themes and compared against the interview guide (S1 Table). Themes reflected the key topics from the interview guide. Using a coding framework, data were charted into a framework matrix (S2 Table). Impressions and interpretation of the framework matrix were discussed with the native speaking interviewer and coauthors. The findings reported include the key high-level codes. Constant comparative analysis was done comparing responses between genders and within bomas. Quotes presented are used to show dominant views from the interviews. Not all interviewees' views are represented but rather more overarching themes included.

Ethics Statement

This study was approved by the Ethics Committees of the National Institute for Medical Research, Tanzania and the London School of Hygiene & Tropical Medicine, United Kingdom. Informed consent was obtained from all participants in Maa and a witness was present for illiterate participants. Permission to digitally record interviews was obtained from each participant. Permission from the male boma elder of the 15 selected bomas was also obtained.

Results

Participant characteristics

A total of 28 adults, 15 women and 13 men, from the 15 study bomas in three villages were interviewed. There were no men available for interview at two bomas due to seasonal migration in search for good pastures and business travel. Despite data saturation being reached, researchers continued to conduct interviews to assure a sense of inclusivity in the community. The participant ages ranged from 18 to 49 years. Exact age was unknown to the majority of participants as they do not maintain documentation of date of birth nor track their ages. Estimated age ranges of participants were as follows: 18-29 years (n=10), 30-39 years (n=9), 40-49 years (n=9). Education level of participants were as follows: no formal education (n=22), attended primary school (n=5), attended secondary school (n=1). All were conducted in a private setting, however for one interview a husband [8-1] insisted that he and his wife [8-2] be present for each other's interview.

What is trachoma?

The Maa term *enaoji* is a condition of the eye associated with irritation specific to the eyelid. Some mentioned white spots on the inner surface of the eyelids, possibly follicles. The most commonly reported symptoms of *enaoji* described included discharge (sometimes described as heavy and yellow), swollen eyelids, redness and itching. Some described pain, light sensitivity, inability to open the eye and an overall ill feeling throughout the body. Regardless of the associated symptoms, *enaoji* was most often explained as being specific to the eyelids.

> *"… when they start to get the disease, there are those who get discharge from their eyes and spots on top of their [everted] eyes [lids]…"* [03-2, female in her 30's]

> *"It happens to the person when he is young when his eyes get infection and become red. It leads eyelids to swell due to spots and after those spots disappears is when trachoma has gone away."* [6-2, female in her early 20's]

> *"It happens when people's eyes get infection and look red. And then eyelids get infection which causes spots on eyelids which cause itching and a patient is forced to rub due to that. So, this is my understanding on this."* [13-1, 20 year old male]

It was often reported to affect young children and some said it occurs within a few days after birth.

> *"It happens when the eyelids of the child swell and in most cases children get infections to their eyes and especially young children of age about one, two or three are most of the cases with this problem."* [02-1, 18 year old male]

> *"It starts when children have discharge, then they get swollen [eyelids] and people say they have enaoji that's why they are swelling."* [01-2, female in her 40's]

> *"You may find a child's eye [lids] get swollen and discharges."* [05-2, female in her 40's and a CDD in 2016]

Some described other symptoms which were not necessarily related to trachoma nor to the local interpretation of *enaoji.*

> *"They can't even open their eyes in sunny places until they get inside where it is dark."* [13-2, female in her late 40's]

> *"After feeling sickness in the whole body, a person feels his/her eyes are not okay."* [2-1, 18 year old male]

Participants were all aware of a condition in which eye lashes turn inward and touch the eyeball, trichiasis, although they have no Maa term for it. Trichiasis was considered a normal condition that occurs with age particularly in women. None of the participants were able to link this with childhood eye infections or *enaoji* although after some probing, they agreed such a link is plausible.

Causes of trachoma and prevention of trachoma

When asked about what causes trachoma, many attributed it to pollen, dust, smoke and climate conditions that seem to vary with the year. Some mentioned "year of the eyes" in which some years there are a lot of eye problems compared to other years. Some participants attributed *enaoji* as a result of magic or a curse being inflicted by someone.

> *"We believe it happens because other people applied magic power, or the patient is cursed. So, we believe maybe the patient did wrong things and was cursed by his/her fellows. We believe that eyes and legs are among the most important body parts and life of the human are in his/her eyes and legs."* [03-1, 45 year old male]

A link to flies was described by many participants but the mechanism was not clear. Some thought the flies had to bite the eye or a part of the body or the fly gets into the nose and goes up to the eyes causing *enaoji*. Others said babies were born with dead flies in their eyes which caused eye problems. Some discussed that when it rains and when there is more milk around during calving season, there are more flies and that was when more children were getting *enaoji*. Only one participant mentioned bacteria and flies as a vector. He was in secondary school, and had the highest level of education of all participants interviewed:

> *"This is a disease which is caused by flies especially children when flies fall on eyes of children, and they do carry bacteria from one person to another or one place to another. And those bacteria make settlements in the chambers of eyelids which later cause trachoma."* [13-1, 20 year old male]

Methods to prevent infection were not mentioned by any participants. When asked if facial cleanliness can prevent trachoma, only a few respondents said that "it helps" but they were unable to elaborate more. Many described it as a treatment for yellow discharge, pain, or irritation rather than for prevention. Although many reported being given information on cleanliness at clinics, most were unsure of the links between a clean environment and preventing trachoma and hence not convinced to follow the advice. Many said that hospitals help prevent disease or “only God can help”.

> *“It [water] cannot help because all these years water is there but the disease is still a problem. God can only help and prevent.”* [08-1, 49 year old male]

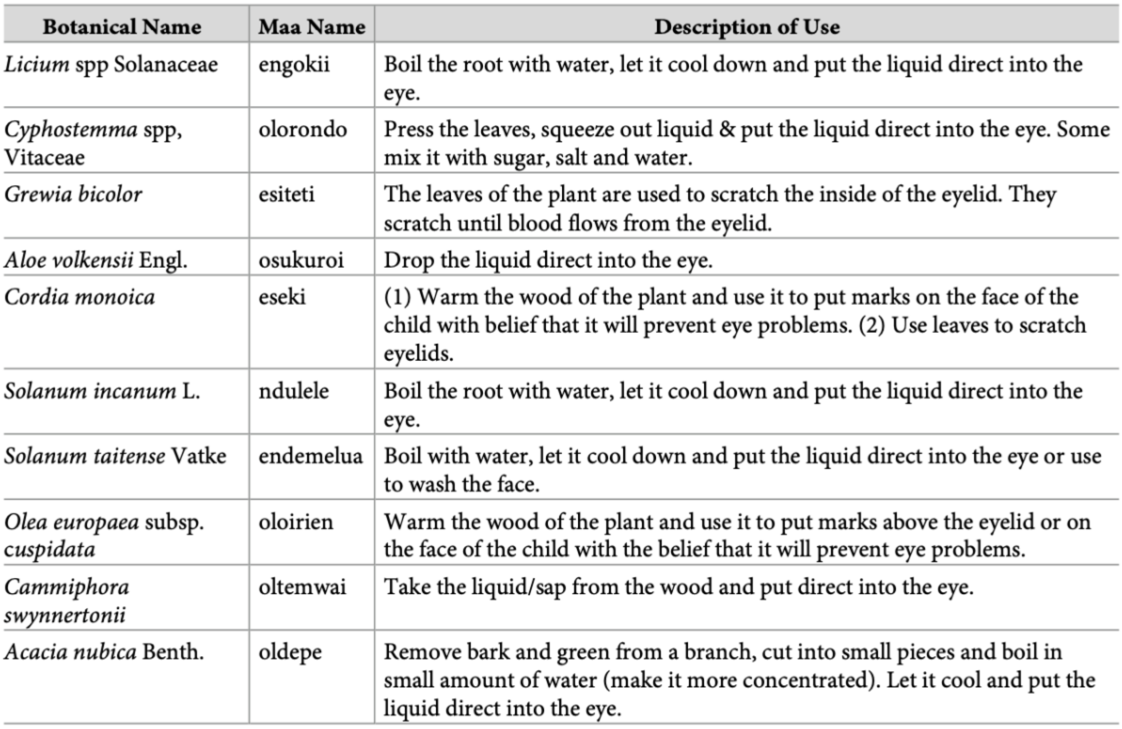
Treatment

Most participants said western medicine is better than local medicines or they are equally effective. Collecting local medicines from trees, plants and shrubs is part of Maasai women’s daily activities. Women prepare tea for their family from local medicines each morning depending on several factors including the weather, activities family members are involved in (ie, grazing, setting out on a long journey), food availability and current illnesses. Some said they go to hospitals if the local medicines do not help. A few participants believed that local medicines are better.

> *“Somehow these western medicines are better because they have directives about how to use. These local medicines are good but due to lack of what quantity should be used sometimes it’s a challenge. Also, they are not filtered like western medicine so sometimes you may put them into your eyes with contaminations which might cause more problems.”* [02-2, 20 year old female]

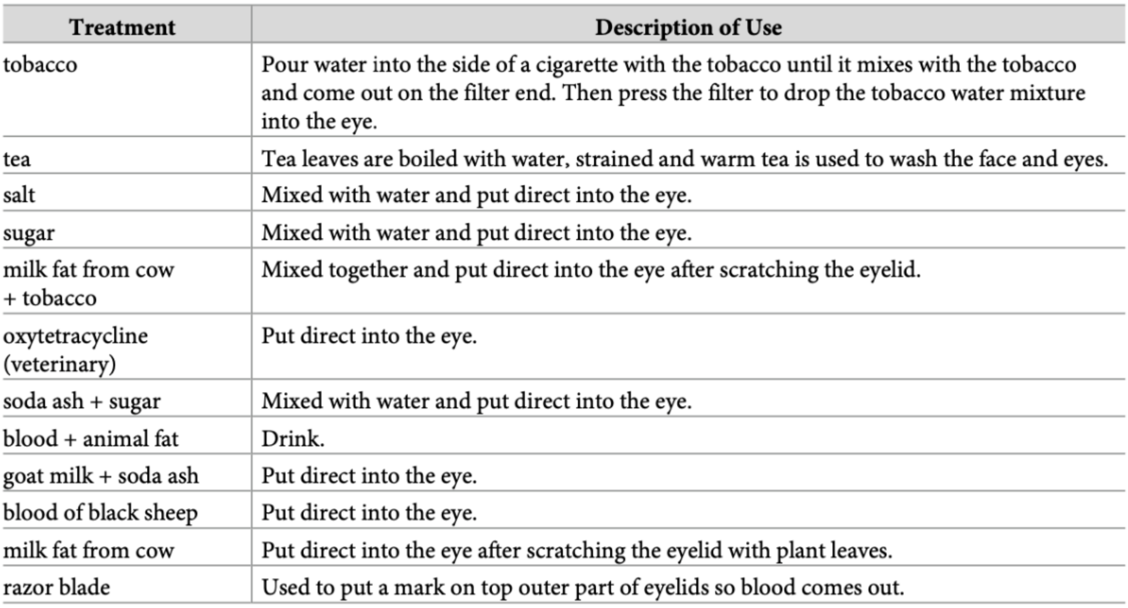
Most participants, however, reported using local medicines or veterinary medicines (such as penicillin and oxytetracyline) for eye problems, mostly because of poor access to western treatments. These included roots, leaves and bark of various trees and plants (Table 6), or other household products (Table 7).

Table 6. Plant medicines used for treatment of trachoma



Botanical Name	Maa Name	Description of Use
Licium spp Solanaceae	engokii	Boil the root with water, let it cool down and put the liquid direct into the eye.
Cyphostemma spp, Vitaceae	olorondo	Press the leaves, squeeze out liquid & put the liquid direct into the eye. Some mix it with sugar, salt and water.
Grewia bicolor	esiteti	The leaves of the plant are used to scratch the inside of the eyelid. They scratch until blood flows from the eyelid.
Aloe volkensii Engl.	osukuroi	Drop the liquid direct into the eye.
Cordia monoica	eseki	(1) Warm the wood of the plant and use it to put marks on the face of the child with belief that it will prevent eye problems. (2) Use leaves to scratch eyelids.
Solanum incanum L.	ndulele	Boil the root with water, let it cool down and put the liquid direct into the eye.
Solanum taitense Vatke	endemelua	Boil with water, let it cool down and put the liquid direct into the eye or use to wash the face.
Olea europaea subsp. *cuspidata*	oloirien	Warm the wood of the plant and use it to put marks above the eyelid or on the face of the child with the belief that it will prevent eye problems.
Cammiphora swynnertonii	oltemwai	Take the liquid/sap from the wood and put direct into the eye.
Acacia nubica Benth.	oldepe	Remove bark and green from a branch, cut into small pieces and boil in small amount of water (make it more concentrated). Let it cool and put the liquid direct into the eye.

Table 7. Other local treatments for *enaoji* (eyelid irritation)



Treatment	Description of Use
tobacco	Pour water into the side of a cigarette with the tobacco until it mixes with the tobacco and come out on the filter end. Then press the filter to drop the tobacco water mixture into the eye.
tea	Tea leaves are boiled with water, strained and warm tea is used to wash the face and eyes.
salt	Mixed with water and put direct into the eye.
sugar	Mixed with water and put direct into the eye.
milk fat from cow + tobacco	Mixed together and put direct into the eye after scratching the eyelid.
oxytetracycline (veterinary)	Put direct into the eye.
soda ash + sugar	Mixed with water and put direct into the eye.
blood + animal fat	Drink.
goat milk + soda ash	Put direct into the eye.
blood of black sheep	Put direct into the eye.
milk fat from cow	Put direct into the eye after scratching the eyelid with plant leaves.
razor blade	Used to put a mark on top outer part of eyelids so blood comes out.

In most cases eye treatment for children is administered by women and the most common local treatments for *enaoji* are brewing medicines for eye drops, direct application of liquid from leaves or scratching the eyelids with a rough leaf. For the later practice, women take the leaf of the plant, *Grewia bicolor*, (Figure 12) and rub the inside of the inverted eyelid until it bleeds.

> *“Instead of going to hospital, I first go look for a local medicine known as olorondo. After using that local medicine, if they eye is still not healed, I go find another local medicine from root of a plant, engokii. And if situation continues to be worse we take a leaf of a certain plant, esiteti and find a person to help to scratch inside of eyelids because we believe that enaoji is the problem and treatment for enaoji is scratching.”* [02-2, 20 year old female]

> *“I have my young child who a few days ago they scratched [his eyelids] with a plant leaf due to trachoma. He had that problem since few days from when he was born and after scratching now he is ok.”* [08-2, female in her 30’s]

Figure 12. Photo of plant leaves commonly used for *enaoji* (eyelid irritation) treatment

(botanical name/ Maa name) **(A)** *Licium* spp Solanaceae/ engokii **(B)** *Cyphostemma* spp, Vitaceae/ olorondo **(C)** *Grewia bicolor/* esiteti **(D)** *Aloe volkensii* Engl./ osukuroi **(E)** *Cordia monoica /* eseki **(F)** *Solanum incanum* L./ ndulele

Although trichiasis was not considered a health condition that can be treated with surgery, most described the use a U-shaped iron, *olputet,* for epilation of eye lashes. Only one participant talked about surgery an old woman in her boma previously had, however on probing it seemed to not be related to trichiasis.

> *“You may find an old person whose eyelashes turn inward and scratch the eyeball. And you can hear a person asking for help from another person to take off that eyelash. After using olputet, then the person feels happy.”* [04-1, 32 year old male]

Mass drug administration of azithromycin was conducted in Sinya in 2015 and 2016. Most participants recalled the MDA although a few were completely unaware of the programme. Most reported that the drugs were probably effective because after the distribution there were fewer eye infections in the community although most were unsure how it helps. Some reported side effects either they or others had including diarrhoea, vomiting and dizziness. Some also reported uncertainty and lack of trust in the drugs:

> *“We just use them and the story ends there. We are not sure if they gave us drugs to stop us from getting pregnant. We had the same drugs given to us in 2015 and we used them too. And to the adult like me we took two tablets. And we feared about those drugs that maybe they are given to us purposely to stop pregnancy.”* [10-2, 38 year old female]

> *“I don’t know [how MDA helps trachoma] because people are ignorant so some took drugs but they didn’t use them due to fear and lack of knowledge about what these drugs are for.”* [12-2, 38 year old female]

Blindness

When asked what causes blindness, most responses were that it is a result of aging. Some other causes mentioned included trichiasis, untreated eye diseases and God. If someone becomes blind at a young age, it was attributed to someone using witchcraft on them. A few women and a man talked about it as a curse for not paying traditional birth attendants after the birth of their child. Despite the traditional beliefs on causes, it did not negatively impact on how they treated the blind person.

All participants remarked that blindness is a serious disability for the individual as they are unable to attend to their daily activities without the assistance of others. They all said it was a significant burden on others in the boma in regard to taking on their responsibilities at the boma including cooking and cleaning and assisting them to the toilet and other basic needs. The economic burden was also mentioned.

> *“The burden is big. Like the one [blind mama] we have at this boma…because she depends on other women in the boma to go look for firewood for her, collect water in the dam and even to repair her house. Other women are responsible to do that.”* [15-2, 22 year old female]

> *“The burden is very big. I’m wondering about the situation my son is facing. For example, when I go outside of his mother’s house to stay with other men, he follows me like you see here now. And during the night when he wants to go back to his mother’s house he asks me who will take him back because he can’t go alone. So, it is a big problem to the young boy like this to lose vision at this age. It is also a burden to us who are supposed to take care of him. Like when I hear him crying on the other side of the boma, I always get scared because I think he got into thorns.”* [03-1, 45 year old male]

Although blindness was considered a burden on the community, all participants discussed supporting blind people in their daily activities. Some family members, including children, were appointed as caretakers.

There was little difference in responses between men and women. Women tended to be more descriptive in the symptoms of *enaoji* as well as the practice of scratching eyelids for treatment. Women were more likely to discuss side effects and rumours of MDA. Analysis of the data between the man and woman within a boma, showed similar responses. This consistency of responses within a boma indicates sharing of knowledge and perceptions around health between men and women.

Discussion

The Maasai have a strong cultural identity and maintain a traditional lifestyle while having limited access to health services. Despite a high prevalence of trachoma in Maasai communities, their experiences and knowledge of trachoma have not been explored. A barrier to effective control of NTDs is lack of knowledge of the disease in the community. Despite the complexity of understanding a community and its response to disease, sharing knowledge is important for engaging the community to perhaps change perceptions and behaviours. Yet, information-based interventions alone are often not effective for behaviour change (Bamani et al., 2013; Edwards et al., 2006). It has been shown that knowledge alone for trachoma control often does not change behaviours in the short term (Bamani et al., 2013; Edwards et al., 2006). Programmes should consider multiple techniques to engage participants at behavioural, social, sensory and cognitive levels (Briscoe & Aboud, 2012); leverage non-health-related motives, and/or improve poor habits (e.g., via nudges, and reminders) (Neal et al., 2016) for sustainable behaviour change. Yet underlying these components is an essential need to understand the social, cultural, and political context of the target community to deliver effective programmes.

There is a danger in approaching health education from a biomedical perspective and not incorporating local understanding, beliefs around illness and traditional healing (Parker et al., 2008). In this study, only one participant had secondary education and he had a more accurate understanding of trachoma than any of the other participants. Haasnoot (Haasnoot et al., 2010) found education of Maasai children was significantly associated with knowledge of TB in terms of awareness and understanding its aetiology compared to adult Maasai with no primary education. School-based interventions may be effective in delivering public health messages to the broader community in areas with low education. Furthermore, control measures are often not compatible with a community’s traditional beliefs, practices and understanding of the aetiology, transmission, prevention, and treatment. Often the complexities of how a society interprets a disease and the cultural beliefs around prevention are reduced to a crude description of that society. Coast (2007) describes this in relation to use of condoms for HIV prevention and the belief among Maasai men and women that condoms waste semen and semen exchange is highly valued by both sexes. Yet NGOs and health workers blame poor condom use on a sexually deviant society rather than the complexities of Maasai sexuality.

This study has shown that the Maasai community is aware of basic clinical symptoms of childhood infections related to eye conditions, particularly related to the eyelids, and that they have a Maa term for it, *enaoji*. However, many of these symptoms are not specific to trachoma. Therefore, *enaoji* may not always be attributable to trachoma, but is understood in terms of an inflammation of the eyelids. Maasai have a traditional practice of using a hot iron to put circular scars on the cheek under the eyes of children. Although today this practice is mostly done for aesthetic reasons, it originated as a means of protecting the individual from *enaoji.* This suggests that *enaoji* is identified by Maasai as a serious problem, despite their poor clinical knowledge. For example, their descriptions of eye infections in infants occurring from birth refers to ophthalmia neonatorum and is usually caused by bacterial infections acquired during delivery, *Chlamydia trachomatis* and *Neisseria gonorrhoeae*. Participants in this study were very aware of a condition in which the eyelashes turn in and scratch the eyes, trichiasis, although they considered it normal and part of aging. All were unaware of a link between childhood infections and trichiasis, a factor that may limit uptake of interventions. This is consistent with reports from Guinea Bissau (Thompson et al., 2015) and the Gambia (Ajewole et al., 2009). Whilst there was a lack of understanding of the aetiology of trachoma many recognized an association between presence of flies and increased infection. Rather than a clinical understanding, this study has revealed that for the Maasai trachoma is attributed to either environmental conditions and/or related to spiritual beliefs (see also Sindiga 1995). In line with our findings other studies looking at other NTDs in other low and middle-income countries similarly found that beliefs on disease aetiology were environmental or spiritually based (Ahorlu et al., 1999; Amazigo et al., 1997; Amazigo et al., 2002; Awolola et al., 2000; Ramaiah et al., 1996). For example, a study in the Gambia revealed bad air was believed to cause trichiasis [naturalistic cause] and bad air affects eyes because ‘enemies’ in the village wish to afflict them [personalistic] (Ajewole et al., 2009).

Our findings on poor understanding of cleanliness and disease prevention (such as face washing and home environment) are corroborated by a study in Guinea Bissau which found only 25% in the rural setting believed there were benefits in good hygiene and were unable to discuss any preventive measures (Thompson et al., 2015). However, in another study in the Gambia women had the knowledge and understanding of a link between personal hygiene and disease prevention although activities related to cleanliness ranked of lower priority in their daily activities (Ajewole et al., 2009). Instead, the Maasai approach to disease prevention is use of plants including the daily consumption of tea from herbs, barks and roots for prevention of various conditions or *orpul*, the commonly practiced healing retreat to maintain health and vigour (Burford et al., 2001; Kiringe, 2006; Sindiga, 1995b).

SAFE strategies should be tailored to the local context to address local beliefs and help dispel misunderstandings (Zondervan et al., 2004).

In relation to treatment, although the Maasai trust western medicine, they primarily use local medicines to treat eye conditions. This may possibly be due to isolation from centers of development (Sindiga, 1994) and a strong cultural identity (Kiringe, 2005). In this area of 223 square kilometres there are only two health facilities. Some residents walk up to 15 km to a clinic often to find no doctor on duty or medicines unavailable. A study conducted with the Maasai of Southern Kenya, found 73% of participants indicated traditional medicine was their preferred form of treatment. However traditional medicine is not the sole form of medical treatment as 98% at times seek medical attention from local dispensaries and clinics (Kiringe, 2006). Reluctance to attend a clinic for care may also be linked to how patients are treated when they go to health facilities (Gessler et al., 1995). The clinic staff do not speak Maa and patients have reported being yelled at for presenting to the clinic late. Health services that demonstrate a lack of consideration for cultural beliefs risk being rejected by the community (Gessler et al., 1995).

Despite the community having numerous outreach programmes for trichiasis surgery none of the participants were aware what it was for, indicating a lack of education and sensitization from the surgical camps. This is not surprising considering the communities' perception of trichiasis as a natural part of aging and not connecting trichiasis to childhood eye infections. Lack of awareness of trichiasis surgery was also reported in trachoma endemic communities in the Gambia and central Tanzania (Bowman et al., 2002; Oliva et al., 1998). A few community members have had cataract surgery and there was more understanding about surgery to improve vision than surgery to protect vision through correcting in turned eyelashes.

While participants were aware of MDA, all were unsure of how it helps and complained of side effects. Effectiveness of an MDA programme often depends on community mobilization and sensitization. This includes addressing possible side effects and ways to prevent them including not taking the drug on an empty stomach. Lack of sensitization around MDA was associated with poor uptake of azithromycin in a study in Kilimanjaro Region of Tanzania in which 56% of respondents reported being satisfied with the amount of information they received prior to MDA and 32%

reported side effects including diarrhoea, stomach ache and nausea (Desmond et al., 2005). In our study, a few women said they heard the drug can cause infertility. This is similar to studies in Ethiopia and Kenya in which women perceived azithromycin as a form of family planning (Gilbert, 2012; Mulugeta et al., 2018). The origin of rumors can be complex. On one hand, they can arise due to misinformation, whilst on the other hand rumors may have a historical or political origin or result from cultural beliefs (Parker et al., 2008). The act of passing on rumors may not be related to whether the person passing it on believes the rumor (Geissler & Pool, 2006) but rather a response to someone’s mistrust or uncertainty of something.

Despite men and women having differential risk and experiences with trachoma, there was little difference in the responses between men and women. This is likely due to the continual exchange of knowledge and experiences of health within the Maasai (Bignante & Tecco, 2013) that may contribute to the little differences in responses within bomas. Women tended to have more descriptive responses likely due to more direct experience caring for children with active infection and being responsible for health of the children (McCauley et al., 1992). Although men are the ultimate decision makers regarding the use of resources for household members to seek health care, they respect women’s judgements regarding health issues and needs to seek health care.

This study had some limitations. Interviews were conducted in the local Maasai language, Maa, by an experienced research assistant. Despite adequate training on trachoma and interview techniques, probing was sometimes not adequate. The lead author was present for all interviews but due to limited understanding of the language was not always able to assist in probing when necessary. The lead researcher, a non-Maasai or *ormeek*, was aware of potential misunderstandings of her position given that the Maasai encounters with non-Maasai tend to be with NGO, government or clinical personnel. To gain trust the lead author lived in the community for sixteen months and spent significant amount of time engaging local leaders in the research. Further to this, Sinya may not be representative of all Maasai communities in Tanzania. This community was chosen as it is traditional and remote in terms of its exposure to bigger towns and cities. Therefore, access to health facilities, health programmes and education are likely more limited in Sinya compared to many other Maasai communities. Despite this, it is important to note that the communal nature of Maasai culture is still very traditional and consistent across different Maasai districts and economic levels. This study focused on knowledge and experiences which alone will not change behaviour (Edwards et al., 2006). Therefore, it is important to consider the political, social, and economic context in which the lives of the people are situated. This study did not explore this context in depth. This study was nested within a larger ethnographic research project investigating the Maasai response to MDA for trachoma from a political economy perspective.

Conclusion

This is the first study to examine perceptions and experiences of trachoma among the Maasai in Tanzania. Additionally, this was the first study to identify a local treatment used in treatment of swollen eyelids among the Maasai. In particular the commonly practiced scratching of eyelids with a rough leaf has not been documented. Children's eyelids are scratched until they bleed. This may potentially lead to secondary scarring related to this local practice. Further studies are needed to explore the effects of local treatment on scarring and progression of disease.

This study found prevention of blindness is important to Maasai. They discussed the social and economic burdens of blind people in the community. Possibly if health education in the community included the connections of childhood infections, trichiasis, and blindness, the community would place greater value on the information to prevent this disability.

It is important to understand the indigenous knowledge of disease to guide effective control programmes. Therefore, further ethnographic research with an in-depth focus on this communities' beliefs, practices and relationships with health care is needed. The National NTD Control Programme has put resources into behaviour change interventions for trachoma control. These findings will provide further understanding of the community to tailor interventions more appropriate for Maasai. Additional research is needed to further explore the effect of a multi-level behaviour change intervention on sustained behaviour change for improved F and E practices among marginalized communities such as the Maasai. While this study focused on the

Maasai in Tanzania, the results may contribute to the broader knowledge base and approach to improving control programmes for other marginalized communities.

Acknowledgements

We would like to extend our gratitude to the participants for their collaboration and participation in this study and to the village leaders for their support and collaboration on the field work. Identification of botanical names of plants used for medicine were provided by Dr. Juma Kayeke of the Tanzania Ministry of Agriculture, Livestock and Fisheries.

Chapter 4: Reality of MDA in a Maasai Community

RESEARCH PAPER COVER SHEET

Please note that a cover sheet must be completed for each research paper included within a thesis.

SECTION A – Student Details

Student ID Number	450695	**Title**	Mrs.
First Name(s)	Tara		
Surname/Family Name	Mtuy		
Thesis Title	Maasai response to mass drug administration for trachoma in a changing political economy in Tanzania		
Primary Supervisor	Dr. Shelley Lees		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	Journal of Biosocial Sciences		
When was the work published?	July 2020		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	NA		
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SECTION E

Student Signature	Tara B. Mtuy
Date	13 May 2022

Supervisor Signature	Shelley Lees
Date	13 May 2022

Overview

In chapter 3, I described the narratives of trachoma among Maasai. Chapter 4 builds on Maasai understanding of trachoma to explore their experiences and responses to a trachoma control programme of mass drug administration. Drawing on data from my field work, I used an analytical framework adapted from (Bardosh, 2018), I and the co-authors assessed the effectiveness of the control programme. Five domains were used to describe factors influencing participation and delivery of the control programme.

This paper contributes to research objectives:

3- To explore the context of uptake of MDA.
4- To compare the experience of MDA in adherers and non-adherers.
5- To investigate the effects of migration in the community on uptake of MDA including the patterns of migration, characteristics of migrants and their experiences with MDA.
6- To describe decision-making around health issues, particularly eye health, among household members.
7- To explore Maasai response to MDA within their cultural perceptions and practices of biomedicine and traditional medicine.

The findings presented in this paper uncovers social, economic, and environmental barriers to programme implementation but furthermore the effects of a complex political economy. Application of a critical bio-social perspective is essential to planning and evaluating trachoma control programmes in hard-to-reach communities. This chapter concludes highlighting that a ‘one size fits all’ approach is less effective in this community, and I provide recommendations for tailoring the programme for Maasai communities.

Understanding "Hard to Reach" Communities: Local Perspectives and Experiences of Trachoma Control Among the Pastoralist Maasai in Northern Tanzania

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Abstract

As progress to eliminate trachoma is made, addressing hard-to-reach communities becomes of greater significance. Areas in Tanzania, inhabited by the Maasai, remain endemic for trachoma. The effectiveness of mass drug administration (MDA) was assessed through an ethnographic study of trachoma amongst a Maasai community.

This study explored the MDA experience in the context of the livelihoods of the Maasai in a changing political economy using participant observation and household interviews. Factors influencing MDA effectiveness within five domains were analysed. *Terrain of intervention*: Human movement hindered MDA, including seasonal migration, domestic chores, grazing and school. Encounters with wildlife were significant. *Socio-cultural factors and community agency*: Norms around pregnancy led women to accept the drug but hide refusal to swallow the drug. Timing of community drug distributor (CDDs) visits conflicted with livestock grazing. Refusals occurred among the *ilmuran* age group and older women. Mistrust significantly hindered uptake of drugs. *Strategies and motivation of drug distributors*: Maa speaking CDDs were critical to effective drug delivery. Maasai CDDs whilst motivated faced challenges of distances, encounters with wildlife, and compensation. *Socio-materiality of technology*: Decreases in side-effects over years improved trust in the drug. Restrictions to swallowing drugs and/or water were relevant to post-partum women and the *ilmuran. History and health governance*: Whilst perceptions of the programme were positive, communities questioned government priorities for resources for hospitals, medicines, clean water, and roads. They complained of a lack of information and involvement of community members in healthcare services.

With elimination in sight, hard-to-reach communities are paramount as these are likely the last foci of infection. Effective delivery of MDA programmes in such communities, requires a critical understanding of community experiences and responses that can inform tailored approaches to trachoma control. Application of a critical social science perspective should be imbedded in planning and evaluation of all NTD programmes.

Introduction

The term neglected tropical diseases (NTDs) not only refers to the biological disease but alludes to an indication of the types of communities affected by these diseases of poverty. It implies the world's poorest societies that are marginalized socially, politically and/or economically. Many communities burdened with NTDs are also hard to reach populations because of geography or socio-culturally different, for example (Bardosh, 2014; Parker et al., 2016).

The "Neglected" in NTDs refers to a diseases' status relative to HIV, TB and malaria but also to prevalence among the world's poorest and marginalized communities (Manderson et al., 2009). Emphasis is typically on the biological aspects of disease while neglect encompasses social constructs and livelihoods of a community (Parker et al., 2016).

The NTD trachoma (ocular infections with *chlamydia trachomatis)*, is the leading infectious cause of blindness*.* In 2019, WHO estimated that 142 million people live in trachoma-endemic areas globally (WHO, 2019). Whilst trachoma is estimated to affect 17% of the population of Tanzania (WHO, 2017), the majority of trachoma endemic areas are predominantly inhabited by the Maasai, a pastoral ethnic group. The baseline prevalence of trachomatous inflammation-follicular (TF) in Longido District was greater than 50% in 2004 (Masesa et al., 2007; Mwingira et al., 2016). Longido District received more than five rounds of MDA before undertaking trachoma impact surveys in 2018, that showed that TF had declined to 7.2%; however, MDA was continued as per the World Health Organization (WHO) guidelines. Prior to 2015, MDA coverage was patchy. Following concerted efforts to improve by the Tanzania NTD control programme and partners, coverage has improved gradually: 43% in 2015, 66% in 2016, 76% in 2017, 87% in 2018 and 94% in 2019.

Mass drug administration (MDA) of azithromycin is one of four components of the surgery, antibiotics, facial cleanliness, and environmental improvement (SAFE) Strategy for the elimination of trachoma. The other components are surgery for trichiasis, facial cleanliness and environmental improvement including management of animal and human feces and access to water. MDA is coordinated by a number of international actors in partnership with government ministries in a vertical approach. Azithromycin (Zithromax®) is donated by the pharmaceutical company, Pfizer, to trachoma endemic countries via the International Trachoma Initiative (ITI). In 2016 more than 85 million people received donated Zithromax® for trachoma worldwide (WHO, 2017). The Tanzania National NTD Control Programme along with implementing partners oversees and coordinates these control measures. MDA campaigns are coordinated by the National NTD Programme and implemented through a train the trainer model with local government offices at district and then village level. Distribution is done by community drug distributors (CDDs).

While prevalence of TF has been reduced in some hard-to-reach Tanzanian communities, evidence suggests that after three rounds of MDA in hyperendemic communities, there is re-emergence of infection and at least seven rounds are required to attain TF prevalence of <5% (West et al., 2011). These hard-to-reach communities are often marginalized communities that require a critical understanding of their social, political, and economic context and therefore a tailored approach. Control of diseases in neglected communities often leads to tensions between local cultural demands and national targets. The same socio-political factors that drive NTD transmission in marginalized communities pose challenges in control efforts (Bardosh, 2014).

There have been efforts to understand the context of MDA and the community response to NTDs including local conflict, physical and social isolation, migrancy, side effects, trust, rumours and disease knowledge (Babu & Kar, 2004; Burton et al., 2005; Cavalli et al., 2010; Desmond et al., 2005; Hastings, 2013; Parker & Allen, 2013; Parker et al., 2008; Ssemanda et al., 2012). In a vertical public health approach, often there is inattention to the socio-cultural, political, and economic influences on the effectiveness of a programme. Reflections on the ways in which these issues influence MDA in hard to reach communities hyperendemic for trachoma are limited (Desmond et al., 2005).

To date there have been no studies detailing MDA for trachoma from a Maasai political economy perspective. The Maasai have complex livelihoods and are confronted with social and political challenges that may affect their interaction with such programmes. Although vaccination coverage is generally high, compared with other tribes, Maasai had lower reports of receiving vaccinations (ranging from 76-95%) and the overall health status of Maasai poor compared with other Tanzanian ethnic groups (Lawson et al., 2014) implying a possible disconnect between the Maasai and health services. This study explored the Maasai experience of MDA using a socio-anthropological framework for assessing the effectiveness of NTD interventions, drawing on an ethnographic study of trachoma among Maasai in Northern Tanzania. The aim of the study was to understand the response to MDA for trachoma against a backdrop of unique livelihoods and a changing political economy. Collinson (2003) defines political economy as the “interaction of political and economic processes within a society; distribution of power and wealth and processes that create, sustain and transform these relationships over time”.

Methods

Study location

This paper is based on ethnographic research carried out from September 2016 to December 2017, looking at Maasai’s experiences and perceptions of trachoma control in in Sinya Ward in Longido District, of Northern Tanzania, which is representative of other Maasai dwelling wards in Northern Tanzania. Sinya is located in the plains between Mt Kilimanjaro and Mt Meru and is situated on the Tanzania-Kenya political border with Amboseli National Park in Kenya bordering Sinya on the north. This hard-to-reach community is 60 km from the nearest large town, Longido. There is no public transport to Longido and dangerous wildlife in the vicinity make the journey by foot hazardous. Sinya is situated within the Enduimet Wildlife Management Area (WMA). WMA is a Tanzania government authority that manages wildlife resources and conservation outside the Tanzania national parks. Sinya, is comprised of three villages, Il Donyo, Leremeta, and Endonyoemali; with a total population of 4,285. There are only two health dispensaries, one boarding primary school and one market held once per week to serve these three villages. Electricity was brought to the ward in 2016 but only serving the trading center. In 2017 three boreholes were constructed but prior to then there was only one borehole in Sinya.

This community was purposely selected for this research for the following reasons: a trachoma hyperendemic community; majority Maasai population; cooperation of village leaders; and reasonably accessible to the lead researcher’s hometown. Most of Sinya's residents have permanent homesteads in the village. There are a few non-Maasai, *ormeek*, staying in Sinya for the purpose of government work in the schools and dispensaries and for trade. The main source of livelihood is traditional livestock production in this purely pastoralist community (Mtuy et al., 2019).

Description of methods and sampling

Sinya ward has had five annual rounds of MDA of Zithromax®, in 2015, 2016, 2017, 2018 and 2019. This study was conducted during the third round of MDA in 2017. The study utilized qualitative methods including participant observations and repeated household interviews (n=40) forming the basis for this analysis. The lead author lived in this community over 16-months involving herself in the livelihoods of the community. Along with a Maasai research assistant, the lead author conducted participant observations in social settings such as the market, people's homes, the community bore holes and celebrations; at two government dispensaries; during trichiasis surgical outreach visits; and informal discussions while accompanying community drug distributors (CDDs) and village leaders during MDA in July 2017.

A boma, or *enkang* in Maa (Maasai language), is a homestead or joint residential unit composed of a number of households. The *enkang* allows for cooperative decision making over pastoralist activities (Coast, 2001). Physically it is designed with a carrel in the centre for the cattle, surrounded by huts and all enclosed with a fence to protect the cattle from wildlife. A boma is headed by one male and in a polygamous culture, each wife with her children have a hut within the boma. Huts are built alternatively on the left and right side in order of marriage to wives (Talle, 1998). Married sons live in their father's *enkang* until his death. The population of bomas vary but with a changing political economy the number of households within a boma are decreasing. In 1998 an *enkang* in Tanzania was comprised of four households compared with seven to nine in 1960's (Coast, 2001). For the purpose of this study, a boma is considered a household with the male elder of the boma as the head of the household. Among the three villages of Sinya, there are a total of 10 subvillages and a total of 107 bomas. Random sampling of bomas was used to allow for transparency in the selection process within the community. The lead author aimed to reduce perceptions of favouritism in a society in which decision making is based on fairness. Internet-based sample builder was used to randomly select two bomas from each subvillage (www.randomizer.org) for household interviews. If the first randomly selected boma was not available, the next boma in the randomization list was approached to participate. As the lead researcher and research assistant had been living among the community for ten months at that time, most residents of the selected bomas were already familiar with the researchers and a rapport had been established.

Semi-structured household interviews were conducted in Maa by a native Maa speaking interviewer in a conversation-like manner. The interview guide for the first round of interviews consisted of open-ended questions on their experiences and perceptions of health and non-health related programmes in the community. The second round of household interviews, conducted one-month post MDA, consisted of open-ended questions on the MDA experience, perception of the programme, decision making, migration and prevention of trachoma. Interviews were audio recorded and later transcribed and translated from Maa to English.

MDA procedures

Longido District had five annual rounds of MDA for trachoma, in 2015, 2016, 2017, 2018 and 2019. Training, supervision, and logistics were organized by the National NTD Control Programme with support from international partners. In a train the trainer model, the national NTD programme trained district level trainers who then trained ward level trainers. In the case of Sinya ward this was the Il Donyo dispensary doctor in charge. The ward level trainer conducted training of Sinya CDDs the week prior to MDA. Zithromax®, donated by the International Trachoma Initiative to the national NTD control programme, was delivered from the government to the district and then delivered to the doctor in charge at Il Donyo dispensary. Only medication for trachoma was distributed during this MDA. MDA was conducted boma to boma by two CDDs per subvillage over the course of four days, although distribution was not done one of the days due to market day. A single dose of Zithromax® tablet(s) dosed according to height was given to individuals above 7 years of age and taller than 120 cm according to national guidelines. Children aged 6 months to 7 years were given Zithromax® paediatric oral suspension dosed according to height (International Trachoma Initiative, 2018). Each day of MDA, the lead author would accompany two groups of CDDs in a village. Ultimately, observations covered parts of MDA in all three study villages.

Data Management and Analysis

Transcription of household interviews was done directly from Maa to English; some transcripts were corrected to ensure more understandable English while assuring meaning was not changed. English transcripts and field observations were entered into NVIVO 11 Software. Initial interpretation included familiarization of the data. Using a thematic content approach, data from interviews and field notes were first coded by lead author, TM, and verified by author SL. Through data immersion, emerging themes were identified and confirmed against the study objectives. Impressions and interpretation of the themes were discussed with the native speaking interviewer and co-authors. Using an analytical framework adapted from (Bardosh, 2018), themes were classified into the framework domains (Figure 13). The domains were modified for the local Maasai context and for the type of data collected specific to trachoma. Narrative text was applied around the framework and direct quotes presented are used to show dominant views of participants.

Figure 13. Five domains for assessing the effectiveness of MDA programmes for trachoma in Maasai communities

Results

Domain 1: Terrain of intervention

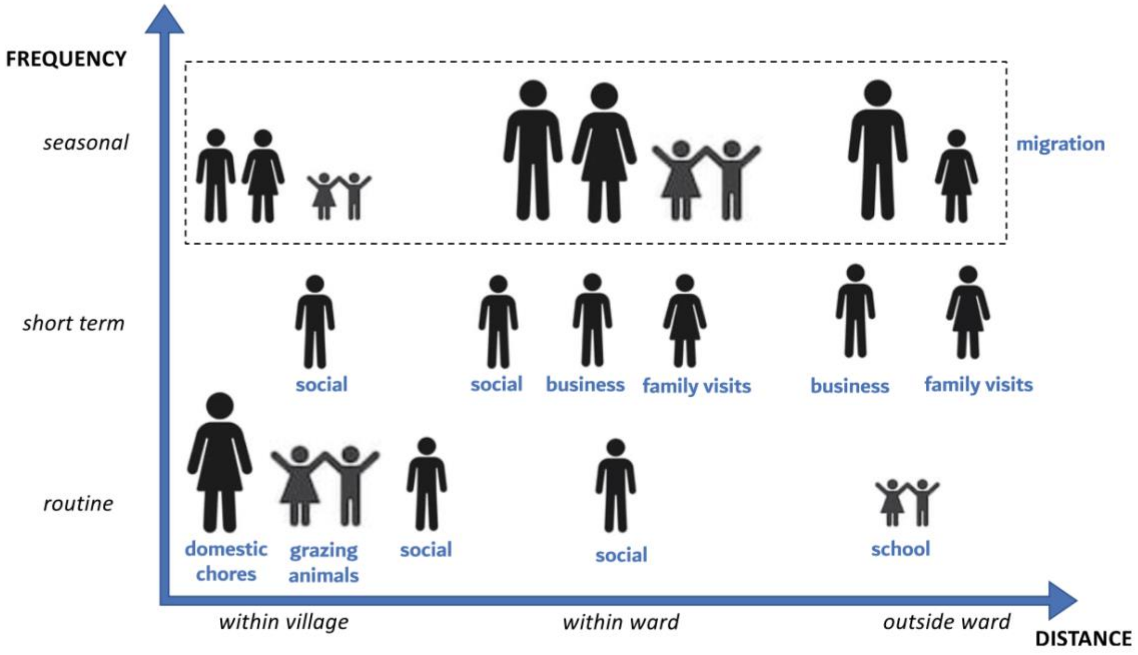
Control programmes, specifically MDA, are delivered in short time frames in a space that, aside from socio-cultural practices and governance histories, is influenced by livelihood, climatic and geographical factors (Scoones, 2009). In Sinya Ward in Northern Tanzania, seasonal fluctuations, human population movement and socio-economic pressures all played an important role in influencing MDA delivery.

Seasonal Fluctuations and Human Population Movement

Figure 14 shows human population movement during MDA in Sinya. The largest contributor toward movement was seasonal migration. Sinya is dependent on rainfall to maintain the pastoralist lifestyle of the local Maasai community. MDA was conducted in July, typically a dry month but with green pastures after the long rains from April-June. In 2017, the rains were shorter than usual, and it was considered a drought year. The village of Il Donyo, for example, has open spaces with green pastures that lie outside areas designated for permanent bomas. Therefore, some households migrated to temporary bomas, *ronjo,* to access these new green pastures, which are still within their village but administratively in another sub-village. This was typically done for the smaller livestock (goats and sheep) and involved the whole family. Temporary bomas are temporary housing structures outside designated community areas for permanent homesteads that are only used in times of drought. These are established by village leaders for land management purposes. Each of the three villages in this study had households who had migrated to temporary bomas within the ward but within different villages.

Figure 14. Human population movement during MDA

Stratified by spatial (distance travelled) and temporal (frequency of travel) characteristics. Routine is within 24 hours and less than 2 weeks. Men, women, and children are represented. The size of the symbol illustrates how common a particular human movement was during MDA.



All CDDs observed during MDA were uncertain how to handle this migration. In most cases the CDDs assumed the CDD from their permanent sub village would locate them and therefore they ignored them. For example, one of the larger bomas in Sinya ward from Leremeta had migrated to Il Donyo village, approximately 18 km away. The CDDs from Leremeta said if the researcher, the lead author, was not present to drive them to the temporary boma they would not have covered this boma. On the other hand, some CDDs added those in *ronjo* to the registers of the new sub village they were temporarily residing in, possibly falsely inflating the census for the village.

> *“Yes I’m aware of that [MDA] however those CDDs didn’t give us drugs because those who came were distributing drugs for people from Il Donyo only and they told us that we have to wait for CDDs from Leremeta because every CDD has his/her area to cover.”* [boma 10-2]

> *“We didn’t take them [Zithromax®]. And not because we refused but because those CDD’s didn’t come here to our temporary boma.”* [boma 10-2]

In almost all bomas visited during observation, most men had migrated outside the ward for up to several months in search for green pastures for larger cattle. This included the warrior group, *ilmuran,* approximately age 15-30 years; some junior elders, *ilpayiani* approximately age 30-50 years; and a few women. Children were always left behind in the ward with mothers and grandmothers, some to continue attending school and some to graze smaller livestock. In some cases, the men had migrated just outside the ward and the women reported that they delivered the drug to the men.

> *"Ilmuran were not at home [during MDA]. They migrated to temporary bomas with cattle. But because we do meet with them daily at the borehole we took their drugs to them."* [boma 13-2]

Aside from seasonal migration, routine human movement as shown in Figure 14, would occur within a day. Such movement affected the availability of community members when CDDs came to the bomas to distribute Zithromax® over the four days of MDA. The largest groups of people moving on a daily basis were women attending to domestic chores, including walking long distances to fetch water and firewood; and children grazing smaller livestock. A few men would visit men of their age sets either within the village or within the ward. In one case, after the exchange of cultural greetings between the CDDs and the elder of the boma, the elder excused himself to go visit a fellow *olpayiani* in the village. Due to age-grade differences between the CDD and the elder, the CDD was unable to question his decision to leave prior to being given the drug.

Many school age children missed MDA. The village of Leremeta has many children who are day students at a school in Kenya. A few children were boarding outside of Sinya. The majority of primary school aged children from all three villages were boarding at Sinya Primary School in Il donyo Village. Sinya Primary School has 928 students of which approximately 75% (n=700) are from Sinya. Distribution was done for all children boarding at Sinya Primary School. For the purpose of documenting distribution to school children, the CDD explained that the school was listed as a 'household' rather than recording at the household level. Yet in some cases, children were listed in the census of the school as well as the household thereby inflating the total census.

Figure 14 shows short-term population movement which occurs over a few days, greater than 24 hours and usually less than two weeks. This included men, usually *ilmuran*, visiting other men in their age sets but still within the village. Part of being an *olmurrani* is moving around with fellow *olmurrani* to engage in cultural activities together. Some men travel outside the ward for business usually to neighbouring Kenya or Longido. Elder women, *koko*, would visit their daughters and grandchildren married out of the village either still within Sinya or outside the ward.

> *A grandmother from outside Sinya is visiting a boma in Sinya to attend a female initiation ceremony. She will stay for another two weeks. CDDs discussed her situation and decided that when she goes back to her home village, MDA will be finished and she won't get the drug. So they decided to give her Zithromax® and add her to the census.* [field notes]

Socioeconomic Pressures

A related issue involves the abundance and seasonal distribution of wildlife in Sinya ward, which is also a challenge to the livelihoods of the local Maasai pastoralists. During MDA in July 2017, there were two separate hyena attacks on cattle. In one case, thirty-six goats and sheep were attacked by hyenas at night. When the CDD arrived at the boma, men were out searching for the remaining cattle and women and children were upset and distracted by the incident and did not want to receive or to use the Zithromax®.

Geographic Terrain

The geographic terrain also inhibits the movement of CDDs. For example, elephants were passing through the village of Endonyoemali during the week of MDA, preventing CDDs from moving from boma to boma to distribute Zithromax®. CDDs also reported covering long distances as sub villages are spread out over a large geographical area. Thus, such distances are not easy to cover by foot in regards to time and dangers of encountering wildlife and bicycles are not available in Sinya.

Domain 2: Socio-cultural factors and community agency

The Maasai have a very strong sense of cultural identity which is expressed in beliefs, norms, and traditions. There is a tendency for public health interventions to expect communities to place high importance on their programme with poor consideration of how interventions fit into the communities' priorities and the complexity of livelihoods (Bardosh, 2014; Hastings, 2016; Martineau et al., 2017; Parker et al., 2008). Communities are a social network influencing norms and behaviours. Control programmes need to understand and account for socio-cultural influences on individual and community decisions specific to marginalized communities in particular.

Disclosure of Pregnancy

Maasai tend to have high fertility rates due to a desire for large families. However, due to social convention women do not publicly discuss their pregnancy status, especially with men. This posed a challenge to CDDs, most of whom were men, as Zithromax® is not to be dispensed to pregnant women. Despite CDDs explaining this at each boma, no women observed disclosed that they were pregnant. Maasai wear a traditional cloth, the shuka, and typically, women wear a few layers of shukas loosely wrapped around their waist and on their shoulders. Due to the multiple layered clothes pregnancy is easily concealed. Instead of disclosing, women tended to imply their pregnancy through refusal.

> *Woman 1: "I can't take it."*
> *CDD: "Why?"*
> *Woman 1: "I have a small problem."*
> *Woman 2: "I can't take that. I may vomit."*

In response, some CDDs would ask if they had problems with their stomach, an indirect and acceptable way of asking if they were pregnant. Not all pregnant women took this action, rather they concealed the drug, likely to dispose of it later.

> *One mama was too shy to say she's pregnant so she accepted the drug and pretended to take it but didn't. She knew we saw so she started laughing along with all the other mamas.* [field notes]

During one household interview women explained that the CDD left drugs for those not present but these were not consumed by the returning pregnant women. In such cases, CDDs recorded these as administrated drugs, which falsely inflated coverage.

While observing MDA at one boma, CDDs estimated there were eight pregnant women in that boma, without evidence. As there was no direct confirmation of pregnancy or reporting though, it was impossible to know if these were refusals for other reasons.

Social Norms

In a pastoralist Maasai community, tending to the cattle is top priority, which was observed when visiting bomas. Traditionally livestock are viewed as a store of wealth, a source of food and symbol of prestige (Hodgson, 1999). Bomas are busy in mornings, requiring participation from most of the household including rounding up cattle, checking for illness, milking, spraying or washing cattle with insecticides, and making plans for grazing with young herders. While nearly all respondents reported this time (around 7am) as the ideal time to find most people home in the boma, tending to the cattle was their priority. While women and children may have been available, the established norm is to first sit down with men, in order to ‘share the news’, *anya ilomon,* and seek permission from the male head of the boma and other men to administer the drug. However, during early morning visits with CDDs men were often busy attending to cattle and CDDs were given limited attention and a low priority.

Decision making/ Social relations

In the socially tight-knit community of the Maasai, individuals can heavily influence the views and decisions of others. Some are more cooperative than others and some refuse, influencing the choices of their family members and neighbours.

Although women said that decision making around uptake of Zithromax® was theirs to make and permission from men is not needed, decisions were influenced by their female peers. There were some cases of active refusal from mothers and grandmothers who walked away with harsh words about the drugs or the programme.

> *Elder woman: “If you don't come with clean water to distribute drug then we don't take it.”*
>
> *Elder man: "Why you causing problems. You use this dirty water everyday. Why is it a problem today? Stop it!"* [field notes]

In another case an elder woman said *"I'm leaving because I have nothing to do with this programme."* The CDD explained the drug is for everyone including older people. The elder woman said *"I'll come back later."* She never came back while the CDDs were at the boma.

In some of these instances, those that 'accepted' did so with hesitation and were not seen swallowing the drug. It was thought some of these cases may have disposed of the drug when CDDs left. The *ilmuran* age group were observed walking away from the boma when CDDs arrived or refusing Zithromax®. This is likely due to norms of collective decision making among this male group. In Maasai culture, groups are based on age and rites of passage, which are an important means of defining your place in society and norms that are to be adhered to. *Ilmuran* are circumcised men, considered warriors. Traditionally they do not marry but are expected to be sexually active. Historically their role is for protection of livestock and property and therefore are exempt from herding. Although *manyattas,* warrior camps, are less common, *ilmuran* still spend most of their time with fellows forming strong bonds through various cultural traditions.

> *"They [ilmuran] didn't take [drug] because they were not around at the boma. So I'm unsure if they were around they would take or refuse. Also ilmuran do not easily swallow anything."* [boma 20-2]

> *"Some ilmuran refused the drug. Yes my husband [olmurrani] refused to take the drug."* [boma 09-2]

The influence of leaders and the people's relationships with CDDs motivated some community members to participate in MDA. Two of the three villages were well informed of plans of MDA and its benefits by village and sub village leaders. This was evident from the level of cooperation among these residents compared with the one village having less active leaders. Here the residents complained they had little information about the programme and showed uncertainty or asked a lot of questions.

Studies have shown higher coverage when CDDs are living close or within the communities (Emukah et al., 2008; Katabarwa et al., 2010; Parker & Allen, 2013). In this study people respected and trusted some of the CDDs of whom they knew and were comfortable with, which motivated them to take Zithromax®. Consistency of CDDs positively impacted coverage; one CDD observed during the 2017 MDA had worked in the same sub village for all 3 years of Zithromax® distribution, which had clearly influenced the high level of trust and positive response to the MDA.

Rumours

There were some misconceptions among women that Zithromax® was for family planning. Although when asked at the household interviews, all denied this belief and provided evidence to say it wasn't plausible.

> *"That [Zithromax® is for family planning] is not true because we took these drugs for three years now but women continue to carry."* [boma 04-2]

Yet some reported they heard this rumour but not at their boma,

> *"That [there is a rumour that MDA is for family planning] is true but this boma has no beliefs like that."* [boma 20-2]

While others linked trust or mistrust in MDA with experiences with trichiasis surgery. One boma (01-2) explained that because many women had no improvement after trichiasis surgery, it discouraged them from participating in MDA.

> *"There was a woman who had trichiasis surgery at this boma and now she is ok and that is why we trust you and your drugs now."* [boma 11-2]

Local Understandings of Disease

Local biomedical understandings of disease in general, of disease prevention and, more specifically, of trachoma are relatively poor in Sinya ward. The Maa term, *enaoji*, given for eyelid irritation, is not specific to trachoma but is recognized as a problem among Maasai (Mtuy et al., 2019). *Enaoji* is associated with environmental conditions or linked with supernatural influences. Prevention was not well understood and MDA was considered only for the purpose of treatment (Mtuy et al., 2019). The value placed on the control programme was low, in line with this local knowledge. And this affected people's motivation to participate. Health education by CDDs was also observed to be brief and inadequate.

On the first day of MDA in 2017, CDDs offered biomedical explanations for trachoma and the benefit of Zithromax® but explanations became notably shorter on subsequent days of MDA. In most cases, the CDDs made people feel comfortable to ask questions. Although overall there were few, most questions asked were related to clarification on side effects. Further explanations did not incorporate local understandings or benefits specific to the community at large. Specifically, the reason for ‘mass’ distribution (verses only for those that were ‘sick’) and the importance of a majority of the community to participate was never questioned nor explanations provided by CDDs, likely because CDD training did not cover this information.

> *There was confusion among the women distinguishing MDA from vaccination. They say the vaccination programme came to the area a few weeks ago for the kids. The CDD explains this is different and is for all people (little explanation on trachoma and the importance of the programme).* [field notes]

Domain 3: Strategies and motivation of community drug distributors

Despite the national NTD control programme providing adequate training materials and train-the-trainer programmes for MDA, there were adaptations to the delivery of the programme. This may have been done purposely to accommodate the local community and their needs or ad-hoc as they were uncertain how to interpret guidelines for localized circumstances. CDD training was conducted for the three villages together at Sinya Primary School.

Selection of CDDs

Selection of CDDs was challenging due to local interpretation of requirements that they can read and write, have completed primary school and are 35 years of age or older, of which few people in Sinya met such criteria. This was a misinterpretation of national guidelines that they only be able to read and write and come from the same community. In most cases CDDs were Maasai community members (n=15) but as some residents of sub villages did not meet the CDD criteria, four non-Maasai working in Sinya were selected as CDDs. A non-Maasai government worker was a CDD, for example. This person is not respected by the community, who claim he speaks harshly to community members and is not trusted. One resident said, *“He goes to MDA training to get allowance but did nothing with MDA... They are not* *serious."* This CDD avoided going boma to boma and requested community members to report to the dispensary for MDA. Many did not attend either because of their poor relationship with this CDD or because of distance needed to walk to the dispensary and the danger of encounters with wildlife.

Maa is the primary language of Sinya and many residents do not speak nor understand Kiswahili. The non-Maasai CDDs (21%) were unable to speak Maa and this proved challenging to provide information on MDA and trachoma and in one case to even pronounce and verify names on the registers. People responded more positively to those CDDs they were familiar with and who spoke Maa. Some remarked more negatively about non-Maasai CDDs, *"the Swahili boy"* or *"the Mchagga"* (person of the Chagga ethnic group). At one boma, the non-Maasai CDD read aloud the name of the male head of the boma. Very upset, an elder woman said, *"why are you calling his name. He is 'Papa'. It is disrespectful to call an elder by his name."*

Compensation

Overall, the Maasai CDDs were extremely motivated to support the programme and as they said 'to contribute toward improving the health of their people'. In many cases they walked 8 km in a day, they spent extensive time at bomas to comply with Maa greetings and norms and in some cases used their own money to hire transport to reach bomas further away or at risk of wildlife attacks such as herds of elephants, lions and cheetahs. Despite the national programme following WHO guidelines for CDDs which defines the role of CDDs as volunteers (WHO, 2020), the community perceived it differently. Maasai CDDs reported low compensation, no assistance with transport and inconsistencies in CDD training over the three years of MDA, including poor quality of training, delays in compensation and unfair selection of trainees. Similar complaints of lack of financial incentives, distances, and inadequate supervision among CDDs have been seen in numerous studies (Emukah et al., 2008; Katabarwa et al., 2010; Parker et al., 2012). At a ward meeting for the introduction of this research in September 2016, many freely spoke about their perceptions of MDA. A few spoke about the demands placed on CDDs. They talked about the challenges faced by these volunteers including locating migrating residents, distances travelled, encounters with wildlife, and poor compensation. They also talked about the unfairness of inconsistencies of compensation to CDDs among villages within the same district. Informal conversations with CDDs indicated mistrust of the district’s management of MDA. CDDS reported in the second year of MDA, 2016, only six out of twenty CDDs were selected to go for training, leaving many uninformed-on MDA procedures. In 2016, while these figures were not verified, from the perspective of participants in this study, the payment to CDDs after distribution was 42% less from 2015. In another village within the same district, CDDs demanded payment greater than a 3-fold increase and the district agreed. CDDs questioned if compensation was provided as per the programme budget if such an increase for one village was allowable. In 2017, despite one district level worker’s support and enthusiasm to accompany the researchers during MDA, she refused when allowances did not meet her expectations.

Transport

Due to geographic distances and time constraints, most CDDs did not revisit bomas to reattempt to deliver MDA to those absent during their initial visit. MDA delivery, therefore, in this widely dispersed community, with neighbouring bomas being up to 2 km apart, was a one-off visit. In cases of residents who were not at the boma during MDA but were still located within the ward (either ‘routine’ or ‘short term’ population movement), CDDs estimated the height of individuals with the assistance of family members and left behind the appropriate number of Zithromax® tablets with the women for family members to take on their return. In such cases, swallowing of tablets, pregnancy status, or updates to the census was not known nor accurately documented. This potentially led to overestimating coverage.

Domain 4: Socio-materiality of technology

Bardosh (2018) speaks of NTD health interventions, in this case MDA, as a technology that is embedded within social relationships. Zithromax® as a technology is perceived differently in different social contexts and by different social groups. In particular, side effects, restrictions of drinking water for post-partum women and *ilmuran* posed challenges for the community to accept the drug despite any understanding of the value of MDA for control of trachoma.

Zithromax® was often referred to as “*indunda naado”* [that red pill] or described as big and pills they had to take many of. One participant (01-1) remarked about the *“pill with corners”.* Although western medicine is accepted and used by residents of

Sinya, physical appearance and possibly the meaning they attribute to Zithromax® was different compared with other biomedicine.

Side effects

Zithromax® was distributed for three years in Sinya and people either experienced first-hand or heard of others who had side effects including vomiting, diarrhoea and less common were headaches and dizziness. In one instance, a girl about age six, was observed vomiting just minutes after taking Zithromax®. Most people reported that the number of people complaining of side effects were less each subsequent year. They mentioned that height sticks were not used in the first year and this may contribute with the large number of reported side effects. Some were not bothered by the vomiting and diarrhoea since that is a common local Maasai treatment for many illnesses, a form of cleansing and ridding the body of illness (Sindiga, 1995b).

Restrictions due to norms

Post-partum women are restricted to only tea for the first six months post-delivery. Some post-partum women refused to take the drug because they could not take it with water and the option of taking it with tea was not raised. Others did so after other women told them it was ok for the purpose of taking medicine. Others had requested clean water in order to swallow Zithromax®. Only one CDDs carried a bucket of water for taking with the drug, although it was not clean. One of the restrictions for the *ilmuran* age group (men ages approximately 15-30) is that they are not allowed to consume any food, beverage or medicines alone. It can only be done in the presence of a fellow *olmurrani*. During MDA, there were few *ilmurrani* in Sinya due to migration and therefore some *ilmuran* either refused or put the Zithromax® away until they met with a fellow *olmurrani*, and it was uncertain if they took the drugs or not. In these circumstances CDDs still recorded individuals as taking Zithromax®, potentially inflating coverage figures.

Domain 5: History and health governance

The Maasai of Tanzania have a history of socio-political subjugation stemming from land allocation and lack of inclusion in the colonial government (Hodgson, 1999; Hodgson 2001; Wagner-Glenn, 1992). According to Hodgson (2011a), the lack of health facilities and schools in their communities, poor health services in urban settings due to language barriers and the different views on their “development” with that of the government and international donors have resulted in their demands for basic human rights. More recently, Maasai have been evicted from part of the Serengeti National Park to create a hunting reserve for the Dubai royal family (Smith, 2014). Access to schools, health facilities, water and roads are still limited compared with the rest of the country (Sikar & Hodgson, 2006). For example, the Maasai have low vaccination coverage which has been attributed to poor engagement with, and availability of, health services in their areas (Lawson et al., 2014). The political-economic context also had a major influence on responses to MDA, most visibly in the community's lack of trust in the governments approaches to delivery of programmes and responses to community concerns including vertical approach of allocating public health resources and misalignment of priorities requiring assistance namely water and animal-human conflicts.

Mistrust

A lack of trust in non-Maasai, *ormeek,* visitors was evident in Sinya. Many *ilmuran* would run into the bush at the sight of the researcher's Land Rover, similar to many government vehicles. The elders would laugh and remark that they thought we (when I was driving CDDs of which I observed) were the government recruiting them for the military. Girls who did not attend school would hide when we arrived at their homes in fear that they would be brought to school as per government regulations but against their fathers' choices.

Many did not know who was involved in the MDA programme beyond CDDs and the village doctors. Although MDA was supported by the national NTD control programme and international partners, participants were concerned that representatives did not visit Sinya around the time of MDA. A few attributed the programme to *wazungu* (white people) or 'a white woman', suggesting either the lead author or a woman who previously provided deworming drugs. People complained of lack of information and involvement of community members in the MDA programme. When the responsible government programme and international partners involved in trachoma control were explained, people showed more respect for the programme.

> *"The drugs come from mzungus [foreigners]? (in positive tone)"* [boma 11-2]

> *"Government should tell us [about partners] and appreciate everyone's contributions."* [boma 14-2]

Misalignment of community verses government's priorities

Whilst perceptions of the programme were positive, the community questioned government priorities including lack of resources including access to hospitals, medicines, clean water, and roads. Many said the MDA programme is beneficial to the community but why can't the government provide health services all the time, clean water, and roads. People were sceptical about the government's efforts to control trachoma while the community's concerns and needs for government assistance in other areas were ignored. A vertical approach of distribution of public health resources from district to front-line primary health facilities and programmes proved ineffective. Availability of drugs in the dispensaries was limited and treatment restricted to a lack of specialized medical skills. For some residents of Leremeta, it is a 17 km journey to the nearest dispensary in Il Donyo. The closest hospital was 60 km away in Longido. There was no public transport to Longido and the journey by foot dangerous due to wildlife. During the time of this study, the only health programmes visiting Sinya was the district vaccination programme, trichiasis surgery camps, and Marie Stopes for family planning services. While a number of NGOs that provide health programmes to Maasai communities were interviewed, most didn't work in Sinya stating it was too remote.

> *"We would like if they use the resources [for MDA] to build a hospital which will have drugs for trachoma and other diseases."* [boma 10-2]

> *"We would like if they [the government] bring a hospital near to us because wild animals are a big challenge to us, especially elephants. So we wish they [the government] will help to solve this challenge because we travel many kilometres to go look for health services."* [boma13-2]

Water was scarce in Sinya. There were three boreholes for the ward. Two were powered by generator, thereby only in operation a few hours a day and one a manual pump. Within three months following MDA, the government improved the existing boreholes using solar power. Some thought this was part of the MDA programme and were appreciative.

> *"I think the programme is ok because for the first time we have clean water by which the government put in boreholes."* [boma 11-2]

Community specific concerns not addressed

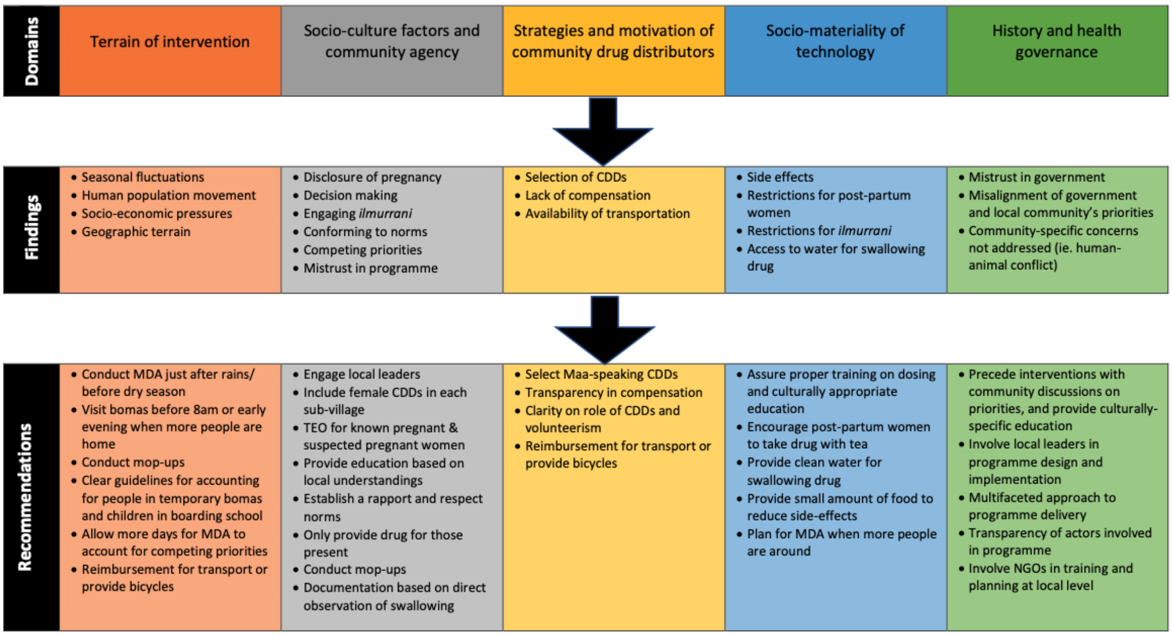
Animal-human conflict is a common occurrence in Sinya, something of major political interest. People remarked of the lack of government involvement or compensation for livestock killed by wildlife while their neighbours on the Kenya side are compensated by the Kenya government. This issue was raised by residents of Sinya in everyday discussions and during household interviews when asked about perceptions of programmes working in Maasai communities. Two NGOs focusing on protection of wildlife and reducing human animal conflict previously worked in and around Sinya. Reasons for why the organizations left Sinya were unclear. Some explained that the NGO saw the community as uncooperative and not wanting to let go of their traditions of hunting lions among the *ilmuran* age group. Others said they do not hunt for traditional reasons but rather kill wildlife in retaliation for attacking their cattle. They claim the government doesn't provide assistance to reduce the conflict or compensate people for losses from wildlife.

The community's perceptions that the government has failed to fulfil promises has potentially impacted their trust in government programmes and officials. In a community meeting with the regional commissioner in November 2016, Sinya residents complained of not receiving promised compensation from a foreign aid project giving to those living on less than $1 per day and compensation from the 2009 draught promised to pastoralists by the previous president. Historically, similar situations have been documented related to government promises to the Maasai on land use (Hodgson, 1999). Many complained of tensions created from tourist camps in that the land rent paid via WMA hasn't been seen by the community. Despite potential local government interference in how money is used, the community blames development actors (such as NGOs) for these disputes.

Discussion

This study identified factors specific to Maasai communities that contribute toward the effectiveness of delivering a mass distribution programme of Zithromax® for trachoma. This research uncovered social, economic and environmental barriers to programme implementation but furthermore the effects of a complex political economy. The implications of these findings and planning recommendations are detailed here, and highlighted in Figure 15, according to the five domains.

Figure 15. Findings and recommendations for planning control programmes



Domains	Terrain of intervention	Socio-culture factors and community agency	Strategies and motivation of community drug distributors	Socio-materiality of technology	History and health governance
Findings	• Seasonal fluctuations • Human population movement • Socio-economic pressures • Geographic terrain	• Disclosure of pregnancy • Decision making • Engaging *ilmurrani* • Conforming to norms • Competing priorities • Mistrust in programme	• Selection of CDDs • Lack of compensation • Availability of transportation	• Side effects • Restrictions for post-partum women • Restrictions for *ilmurrani* • Access to water for swallowing drug	• Mistrust in government • Misalignment of government and local community's priorities • Community-specific concerns not addressed (ie. human-animal conflict)
Recommendations	• Conduct MDA just after rains/ before dry season • Visit bomas before 8am or early evening when more people are home • Conduct mop-ups • Clear guidelines for accounting for people in temporary bomas and children in boarding school • Allow more days for MDA to account for competing priorities • Reimbursement for transport or provide bicycles	• Engage local leaders • Include female CDDs in each sub-village • TEO for known pregnant & suspected pregnant women • Provide education based on local understandings • Establish a rapport and respect norms • Only provide drug for those present • Conduct mop-ups • Documentation based on direct observation of swallowing	• Select Maa-speaking CDDs • Transparency in compensation • Clarity on role of CDDs and volunteerism • Reimbursement for transport or provide bicycles	• Assure proper training on dosing and culturally appropriate education • Encourage post-partum women to take drug with tea • Provide clean water for swallowing drug • Provide small amount of food to reduce side-effects • Plan for MDA when more people are around	• Precede interventions with community discussions on priorities, and provide culturally-specific education • Involve local leaders in programme design and implementation • Multifaceted approach to programme delivery • Transparency of actors involved in programme • Involve NGOs in training and planning at local level

Climatic conditions are central to the livelihoods of pastoralists and impact the optimal timing for community-based interventions. Similar seasonal challenges were seen in a rabies control programme among pastoralists in Tanzania (Bardosh et al., 2014) and interventions competing with harvest season (Bardosh, 2015; Bardosh et al., 2014). MDA programmes should be planned around seasons to reduce the frequency and distance of human population movement and reduce the stress that comes with draught and missed economic opportunities. Accounting for the complexities of human population movement in this Maasai community, the programme should consider additional resources to allow for return visits and traveling to those who are temporarily relocated outside their village. This would improve actual coverage and not rely on assumptions that individuals would take the drug left behind with family members. It is likely coverage was falsely inflated based on this assumption. Although rates of trachoma have decreased in these communities, research has shown in the absence of socioeconomic changes, prevalence of NTDs often return to former levels (Amin & Abubaker, 2017; Nikolay et al., 2015). The high volume of human population movement among Maasai communities need to be considered in regards to reoccurrence of infection as seen in some migrant trachoma endemic communities (Burton et al., 2005; West et al., 2015). Compliance, which should be differentiated from coverage, is the frequency in which individuals have taken the drugs over repeated treatment rounds (Bockarie et al., 2013). Special attention needs to be given to non-compliers as potential sources of reinfection.

Although this community recognized trachoma as a problem (Mtuy et al., 2019) it was not a priority against a back drop of complex livelihoods. Other ‘needs’ took precedence making it clear that MDA should work around those needs. This was not unique to the Maasai or to trachoma control but seen more broadly in countries of poverty (Bardosh, 2016; Bardosh et al., 2014; Parker et al., 2012). The push for programmes to demonstrate high coverage and value for money obscure the need to articulate social realities in the communities. Additionally, rumours and refusals were evident in the community partly owing to misinformation. Rumours may also have a historical or political origin or result from cultural beliefs (Hastings, 2016; Parker et al., 2008). Rumours of health interventions causing sterility or containing contraceptives has been documented since the 1920s in Africa including vaccinations, malaria treatment and vitamin supplementation. Rumours of drug-induced sterility as well as cancer were reported in MDA for trachoma in Tanzania (Desmond et al., 2005). The act of passing on rumours may not be related to whether the person passing it on believes the rumour (Geissler & Pool, 2006) but rather a response to someone’s mistrust or uncertainty in something. It is critical that rumours be recognized, analysed and addressed, rather than seeing them as impediments to a public health programme (Kaler, 2009).

Knowledge of trachoma is poor in this community (Mtuy et al., 2019) and education provided by CDDs were observed as being minimal. A common belief is that if one is feeling well then there is no need for treatment (Desmond et al., 2005; Parker et al., 2008; Ssemanda et al., 2012). In another study in Tanzania (Desmond et al., 2005), sensitization was also poor with 56% of respondents being satisfied with the amount of information they received prior to Zithromax® distribution. Additionally, poor knowledge transfer can be linked to inadequate financial incentives for CDDs and village leaders (Bardosh et al., 2014).

Additional sensitization should be done with the *ilmuran* age set including their leaders and elders. Local leaders can help mobilize this more resistant group and engage them in meetings and education. There is motivation to help within the community when fair and transparent compensation is promised. Strategies for distribution among this group can be done more collectively to avoid cultural barriers such as issues of masculinity and conforming to norms and peer choices. Importantly, such strategies require financial incentives.

All people ineligible for Zithromax, should get tetracycline eye ointment (TEO) as per ITI guidelines. Guidelines in Tanzania should be updated to include TEO for known pregnant and suspected pregnant women. MDA programmes should consider including a female CDD in each sub village to engage with women. Female CDDs can provide more education and solicit more information from women to assure dispensing of appropriate forms of antibiotic and improve actual coverage. With high fertility rates in Maasai communities, there is a potential reservoir of untreated *chlamydia trachomatis*. A combined programme of MDA with F and E components of SAFE may reduce infection as seen in Sudan (Ngondi et al., 2006) particularly as transmission is highest between mothers and children (Congdon et al., 1993).

Despite self-motivation of Maasai CDDs, the shortfalls of the programme had a trickle-down effect. CDDs were straddling the context of the programme and the interests of their community. Limited resources, pressures for high coverage and challenges with actors imbedded in the programme left CDDs frustrated and less motivated to provide much needed education during MDA. Similar to other control programmes, far distances to be covered (Bardosh, 2016; Parker & Allen, 2013; Parker et al., 2012) and possible encounters with wildlife were the main barriers for CDDs to deliver MDA to the community. Programmes can consider resources for transportation either through reimbursement or providing bicycles. Furthermore, the national programme’s expectation of the role of CDDs and their notion of volunteerism should be communicated prior to MDA and be consistent across the district to avoid misunderstandings. Additional catchment areas assigned to CDDs should be well estimated to assure CDDs can carry out responsibilities effectively-providing education, covering long distances, conducting mop-ups and engaging leaders.

Side effects of Zithromax® were commonly reported as seen in other studies (Astale et al., 2019; Desmond et al., 2005). This is likely to be partly due to improper dosing. In some instances, CDDs didn't use the dose poles and estimated doses. Additionally, side effects are likely due to having empty stomachs when swallowing the drug. This should be considered in timing of distribution or better, yet programmes consider resources for providing a small amount of food and water during distribution.

This control programme is situated within a context of politics, history and a shifting economy possibly influencing the response to the government and donor-led programme. Land tenure policies created by the colonial administration in early 1900, many of which still exist today, were an effort to consolidate or isolate the Maasai and their cattle into designated areas and restricting their movement and interactions outside those areas (Hodgson, 1999; Wagner-Glenn, 1992). Examples of resistance are noted in their history including the reaction to the colonial administration's veterinary policies (Hodgson, 1999) and poor guidance by international NGOs focusing on the indigenous movement for Maasai (Hodgson, 2011a). More recently, media reports have indicated a continued sense of political subjugation, marginalization and cultural discrimination of the Maasai (Magubira, 2014; Mjema, 2014; Smith, 2014). The traditional lifestyle of the Maasai is fragile with changes in traditional migration due to reduced access to land and changes in weather; shifts in gender roles as women demand more ownership rights and decision-making power, and economic shifts due to drought and reduced grazing land leading men to migrate for work and women seeking income generating projects. This historical context and cultural shift have possibly led Maasai to uncertainty and suspicion of government programmes. Although appreciation was expressed for the government's efforts with this programme they questioned the lack of transparency of local and international actors involved. Repeatedly they felt frustrated by what they perceived as conflicting messages- distribution of drugs for NTDs yet essential needs for water or dispensaries with available medicines are not met. Other studies in Tanzania have seen similar barriers related to the nature of vertical programmes and the involvement of NGOs, government, and local communities in control of NTDs (Bardosh et al., 2014; Madon et al., 2014; Mubyazi et al., 2004; Parker et al., 2008; Samsky, 2011).

This study had some limitations. The lead researcher, a non-Maasai or *ormeek*, was aware of potential misunderstandings of her intentions of residing in the community. She may have been seen as representing NGOs or the government associated with MDA. To assure understanding of her position, the lead author lived in Sinya for ten months prior to MDA and spent significant amount of time engaging community members and local leaders in the research. It is also possible that the lead author's presence during MDA could have altered the choices and behaviours of the community. Her presence may have motivated trainers to conduct a more thorough CDD training, CDDs may have provided more education during distribution and community members may have been less resistant to the drug in the presence of a trusted outsider. The lead author assisted in providing transportation to CDDs and community members in a few instances. Although this was only done in cases in which households had temporarily moved out of the sub village, is it possible that it could lead to future expectations that the programme support transportation for CDDs. With coming face to face with realities of communities, field researchers are often in the position to empathise with the needs of those in the community (Kingori, 2013). This study did not verify reports of programme planning and implementation from the national programme and at district level as the focus was on the perspective of the community. Further to this, the representativeness of Sinya to other Maasai communities in Tanzania remains unclear. This purely pastoralist community may overrepresent human population movement compared to agro-pastoralist Maasai communities, for example. Despite this, it is important to note that the communal nature of Maasai culture is still very traditional and consistent across different Maasai districts and economic levels.

In conclusion, implementing MDA programmes at the district level could be more effective as a joint SAFE programme rather than implementing them independently. To assure more accurate documentation of coverage, CDDs should distribute drugs only to those present as per guidelines, using a directly observed treatment (DOT) approach. Due to a high degree of human population movement in this population, return visits and tracking of migrating individuals would assure improved coverage. Use of electronic data capture can allow for tracking individuals and distributing drugs to those who may have temporarily migrated from another sub village. Education underpins all five domains. Knowledge and transparency allow the community to make more informed choices, avoids misunderstandings and rumours and improves respect for control programmes, ultimately improving cooperation and uptake.

As the end game of trachoma elimination is near, hard to reach communities are likely to be the last foci of infection. Effective delivery of MDA programmes in hard-to-reach communities, including Maasai, requires a critical understanding of community experiences and responses that can inform tailored approaches to trachoma control. It comes down to a commitment of additional resources as the current strategies will not achieve similar outcomes in these hard-to-reach communities of poverty. Application of a critical bio-social perspective should be imbedded in planning and evaluation of all NTD programmes.

Acknowledgements

The study team would like to extend its gratitude to the community for their collaboration and participation in this study and to the village leaders for their support and collaboration on the field work.

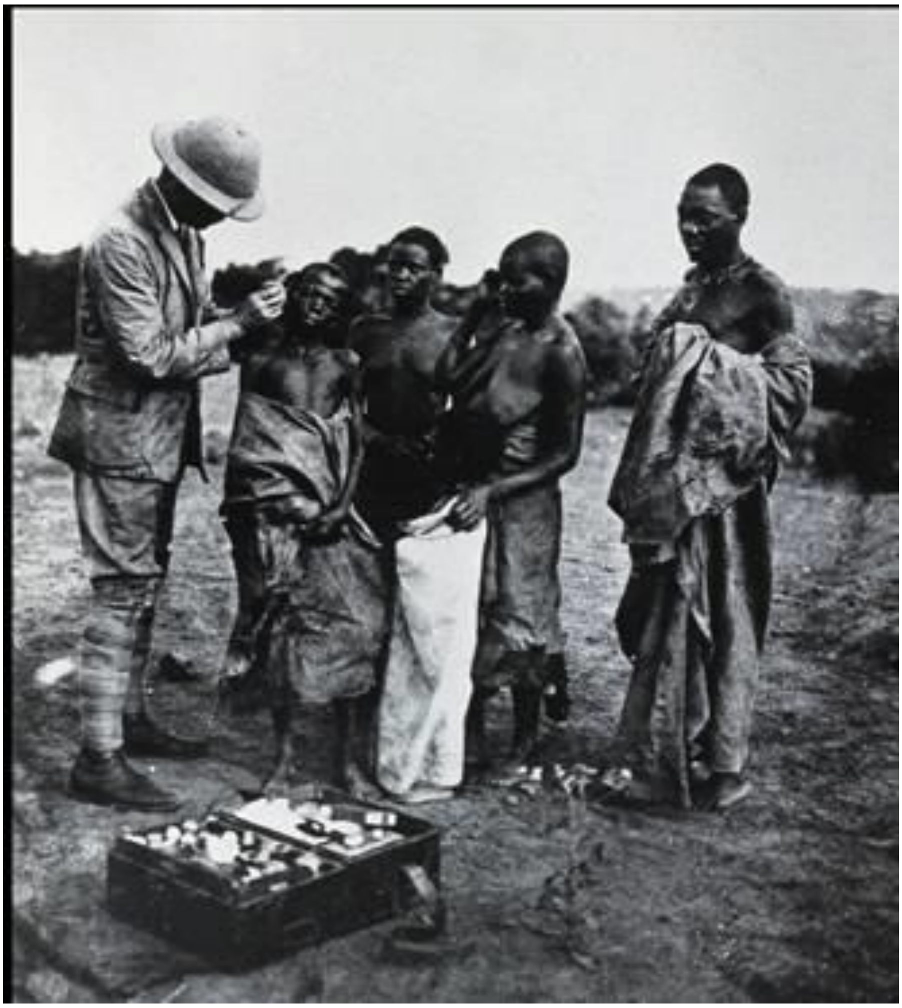
Ethics

This study was fully compliant with the ethical principles set out in the Declaration of Helsinki. The study was approved by the Ethics Committees of the National Institute for Medical Research, Tanzania and the London School of Hygiene & Tropical Medicine, United Kingdom. Free and informed consent for household interviews were obtained from the male head of the boma in Maa and a witness was present for illiterate participants. Permission to digitally record interviews was obtained from each male boma elder.

Conflicts of Interest

The authors have no conflicts of interest to declare.

Chapter 5: Engaging with Health Care: Expectations and Experiences



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Surname/Family Name	Mtuy		
Thesis Title	The role of cultural safety and ethical space within postcolonial health care for Maasai in Tanzania		
Primary Supervisor	Dr. Shelley Lees		

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Stage of publication	**In press**

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SECTION E

Student Signature	Tara B. Mtuy
Date	24 October 2022

Supervisor Signature	Shelley Lees
Date	24 October 2022

Overview

The previous chapters (3 and 4) focused specifically on trachoma, namely discourse and response to control programmes. In chapter 3, I describe the influence of indigenous knowledge for managing trachoma. In chapter 4, I discuss the impact of the historical and political context of Maasai on their response to mass drug administration and the importance of a biosocial perspective on delivering health programmes. Chapter 5 aims to bring together these historical, political, and social concepts by exploring, more broadly, at how Maasai engage with health care using a postcolonial discourse. I explore the barriers and facilitators to accessing health services within the framework of cultural safety and ethical space. Although older concepts originating from nursing care in the 1990's, these concepts have previously only been applied to indigenous groups in high income countries where indigenous groups have been marginalised. I adopt these frameworks to explore the Maasai as a marginalised indigenous group in this African context. This thread of engaging with health services emerged throughout all my field work and therefore I draw on all my data to conduct analysis for this chapter.

This paper contributes to research objective 8:

8- To explore the Maasai's access and response to health care services more broadly.

The findings presented in this paper sheds light on power relations that emerged from colonial and post-colonial political systems in Tanzania and show how systems of dominance transcend health care settings. The findings reveal, an imbalance of trust, respect, and consideration between health seeking Maasai and health care works alongside attempts to accommodate indigenous practices and beliefs into health care practices in services used by the Maasai. I highlight the importance of utilizing cultural safety and ethical space to make health care services accessible and safe for Maasai.

The role of cultural safety and ethical space within postcolonial health care for Maasai in Tanzania

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Abstract

The history of the Maasai tribe in northern Tanzania, is characterized by marginalization, discrimination, and political subjugation. Inequities enacted through power relations, influence health care access, practices, and outcomes among the Maasai. Cultural safety and ethical space provide lenses into social, political, and historical influences on access to care, helping to understand the realities of historically marginalized populations such as the Maasai, and responses to health services. This study aims to examine Maasai experiences of accessing and uptake of health services within a postcolonial discourse in Tanzania.

In an ethnographic study examining access and perceptions of health care services in Maasai communities, lead authors conducted participant observations, and at health facilities to document experiences. Household interviews, a group oral history and interviews with NGOs working with Maasai communities contributed to the data analysed. Inductive thematic analysis was used to understand health care experiences within a framework of cultural safety and ethical space.

Despite trust in biomedicine, Maasai people have a strong desire for health services with particular characteristics. Quality of care, including facilities and diagnostics available and utilized was important. A sense of fairness was a determinant in respecting services including ‘first come first serve’ system and transparency when unable to treat a condition. Trust in health services was also influenced by personal interactions with health workers including provision of health information provided to patients and instances of being mistreated.

These findings offer an understanding of ways in which spaces of health care can be more approachable and trusted by Maasai. Incorporating cultural safety and ethical spaces to understand health care access can help to reduce the power imbalance possibly resulting from a history of marginalization. This can inform development of culturally appropriate programmes, used to educate health care professionals and advocate for improved health care services for marginalized groups.

What is already known on this topic

The Maasai tribe of Tanzania are particularly disadvantaged in their health status. Considering a history of social and political subjugation, trust and access in health services can be a result of how Maasai have been treated historically. Indigenous peoples are overlooked in health care policy and practice.

What this study adds

This study utilized a framework of cultural safety and ethical space to explore historical, social, and political influences impacting Maasai experiences with health care and interpersonal relationships in Tanzania. Quality of care, facilities, diagnostics, and a sense of fairness are determinants in respecting services. This study highlights the impact of trust, power, and language on accessing and uptake of health services resulting from colonialism.

How this study might affect research, practice, or policy

These results demonstrate a need to involve Maasai and other marginalized groups in defining their needs for cultural safety in health care settings. This can inform development of culturally appropriate health programmes for these communities and inform policy to incorporate cultural safety into training of health care professionals.

Introduction

Since the turn of the twentieth century, the Maasai, a traditional pastoralist tribe in East Africa, have encountered social and political subjugation. The Maasai tribe and similar tribes who share the same language have settled in parts of Kenya and Tanzania, having different historical, political, and socioeconomic influences. This research focuses on Maasai in Northern Tanzania.

In the early 1900s, periods of colonial rule by the Germans followed by the British, led to a land shortage for the Maasai of Tanzania. Land tenure policies, many of which still exist today, were an effort to consolidate and isolate the Maasai people and their cattle into designated areas and restrict their movement and interactions outside those areas (Benjaminsen et al., 2013; Brockington, 2004; Homewood, 1995; Homewood et al., 1987; Spear & Waller, 1993; Sulle & Banka, 2017; Wagner-Glenn, 1992). Land tenure policies were motivated by efforts to establish and protect conservation areas and national parks in Tanzania and further to protect revenue generating from European trophy hunting. They were also a response to British colonialists efforts to capitalize on what they saw as economic benefits from the pastoralists (Hodgson, 1999; Lankester & Davis, 2016). Among the Maasai, resistance to such policies led to avoidance of cattle inoculations, circumventing cattle quarantine restrictions and disregarding restrictions on their movement in and out of areas (Hodgson, 1999; Lankester & Davis, 2016; Waller, 2004; Waller & Homewood, 2017). This marginalization and power imbalance wove into many facets of life for Maasai people carrying into the present, in which Tanzanian society post-independence has redefined local norms and shaped social structures including health care delivery and access (Anderson et al., 2003).

Today, land disputes continue to complicate the livelihoods of Maasai and builds on a historical sense of marginalization and cultural discrimination. The lack of health facilities and schools in their communities, poor access to health services in urban settings partly due to language barriers and the different views on their “development” held by government and international donors have shaped access to opportunity, economic conditions and overall health of Maasai (Hodgson, 2011b).

The Maasai originated in what is today Sudan and the lower Nile Valley and slowly migrated south along the Rift Valley to Tanzania (Spear & Waller, 1993). Although

Maasai are one of around 120 ethnic groups in Tanzania (Malipula, 2014) of which it can be argued are all indigenous, the focus on Maasai as 'indigenous' for this analysis is the maintenance of a way of life and a history of social and political marginalization. Indigenous peoples conform with social, economic, and cultural customs that are sharply distinct of dominant groups. There is a lack of control to preserve traditions through their political position and policies from imposed cultural hegemony (Corntassel, 2003). We argue that Maasai people are similar to indigenous groups in North America, New Zealand and Australia with respect to the value of upholding historical traditions and their struggles to maintain a particular way of life.

Access to Healthcare

Whilst health care delivery to rural settings in Tanzania has improved in recent years, there has been little attention to tailoring services for marginalized communities, including Maasai (Lawson et al., 2014; Mtuy et al., 2021; Wanzala et al., 2005). Poverty and poor health care exist among other ethnic groups in Tanzania yet the Maasai are particularly disadvantaged with regards to zoonotic diseases (Bodenham et al., 2020; Kriegel et al., 2021; Mwakapeje et al., 2018), antimicrobial resistance (Caudell et al., 2017; Mangesho et al., 2021; Roulette et al., 2017), women's health (Birks et al., 2013; Lennox et al., 2017; Powell et al., 2020; Roggeveen et al., 2013), and nutrition (Galvin et al., 2015; Homewood, 1992; Lawson et al., 2014). In comparing the health status of five ethnic groups of northern Tanzania (Lawson et al., 2014), in which poverty exists in all groups, the Maasai were the most disadvantaged in regard to child nutritional status and disease compared to the Rangi, Sukuma, Meru and mixed ethnicities. Food insecurity was severe and vaccination coverage the lowest among the Maasai. Poor health status among the Maasai people may be linked to reduced access to health care, access to knowledge and poor health seeking behaviours (Wanzala et al., 2005). Trust and access in health services can be a result of how groups of people have been treated or are seen by others. The commonest reasons for dissatisfaction with health services in Tanzania include long waiting times; only brief encounters with medical staff; negative attitudes of staff toward patients; feelings of confusion and being alone in an unfamiliar environment; and prescribed medication with no explanation of the cause of illness (Gessler et al., 1995; Gilson et al., 1994; Muhondwa et al., 2008). Consequently, such experiences may contribute towards a level of mistrust in health systems particularly among marginalized groups.

In considering the Maasai’s access to healthcare, we argue that low uptake of the formalized healthcare system among Maasai people is linked to blame for their ‘culture’ and for health services not being aligned with their social norms. Although the shifting concept and definition of ‘culture’ is highly debated (Baldwin et al., 2006; Jahoda, 2012; Mironenko & Sorokin, 2018), culture is a multidimensional phenomenon that encompasses processes, products and results of human activity, material and spiritual, transmitted from generation to generation in a non-biological way (Mironenko & Sorokin, 2018). Yet the focus of culture as only external, differentiated societies and labelled Maasai as “primitive”, “backwards” or “different”. Culture is a problematic concept and ways in which it is negatively deployed, results in indigenous groups being blamed for their social norms. Ferguson (2013) argues that rather than cultural inferiority, inequities should be understood in terms of political, economic inequality or a result of hierarchical relations.

Health systems are dominated by values, procedures and processes often not aligned with and less inclusive of marginalized populations. Barriers encountered by Maasai people when accessing health services are rooted in a historical, political context. This impact on the relationship between the health system and Maasai community has not been well explored by researchers. These inequities are enacted through power relations and influence health care access, practices, and outcomes among this community.

Postcolonialism

The definition of postcolonial varies and is dependent on time periods, geographical context, and the experiences of colonialism, past and present. In Tanzania, it is the way in which culture, ethnicity, and race have been constructed and experiences of oppression and resistance as a result of German and British colonial practices (Anderson et al., 2003; Browne et al., 2005). Drawing on Smye and Browne (2002) McConaghy describes post-colonial as a time for back and forth reflection, on ideas of the past, solutions for today and the structures that create them.

Referred to as ‘The Disaster’ from 1884-94 outbreaks of bovine diseases wiped out 95% of cattle in East Africa (Waller, 1976; Waller, 2019). Introduced diseases such as smallpox and leishmaniasis coupled with famine wiped out two thirds of the Maasai population (Waller, 2019). One of the results of their reduced population was a reduction in the practice of traditional ecological control measures and increase in tsetse flies and a rinderpest epidemic among wildlife, decreasing populations among some species while creating resistance among others. This coincided with the start of German rule of Tanganyika (name given to mainland Tanzania pre-independence) that was formalized in 1890 by the Anglo-German Agreement (Hodgson, 1999). German colonialists were confronted with an environment scarcely populated by people and wildlife impacted by rinderpest, setting “a benchmark by which wildlife conservation has been judged ever since” (Lankester & Davis, 2016). Despite Maasai playing a significant role in ecological balance, the German colonial government assumed the Maasai people, and their cattle were incompatible with the landscape. This initiated the separation of wildlife conservation, hunting and pastoralism and the implementation of practices of state rule and discriminatory policies against Maasai.

The German administration imposed direct rule and established a system of monitoring and controlling Maasai raiding and movement (Hodgson, 1999; Waller, 1976). Germans allied with the Maasai’s neighbouring tribe of Kilimanjaro, the Chagga, to defend against Maasai raids of Chagga settlements for their cattle. The German administration formed a Maasai Reserve to consolidate the ethnic group to make way for European settlement and cutting them off from important trade opportunities and critical grazing areas (Hodgson, 1999; Waller, 1976).

These practices were later continued and expanded by the British colonial government who took over Tanganyika informally in 1915 and formally in 1920 under a League of Nations mandate. In 1929, central Serengeti became a game reserve and in 1951 a national park, moving Maasai communities to Ngorongoro Conservation Area. Up to the present, further establishment of game reserves, national parks and Wildlife Management Areas in Maasai land led to evictions or restrictions on cultivation (Homewood, 1995; McCabe, 2003). The British set up a system of indirect rule of the Maasai, reshaping gender and age relations within their communities. Specifically, this system of government extended authority to men, particularly elder men, to hold new rights and responsibilities including collecting taxes, enforcing livestock decisions, and codifying customary law (Hodgson, 2001).

A plural wives tax put women in the same category as taxable property and from 1927 to 1940's, Tanganyika's highest tax rate was paid by Maasai (Hodgson, 2001). Gendered spaces of 'political' and 'domestic' were partly attributed to the gendered nature of the British administration itself. Veterinary policies implemented under British colonial rule included a permit system for the Maasai's movement of cattle within and outside of the reserve, quarantines for cattle to be inoculated and systems to 'improve' Maasai animal husbandry practices. Such livestock restrictions were a form of control over the pastoralist's lifestyle and their strong social relations (Hodgson, 1999; Homewood, 1995; Waller & Homewood, 2017). Public health and medical services were designed and introduced by the British administration, as a system catered to protect the colonialists (Turshen, 1977).

Such colonial practices created norms of oppression that were carried over into independence by the Tanzanian government from 1961 and shaped the power imbalances between the Maasai and the state. This included further restricting access to rangeland, greatly reduced market for livestock trade and limited access to health facilities and education (Hodgson, 2011a; Homewood, 1995). A discourse of blaming Maasai for irrational pastoralism influenced state led development programmes to modernize land management, settle communities and manage resources through an introduction of villagisation, ranches and Wildlife Management Areas (Benjaminsen et al., 2013; Homewood, 1995; Lankester & Davis, 2016; Sulle & Banka, 2017). Maasai epistemology of health is pluralistic incorporating biomedicine and veterinary knowledge. Current 'livestock policies further embedded livestock and human health policies, processes and provisioning of services in separation and bordering" (Davis and Sharp 2020, p.5).

Today health care workers are not descendants of colonialists but descendants of Africans from many ethnic groups also living in Tanzania for centuries (Malipula, 2014). Health worker's discriminatory practices toward nomadic groups and in particular Maasai has been well documented (Ali et al., 2019; Karanja et al., 2018; Mbwele et al., 2019; Mosley et al., 2020; Roggeveen et al., 2013). This legacy of the ethnic groups' colonial past and neo-colonial present along with globalization has shaped the relationships between Maasai and other African Tanzanians in health care settings. The colonizer or oppressor, and the colonized or oppressed are fluid categories with restructuring of global capital, new information technologies and emerging thought and power relations that define the elite and the marginalized today (Anderson et al., 2003). It is important to recognize the complexity of social interactions that do not lend themselves to binary distinctions. In doing so there is a danger of supporting the power imbalances aiming to be disassembled (Anderson, 2004; Yeung, 2016). Rather McConaghy (2000) describes the focus as, “an important task to better understand the specific nature of specific oppressions at specific sites: to understand current forms of oppression” (p.8). Aware of this critique, postcolonial discourse is a useful and important perspective for understanding and addressing health inequities among Maasai people.

Theory

Cultural safety and ethical space

Cultural safety provides a lens to reflect on how cultural and social power dynamics impact health worker and patient relationships. Cultural safety is an approach of focusing health care delivery based on the experience of the patient and, in particular, the attitudes and interactions of the health professionals with whom they interact with. Culturally safe practice involves “actions which recognize, respect and nurture the unique cultural identify of an ethnic group and safely meets their needs, expectations and rights” (Wood & Schwass, 1993).

Cultural safety should not be confused with cultural competence, knowledge, awareness, understanding, or sensitivity although all of these are antecedents of cultural safety (Yeung, 2016). Cultural competence, when combined with self-reflection, is a necessary element of cultural safety that aims to shift the power imbalance so health care workers do not assume complete command of others’ culture (Ramsden, 2002; Tervalon & Murray-Garcia, 1998). It requires mutually trusting relationships between health worker and patient. A model of cultural safety developed by Wood and Schwass (1993) depicts culturally unsafe practices with “3 D’s” (demean, diminish, disempower) and cultural safety by “3 R’s” (recognize, respect, rights) (Figure 16). ‘Safety’ in this concept refers beyond avoiding physical injury and avoids any feelings of inferiority or alienation or depriving a patient of health care (Parisa et al., 2016). Cultural safety focuses on recognizing social, economic and political influences that contribute toward marginalization of a group, community or society.

Figure 16. Visual representation of Wood and Schwass (1993) model of cultural safety and cultural risk

Cultural safety emerges from critical social theory reflecting on the postcolonial period (Anderson et al., 2003; Browne et al., 2005; Smye & Browne, 2002). The concept emerged in response to health inequities of Māori, the indigenous people of New Zealand (Papps & Ramsden, 1996), resulting from power imbalances stemming from colonialism that continue into health care settings today (Dyck & Kearns, 1995; Ramsden & Spoonley, 1994). The impact of colonization on health inequities among indigenous peoples globally and the current poor response to the impacts on these communities by governments has been well documented (Anderson et al., 2006; Gracey & King, 2009; Hackett, 2005; Kelm, 1998; King et al., 2009). Cultural safety addresses power imbalances resulting from post-colonial discourse and the health worker patient dynamics in many settings. The ways in which cultural safety supports a shift in power in practice is dependent on the historical, social, and political context and needs of a marginalized group. Cultural safety can be applied to any group who differ from that of their health care provider in regards to age, gender, sexual orientation, socioeconomic status and class, ethnicity, religious or spiritual beliefs or disability (Jungersen, 2002).

Ethical space is a framework for guiding respectful interactions across cultural differences to mutually explore epistemologies and ontologies entering that space (Nelson & Wilson, 2018). Ethical space "is formed when two societies, with disparate worldviews, are poised to engage each other" (Ermine, 2007). It moves from a monoculture in health care, which can inadvertently create health inequities, to listening, acknowledging, and working with local knowledge and beliefs and voices of marginalized groups. The space can be simultaneously physical, social and psychological (Ramsden & Spoonley, 1994) although more widely understood in terms of active space of process, action and energy (Greenwood et al., 2017). Barina (2015) discusses space as being value-laden and the need to assess the values produced in health care spaces. The application of ethical space in assessing health care is scarce although it has been used among indigenous groups to facilitate discussions and collaborations on health care (Zehbe et al., 2012) sustainability and conservation (Crowshoe & Lertzman, 2020; Nikolakis & Hotte, 2022).

Through the lens of cultural safety and ethical space, against a backdrop of postcolonial discourse, we analyse how historical, social, and political influences impact individual choices and decisions around health care and interpersonal relationships in this setting. We aim to highlight experiences of accessing and uptake of health services among Maasai people in Tanzania within a postcolonial discourse in order to facilitate transferring power to health care recipients.

Methods

The findings, on which this paper is based, are drawn from an ethnographic study, using non-positivist inquiry to examine experiences of access to health care among a Maasai community in Northern Tanzania. Non-positivism maintains that there is no single ‘true’ position, and that meaning is dependent on the context and interpretation of social actors (Aliyu et al., 2014). The constructivist approach to this inquiry assumes that it is meaningful to generate knowledge by making sense of realities, specifically social constructs (Schwandt, 1994). The emphasis is on introspective-investigator accounts of social contexts. The researcher examines and interprets the forces that shape and influence behaviours (Denzin, 1971). The research was carried out by TM and JM from September 2016 to December 2017 in various settings to understand the lived experiences of the Maasai tribe.

Data collection

Qualitative data were collected by employing a variety of methods in the larger project of ethnographic research looking at Maasai people’s experiences and perceptions of health care with a case study of trachoma control in Sinya Ward in

Longido District. This paper will report on the methods used for this paper's analysis (Table 8).

Table 8. Data collection methods

Method	Sample	Sample size	Sampling method	Date of data collection
Observations	Sinya community, health care facilities, outreach health programmes	NA	NA	September 2016- December 2017
Household Interviews (round 1)	all households in Sinya	20	random	March- July 2017
Oral History	women aged approximately 90+ years residing in Sinya	5	purposeful	9 November 2016
NGO Interviews	NGOs working with Maasai communities in Tanzania	12	purposeful	February 2017- March 2019

Observations

Along with a Maasai research assistant (JM), the lead author conducted participant observation in three villages in Sinya Ward of Longido District- Il Donyo, Leremeta, and Endonyoemali. Observations were conducted in social settings, such as the market, people's homes, community meetings, the community bore-holes, celebrations; in two government dispensaries; and during various medical outreach programmes. Outside of the villages, TM and JM conducted observations in different health care settings in Arusha and Kilimanjaro regions, accessed by Maasai and non-Maasai patients including private, and NGO based health facilities, a district hospital and a referral hospital to understand experiences. Observers were based in patient waiting rooms and interactions with Maasai patients and families occurred naturally and willingly via a Maasai research assistant

Household interviews

Household interviews were conducted with twenty randomized households in the three villages of Sinya Ward with a set of questions on experiences, perceptions and access to health services used in this analysis. Internet-based sample builder was used to randomly select two *enkang* from each of the ten sub villages (www.randomizer.org) for household interviews. An *enkang* is a homestead or joint residential unit composed of a number of households. They are headed by one male and in a polygamous culture, each wife with her children have a hut within the boma (Mtuy et al., 2021). If the first randomly selected *enkang* was not available, the next *enkang* in the randomization list was approached to participate. The interview guide consisted of open-ended questions on their experiences and perceptions of health and non-health related programmes in the community. Interviews were conducted at the *enkang* with both men and women present and lasted one-hour on average.

Oral history

An oral history was recounted by elderly Maasai women to furnish an understanding of the history of medicine among the Maasai. Community leaders and Maasai research assistants advised that women are the carers in the *enkang.* Despite men making the final decision around health care seeking, men rely on and respect women's opinions and choices. Five elders were selected using purposeful snowball sampling to assure inclusion of women estimated to be older than ninety years to allow for a richer history of medicine among Maasai. The two-hour discussion was guided by a topic guide consisting of significant historical time points and the impact on health and medicine in the Maasai context. The venue for the discussion was under a tree near the market on a non-market day.

Semi-structured household interviews and oral history were conducted in Maa, the primary language spoken by Maasai people, by a native Maa speaking interviewer, JM, in a conversation-like manner, with TM present for all interviews. The discussions were audio recorded and later transcribed and translated from Maa to English by JM.

NGO interviews

TM also conducted in-depth interviews with NGOs working with Maasai communities. Purposeful sampling was used to include as many NGOs that met the criteria of supporting Maasai communities in areas of health or development. Of 14 NGOs contacted, five NGOs from Arusha region agreed to have a representative interviewed. The interview guide consisted of open-ended questions on their experiences and perceptions of health and non-health related programmes in the community. This analysis includes three of those interviews in which the topic of access to health care was discussed. Interviews were conducted in English, lasting 90 minutes on average and detailed notes were taken.

Data management and analysis

Transcription of household interviews and oral history was done directly from Maa to English; some translations were corrected to ensure more understandable English while assuring meaning was not changed. Participants that were interviewed were assigned a unique identification number and data anonymized in the transcription process. Audio recordings, transcripts and field notes were stored in a locked cabinet in the field and later in a locked office in Moshi, Tanzania. English transcripts and field notes were entered into NVIVO 11 Software. Initial interpretation included familiarization of the data. Using a thematic content approach, (Vaismoradi et al., 2016) data were first coded by lead author, TM, and verified by author SL. Through data immersion and ongoing review and discussions on the data with Maasai research assistants throughout the ethnographic fieldwork, emerging themes were identified. Impressions and interpretation of the themes were discussed with the native speaking interviewers and co-authors. Narrative text was applied around the constructs and direct quotes presented are used to show dominant views of participants.

Ethics

This study was approved by the Ethics Committees of the National Institute for Medical Research, Tanzania and the London School of Hygiene & Tropical Medicine, United Kingdom. Information about the oral history, was read aloud in Maa to the elderly women in a group setting. Information about the household interviews were discussed in Maa and consent obtained from the male head of the *enkang*. The Maa speaking interviewer again repeated information about the interview to the entire household at the start of the interview. Written informed consent was obtained for all interviews. A witness was present for non-literate participants and signed in addition to the participant making their mark. Permission to digitally record interviews was obtained from each male head of *enkang*, and the elderly women for the oral history. The NGO respondents did not consent to be audio recorded and therefore detailed notes of these interviews were taken. Consent for ethnographic field observations was obtained from community leaders and members including men and women at a meeting to introduce the research in September 2016. Permission to conduct observations at health facilities was verbally granted from persons in-charge at facilities. Financial incentives were not provided rather a sign of appreciation with sugar and soap was provided to individuals and households who participated in interviews.

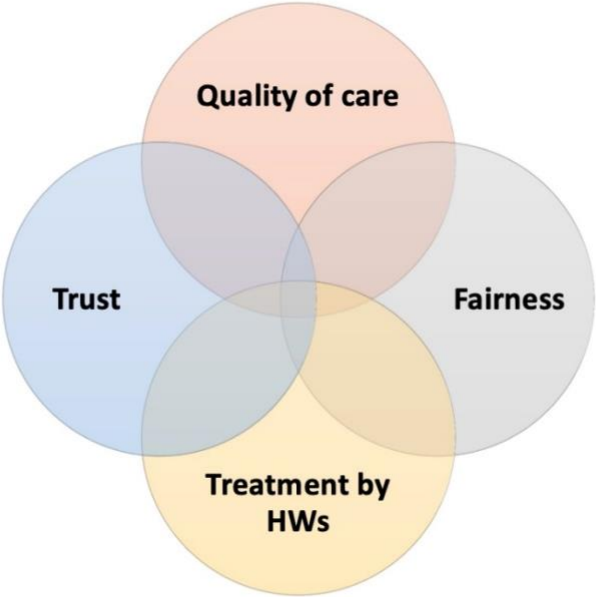
Patient and public involvement

Patients were not involved in this study. The fieldwork for this research was discussed with community leaders prior to entering the field and later presented to a wider community audience for feedback and inputs on research questions, design and approaches to carrying out data collection. Involvement of community leaders and members was continuous throughout fieldwork to assure recruitment approaches were respectful and appropriate. At least one community member escorted researchers in the field and assisted with introductions for interviews. Dissemination of initial study findings was conducted at a larger community meeting and consultation with community members continued thereafter to confirm ongoing analyses. (See supplemental file 1- statement of author reflexivity.)

Findings

Inductive thematic analysis of Maasai people's experiences of facilitators and barriers to accessing health care were categorized into four themes: fairness, personal interactions with health workers, trust, and quality of care. Although presented as distinct themes, these concepts are interconnected (Figure 17). What defined each theme is through the lens of the Maasai in this study. Fairness is about transparency in the processes to serve people in health care settings. Quality of care is the perceptions of health care regarding technology and thoroughness of examinations. Treatment by health workers is the health workers use of language and ethical treatment of people. Trust was determined by the level of cultural understanding and involvement of Maasai leaders in decisions and delivery of health services.

Figure 17. Facilitators and barriers to accessing health care among Maasai



Theme 1: Fairness

Fairness emerged in how Maasai were being respected and treated. This came out in observations of Maasai patients in comparison with non-Maasai patients, and Maasai respondents and NGO elicited experiences. Health workers were observed giving Maasai patients and their family members less information and instructions compared to non-Maasai patients, which was interpreted as assuming Maasai people speak minimal Swahili, the national language of Tanzania, or do not have the education to understand. It was observed at facilities that Maasai patients seemed to be less prioritized than non-Maasai patients. In one case, the researcher (TM) brought a Maasai patient to clinic and his file was the first given to the nurse. After an hour, he was still not attended to while other patients were. The researcher asked the nurse why and she replied, *"Oh he's with you. He will be next."* It mattered who you are and/or who you know to receive timely and fair care. The Maasai valued a system where patients were attended to in the order in which they had arrive at the health facility.

> *When you go to our clinic centers there is no proper arrangement of treating people as per the time they came… In this clinic [NGO based health facility serving Maasai community], people are equal and you will be treated as per time of your attendance and not otherwise.* [household interview 4-1]

Maasai respondents reported that quality health services and health workers are those that demonstrate honesty and transparency with regards to what they can treat and availability of treatment.

> *They [health workers in an NGO based health facility serving Maasai community] are not cheating because if they are not able to treat you, they can advise you to go for referral.* [household 4-1]

Yet several instances were reported in which heath workers would promise things but not deliver. A common example was outreach programmes that would offer medical examinations to people and say they would return for follow up or treatment but never returned.

> *Koko that was present said she used olputet [locally made tweezers] 10 min before we arrived and had used it a few times for epilation. She told us she was not around when case finders came to check a few weeks ago. There was another koko in the boma that case finders identified [as having trichiasis] and promised to come back to take her for surgery and examine this koko that missed them when they previously came. The organization never came back, and both are willing to have surgery*. [field notes]

Theme 2: Personal interactions with health workers

Interactions with health workers included overall ethical treatment and respect for cultural knowledge, the setting, and norms. Many Maasai respondents told stories of health workers using harsh words, insulting, and even beating Maasai patients. Despite women knowing the importance of antenatal visits and following the childhood vaccination schedule, they sometimes missed visits due to migration in the dry season or competing economic priorities. When they attended clinic visits late, the nurses would punish them by hitting them, serving them last, and, in some cases, charging them money when such services are free. *"We do follow [vaccination schedule] because there are many good things which we saw from that programme and even now a days, nurses are very serious and they even hit us if we don't follow those timetable,"* [household interview 01-1].

An NGO working in Maasai communities discussed with local government officials about the poor quality of services in Maasai communities including the language barrier, lack of medical resources and fewer health facilities. She reported that the response from government was: “*You Maasai think you are special,*” [NGO interview 104]. There is also a perception in government facilities that Maasai people cannot afford health services resulting in delivery of inadequate care. Yet a health worker at a facility which was highly regarded by the Maasai told us, *“Maasai are honest, we trust them. Some cannot pay on the spot but then they go home to sell cows and return to pay*” [NGO interview 103]. Workers at this same facility discussed the importance of knowing your population, their culture, and the barriers.

Maasai responded more positively to health workers who involved the family in sharing information and decision making, who did not exert authority and asked permission to do procedures and treatments. One participant told the story of a female elder who had surgery without appropriate permissions of family members.

> *The surgical outreach team came on market day when the family were not at home and took her to the dispensary where they were performing surgery. ‘We returned from market they found her bandaged,’ the family member said, ‘They did surgery to her and even she didn’t realize they were doing surgery on her. We were not happy’. They requested that I, as a trusted outsider, to explain to the outreach programme that they should be involving local leaders and family and provide adequate information about the patient’s condition.* [field notes]

Decision making among Maasai is collective including other family members, elders, and leaders. Health seeking choices are initiated by women with men making final decisions often dependent on household economics. The response to health services is linked to the extent to which the decision-making process according to their social norms is respected and allowing for time to discuss health care decisions with family.

In many Maasai settings, market day comes only once a week and often their only opportunity to obtain food and supplies. Market day is an economically and socially important part of their livelihoods. Several health programmes would visit communities on market day and observations showed how Maasai people reacted bitterly that it was disruptive to their activities related to market. It also indicated to them that the programmes did not respect social norms of including village leaders in planning and decisions making to provide services. If they had, the leaders would have informed them not to come on market day.

It was observed that health workers would examine patients without explaining what they were doing and asking permission to touch patients and do a procedure. Yet often Maasai patients would ask the health worker what they were doing, what the problem is and request clarification on treatment, often to be ignored or shushed. In one case, an outreach doctor listened and respected a patient’s needs and choices and negotiated an alternative treatment.

> *A younger mama needed trichiasis surgery on one eye. They had come on market day to take her for surgery. She insisted that getting food for her family was more important than her eyes at the moment. The doctor instead epilated an eye lash from her and the women was pleased she didn’t need surgery. She walked away satisfied and went to market.* [field notes]

This particular doctor was well received by Maasai patients. Although she does not speak Maa, she waited for someone to translate, provided thorough information and asked permissions to examine patients. This is contrary to a lot of health workers in outreach programmes who appear to be rushed and poorly engage with the patient and their needs. It was observed in some instances, that health workers assumed a Maasai patient does not speak Swahili. They would limit the information provided to patients, talk direct to family they knew spoke Swahili, or in some cases speak poorly about the patient assuming they cannot understand. When it was apparent that a Maasai patient did not speak Swahili, health workers made little or no effort to find a translator.

Theme 3: Trust

Trust is a key component to uptake of health services. We observed in health facilities that non-Maasai Tanzanians trusted nurses and doctors. They did not question clinicians nor hesitate to follow doctors’ orders. Yet Maasai tended to demonstrate more trust when they felt there was cultural respect. Respected services and outreach programmes were those that involved local leaders in the process to give trust to the community. They also responded positively to health workers and services that provide education in addition to the services. Several respondents talked about getting second opinions or in some instances of visiting several health facilities until the care ‘felt’ right.

> *The doctor [at one of the village dispensaries] said when the eye programme team from the regional hospital go to the village there is a better response*

> *because although they may be looking for something specific, they treat patients with other problems and counsel them. Whereas the case finders are only for trichiasis and give no attention to other eye issues or providing education.* [field notes]

> *"It is like this, even if all doctors are good at the clinic, but the best doctor is the head who is a Maasai. This is because he is the one who is taking people for x-ray and again, he always doing two best things. The first is when patients are many he first gives seminar about the importance of having health insurance card which is active for one year. And always he insists us that after having that card to never pay any money when you come to hospital, because your card will be used to pay all bills and if there will be any doctor who will ask any money before you pay ask him for receipts. Second, he is a Maa person so we can speak with him for those that don't understand Kiswahili,"* [household interview 05-1]

NGOs working in Maasai communities emphasized the need to build trust. They offered suggestions such as health programmes having satellite offices close to Maasai communities for better oversight. Staff of health programmes in the cities are not aware of what is happening at the community level. It was also observed that the main offices for health service programmes would have quotas to meet and health workers in the filed were under pressure to report numbers on delivery of services.

Additionally, there is a lack of trust in the government providing adequate services associated with the existing poor quality of services and access in some areas. One household [04-1] explained *"the vaccination posts are few and far away from bomas. Distances are even more when we migrate [in dry season]".* There is little consideration of threats of wildlife on the journey to posts. Despite this, households plan for one woman in the *enkang* to take all the children for vaccinations while most other households fail to attend. Yet this household [04-1] reported there was a shortage of vaccines in the previous year. There appeared to be apprehension to trust in the services in the context of complex livelihoods.

> *There is only one district hospital in this region. Some villages are very remote and have no access. Yet the largest part of the government revenue comes from tourism here so why are they not helping the communities of this area?* [NGO interview 103]

The study uncovered a few instances in which inadequate and/or inaccurate information was provided to Maasai patients. Few understood the purpose of outreach programmes providing screening, or drugs for prevention or treatment. Without this understanding there were refusals and lack of trust in the outreach programme. Observations revealed focus was more on achieving the programme's target numbers rather than providing quality and appropriate services. In government facilities and some outreach health programmes, little information was given on the diagnosis, treatment, and possible outcomes.

> *A health worker in a Maasai community said "Maasai like to have all the information before making decisions and they want respect. But once they change, they are committed."* [field notes]

Theme 4: Quality of care

Quality of care tended to be measured by the type of, and extent of, diagnostics done. This was not related to actual treatments provided but rather reassurance that diagnosis and treatments were based on evidence. This includes taking of vital signs and further diagnostics such as laboratory tests, ultrasound, and x-rays.

> *The big issue in Maasai is measurement. If you take a person to the hospital and the doctor doesn't take measurements, they don't feel they have been treated well.* [household interview 5-1]

Elders explained that post- independence in Tanzania (1960's-1980's) "*diagnostics were available at health facilities and doctors were treating patients well, but it is not like this today"* [oral history]. Many respondents reported that they were treated based on symptoms. No vital signs or physical exam conducted, *"they just look at you and give drugs"* [household interview 16-1]. This was not considered quality care.

Inadequate health resources in facilities were often reported in Maasai communities, in particular supplies of medicines, health care personnel, equipment, and outreach programmes. Maasai respondents talked about health facilities (government, private and NGO) that they perceived as 'excellent' but which many had never attended, yet simply based on them having an ultrasound or x-ray machines they were highly regarded.

Box 1- ‘Safe Space’

Observations and informal discussions were done at an NGO based health facility near to a Maasai community. This facility was always busy with Maasai patients some who had travelled hours by foot to access what they deemed a safe space for health services. One elderly woman, *koko*, had travelled four hours, 20km on the back of a donkey while her two sons and daughter-in law accompanied her on foot until they could access public transport for another 80 km to the facility. She had a tumour in her neck that was obstructing her ability to eat and her breathing was laboured. The family had taken her to several health facilities near their home where she was not diagnosed and told there was nothing they can do. The sons said no physical or laboratory exams were done at other facilities. A few days after meeting this patient and her family, she had been diagnosed with untreatable cancer after having blood tests, a biopsy, and ultrasound performed. The daughter-in-law remarked that doctors asked them a lot of questions, performed diagnostics, and provided information on the diagnosis and management. Despite the diagnosis, the family was very happy with the support and care. They were relieved to get a specific diagnosis for *koko*, to be educated on cancer, to be supported on managing her and what was sensed as being treated as an equal. The health care workers at this facility were a mix of Maasai, other Tanzanians and non-Tanzanians. They displayed cultural competency of Maasai social norms and further, a respect for the patients. Communication was observed to be an important link to patients and more thorough and mutual compared to other health facilities. Communication was more than speaking Maa but included a language of respect by providing information and allowing patients to communicate. Maasai patients and their families were more open to health care providers at this facility than others due to the safer space created.

Discussion

This study aimed to examine experiences of accessing and uptake of health services among Maasai people within a postcolonial discourse. Overall, the findings reveal that Maasai value biomedicine and the importance of health services but that there are significant barriers to accessing services and to feeling safe in health care settings including lack of fairness, quality of care, treatment by health workers and trust. Similar themes of communication and trust have been identified it other studies of Maasai perceptions of heath programmes (Davis, Virhia, et al., 2022; Mtuy et al., 2021). The barriers and facilitators identified do not stand alone but rather in many cases one factor might carry more weight than others in uptake of services. For example, some facilities such as government referral hospitals were well equipped with medical resources, diagnostics, and staff but the health care workers were reported to mistreat Maasai people, and many avoided such facilities. The findings indicate that many facilities and services are not safe spaces for Maasai people limiting their choices to accessing services. In understanding these factors that influence safe health care spaces through the lens of cultural safety and ethical space, it highlights the importance of social and political influences on everyday experiences.

Power

Overall power imbalance was a common thread in examining barriers and facilitators effecting choices in accessing services and ultimately respecting human rights. Politics and power relations have created a subaltern voice and impacted the cultural, economic and social effect on uptake of public health programmes (Gore & Parker, 2019). From the first interactions with ‘outsiders’, power has been a central theme in social relations with the Maasai from relocation from their land, restricted movement and agricultural policies (Hodgson, 1999). Historically power has shaped medicine in general in Tanzania (Langwick, 2011), as well as the culture of the Maasai (Hodgson, 1999; Hodgson, 2001) so has it influenced their decision-making and responses to health services (Davis & Sharp, 2020; Lawson et al., 2014). Critical to establishing trust, respect, honesty and empathy is the health workers ability to deconstruct the power imbalance between the patient and themselves (Kearns, 1997).

Participants talked about shopping around for health services to find one that ‘feels right’; a search for a fair share of power in the health care relationship. Maasai women’s preferences for home deliveries with traditional birth attendants has been well documented and partially attributed to experiences of women in labour being turned away from health facilities and poor health worker attitudes (Karanja et al., 2018; Mbwele et al., 2019; Mosley et al., 2020; Roggeveen et al., 2013). Gendered experiences can also be attributed to women having to seek permission from husbands who are in positions of power regarding material resources (Hodgson, 1999; Woodhouse & McCabe, 2018).

Jungersen (2002) discusses considerations to make health care spaces safe for Māori in New Zealand. The context; a patient’s home, their community, or a clinic; defines different ways of being and requires an awareness of verbal and non-verbal cues to navigate the health care setting. For example, honouring cultural protocols of introductions demonstrates a level of respect, reducing the power differential.

Trust

Trust in this study is linked to respect, kinship, and sense of connectedness. It assumes power will not be used against a patient's interest. If health workers take time with patients, announce outreach visits in advance, provide information, and engage family, they would transfer some power to the patients and gain more trust. Trust is not a mental state. It is earned, built, and created. Gilson (2003) discusses 'particularized trust' among groups that define themselves in opposition to other groups. Further it is easier for those with power and access to the social, economic, and political system than those who are more marginalized.

The historical shift from a socialist to a neoliberal public health system in Tanzania impacted inequities in health care access (Young, 1986). Factors important for Maasai participants to trust and access care are similar to those reported since this transition to more recently in Tanzania including availability of diagnostics and medicines, competent health workers, and respectful communication (Davis, Lembo, et al., 2022; Hulsbergen & van der Kwaak, 2020; Kamat, 2008). Trust among indigenous groups is further complicated by historical experiences of being misled and marginalized. Maasai participants discussed mistrust in vaccination programmes possibly linked to colonial veterinary and human disease control methods used to capitalize on land resources and restrict their movement (Benjaminsen et al., 2013; Brockington, 2004; Homewood, 1995; Homewood et al., 1987; Spear & Waller, 1993; Sulle & Banka, 2017; Wagner-Glenn, 1992). Participant references to the government prioritizing tourism over health care resources in Maasai communities, originates from colonialists protecting lands for financial gains of trophy hunting. Since then, several national parks and conservation areas have been established on lands inhabited by Maasai, forcing them to relocate to more harsh environments. Few efforts to share the financial benefits of tourism with Maasai communities have been successful often attributed to the lack of communication, trust, and respect for the community (Benjaminsen et al., 2013; Davis & Goldman, 2019; Sulle & Banka, 2017).

We saw particularly in outreach programmes, driven by reporting numbers, that there was no space for building trust to ultimately improve responses to such health programmes. Alternatively, trust in community health workers in Tanzania was attributed to them being embedded or ‘connected’ to the community (Rafiq et al., 2019). Trust can be built by including the target population in planning and delivery of programmes. In studies in Tanzania, and other countries in Africa, kinship relations or an ‘insider’ link provided a strong basis for positive, trusting relations between communities and health workers (Ajayi et al., 2008; Kok et al., 2017; Rafiq et al., 2019). In a study of a hard to reach community in Tanzania, men who engage in sex with other men, trustworthy health services were those that employed people from their community, have friendly staff and provide training to health workers on the lived realities of same-sex attracted men (Ishungisa et al., 2021). Maasai respondents did not articulate the issues of (mis)trust or unsafe spaces but in many instances identify other reasons for inadequate services such as an increased population and lack of resources. This may be due to a strong sense of hope. Indigenous people’s resistance and resilience to colonialism, racism, and oppression in an effort for social justice requires a strong sense of hope. First nations author, Absolon (2016) explains that hope affirms the possibilities, strengths and indigenous knowledge that guide a shared desire for social inclusion. Hope is made, in practice, and can be a guiding force in Maasai maintaining a traditional lifestyle.

Language

De and Richardson (2008) put communication and language at the top of the skillset for achieving cultural safety. Language can create a power imbalance. Beyond dialect, language includes how people use it to engage with others and creating a familiar and comfortable space. For example, this may include use of terminology not familiar to patients or not communicating diagnosis or treatment options. Transparency was often lacking and a barrier to accessing health services in this population. Swahili is the national and dominant language in Tanzania while Maa is only spoken by a few pastoralist groups including the Maasai tribe. When a health worker spoke Maa, it was more than a common dialect but reassurance of being understood culturally and gave permission for Maasai patients to be open with the health care worker.

In the case described in box 1, health care workers displayed cultural competency of Maasai social norms and further, a respect for patients. Communication facilitated a safer space for patients. It was more than speaking Maa but included a language of respect by providing information and allowing patients and families to communicate. Culturally safe occupational therapy with Māori patients in New Zealand requires a recognition that boundaries for 'therapy' are variable, contrary to a more compartmentalized western expectation (Jungersen, 2002). Safe practice is about health care providers approaching patient care with humility and openness. In a prenatal wellness programme for Canadian indigenous communities, cultural safety includes care provided in the local language as well as integrating traditional values and understandings into prenatal care. A collaborative community partnership includes elders to explain to women prenatal care to be received through the formal health system in the context of indigenous teachings and traditions (Di Lallo, 2014).

Applying cultural safety and ethical space

Indigenous groups as well as Maasai have complex knowledge and beliefs of health and wellness that may be seen as backwards or stigmatizing them as difficult patients in health care settings. Central to Maasai sense of well-being is the value of land and livestock contributing to their cultural identity, security and wealth (Woodhouse & McCabe, 2018). Yet colonialists ideals of what the African landscape 'should' be, led to the use of binary terms of wilderness and domestication (Davis & Sharp, 2020) despite centuries of pastoralists living in harmony with nature (Lankester & Davis, 2016). This sentiment highlighted by Hodge in (Davis & Sharp, 2020) describing pastoralists as "roaming over the landscape" rather than being "proper" inhabitants. Pastoralist knowledge and experiences of disease control in the African environment were undermined by colonialists importing western veterinary and quarantine practices (Waller, 2004). Maasai management of animal and human disease is embedded in spiritual beliefs and relations to nature. For example, burning grasses for tick control and use of *orpul* healing retreats for cleansing and healing, opposed western approaches to maintaining animal and human health (Burford et al., 2001; Lankester & Davis, 2016; Sindiga, 1994; Waller & Homewood, 2017).

The poor understanding and respect for their beliefs and practices impedes on relationships today. According to Farmer (2003), public health authorities are guilty of a social framing of disease by which suffering is attributed to culture rather than disease or poverty. This leads to a harsh judgement on marginalized communities' ability to take responsibility and care for themselves. This ignites the resentment of colonialism and post colonialism practices and mistrust in development among marginalized populations (Keller, 2006). The politics of blaming vulnerable populations for the spread of disease (Keller, 2006) exists among the Maasai. Women reported being mistreated by health workers with harsh words or even beaten when they missed vaccination visits yet there was little concern for the local context including competing economic priorities, few vaccination posts and far distances in harsh environments.

Cultural safety and ethical space provide a useful framework that allows for health care workers and systems to reflect on and appropriately change interactions and behaviours to avoid unsafe healthcare relationships and experiences (Greenwood et al., 2017). Polaschek (1998) emphasizes that cultural safety is about recognizing the position of a group in society and how they are treated and perceived more so than the things that make a group different. In the case of the Maasai, it is the current social political subjugation most evident in land tenure policies. It is marginalization regarding reduced access to education and health services. Cultural safety goes beyond cultural competency and focuses on sharing; "shared respect, shared meaning, and shared knowledge and experience, of learning together with dignity and attention" (Williams, 1999).

Ethical space could be analysed in terms of the boundaries created in the health care space that may be interpreted as 'policed by gatekeepers' (Nelson & Wilson, 2018) a similar historical experience for Maasai. For example, longer waiting times than non-Maasai patients, lack of information provided, and mistreatment of patients were experiences reported in these spaces. Although it was not possible to assess self-reflection of health care workers in this study, a critical component of cultural safety, it was evident that in those health facilities that Maasai patients felt safe, there was a sense of respect for this community. Traditional practices of healing including the use of traditional medicines and rituals are well incorporated into notions of healing among Maasai (Bignante & Tecco, 2013; Sindiga, 1994). Health workers understanding, acknowledgement and incorporating indigenous knowledge or practices into the heath care setting may contribute toward creating ethical spaces as has been done for other indigenous groups (Greenwood et al., 2017; Jungersen, 2002; Yeung, 2016).

New Zealand, Australia and Canada have adopted cultural safety as an educational component to address the needs of indigenous populations (Baba, 2013; Nguyen, 2008; Papps & Ramsden, 1996; Williams, 1999). In Tanzania, consideration should be given to ensuring that Maa speaking staff acting as translators and/or patient advocates are available at all large health facilities and in predominantly Maasai communities. In Canada, the concept of “Two-Eyed Seeing” was developed by indigenous elders (Greenwood et al., 2017; Martin, 2012). This emphasizes a way of “walking in two worlds” by incorporating traditional knowledge and modern or western knowledge into health care settings and interactions. Similarly, Maasai and other marginalized groups in Tanzania can inform policy, education, and health care delivery to acknowledge these groups, breaking down barriers, and assuring ethical space in health care settings. To address cultural safety and ethical space in Tanzania, medical and nursing training curricula should incorporate cultural competency and patient-focused care.

Limitations

There are limitations. The lead researcher is not from Maasai community, which may have led to power differentials in interviews and conversations. Maasai respondents often did not articulate what was observed by researchers and this may be explained by a history of not feeling authorized to offer critiques to ‘outsiders’. This was mitigated by the researcher spending extended periods of time in a Maasai community along with a Maasai research assistant. The emic and etic perspectives were shared and together formed a more cohesive interpretation of observations and findings. The domains of cultural safety identified in this study are specific to the Maasai population in Tanzania. We realize that these domains are not “one size fits all” but provides a framework to be extended to the assessment of barriers and facilitators in other marginalized populations.

Conclusion

These findings highlight the importance of deploying cultural safety and ethical space to inform shifts in health care spaces to make them more accessible, trusted, and safe for Maasai people and other marginalized populations. This postcolonial discourse sheds light on ongoing power relations and how systems of dominance transcend health care settings, raising ethical questions about health care practice.

Employing Maa speaking professionals or use of translators and/or patient advocates should be a more immediate consideration in Maasai communities.

There is a need to enable Maasai and other marginalized groups to define their needs for cultural safety that can be met in a resource limiting context. This can inform development of culturally appropriate programmes and be used to educate health care professionals on culturally safe practices for marginalized groups.

In the long term, there is a need to redefine the health care worker, patient relationship including changing perceptions of patients toward a “person of value” (Anderson et al., 2003), a need for critical reflection of power relations and avoid making assumptions. Cultural safety should be used as a moral discourse guiding national policy and evaluating inclusion and equity for marginalized populations in Tanzania.

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Supplemental file 1. Statement on author reflexivity

Domain	**Guiding questions**	**Author's response**
Study conceptualization	1. How does this study address local research and policy priorities?	Access to health services is critical to achieving SDG 3, 'good health and well-being'. It is important to address barriers and facilitators to accessing care. This study draws on experiences of a marginalized population in accessing the formalized health system. This can inform policy on training of health professionals, priorities for health care resources and overall improved health care services.
	2. How were local researchers involved in study design?	The fieldwork for this research was discussed with community leaders prior to entering the field and later presented to a wider community audience for feedback and inputs on research questions, design and approaches to carrying out data collection. Local researchers informed the development of all interview guides, implementing data collection and provided extensive feedback on interpretation of findings.
Research management	3. How has funding been used to support local research team(s)?	Funding for this research supported costs associated with the local research team time and the data collection activities.
Data acquisition and analysis	4. How are research staff who conducted data collection acknowledged?	The data collection team leader is second author on the paper and the additional support on data collection is acknowledged in section 3.3 of the paper on community involvement.
	5. How have members of the research partnership been provided with access to study data?	All members of the partnership have access to data.
	6. How were data used to develop analytic skills within the partnership?	Conducting qualitative data was a new experience for members of the research team. Development of the tools, data collection and analysis were learning experiences for the field team.
Data interpretation	7. How have research partners collaborated in interpreting study data?	All researchers, both local and outside Tanzania, critically reviewed the analysis and discussed interpretations in-depth.
Drafting and revising for intellectual content	8. How were research partners supported to develop writing skills?	All research partners were encouraged to provide feedback and review of the manuscript.

Chapter 6: Public Engagement as a Culmination of Field Work

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SECTION A – Student Details

Student ID Number	450695	**Title**	Mrs.
First Name(s)	Tara		
Surname/Family Name	Mtuy		
Thesis Title	Maasai response to mass drug administration for trachoma in a changing political economy in Tanzania		
Primary Supervisor	Dr. Shelley Lees		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	Research Involvement and Engagement		
When was the work published?	July 2021		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	NA		
Have you retained the copyright for the work?*	**Yes**	Was the work subject to academic peer review?	**Yes**

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Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I designed the study, developed the tools and protocol. I led on the intervention and wrote the full first draft of this paper and did the final editing.

SECTION E

Student Signature	Tara B. Mtuy
Date	13 May 2022

Supervisor Signature	Shelley Lees
Date	13 May 2022

Overview

The previous chapters highlight the ethnographic research conducted over 16 months in a Maasai community. The process of collecting interview data informing chapter 3 also served the purpose of guiding my entry into the community. Similarly, I wanted to be thoughtful about my exit from the field work; to acknowledge the community's contributions toward this research. I also wanted to thank the community for the fieldwork experience, which has positively impacted me as an individual. Together with Maasai research assistants and community leaders, we co-produced a public engagement activity drawing on the data previously collected and our embedded understanding of the community through 16 months of fieldwork.

Chapter 6 describes a train-the-trainer intervention to disseminate information about trachoma. The design was composed of activities specific to the Maasai community with the aim of making it applicable to their environment, their livelihoods and geared toward their level of understanding as described in chapter 3. To evaluate the trachoma training session and the extent to which it motivated women to train others in the community, photovoice method was used to aid in a post-intervention discussion. In this chapter, I discuss the unintended consequence of the activities: how Maasai women disclosed feeling empowered through their participation. Additionally ethical issues of informed consent and consideration of gender differences specific to this community are described.

This paper contributes to research objective 9:

> To design and deliver a contextual appropriate public engagement intervention informed by this ethnographic research.

Empowering Maasai women behind the camera: Photovoice as a tool for trachoma control

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Abstract

Background: Photovoice is a method used to help engage community members to understand local realities and promote social change. Photovoice uses cameras in the hands of participants as a tool to visually document a specified topic. Photos taken by participants allow for reflection and stimulate dialog on an issue to ideally lead to social change. Trachoma, hyperendemic in Maasai communities in Northern Tanzania, is the commonest infectious cause of blindness worldwide, caused by *chlamydia trachomatis.* The bacterial infection commonly occurs in childhood and over many years repeated infections lead to inflammation and scarring of the eyelid. Often as adults this leads to the upper eyelid turning inward and eyelashes scratching the eye, resulting in pain, and eventually blindness. We used photovoice as a tool for Maasai women to share their lived experiences of educating peers on trachoma and ultimately empowering women in this society.

Methods: This public engagement intervention was conducted September thru October 2017. We held a workshop on trachoma control for 20 Maasai women including use of photovoice method. Women were asked to disseminate information from the trachoma control workshop to their community, and to capture their experiences using disposable cameras. Five weeks post-workshop we facilitated a discussion, and women displayed photos of the successes and challenges they encountered as advocates for trachoma control in their community.

Intervention Outcomes: It was observed throughout the process and at the photo discussion meeting, that women articulated empowerment by this experience; as educators, agents of change, and a source of valued information.

Conclusion: Photovoice should be considered for future interventions as a communication tool on health issues, and to empower women to be ambassadors for health promotion.

Introduction

Photovoice “is the process by which people identify, represent, and enhance their community through a specific photographic technique” (Wang et al., 1996). It enables community members to record, and share their realities about a phenomenon through their own photography. Visual images are used to promote a participatory means of sharing knowledge, perceptions, and experiences. They act as a tool to enable people to more critically think about community, and open up discussion around social and political influences in their lives (Freire, 2000).

Photovoice puts cameras in the hands of participants as a tool to visually document a specified issue. Participants take photos or videos to capture the issue in their everyday lives to document how they interpret the issue. Photos taken by participants are reviewed either individually or in a group to allow for reflection and stimulate dialog to ideally lead to social change. Photovoice is used in research, development work, and interventions. It is a method increasingly being used in research of marginalized populations to explore and address health inequities (Christensen, 2018; Mamary et al., 2007; Packard, 2008; Thomas et al., 2015), and inform policy. Photovoice is a means of generating knowledge as a needs assessment tool to provide researchers or development programmes with “the possibility of perceiving the world from the viewpoint of the people who lead lives that are different from those traditionally in control of the means for imaging the world” (Ruby, 1991). This brings forth the concerns from the community themselves rather than what the researcher or programmes think is important. As an intervention, photovoice is an alternative participatory method to share and disseminate knowledge. Other methods of obtaining and sharing information include interviews or focus group discussions. These methods have the possible limitation of power differentials between the researcher and participants. Maasai may not well articulate their experiences and perspectives through these methods, possibly explained by a history of not feeling authorized to offer critiques to ‘outsiders’. Photovoice helps break down the power differential between researchers and the researched, (Packard, 2008) as well as programmes and the community, by giving them more autonomy in the data collection process.

This paper describes a public engagement intervention of which one component was photovoice, a participatory method used with Maasai women to share their lived experiences of educating peers on trachoma, and ultimately empowering women in this society.

Context

Trachoma is the commonest infectious cause of blindness worldwide, caused by the bacteria, *chlamydia trachomatis.* The clinical features of trachoma are divided into those related to ‘active’ disease which is characterized by repeated infections, and are most common in children under 10 years; and those associated with scarring. Early stages of trachoma are characterized by follicles and inflammation in the conjunctiva of the upper eyelid. Over time, contraction of scar tissues causes eyelids to turn inward. Eventually eyelashes may touch the eyeball, trichiasis, leading to blindness (Hu et al., 2010).

Trachoma is a major public health concern in Maasai communities in Northern Tanzania. In 2016, the prevalence of trachoma in predominantly Maasai districts in northern Tanzania was more than 50% (Mwingira et al., 2016). Risk factors for trachoma include limited access and use of water (Bailey et al., 1991); limited face washing (Schemann et al., 2002; West et al., 1995; West et al., 1991); poor sanitation (Emerson et al., 2004; Schemann et al., 2003); and crowding (Bailey et al., 1989). Residents of Maasai communities in Tanzania and Kenya have shown a limited biological and public health knowledge of trachoma, transmission, prevention, and control measures. Despite experiences and awareness of trachoma as well as an indigenous understanding, there was poor understating of aetiology and prevention (Mtuy et al., 2019; Njoma et al., 2016). Control of trachoma is based on the World Health Organizations (WHO) SAFE Strategy composed of four public health interventions: Surgery for trachomatous trichiasis; Antibiotic treatment to eliminate the infection; Facial cleanliness promoting hygiene to reduce transmission; and Environmental change which includes management of human and animal faeces, cleanliness to reduce flies, crowding and access to water (WHO, 2012). Despite the Tanzania National Neglected Tropical Disease (NTD) control programme coordinating the delivery of improved SAFE strategies in these communities, trachoma remains a concern in Maasai districts in Tanzania. Mass drug administration (MDA) of antibiotics has challenges including logistics in the environmental terrain of pastoralist societies, but additionally socio-cultural factors and political history influencing perceptions of the programme. A study looking at MDA in a Maasai community in Tanzania found that norms around pregnancy led women to accept the antibiotic but hide their refusal to swallow the drug. The timing of drug distributor visits conflicted with livestock grazing, and women attending to household chores such as fetching water or firewood. Refusals occurred among the *ilmuran* age group (young adult men) due to cultural norms related to creating strong bonds within their age group. Mistrust significantly hindered uptake of drugs possibly due to a history of political and social subjugation (Mtuy et al., 2021). Land tenure policies in Maasai communities created during colonialization, many of which still exist today, were an effort to consolidate and isolate the Maasai and their cattle into designated areas and restricting their movement and interactions outside those areas (Wagner-Glenn, 1992). Maasai questioned the government's efforts to distribute antibiotics for trachoma against what they saw as important yet neglected priorities for resources for hospitals, medicines, clean water and roads (Mtuy et al., 2021)

The lead researcher (TBM) conducted ethnographic field work in northern Tanzania from September 2016 to December 2017 (Mtuy et al., 2021; Mtuy et al., 2019). The purpose of the research was to document the community's understanding of trachoma, and responses to the national NTD control programme for trachoma elimination. In an effort to disseminate accurate information on trachoma following the research, a public engagement intervention using photovoice method was conducted in the same research community by the lead researcher. The National Co-ordinating Centre for Public Engagement in United Kingdom defines public engagement as the myriad of ways in which activity and benefits of higher education and research can be shared with the public. Engagement is a two-way process, with a goal of generating mutual benefit (NCCPE). This paper describes the experience of women participating in the public engagement intervention, ways in which women were enabled to learn and to be teachers around trachoma within their community, and ultimately empowering women in this society.

While this project could be used to inform health education, the primary purpose of photovoice in this project was as an intervention to visually document the outcomes of a health education programme. Measuring the translation of knowledge into practice has challenges and takes time. Use of photovoice to visually document women’s efforts to transfer knowledge into practice aimed to, (1) provide an alternative method to other qualitative methods to reflect and share experiences and challenges of trachoma control methods; (2) shift power to the women by allowing them to be instrumental in the data collection process and motivate them to fully participate; and (3) measure success of the intervention. This project put Maasai women behind the camera, to use photography as a means to describe their role as advocates for trachoma control and its impact.

Methods

This was a public engagement intervention for Maasai women, aimed to raise awareness about trachoma infection and control measures in a trachoma endemic community in Tanzania. The intervention consisted of a workshop which included photovoice training, participants disseminating knowledge from the workshop within their sub-villages, documentation of trachoma control in the community through photography, and ending with a group discussion of the participants’ photos. The flow of the project is shown in figure 18. Findings were based on observations during the intervention, follow up visits, and discussions during the photo sharing workshop.

The aim was to co-design the intervention and give power to the community to be actively involved in aspects of the intervention. Local leaders and lay Maasai men were consulted for various aspects of the intervention design: recruitment of women, consent, plans for follow up post-workshop, logistics of collecting cameras, and distribution of photos to women. Men are primarily involved in official planning due the gendered hierarchical system in Maasai culture. Yet the research team informally included women’s suggestions in the intervention. Women requested during the workshop, that the researchers introduce the photography aspect to their husbands and heads of household, which was implemented.

The participants were 20 Maasai women coming from three villages, Il Donyo, Leremeta, and Endonyoemali, in northern Tanzania. The three village chairmen selected two women in each sub-village (total of 10 sub villages) to participate in the intervention and contacted them directly. In Maasai communities the village chairmen should be included in any decision-making regarding programmes in their village. Typically, communities hold a lot of respect for village chairmen, their leadership, and decisions. Decision-making in Maasai society is more collective rather than individualistic, and it is the village chairman that is expected to facilitate discussions related to village activities and decisions. A Maasai leader advising the research group advised that village chairmen would choose women who had experience participating in other community programs, and were proactive in transferring information from programmes to the community. It was expected that village chairmen would fairly choose appropriate women based on these criteria to represent their sub villages. Feedback from the community indicated selection was fair in two villages while one village chairman was accused of selecting women based on personal interest (his wives and other relatives). It was not known if women ‘voluntarily’ accepted participation after being chosen by the village chairmen. Our experience in this Maasai community and particularly with the selection of community drug distributors for MDA for trachoma control in the same setting, people are willing and honoured to participate in programmes intending to improve the lives of their community. There is a respect and prestige associated with attending programmes. It should be noted that unintended coercion is possible when selection of participants is done by a community member. The decision to have the village chairmen central to the selection process was to respect the local hierarchical system and culture. Despite positive feedback on the intervention from all women

Figure 18. Flow of photovoice activities

who participated, the researchers were unable to assess if there was any coercion to participate.

The workshop was conducted at the Il Donyo village office in September 2017. Women were given transport allowance, and all who were invited attended the workshop. The workshop was conducted by two Maasai research assistants (JM, JL), supported by the lead researcher, who were familiar with the community, and who had established a rapport with leaders and community members during the course of the fieldwork pre-empting this engagement activity.

The use of photos taken in a photovoice project requires consent from third parties captured in the images (Wang & Redwood-Jones, 2001). Consent allows for use of the photos to raise public awareness and to share with collaborators. An additional goal of this photovoice intervention was to display the photos taken by the women at the weekly village market day to raise awareness of trachoma control among community members, local leaders, and health officials. The issue of asking workshop participants to obtain consent was discussed with Maasai researchers and village leaders, who strongly advised against it. They advised it would not be possible due to low literacy of the entire community. Additionally, it was thought to lead to potential mistrust in the lead researcher and the project.

The workshop was delivered in Maa (Maasai language) by two Maasai research assistants. The lead researcher designed the curriculum of the participatory workshop using the local understandings of the disease as a foundation gained from previous research (see (Mtuy et al., 2019). The workshop was approximately three and a half hours and covered basic information on causes and pathology, transmission, signs and symptoms, treatment, and prevention. Women were then asked to go back to their villages as advocates or ‘trachoma control ambassadors’, providing education, advising, and mobilizing the community. In this role as ambassadors, women shared their knowledge from the workshop with other women in their village, and facilitated discussions on control measures within their socio-cultural context. The following participatory methods were used in the workshop.

Giant fly models

Giant stuffed, *M. sorbens,* were used to show transmission of *chlamydia trachomatis*. Baby powder, representing *chlamydia trachomatis*, was put around the eyes of women. It was demonstrated that when the giant fly landed on their eye, it got some baby powder on its feet and then flew off and landed on another woman's eye, leaving some baby powder on her eye.

Story telling

Issues around trachoma infection and treatment were conveyed through a story telling session, using an adapted version of the story of Kokwana from the book "a Village Struggles for Eye Health" (Sutter et al., 1989), translated into Maa.

Video demonstration

A short video by Sightsavers, "Leaky Tin: A Simple Solution", was shown and simultaneously translated in Maa to show a simple and effective way to wash faces and hands using minimal amounts of water. This demonstrates the use of a container with a hole poked into the bottom. When filled with water, hand and face washing can be done with the water slowly trickling down. The hole can be plugged with a thorn when not in use. Since the video was of Maasai from Kenya it was thought to have more of an impact with members of their own community addressing trachoma prevention than seeing people outside their community on the video (Freudenthal et al., 2006).

Discussion groups

Women were asked to go back to their villages as trachoma control ambassadors by sharing knowledge from the workshop with other women in their village and facilitating discussions on control measures within their socio-cultural context. Through three small discussion groups based on the villages they came from, women planned ways of disseminating knowledge from the workshop to other women in their village. All three groups decided that the two women selected from each sub village would 'co-teach' the knowledge they gained from the workshop at a meeting of mothers and grandmothers in their sub village.

Photography

Women were given disposable cameras to document their efforts as trachoma control ambassadors and the challenges raised around trachoma control. They were taught how to use the disposable cameras, what types of images they can capture, and the ethics of photography including seeking permission prior to photographing people or private property and respecting people's choices not to be photographed

(Figure 19). Women were asked to photograph people, activities, and things that convey their efforts as trachoma control ambassadors including successes and challenges. Women were encouraged to consider the confidentiality of people and places being photographed by taking metaphorical photos, aimed at using creative ways to depict a situation symbolically (Ponic & Jategaonkar, 2012). Examples given at the workshop included photos of soap and water rather than a person bathing; or clean clothes drying on a line rather than a woman washing clothes.

Figure 19. Participants practicing use of disposable cameras

The day of and the following day of the workshop, the two Maasai research assistants, one village leader, and the lead researcher visited the homes of each participant to meet their husband or the male elder of the *enkang*[6]. The visits aimed to seek permission for woman to use cameras to document their experience as trachoma control ambassadors. All agreed for them to use cameras. The decision to include husbands or heads of household was an afterthought when women at the workshop requested this be done to explain why a woman in their home has a camera and will be taking photos. The women wanted this additional permission to carry out the intervention.

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[6] An *enkang* is a homestead or joint residential unit composed of a number of households. They are headed by one male and in a polygamous culture, each wife with her children have a hut within the boma Mtuy, T. B., Bardosh, K., Ngondi, J., Mwingira, U., Seeley, J., Burton, M., & Lees, S. (2021). Understanding hard-to-reach communities: local perspectives and experiences of trachoma control among the pastoralist Maasai in northern Tanzania. *Journal of Biosocial Science, 53*(6), 819-838.

A week after the workshop, the research assistants and lead researcher again visited each woman to follow up on their progress as trachoma control ambassadors and to make sure they were comfortable using the cameras. Women were asked to return the cameras to the research team two weeks later on market day. All 20 cameras were returned. The cameras were sent for film development.

Five weeks post-workshop, the lead researcher and research assistants held a follow up meeting with the women. Each woman received their set of photographs to keep. The women were asked to select two photos to discuss with the group- ideally one showing a success and one a challenge in their efforts as trachoma control ambassadors. The lead researcher led a group discussion whereby each woman individually shared their photos with the group. Woman described their two photos and all women engaged in discussions related to the photos based on SHOWeD (C. Wang, 1999a): What do you See here?, What is really Happening here?, How does this relate to Our lives?, Why does this situation of concern or strength exist?, What can we Do about it?, How can this image educate others?

Intervention Outcomes

The most commonly shared photos were of children either washing their faces, or displaying clean faces with no flies. Women shared photos of individuals cleaning up trash or human and animal faeces, cleaning clothes and displays of ‘leaky tins’ at their *enkang*. Some women shared photos of themselves conducting meetings with other women in their village to educate them on trachoma. Very few women shared photos of challenges, but of those that did the photos showed traditional practices of treating trachoma-like symptoms (Mtuy et al., 2019) and of animal carcases. The workshop only mentioned faeces as a source of flies and despite this, women concluded on their own that animal carcases were a source of flies. This is a very real source of flies in this community with a lot of carcases of wildlife and donkeys close to their *enkang*.

Empowerment

Although empowerment was not systematically measured, it was observed that women articulated empowerment as participants in this public engagement intervention. Budig's (2018) areas of empowering women is used to reflect on its application through participation in photovoice.

A gain in knowledge and skills

Women gained knowledge about trachoma from the workshop. Photovoice provided a means to share how women transferred knowledge from the workshop to their community and the response from the community. This was evident from the follow up visit to their homes, and the photos they shared particularly those taking action to reduce risk factors in their homes. There was evidence through the photos of women cleaning up animal faeces at their *enkang,* erecting leaky tins for hand and face washing, and increased face washing for children and adults. Photovoice provided a personalized perspective that researchers or NGOs would not otherwise experience-images inside people's homes, engaging in social activities, and documenting behaviours that words could not fully capture. Women also gained skills of using a camera.

Changes in self-perception

Women felt proud to be selected by male community leaders to take on the responsibility of representing their sub-village and acquiring new knowledge. They felt valued as experts within their community when they disseminated their newly acquired knowledge. Women were agents of change in their community by spreading the trachoma education they received to other women in their communities. Conversations and photographs demonstrated participants effectively stimulated social change. The most obvious example was the implementation of leaky tins in nearly all *enkang* visited by the research team one-week post-workshop. Women and men proudly guided the researchers to the newly erected hand and face washing station. Additionally, the local boarding primary school constructed a larger, sturdier version made from metal pipes, and numerous children can wash simultaneously (Figure 20).

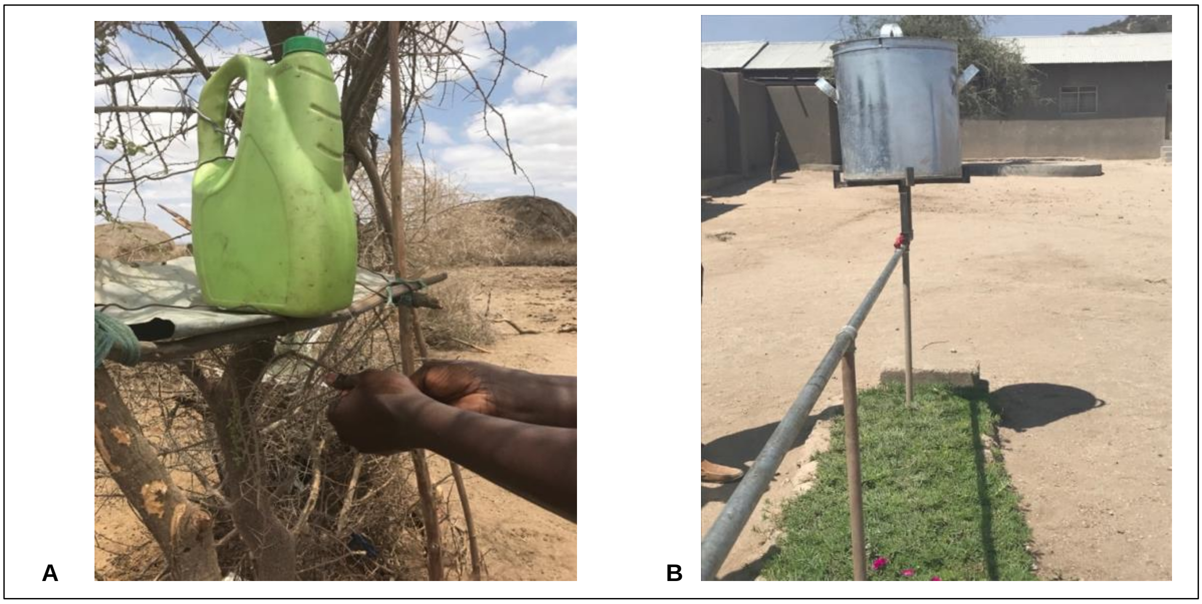
At the 5-week post workshop meeting, women showed excitement and pride when they received the photos they took and were pleasantly surprised and expressed appreciation when it was explained that the photos were theirs to keep.

Access to and use of resources

Women were given the opportunity to use cameras, a first time for all the women. When first given the cameras, they were unsure which way to hold them, or what the mechanism was to capture an image. Through demonstrations and practice, they proudly mastered locating an image, focusing on it, and pressing the shutter-release. The women were being trusted to provide information with cameras which added additional value for them. Through gaining knowledge to control trachoma, women were trusted by husbands to utilize household resources to aid in control measures such as containers for leaky tins, purchasing soap for washing bodies and clothes, and use of limited water for preventive techniques.

Figure 20. Leaky tins

Installed at **(A)** a participants' home, and **(B)** local primary school, after the trachoma workshop



Photography and public trust

Documenting community reality and discussing community change are walking a fine line of politics (Wang & Burris, 1997). Participants may face uncertainty or experience unintended consequences. Participants reported that community members questioned the real intentions of using cameras to capture the livelihoods of their people. They questioned if the *mzungu* (white person) researcher was going to sell the photos or use them for tourism. Photographic safaris are a source of income for Maasai where they often welcome tourists into their *enkang* for traditional dances and pose for photos on the side of roads. Despite the income generated, Maasai explained that photos taken by tourists is perceived as exploitation of their people. One elder discussed a recent incident in which tourists in Sinya, had photographed him while bathing in a dam. “Photography is an aggressive act, at least in the context of international tourism, where it is a means of dominating the object” (Barthes, 1981; Sontag, 1973). Participants were able to clarify the goals of the use of the cameras to many community members, but some still did not understand nor trust the photographer’s intensions and use of the photos. This was evident in some photos, that depicted people walking away, hiding their faces and, in one case a man waving a stick at the photographer. All women said they faced challenges related to the cameras, but most felt confident their clarifications were well received. *“There’s always a few people that have doubts so its ok”* [woman participant 6].

The ethics of photography was discussed in the workshop, including requesting permission to take photos, and respecting people’s requests not to have their photo taken. It was explained at the workshop to take metaphorical photos; photos did not need to include people or show their faces to display their efforts as ambassadors or the successes and challenges around trachoma control. Despite the efforts to avoid problems in the community around the use of cameras, there were few unintended or negative consequences.

Discussion

As a socially and politically marginalized population it was anticipated that putting Maasai women behind the camera would be empowering, provide an insider perspective of their livelihoods and an effective means to promote trachoma awareness within the community. This public engagement activity explored the use of photovoice as a tool to empower women to be agents of change for trachoma control in their communities. Health education accompanying health service delivery programmes including trachoma control programmes is inadequate and often ineffective due to budget and time constraints (Hastings, 2013; Mtuy et al., 2021). Community level health behaviour change requires moving beyond didactic methods to include skill development, knowledge acquisition and active community involvement. An informal participatory approach to health education is effective; “a process that enables, encourages, supports and facilitates, but does not impose" (Brieger, 1996). Participatory methods, including use of photovoice, used in this project were effective beyond knowledge transfer and awareness raising in that it promoted social and emotional connectedness through a shared experience, a sense of solidarity.

The use of photovoice was an effective tool for motivating and facilitating community discussion about trachoma control, and ultimately empowered women engaged in the intervention. Similarly, photovoice used in other Maasai contexts were effective in engaging Maasai in discussions prompted by their own photography on topics of women's perceptions of development (Fraser et al., 2012) and animal health needs (van der Meer et al., 2015). Yet unlike prior photovoice projects in this community, this was the first time that photovoice was used for public engagement. Some of the advantages of using photovoice specifically with Maasai women includes documenting their socio-cultural settings including their risk behaviours; to allow the community to showcase the assets of their social network (McKnight, 1987), and possibly stimulating social action by encouraging women to be proactive around their community's well-being (Wang & Burris, 1997). The researchers recognize the ethical tension of engaging this vulnerable population in this participatory method of generating knowledge. Yet with recognizing the ethics of photovoice, and culturally appropriate engagement of community leaders prior to the photovoice project, any unintended consequences were greatly reduced.

In a patriarchal culture such as the Maasai, coupled with women being at the forefront of health issues in their community (Hodgson, 1999), women's' voices are imperative. Photography of the Maasai is embedded in their culture on different historical levels. The Maasai have been depicted as exotic, noble savages in various visual images from 'trade cards' in the late nineteenth century to today contemporary coffee table books. Considered a must see along with the 'Big 5' on photographic safaris in Tanzania and Kenya, Maasai are sought out to capture images of them adorned in beads and posing with spears (Bruner & Kirshenblatt-Gimblett, 1994; Sobania, 2002). Yet, this intervention put the cameras in the Maasai's hands giving them a sense of control and power in photography.

Feminist theory implies that power is held by those who voice, set language, make history and participate in decisions (Smith, 1987). It honours local understandings which cannot be fully conceptualized from outsiders (Castleden et al., 2008). This intervention demonstrated that participation in photovoice in this context empowered Maasai women according to three areas described by Budig et al (2018): (1) a gain in knowledge and skills, (2) change in self-perception and, (3) access to and use of resources. Photovoice carried out by women intends to be by and with women rather than on women. It aims to honour women and values their experience and position in society (Wang, 1999). Empowerment can include a change in how participants access and use resources or information; and the formation and potential of social relations (Budig et al., 2018; Zimmerman, 2000). Empowerment has been described as a significant outcome in photovoice projects (Duffy, 2011; Molloy, 2008; Wilson et al., 2007). Although there are several factors that may contribute toward empowerment in these projects it is the totality of the method that includes a sense of trust in participants being photographers, a catalyst to explore, and share lived experiences and feeling valued for their contribution toward social change.

Despite efforts to emphasize metaphorical photos, most photos depicted community members. Women discussed the enjoyment in taking photos of family and friends, something they had never done and the thrill of receiving the print photos of people they took themselves. Therefore, the researchers were unable to display the photos in public since consent from those being photographed was not given. As the photos were only in print format, they were given to the women who took ownership of them, and the negatives destroyed by the lead researcher. In many cases women gave photos to the people captured in the image. Despite this inability to disseminate photos more broadly to the community, the participants were comfortable to discuss their experiences with the lead researcher and bring information back to the community. An additional benefit was the positive experiences in being given autonomy to photograph as they chose. Maasai reported similar experiences in other photovoice projects (Fraser et al., 2012; van der Meer et al., 2015).

Lessons learned of using photovoice in resource poor-contexts

Informed consent was not obtained for this public engagement activity as it was viewed as a barrier to the community feeling comfortable and open to share and participant in activities; it was advised that it would affect trust in the intervention and the researcher. Informed consent in research is based on a western context focusing on individual rights, a sense of the ‘self’ and a legal protection (Grady, 2015; Levine, 1991). In Maasai communities, similar to many African contexts, emphasis is on community and collective decision-making (Krogstad et al., 2010; Metz & Miller, 2013). To respect this interdependence within the community, the research team obtained permission from community leaders to conduct the public engagement activity, and from heads of households to allow women to take photos in the community. The disadvantage of not obtaining consent is that it does not allow the researcher to formally analyse and interpret the ‘data’ (in this case photos and transcripts of feedback session) nor display or publish the photos. Yet with reciprocity, being the aim of this public engagement activity and not research, the researchers were agreeable to not obtaining informed consent. It should be emphasized that it is the story and experience around the images that is more important than the images itself.

The lead researcher’s acceptance of the communities advice not to obtain third-party photo release forms, and her ability to be reflexive about her own power in the project was critical to acknowledge the ethical context and safety of the participants (Ponic et al., 2010). There was flexibility from traditional ethics to adhering to situational ethics, seemingly more relevant in this community. Traditionally, decision making to participate, and the concept of autonomy is based on self-determination. Relational ethics is based on the principles of “engaged interaction, mutual respect, embodied knowledge, uncertainty and vulnerability and interdependent environment” (Austin et al., 2014). It views decision-making as being ‘with’ a participant, rather than ‘for’ a participant. From a relational perspective, the social, economic, and political context of participants influences their decisions. Decisions are framed by their relations both within their community and with researchers; embedded in systems of power (Varcoe, 2006). Interpreting autonomy in terms of individual choices without considering the context, potentially ignores a community’s socio-cultural system, and adds additional power imbalances to participation. Relational ethics in photovoice has been used with vulnerable women (Ponic & Jategaonkar, 2012) and is relevant to consider in the African context (Metz & Miller, 2013).

In photovoice the images including film negatives are considered the property of the photographer (Wang & Redwood-Jones, 2001). A researcher must obtain informed consent from the participant, “photographer”, as well as consent from third parties whose images are captured. In this intervention, printed images were handed over to the participants to keep and negatives of the prints destroyed by the researchers. This was discussed with community leaders to allow for transparency in the purpose of the activity.

Issues of respect for privacy are embedded in the ethics of capturing images. The act of capturing an image may invade one’s personal space in addition to invading privacy by capturing a personal moment. A photographer’s depiction of people or a situation may be portrayed differently in their photos, the use of photos, and the description of photos from how a person or group of people see themselves and/or want to be seen. Although some argue that a photograph is no different from a fully written description (Gross et al., 2003) “such an action is not ethically neutral” (Wang & Redwood-Jones, 2001). The power of a photographer to produce, interpret, and potentially benefit from images creates a vulnerability of those being photographed. With Maasai so often photographed in tourism, this activity shifted power to Maasai photographers, and women discussed the pleasures in being on the other side of the camera. It was noted that giving this power to women in a patriarchal community required permission which were obtained from the male heads of households for each participant. Women were taught the ethics of photography, and to assure the safety of themselves and those in the community by taking metaphorical photos. This strategy was highly effective in minimizing the number of identifiable photos and minimizing pushback from people not wanting their photos taken.

Photovoice projects have used video cameras, digital cameras, disposable cameras, and smart phones. Each has its strengths and weakness (Tornbom et al., 2019; Wang, 1999). A final reflection was the challenge of using disposable cameras in this photovoice project due to budget constraints, low use of smart phones, and illiteracy in this community. Whilst the women had never used a camera before, they found the simple cameras easy to use. However, it was challenging to develop the film as such services were not available in Tanzania. Instead, the cameras had to be sent to UK for film development. This led to a three-week delay between collecting the cameras and holding a meeting with the women to discuss their photos and experiences. There was the possibility of lost to follow up of women or recall bias. Fortunately, neither was an issue in this intervention as all women returned for the meeting, and a combination of the photos with dialog between the women assisted in recalling their experiences.

Conclusion

While this was not the first photovoice project in Maasai community (Fraser et al., 2012; van der Meer et al., 2015), it is the first focusing on health and specifically trachoma control. Although this project was not designed to collect research data to inform future interventions or policy, it was effective in empowering women to be change makers, and to encourage them to have a voice in educating their communities on trachoma control. The project also provided a guided and systematic approach for the women to discuss openly what risk behaviours are reasonable to change and those that are challenging in their socio-cultural context. This public engagement intervention showcased an effective method to share with the public aspects of the ethnographic research conducted in their community. Through a mutual benefit, the researchers confirmed the effective use of photovoice as a tool to engage the public in the research topic of trachoma control, and for empowerment among women that participate. Effective health promotion occurs within the community. Photovoice enabled women to promote positive health behaviours, and to initiate conversations around trachoma. Photovoice should be considered for future public engagement as a communication tool on health issues, and to empower women to be ambassadors for health promotion.

Competing Interests

The authors declare that they have no competing interests.

Acknowledgements

We would like to extend our gratitude to the women who participated in this public engagement project and to the village leaders for their support and collaboration.

Chapter 7: Discussion and Conclusion

In this final chapter I synthesise the findings and discuss how they contribute to the overall aim and objectives for this thesis (chapter 1, p.42), reflect on the applied and theoretical contributions of this work, and detail recommendations for policy, programming, and future research. Also, I reflect on the strengths and limitations of this research more broadly building on chapter 2. I end with concluding remarks on this thesis.

History repeats itself

As I sit down to reflect on my research and write this final chapter, I am hearing from many Maasai friends and collaborators of unfortunate news of the latest land evictions in Loliondo, an area of northern Ngorongoro District in northern Tanzania. The government is claiming they are moving people from this area bordering Serengeti National Park, for the purpose of conservation. Yet the reality is neo-colonial land snatching for the Dubai royal family's game hunting holidays. Reports describe Maasai being forced off their land by police and officials using tear gas and guns as scare tactics. Some have reported being shot at in the leg. Kids are wounded from stones thrown at the crowds. More disturbing is that they are not safe to seek medical care. When someone suffers any physical injuries in Tanzania, they need a permit from the police to prove to the health facility that they are innocent and not a possible thief or criminal that needs to be reported to the police. Yet the Maasai are afraid to go to the police to get this permit as they are the same people that are injuring them, and they fear being locked up or beaten. They are also afraid to go direct to the health facility, for fear that health workers will report them to the police. Injured Maasai are crossing into Kenya to seek the medical care they cannot access in their own country.

Here is an excerpt from a statement of the Maasai of Loliondo presented at the United Nations, Convention on Biological Diversity in June 2022 (Forest Peoples Programme, 2022):

> *We are not against conservation, but we see and conceptualize it from a different perspective! We have never been given a space to share our perspective, instead, we have been categorized as enemies – people who should not be consulted.*

> *On 10 June 2022, our villages in Loliondo were invaded and occupied by military; we were not notified despite the fact that we have a court case coming to its judgment at the end of June 2022.*
>
> *We have been shot, harassed, injured, and displaced – especially women. Thousands have been displaced including 1,576 children, who are now homeless and seeking refuge in Kenya. Most of them are lacking basic needs, including food supplies, medical care, and accommodation.*
>
> *We are being accused by our government as being destroyers of our environment and denied citizenship of Tanzania – those who crossed to Kenya in fear are now said to be Kenyans.*
>
> *This is the fourth forceful eviction from our land. And our leaders languish in detention in big numbers – 20 of them are being charged with murder.*
>
> *We cannot tell the world of the happenings because media is banned from covering our story.*

These first-hand narratives reemphasize the discrimination and marginalization Maasai are experiencing like their ancestors' experiences over a century ago. I cannot help but wonder how health care planning can ignore the impacts of these historical, political, and social complexities.

One size does not fit all

In chapters 3 and 4 I describe the landscape of trachoma in this Maasai community including their knowledge, discourse, decision making, and the ways in which MDA did not align with the local context and livelihoods. These findings demonstrate that the 'one size fits all' approach to trachoma prevention and control is not suitable for this community. Prior to 2018, the prevalence of TF was greater than 50% in Longido district. Since this field work and rounds of MDA, prevalence decreased to 5-9.9% in 2018 and 2019. The past two years have seen a re-emergence with TF prevalence bouncing up to 10-29.9% (International Trachoma Initiative, 2022). This has been seen in other countries (Burton et al., 2005; Lakew et al., 2009; West et al., 2005) with little research to better understand the reasons behind the re-emergence and persistent infection. Here I discuss a need for a tailored approach to trachoma control specific to delivery of MDA and broader considerations of integrated programmes.

MDA as biosocial

In 2021, WHO convened an informal consultation on trachoma end game challenges, offering expanded opportunities for countries to consider alternative MDA strategies, such as modified MDA approaches (increased frequency or increased rounds), use of geospatial analysis, and alternative survey indictors to measure infection (Palmer et al., 2022). As a result, Tanzania NTD Control Programme modified the MDA strategy in Longido District to implement MDA every six months for five rounds from August 2022 and will synchronize delivery of MDA with the cross-border districts in Kenya. Despite more focused efforts on these endemic communities, MDA is continued to be viewed as a biotechnological problem, ignoring the biosocial perspective.

Chapter 4 describes the multiple factors influencing the effectiveness of MDA driven by complex livelihoods, discourse and experiences linked to (mis)trust. There was an assumption from national and district level that individuals' activities would pause in Sinya to accommodate community drug distributors to distribute drugs to individuals. Yet I observed a very different scenario, the impacts of a challenging political-economic context including population movement, prioritizing local traditions over MDA, and the effects of poor knowledge and past experiences on attitudes toward MDA.

Several social scientists in the NTD field have discussed the reliance on MDA as a "magic bullet" compared to more integrated strategies and at the expense of engagement with social and economic determinants of health that also drive transmission (Allen & Parker, 2011; Allotey et al., 2010; Bardosh et al., 2014; Gupta-Wright, 2019; Parker & Allen, 2013). "Low hanging fruit" has been used to describe cost-effective, high impact interventions through MDA (Bardosh, 2014; Gupta-Wright, 2019). This research demonstrates how this narrow technical solution is not adequate alone and requires a 'deep dive' into social relations to tailor integrated approaches.

Further research that provides an additional perspective to this thesis was conducted in Tanzania to understand the perceptions of programme planners, managers, and implementers on the challenges of MDA implementation in these hard-to-reach communities (Tsang et al., 2021). On one hand, there was recognition of some of the broad contextual factors affecting intervention implementation discussed in chapters 3 and 4, including low knowledge, poor environmental conditions, seasonal migration, mistrust, and community values. NGO representatives acknowledged a need to tailor programmes for specific communities yet did not provide any suggested measures to overcome these challenges. For example, many NGOs assumed Maasai understanding of trachoma was limited and impacts uptake of MDA and trichiasis surgery, yet continue implementation as per status quo rather than reconsidering approaches that address these challenges. Recognition of the challenges in Maasai communities is a positive step. Moving forward, key actors involved in planning MDA need to strategize and deliver programmes that acknowledge and are tailored around these barriers. Due to the top-down approach of programmes, programme planners and decision makers need to engage with communities and implementers on the ground, namely CDDs, to better understand the realities.

In chapter 3, I discuss that the Maasai recognize, trust, and use western medicine yet NGOs implementing trachoma control programmes tended to blame the use of traditional healers for poor uptake of treatment (Tsang et al., 2021). This blaming of communities increases the imbalance of power, negatively impacting the effectiveness of programmes. There tends to be scapegoating of communities rather than reflecting on the suitability of approaches and monitoring programme operations. None of the interviewees in this study discussed inaccuracies in reporting of MDA. In chapter 4, I discuss the realities of non-adherence due to population movement and 'hidden pregnancies' despite CDDs recording such individuals as receiving MDA in the registers.

Integrated approaches

The SAFE strategy has not been operationalized as the holistic strategy it is designed to be. While three of the four SAFE strategies are focused on prevention and control of infection, priority has been given to one of the three preventive methods, the "A", antibiotics as preventive chemotherapy. To date, less attention and resources have been on "F" and "E", facial cleanliness, and environmental improvement, requiring behaviour change interventions. These approaches may be seen as "one size does not fit all" since they require a more context-specific, subjective approach with a different set of tools to measure success beyond quantitative measures for uptake and impact of surgery and MDA. Surgery and antibiotics are a biomedical solution, whilst behaviour change programmes requires a “long-term solution will not be arrived at quickly and it will not be cheap” (Emerson, 2000, p 524). A large component of the “E” is management of livestock through application of one health and vector control, strategies known to have helped but have been side-lined (Hollingsworth et al., 2015; Molyneux et al., 2018). Additionally, “F” and “E” require WASH interventions such as improving access to water and latrines at schools, which may be viewed as the responsibility of national governments and possibly shifting blame of the disease from endemic communities to national governments. Such interventions in marginalized communities may require governments to reprioritize development activities contrary to what has been planned for a country.

In chapter 6, I discuss a participatory approach to educating and empowering Maasai women to engage in trachoma control. Although this was not intended to measure the impact of behaviour change or sustainability of the intervention, it did enhance women’s ability to be engaged in behaviour change. Much of the behaviour change interventions related to facial cleanliness are criticized for not being transferrable to other settings. The Behaviour Centred Design (BCD) approach is based on the notion that human behaviour can be modified by altering the ‘environment’- physical, social, or biological. In doing so the mind and body response is altered and ultimately impacting a new behaviour. The means of producing this change in behaviour is through ‘surprise, revaluation and performance’ (Aunger & Curtis, 2016). The ‘right’ type and level of exposure to an intervention that grabs the attention of the target audience produces ‘surprise’. ‘Revaluation’ involves altering the motives that drive behaviour and increasing rewards. Finally, ‘performance’ is encouraging the target behaviour through changes in the setting and to reduce the costs of engaging in the behaviour. This intervention of providing individuals with knowledge through an interactive workshop (surprise), and hygiene practices revalued via practices Maasai women deemed appropriate and specific to their socio-cultural context, has implications for sustainability. In a study assessing WASH among a Maasai community, many participants attributed improved knowledge, attitudes, and practices of WASH to COVID-19 related education. Yet the use of law enforcement to change behaviours, in this case Tanzania law requiring latrines at each household, was less effective. Some reported never using the latrines and throwing meat scraps in them to produce an odour when government officials would come to their homes to inspect (Beange, 2022). Undeniably behaviour change programmes must focus on ‘situatedness’ of behaviour in social and physical settings and the context of other behaviours (Aunger & Curtis, 2016).

As global trachoma control actors consider the ‘end game’, what may have been seen as biomedical ‘quick fixes’ needs to be revisited from a biosocial perspective and the focus shifted toward integrated approaches tailored to local contexts. The new WHO NTD Road Map (WHO, 2021) aims toward a more holistic approach that acknowledges integration of interventions. This includes coordination with health-related programmes such as WASH and vector control and collaboration beyond human health considering environmental, veterinary health and education (WHO, 2021). This global strategy is a significant step toward moving from the top-down approaches and toward the inclusion of the biosocial in NTD control and elimination. To assure inclusion of complementary strategies addressing the ‘social’, Spiegel et al. (2010) suggests a ‘social offset’ by allocating a proportion of funding for NTD programmes to ‘offset’ to address manifestations of the ‘neglect’.

Untangling ‘hard to reach’

NTDs are diseases of poverty, both as drivers and manifestations of poverty (Bardosh, 2014; Hotez et al., 2009). In addition to individual risk factors, diseases of poverty encompass structural inequality in access to health care, infrastructure, food, education, political voice, and markets (Bardosh, 2014). Inequities among ‘hard to reach’ communities are further compounded by conflict, struggles for human rights, or neglected by governments (Hotez & Pecoul, 2010; Jacobson & Bush, 2018). While the burden of NTDs in ‘hard to reach’ communities are also linked to geography and socio-cultural differences, communities with persistent infection require a deeper understanding of social constructs and livelihoods.

This research utilized a political economic perspective to underpin the analysis of Maasai experiences and responses to MDA and health services more broadly. This emphasizes social relations of power as a key component of resource production and distribution (Goodman and Leatherman, 2010, p.19). This thesis took a different approach beyond looking at socioeconomic indicators to the impact of social processes and factors that perpetuate marginalization. In chapter 4, I highlight the impact of power directly and indirectly from the MDA programme. Its top-down approach involves various global and national actors making decisions, and implementing the programme with no involvement from the community.

Important to unpacking political economy is consideration of biopower, ways in which political governance exerts power by controlling bodies and populations (Foucault, 1982). In chapter 5, I discuss how external forces of power are constructed from colonial and neo-colonial experiences, and how Maasai have internalized these unequal social relations resulting in mis-trust and resistance. Scott (1985) has demonstrated how global health interventions can be reinterpreted based on social, historical, political contexts, resulting in resistance, non-compliance, or avoidance. This provides an alternative focus on building trust and tailoring programmes to the local concern, needs, and discourse (Bardosh, 2014).

Recommendations

Policy and Programmes

Country ownership is the third pillar of the new WHO NTD Road Map, acknowledging that countries are ‘both the drivers and the beneficiaries’ of progress to meet targets (WHO, 2021). Control programmes must be nationally owned and embedded within their national health plans. Yet this is still challenging for ethnically marginalized groups such as Maasai who will continue to be denied access to essential medicines and basic services (Hotez et al., 2009), particularly as political and environmental shifts are influencing access to water and land resources, threats to pastoralism, human-animal conflict, and food security. Programme planning needs to start from national government’s concern for, and engagement of, communities, which can only assist to rebuild relations and trust. This requires multi-disciplinary and multi-sectoral expertise while inviting communities to the table to inform planning. The WHO Road Map recommends engaging local governments (WHO, 2021), yet this should go one step further to recommend including communities, specifically CDDs and lay persons. NTD control programme review and co-designing needs to be informed by evidence including existing social science research.

Approaches to trachoma control need to be tailored and multi-facet, rather than reliance on MDA. Time and financial restraints should not be seen as a barrier. Finding more costly solutions that work may be more cost effective than less effective "value for money" solutions over time. The often-side-lined interventions must be considered for integrated programmes including education, behaviour change, one health and vector control. The WHO consultation for national programmes to provide expanded programmes of alternative approaches to MDA is a positive step toward incorporating tailored programmes. Tanzania should consider integration of these other approaches based on the knowledge generated from this thesis and prioritize social science perspectives to these approaches.

Control of NTDs and specifically trachoma has been working in parallel to national health systems. To align with the Sustainable Development Goals (SDGs) and an aim for universal health coverage, the global NTD network needs to encourage and equip countries to integrate NTDs into health systems (Bangert et al., 2017). This should start by building knowledge of NTDs within communities, the health system, and health care governance. This includes building up skills among primary care health workers, integrating NTDs into medical training curriculum, embedding ongoing monitoring systems at district level and improve referral systems (Falisse et al., 2022; Warne & Mukhier, 2021). As discussed in chapter 5, there is also a need for health systems to prioritize quality of care and respectful care particularly for marginalized communities, to improve trust, and access to care. Although this is beyond the scope of NTD policy, integration of health programmes into health systems builds confidence both in health workers and the community.

Future Research

Global health research is far too often uniform and 'global' (Adams et al., 2014). I recommend a shift toward more attention on political economies that challenge this more universal approach. There is a need to answer many of the 'why' questions- why coverage is not aligning with prevalence, why re-emergence of infection, why are some refusing MDA. Research on hard-to-reach communities requires a shift from comparability to other settings, to specificity to local contexts ultimately informing more person-centred approaches to programme delivery.

There is a need for operational and implementation research to deliver context appropriate and sustainable strategies with involvement of social scientists on research teams. Social science research is needed to understand the context and livelihoods of hard-to-reach communities. Historically social science has been considered time-consuming, complex, costly, yet when done contextually, findings can inform more effective planning and programme implementation. Resources exist that suggest several qualitative methods (Baker et al., 2021) and a comprehensive tool (Fitch et al., 2021) for using qualitative methods to better understand local realities and inform programme delivery (Table 9).

Findings from social science research for NTDs are often not translated into the design and evaluation of programmes (Baker et al., 2021). In this thesis I highlighted key groups in Maasai communities, namely child-bearing women and the *ilmuran* age set, that require further research on alternative approaches to reduce prevalence and transmission of trachoma for these groups. Building on the community engagement intervention in chapter 6, further research should be done to evaluate the long-term impact of a participatory workshop on knowledge and behaviours and possibly scale up of the workshop for Maasai women.

Table 9. Summary of qualitative and participatory methods to inform MDA programmes (in addition to focus groups and in-depth interviews)

Method	Description	Potential application for improving MDA
Social maps	Participants work as a group to draw a map of their community, highlighting key features in relation to a specific question or problem. They can also be sued to elicit solutions to a problem	Use to identify different social and ethnic groups and discuss if those houses are being visited during MDAs, or where to locate distribution posts to best reach them and/or to avoid over clustering.
Transect walk	Systematically walking around an area with key informants, observing, asking questions and facilitating a group discussion and analysis of an issue	Visit distribution posts and discuss who comes there, and why many not be able to come and why. Could also be used to identify where to reach specific groups (e.g. youth, people with disability).
Programme timeline	Participants draw a timeline from the first year of MDA to the present and mark key community events and discuss how MDA had changed during that time.	Evaluate events in past that have positively and negatively impacted MDA.
Seasonal calendar	Participants describes what a typical year looks like, identify events such as rainy season, planting and harvesting, important holidays and festivals, important dates in school year and migration times. Can be adapted to weekly or daily calendars.	Identify where the MDA falls in relation to other events and assess whether it could be held at a better time of year/week/day. Use with migratory groups to identify movement patterns and best time for MDA.
Case studies or vignettes	A fictional character, similar to participants, is introduced to the group. Participants describe the individual’s characteristics, and then discuss how that character would react or respond to various scenarios.	Explore how different household members might respond to female distributors vs male distributor, or explore why this character might not have taken the tablets, or explore issues impacting drug distributor ability and motivation to work.
Change stories or outcome stories	Group members tell personal stories or stories they have heard on a chosen topic.	Generating multiple perspectives on the MDA and understanding of what is driving coverage.
Participant observation of other health programmes	Staff participate in the implementation of other public health campaigns and observe and ask questions.	NTD programme manager takes part in malaria seasonal chemoprophylaxis or immunization campaign in a community where that programme has historically had better coverage.

Source: Baker et al. 2021

Specific recommendations

The findings of this thesis describe gaps in the MDA programme and several specific recommendations resonate that may inform similar programmes and research in Maasai and other hard-to-reach communities.

- Flexibility in the use of methodologies can impact on the quality of data and the relationship with the community. Approaches need to be considerate of fairness and inclusiveness and allow for acceptance into the research community. This research used unconventional methods for ethnographic research (i.e., sampling techniques) to reassure the community of fairness in who was involved in aspects of the research. I recommend the use of less confrontational and intrusive methods initially to ensure acceptance by the community. In this research, this was understanding knowledge and experiences of trachoma prior to exploring sensitive topics unveiling social and political inequities. This initial approach gives the researcher purpose rather than being seen by the community as an outsider observing them.

- MDA and health programmes more broadly in hard-to-reach communities need to move toward using tailored approaches with a more holistic understanding of the community. For programmes specifically in Maasai communities, use of the framework of five domains (Figure 13) to guide planning will improve effectiveness. Beyond logistical factors, this framework considers the impact of contextual, cultural, social, and political factors on the success of a programme.
- Behaviour change interventions for trachoma, specifically facial cleanliness, and environmental improvement, cannot be avoided for hard-to-reach communities. In addition to these being fundamental human rights to water, sanitation, and hygiene, it is also linked to education. This research highlighted the Maasai appreciation for and improved engagement with health services that educate and offer explanations. Education used in behaviour change empowers people ultimately impacting positive change. This was demonstrated through a community engagement activity, specifically in constructing leaky tins and larger hand washing stations at schools. Yet this research emphasizes the importance of behaviour change interventions coming from within the community by participatory design approaches assuring they are contextually specific, appropriate, and acceptable.

Strengths and Limitations

The use of an ethnographic approach to this research allowed for a more nuanced understanding of the local context and a deep connection with the people. Focusing on the importance of my relationships in the community by being open minded, willing, and able to live in their community and engage within their social context, was instrumental to ensuring mutual trust and openness. The slow, but meaningful, process of gaining trust and acceptance was evident. This concept of ‘slow research’, calling for attention to the local context where knowledge is produced and used, and prioritizing particularity and specificity (Adams et al., 2014) is essential in a hard-to-reach community while rethinking more appropriate and sustainable approaches to trachoma control. My data collection was strategically based on this slower and meaningful process. For example, using individual interviews initially allowed for more one-on-one engagement. At the beginning of fieldwork, I limited data collection to discourse and experiences of the disease, rather than data generated later in my field work that touched on more sensitive subjects of relations with government and programmes linked to political subjugation or discrimination. The long period in the field allowed for ongoing assessment of relationships and the context to inform when and how to proceed on aspects of data collection.

This links with the strength of ongoing community engagement throughout the research process which guided, confirmed, and encouraged my interactions and approaches throughout field work. As discussed in chapter 2, community leaders and officials were instrumental in this process and a few of those key actors were more intensely involved on a daily basis in co-creating aspects of this research. In chapter 6, I describe the co-creation of a workshop to educate women on trachoma and empowerment as a positive unintended consequence.

When considering the generalisability of this work, the aim was to generate sensitising concepts and hypotheses (Green & Thorogood, 2018) about the experiences of Maasai and how MDA for trachoma is situated in their complex livelihoods. The intention is to bring to light the need to understand specific contexts in which there are health inequities and shift thinking from a biomedical perspective to a biosocial approach. Although as a group the Maasai are facing similar general concerns, small and more remote communities may not have the same daily problems as those in other regions. For example, I am aware that Sinya is also in an area where elephant poaching is currently drawing a lot of attention and many conservation groups are doing a lot of education programmes and ranger patrolling in the area, while other Maasai districts are facing forceful evictions. Therefore, my findings may not be representative of all Maasai, although that is not what I set out to claim. Rather my intention was to uncover a case study of the response to MDA for trachoma and potential challenges to participating in MDA among the Maasai. I intend for the findings to be useful in considering the social context in marginalized communities that may influence the participation and response to public health programmes.

Conclusion

The quick fix or magic bullets did not achieve elimination of trachoma in 2020 as hoped. This points toward to the urgent need to consider the political economy of endemic communities which shapes attitudes, practices, and ultimately engagement in global health programmes. Global and national NTD actors must refocus on thoughtful approaches to tackling diseases in hard-to-reach communities.

Through the lens of a Maasai community, this thesis provides applied and theoretical contributions toward the field of global health and specifically trachoma control. The ‘end game’ toward eliminating trachoma requires a critical perspective. Global health has historically viewed its role as being action oriented in providing health services to populations. It is time to incorporate social theory into understanding the root causes of global health problems and furthermore to design practical solutions. I have demonstrated that strategies tailored to a community’s historical, social, political, and economic context are essential to relieve suffering from the burden of trachoma. I propose more careful attention and holistic approaches to break down historical biopower and rebuild trust in health systems.

“If there is a single overarching theme to a political-economic perspective it is in focusing upstream on the intersection of forces which place people by the river and push them in” (Goodman and Leatherman, 2010, p. 33).

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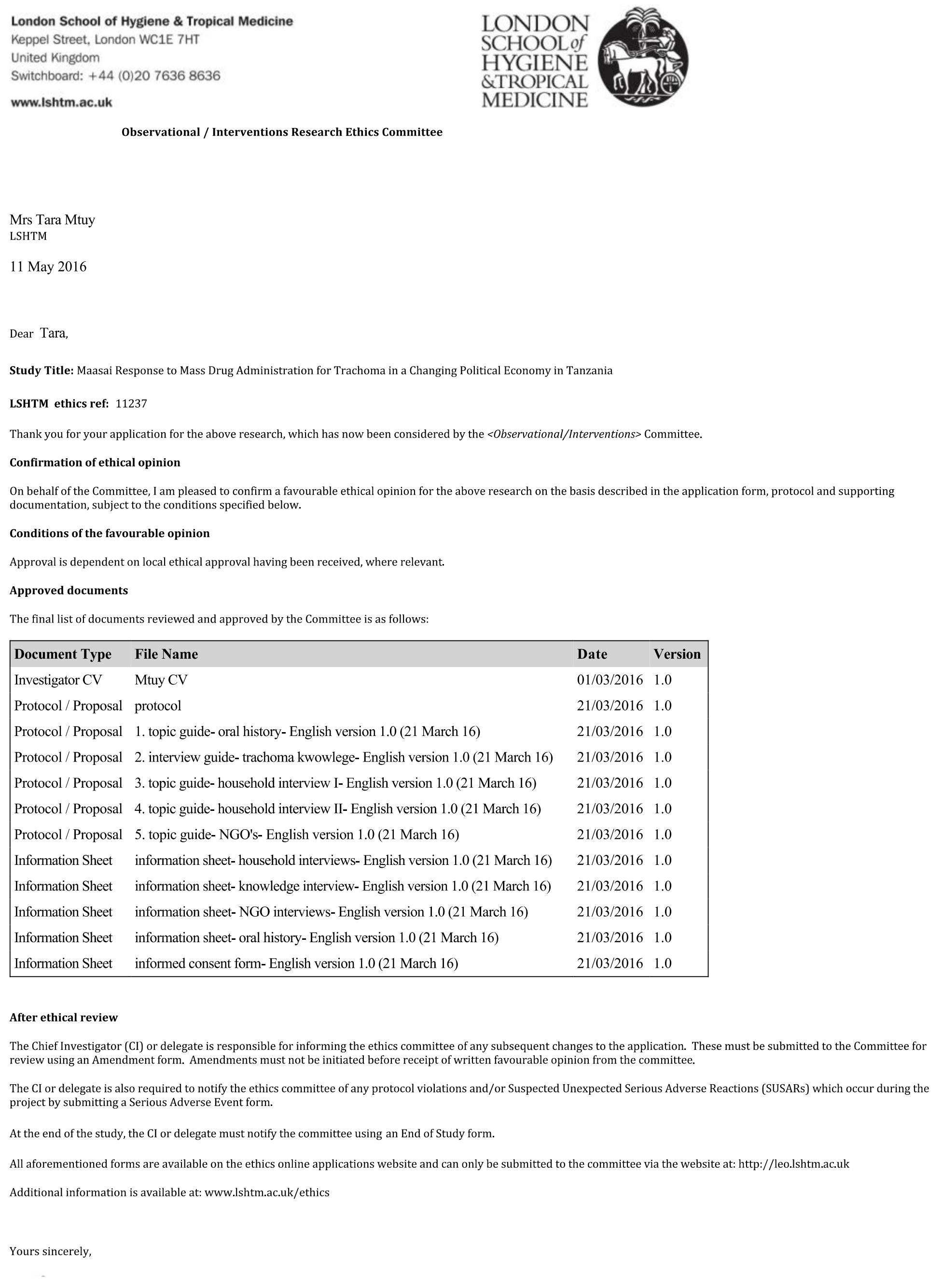
Appendices

Appendix 1. Ethical Approvals



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Observational / Interventions Research Ethics Committee

Mrs Tara Mtuy
LSHTM

11 May 2016

Dear Tara,

Study Title: Maasai Response to Mass Drug Administration for Trachoma in a Changing Political Economy in Tanzania

LSHTM ethics ref: 11237

Thank you for your application for the above research, which has now been considered by the *<Observational/Interventions>* Committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Investigator CV	Mtuy CV	01/03/2016	1.0
Protocol / Proposal	protocol	21/03/2016	1.0
Protocol / Proposal	1. topic guide- oral history- English version 1.0 (21 March 16)	21/03/2016	1.0
Protocol / Proposal	2. interview guide- trachoma kwowlege- English version 1.0 (21 March 16)	21/03/2016	1.0
Protocol / Proposal	3. topic guide- household interview I- English version 1.0 (21 March 16)	21/03/2016	1.0
Protocol / Proposal	4. topic guide- household interview II- English version 1.0 (21 March 16)	21/03/2016	1.0
Protocol / Proposal	5. topic guide- NGO's- English version 1.0 (21 March 16)	21/03/2016	1.0
Information Sheet	information sheet- household interviews- English version 1.0 (21 March 16)	21/03/2016	1.0
Information Sheet	information sheet- knowledge interview- English version 1.0 (21 March 16)	21/03/2016	1.0
Information Sheet	information sheet- NGO interviews- English version 1.0 (21 March 16)	21/03/2016	1.0
Information Sheet	information sheet- oral history- English version 1.0 (21 March 16)	21/03/2016	1.0
Information Sheet	informed consent form- English version 1.0 (21 March 16)	21/03/2016	1.0

After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.lshtm.ac.uk

Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,

Page 1 of 2

[redacted]

Professor John DH Porter
Chair

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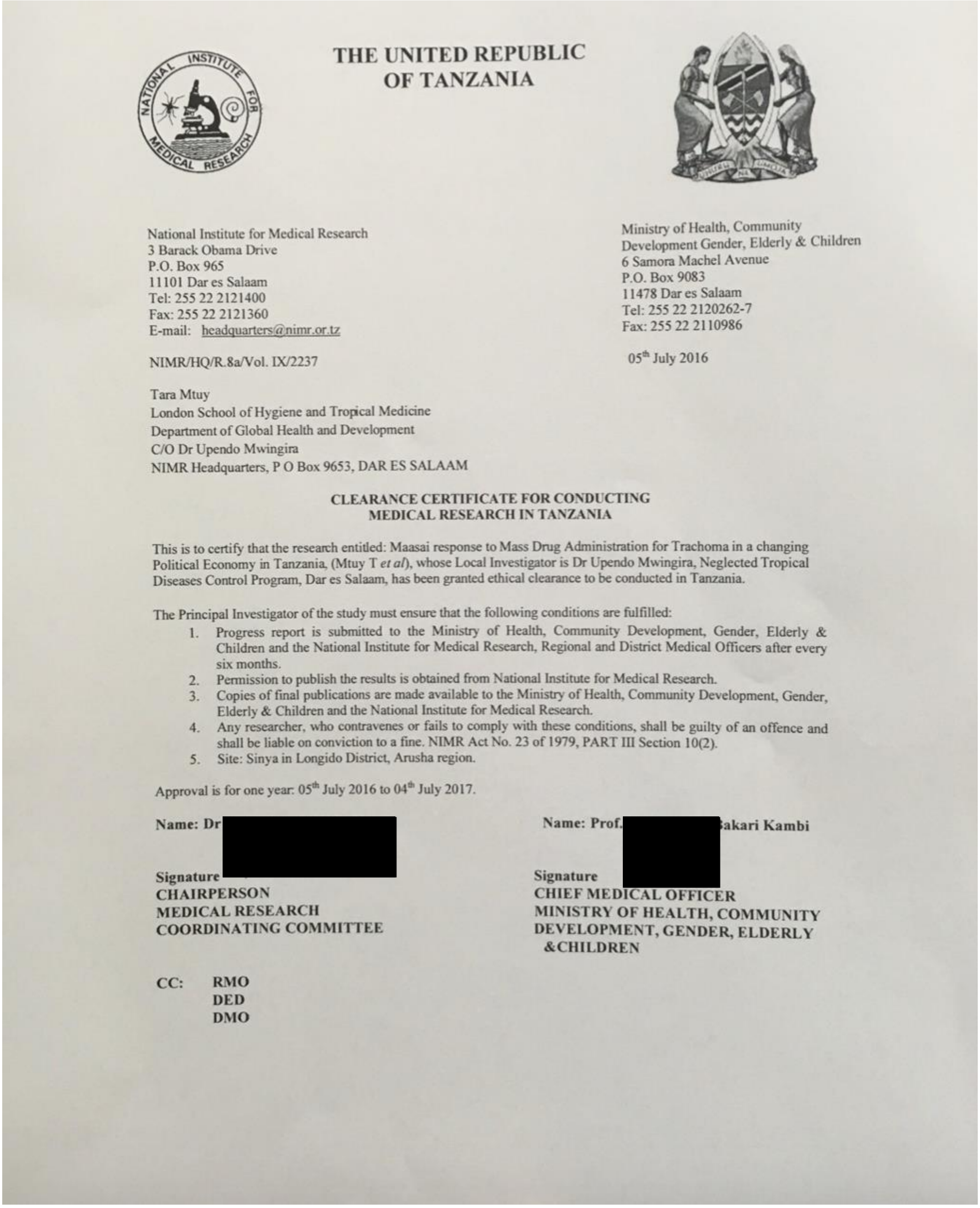
http://www.lshtm.ac.uk/ethics/



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NIMR/HQ/R.8a/Vol. IX/2237

05th July 2016

Tara Mtuy
London School of Hygiene and Tropical Medicine
Department of Global Health and Development
C/O Dr Upendo Mwingira
NIMR Headquarters, P O Box 9653, DAR ES SALAAM

CLEARANCE CERTIFICATE FOR CONDUCTING MEDICAL RESEARCH IN TANZANIA

This is to certify that the research entitled: Maasai response to Mass Drug Administration for Trachoma in a changing Political Economy in Tanzania, (Mtuy T *et al*), whose Local Investigator is Dr Upendo Mwingira, Neglected Tropical Diseases Control Program, Dar es Salaam, has been granted ethical clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is submitted to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine. NIMR Act No. 23 of 1979, PART III Section 10(2).
5. Site: Sinya in Longido District, Arusha region.

Approval is for one year: 05th July 2016 to 04th July 2017.

Name: Dr [redacted]

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Prof. [redacted] **akari Kambi**

Signature
CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, COMMUNITY
DEVELOPMENT, GENDER, ELDERLY
&CHILDREN

CC: RMO
DED
DMO

JAMHURI YA MUUNGANO WA TANZANIA
OFISI YA RAIS
TAWALA ZA MIKOA NA SERIKALI ZA MITAA

Telegrams: "REGCOM"
Simu Na.: 027 250-8751 - 2
Fax Na.: 027 2544904
Barua Pepe:
mountmeruhospital @habari.co.tz
Unapojibu Tafadhali Taja:-

OFISI YA MKUU WA MKOA,
IDARA YA AFYA,
S.L.P. 3092,
ARUSHA.

Kumb.Na.RMO/AR/P/5/267

27/08/2016

Mkurugenze Mtendaji,
Halmashauri ya Longido,
S.L.P.
LONGIDO.

YAH: KUMTAMBULISHA KWAKO TARA B. MTUY ATAKAYEFANYA UTAFITI WA TRACHOMA KWA WAMASAI KATIKA KIJIJI CHA SINYA – LONGIDO.

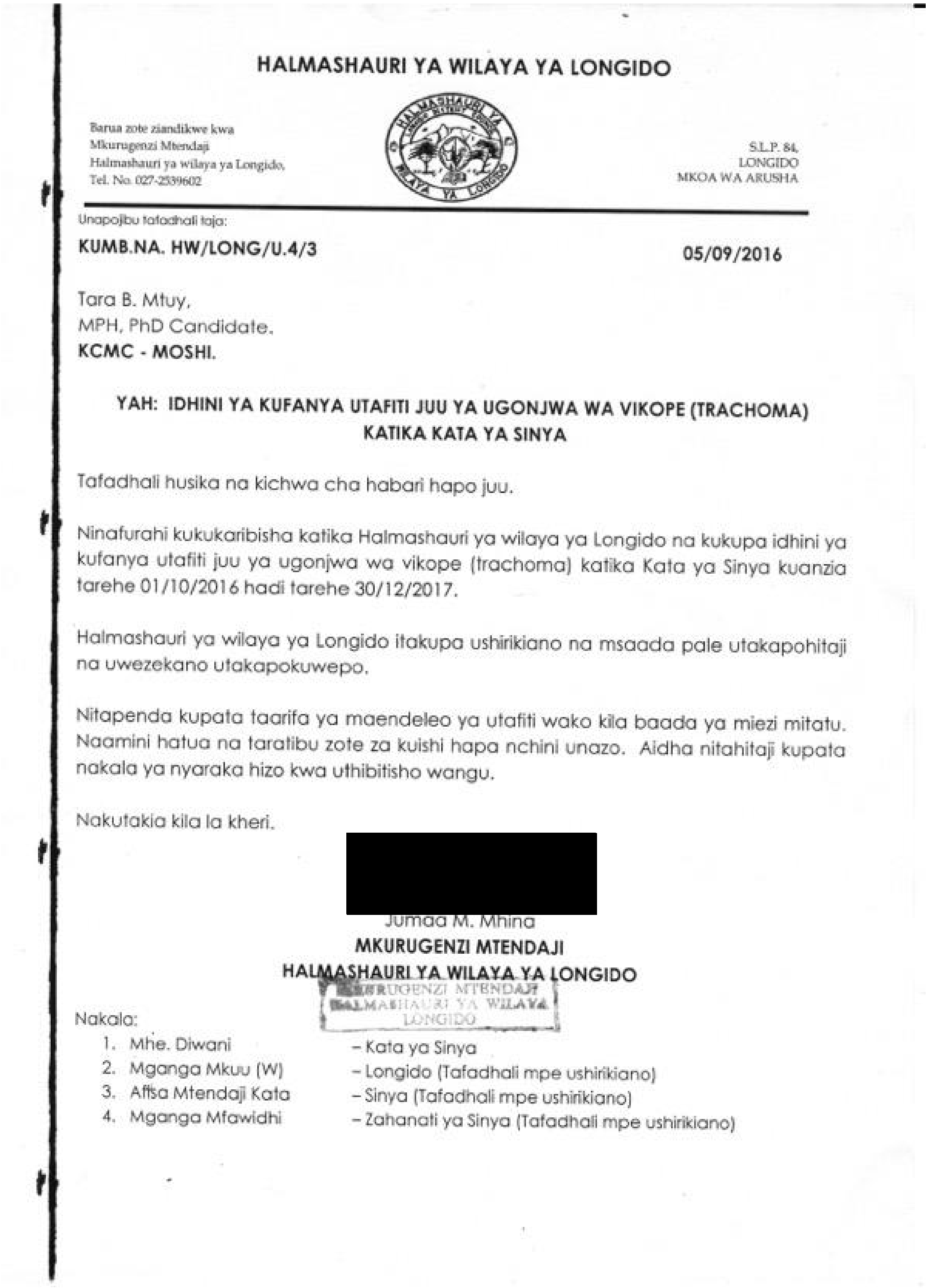
Napenda kumtambulisha kwako ***TARA B. MTUY*** kwa ajili ya kuja kufanya utafiti wa ugonjwa wa Trachoma katika Halmashauri yako. Bi Tara B. Mtuy amepata "Research Clearance" toka NIMRI na Wizara ya Afya, Maendeleo ya Jamii, Jinsia Wazee na Watoto. Nakala ya "Research Clearance" imeambatanishwa.

Tafadhali mpokee na umpe ushirikiano.

Nashukuru kwa ushirikiano wako.

[redacted]

Dr [redacted]
Kny: KATIBU TAWALA WA MKOA
ARUSHA.



HALMASHAURI YA WILAYA YA LONGIDO

Barua zote ziandikwe kwa
Mkurugenzi Mtendaji
Halmashauri ya wilaya ya Longido.
Tel. No. 027-2539602

S.L.P. 84,
LONGIDO
MKOA WA ARUSHA

Unapojibu tafadhali taja:

KUMB.NA. HW/LONG/U.4/3 **05/09/2016**

Tara B. Mtuy,
MPH, PhD Candidate,
KCMC - MOSHI.

YAH: IDHINI YA KUFANYA UTAFITI JUU YA UGONJWA WA VIKOPE (TRACHOMA) KATIKA KATA YA SINYA

Tafadhali husika na kichwa cha habari hapo juu.

Ninafurahi kukukaribisha katika Halmashauri ya wilaya ya Longido na kukupa idhini ya kufanya utafiti juu ya ugonjwa wa vikope (trachoma) katika Kata ya Sinya kuanzia tarehe 01/10/2016 hadi tarehe 30/12/2017.

Halmashauri ya wilaya ya Longido itakupa ushirikiano na msaada pale utakapohitaji na uwezekano utakapokuwepo.

Nitapenda kupata taarifa ya maendeleo ya utafiti wako kila baada ya miezi mitatu. Naamini hatua na taratibu zote za kuishi hapa nchini unazo. Aidha nitahitaji kupata nakala ya nyaraka hizo kwa uthibitisho wangu.

Nakutakia kila la kheri.

[redacted]

Jumaa M. Mhina
MKURUGENZI MTENDAJI
HALMASHAURI YA WILAYA YA LONGIDO

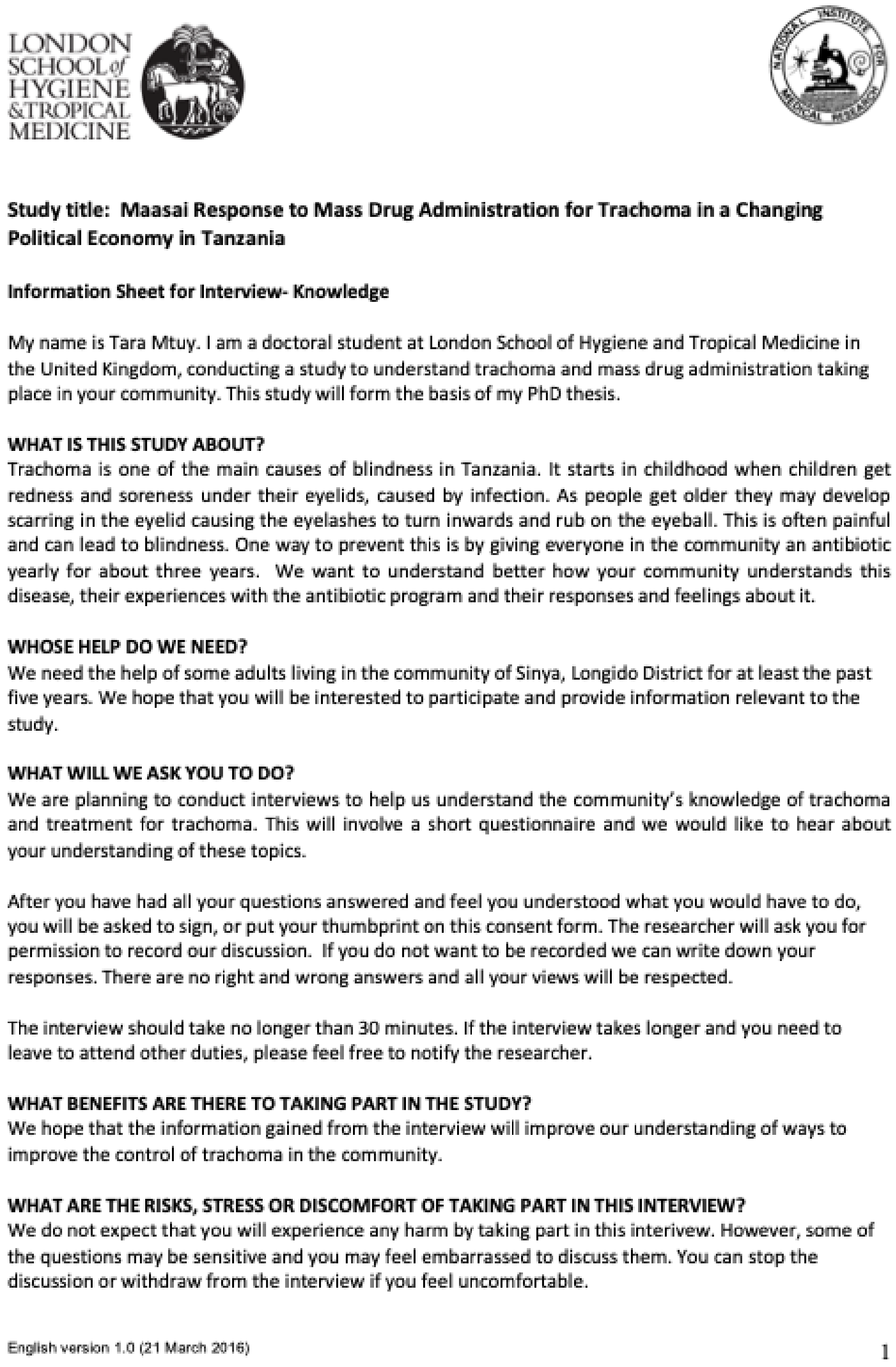
MKURUGENZI MTENDAJI
HALMASHAURI YA WILAYA
LONGIDO

Nakala:

1. Mhe. Diwani – Kata ya Sinya
2. Mganga Mkuu (W) – Longido (Tafadhali mpe ushirikiano)
3. Afisa Mtendaji Kata – Sinya (Tafadhali mpe ushirikiano)
4. Mganga Mfawidhi – Zahanati ya Sinya (Tafadhali mpe ushirikiano)

Appendix 2. Information sheets and consent form

Information sheet for Individual In-depth Interviews



LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

NATIONAL INSTITUTE FOR MEDICAL RESEARCH

Study title: Maasai Response to Mass Drug Administration for Trachoma in a Changing Political Economy in Tanzania

Information Sheet for Interview- Knowledge

My name is Tara Mtuy. I am a doctoral student at London School of Hygiene and Tropical Medicine in the United Kingdom, conducting a study to understand trachoma and mass drug administration taking place in your community. This study will form the basis of my PhD thesis.

WHAT IS THIS STUDY ABOUT?

Trachoma is one of the main causes of blindness in Tanzania. It starts in childhood when children get redness and soreness under their eyelids, caused by infection. As people get older they may develop scarring in the eyelid causing the eyelashes to turn inwards and rub on the eyeball. This is often painful and can lead to blindness. One way to prevent this is by giving everyone in the community an antibiotic yearly for about three years. We want to understand better how your community understands this disease, their experiences with the antibiotic program and their responses and feelings about it.

WHOSE HELP DO WE NEED?

We need the help of some adults living in the community of Sinya, Longido District for at least the past five years. We hope that you will be interested to participate and provide information relevant to the study.

WHAT WILL WE ASK YOU TO DO?

We are planning to conduct interviews to help us understand the community's knowledge of trachoma and treatment for trachoma. This will involve a short questionnaire and we would like to hear about your understanding of these topics.

After you have had all your questions answered and feel you understood what you would have to do, you will be asked to sign, or put your thumbprint on this consent form. The researcher will ask you for permission to record our discussion. If you do not want to be recorded we can write down your responses. There are no right and wrong answers and all your views will be respected.

The interview should take no longer than 30 minutes. If the interview takes longer and you need to leave to attend other duties, please feel free to notify the researcher.

WHAT BENEFITS ARE THERE TO TAKING PART IN THE STUDY?

We hope that the information gained from the interview will improve our understanding of ways to improve the control of trachoma in the community.

WHAT ARE THE RISKS, STRESS OR DISCOMFORT OF TAKING PART IN THIS INTERVIEW?

We do not expect that you will experience any harm by taking part in this interivew. However, some of the questions may be sensitive and you may feel embarrassed to discuss them. You can stop the discussion or withdraw from the interview if you feel uncomfortable.

English version 1.0 (21 March 2016)

1

DO I HAVE TO TAKE PART IN THE STUDY?

You do not have to take part in this study; it is entirely voluntary.

HOW WILL THE INFORMATION I GIVE BE KEPT PRIVATE?

Your contact details will be confidential and only be available to the staff involved in the study. The copy of the recording will not have your name attached to it. All information collected in this study will be kept securely and confidential in a locked location. Your name and details will not be recorded on the notes written during the discussions or in reports from the study and your identity will remain private and confidential. Reports about this study may quote some of the words you tell us. Any words that you have told us during the discussion will not have your name attached to them.

ARE THERE COSTS ASSOCIATED WITH PARTICIPATING IN THIS STUDY?

There are no direct costs to you for participating in this study.

HOW WILL I HEAR THE RESULTS OF THE STUDY?

After we have completed the research we will inform you of the outcomes of this study through meetings which will be organized in the community.

WHOM CAN I CONTACT IF I HAVE QUESTIONS OR NEED ADDITIONAL INFORMATION?

We would like to answer all your questions. If you have any questions now, please ask us. If you have any questions later, please contact:

Tara Mtuy- +255 755 162 677
(will insert research assistant name and contact)

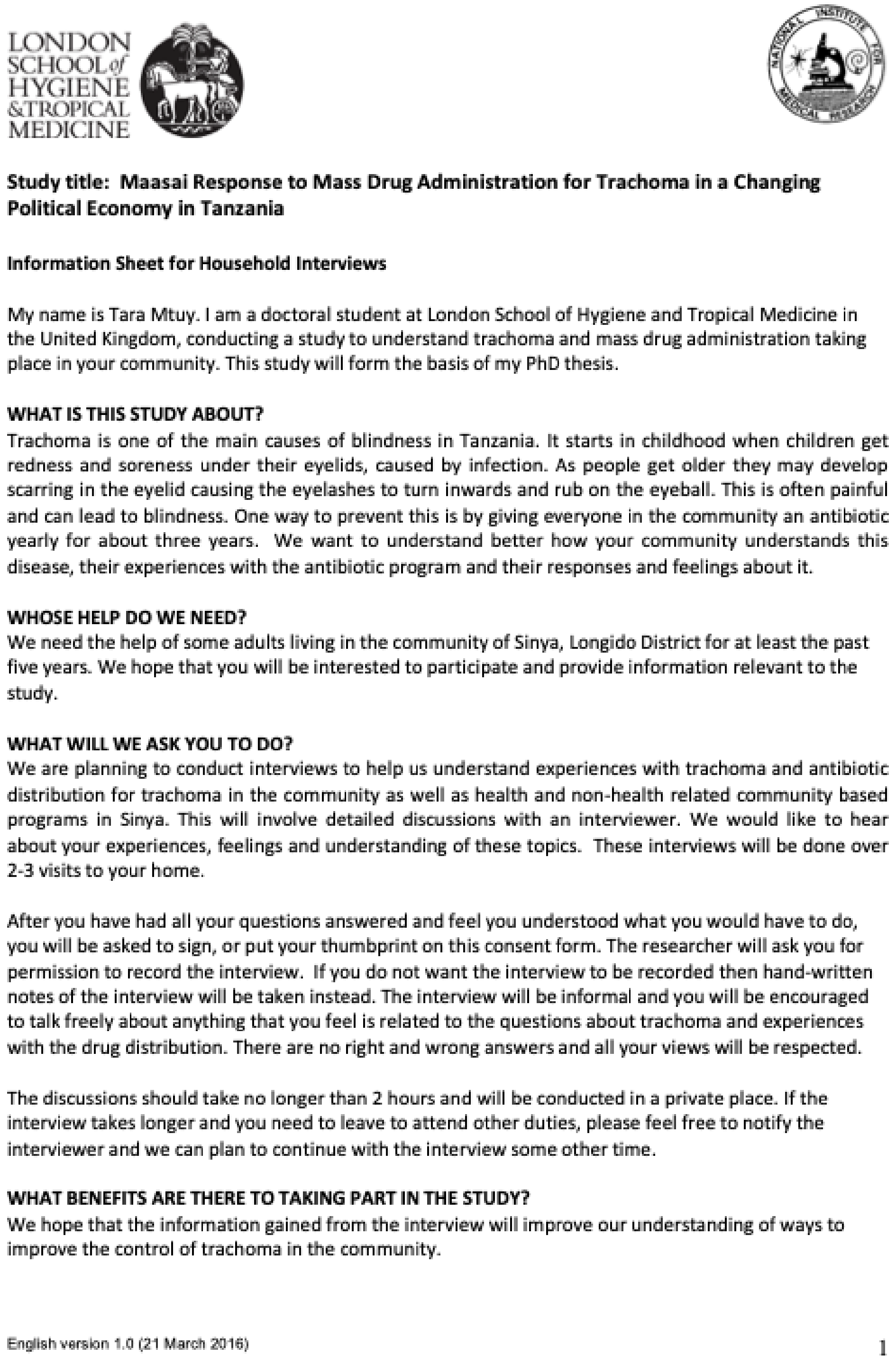
This study has been reviewed and approved by the Tanzania National Institute for Medical Research, which makes sure that people who take part in research studies in Tanzania are protected from unnecessary harm. If you have any questions about your rights as a person taking part in a research study, please contact:

The Chairperson
National Health Research Ethics Committee
3 Barack Obama Drive
P.O. Box 9653
11101 Dar es Salaam
+255 22 2121400

WHAT AM I REQUIRED TO DO?

If you agree to participate in this research, please sign below.

Information sheet for Household Interviews



Study title: Maasai Response to Mass Drug Administration for Trachoma in a Changing Political Economy in Tanzania

Information Sheet for Household Interviews

My name is Tara Mtuy. I am a doctoral student at London School of Hygiene and Tropical Medicine in the United Kingdom, conducting a study to understand trachoma and mass drug administration taking place in your community. This study will form the basis of my PhD thesis.

WHAT IS THIS STUDY ABOUT?

Trachoma is one of the main causes of blindness in Tanzania. It starts in childhood when children get redness and soreness under their eyelids, caused by infection. As people get older they may develop scarring in the eyelid causing the eyelashes to turn inwards and rub on the eyeball. This is often painful and can lead to blindness. One way to prevent this is by giving everyone in the community an antibiotic yearly for about three years. We want to understand better how your community understands this disease, their experiences with the antibiotic program and their responses and feelings about it.

WHOSE HELP DO WE NEED?

We need the help of some adults living in the community of Sinya, Longido District for at least the past five years. We hope that you will be interested to participate and provide information relevant to the study.

WHAT WILL WE ASK YOU TO DO?

We are planning to conduct interviews to help us understand experiences with trachoma and antibiotic distribution for trachoma in the community as well as health and non-health related community based programs in Sinya. This will involve detailed discussions with an interviewer. We would like to hear about your experiences, feelings and understanding of these topics. These interviews will be done over 2-3 visits to your home.

After you have had all your questions answered and feel you understood what you would have to do, you will be asked to sign, or put your thumbprint on this consent form. The researcher will ask you for permission to record the interview. If you do not want the interview to be recorded then hand-written notes of the interview will be taken instead. The interview will be informal and you will be encouraged to talk freely about anything that you feel is related to the questions about trachoma and experiences with the drug distribution. There are no right and wrong answers and all your views will be respected.

The discussions should take no longer than 2 hours and will be conducted in a private place. If the interview takes longer and you need to leave to attend other duties, please feel free to notify the interviewer and we can plan to continue with the interview some other time.

WHAT BENEFITS ARE THERE TO TAKING PART IN THE STUDY?

We hope that the information gained from the interview will improve our understanding of ways to improve the control of trachoma in the community.

English version 1.0 (21 March 2016)

WHAT ARE THE RISKS, STRESS OR DISCOMFORT OF TAKING PART IN THIS INTERVIEW?

We do not expect that you will experience any harm by taking part in this interview. However, some of the questions may be sensitive and you may feel embarrassed to discuss them. You can stop the interview or withdraw from the interview if you feel uncomfortable.

DO I HAVE TO TAKE PART IN THE STUDY?

You do not have to take part in this study; it is entirely voluntary.

HOW WILL THE INFORMATION I GIVE BE KEPT PRIVATE?

Your contact details will be confidential and only be available to the staff involved in the study. The copy of the recording will not have your name attached to it. All information collected in this study will be kept securely and confidential in a locked location. Your name and details will not be recorded on the notes written during the interview or in reports from the study and your identity will remain private and confidential. Reports about this study may quote some of the words you tell us. Any words that you have told us during the interviews will not have your name attached to them.

ARE THERE COSTS ASSOCIATED WITH PARTICIPATING IN THIS STUDY?

There are no direct costs to you for participating in this study.

HOW WILL I HEAR THE RESULTS OF THE STUDY?

After we have completed the research we will inform you of the outcomes of this study through meetings which will be organized in the community.

WHOM CAN I CONTACT IF I HAVE QUESTIONS OR NEED ADDITIONAL INFORMATION?

We would like to answer all your questions. If you have any questions now, please ask us. If you have any questions later, please contact:

Tara Mtuy- +255 755 162 677
(will insert research assistant name and contact)

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WHAT AM I REQUIRED TO DO?

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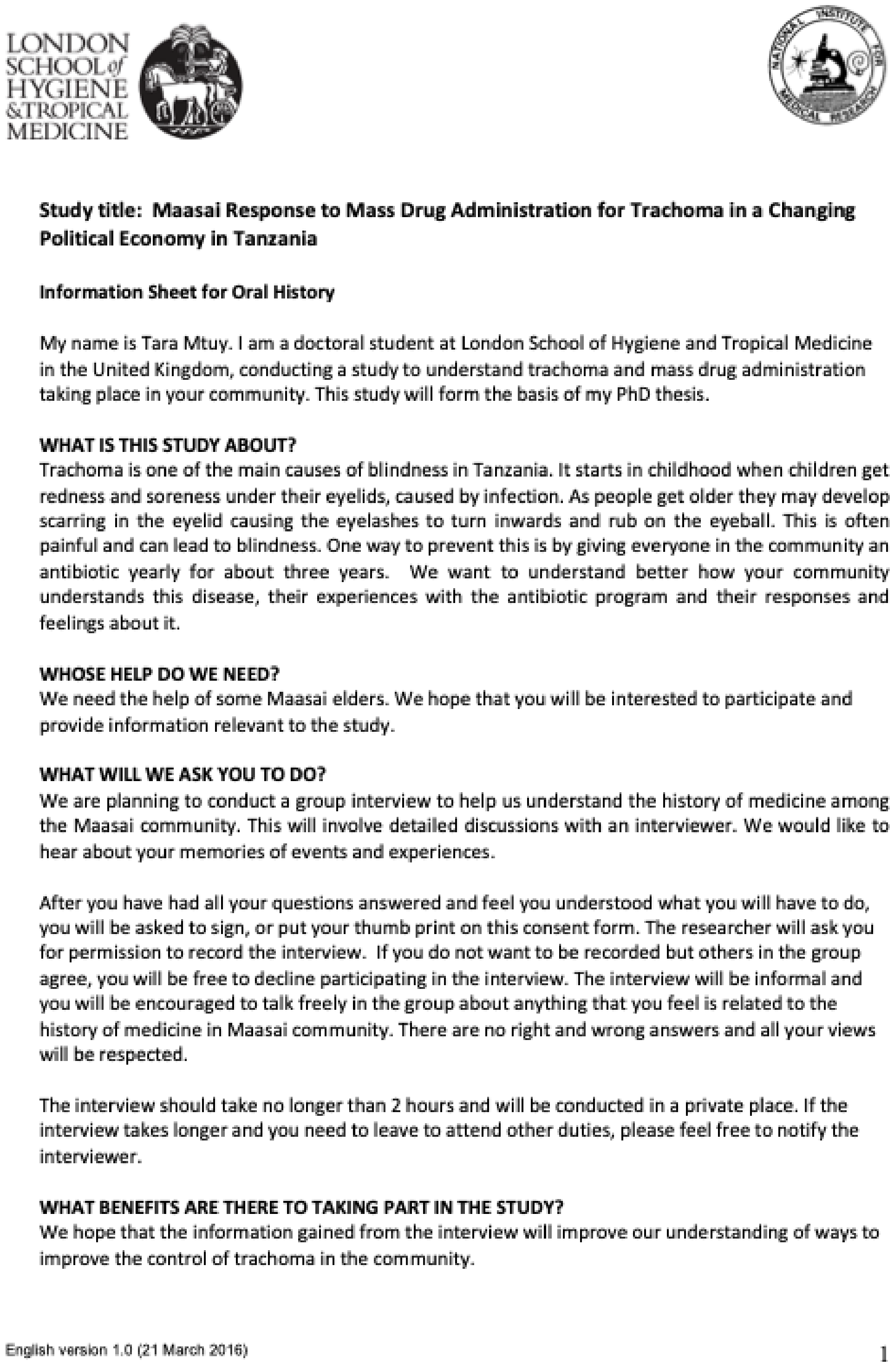
Information sheet for Oral History



Study title: Maasai Response to Mass Drug Administration for Trachoma in a Changing Political Economy in Tanzania

Information Sheet for Oral History

My name is Tara Mtuy. I am a doctoral student at London School of Hygiene and Tropical Medicine in the United Kingdom, conducting a study to understand trachoma and mass drug administration taking place in your community. This study will form the basis of my PhD thesis.

WHAT IS THIS STUDY ABOUT?
Trachoma is one of the main causes of blindness in Tanzania. It starts in childhood when children get redness and soreness under their eyelids, caused by infection. As people get older they may develop scarring in the eyelid causing the eyelashes to turn inwards and rub on the eyeball. This is often painful and can lead to blindness. One way to prevent this is by giving everyone in the community an antibiotic yearly for about three years. We want to understand better how your community understands this disease, their experiences with the antibiotic program and their responses and feelings about it.

WHOSE HELP DO WE NEED?
We need the help of some Maasai elders. We hope that you will be interested to participate and provide information relevant to the study.

WHAT WILL WE ASK YOU TO DO?
We are planning to conduct a group interview to help us understand the history of medicine among the Maasai community. This will involve detailed discussions with an interviewer. We would like to hear about your memories of events and experiences.

After you have had all your questions answered and feel you understood what you will have to do, you will be asked to sign, or put your thumb print on this consent form. The researcher will ask you for permission to record the interview. If you do not want to be recorded but others in the group agree, you will be free to decline participating in the interview. The interview will be informal and you will be encouraged to talk freely in the group about anything that you feel is related to the history of medicine in Maasai community. There are no right and wrong answers and all your views will be respected.

The interview should take no longer than 2 hours and will be conducted in a private place. If the interview takes longer and you need to leave to attend other duties, please feel free to notify the interviewer.

WHAT BENEFITS ARE THERE TO TAKING PART IN THE STUDY?
We hope that the information gained from the interview will improve our understanding of ways to improve the control of trachoma in the community.

WHAT ARE THE RISKS, STRESS OR DISCOMFORT OF TAKING PART IN THIS INTERVIEW?

We do not expect that you will experience any harm by taking part in this interview. However, some of the questions may be sensitive and you may feel uncomfortable to discuss them. You can stop the interview or withdraw from the interview if you feel uncomfortable.

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You do not have to take part in this study; it is entirely voluntary.

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There are no direct costs to you for participating in this study.

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After we have completed the research we will inform you of the outcomes of this study through meetings which will be organized in the community.

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WHAT AM I REQUIRED TO DO?

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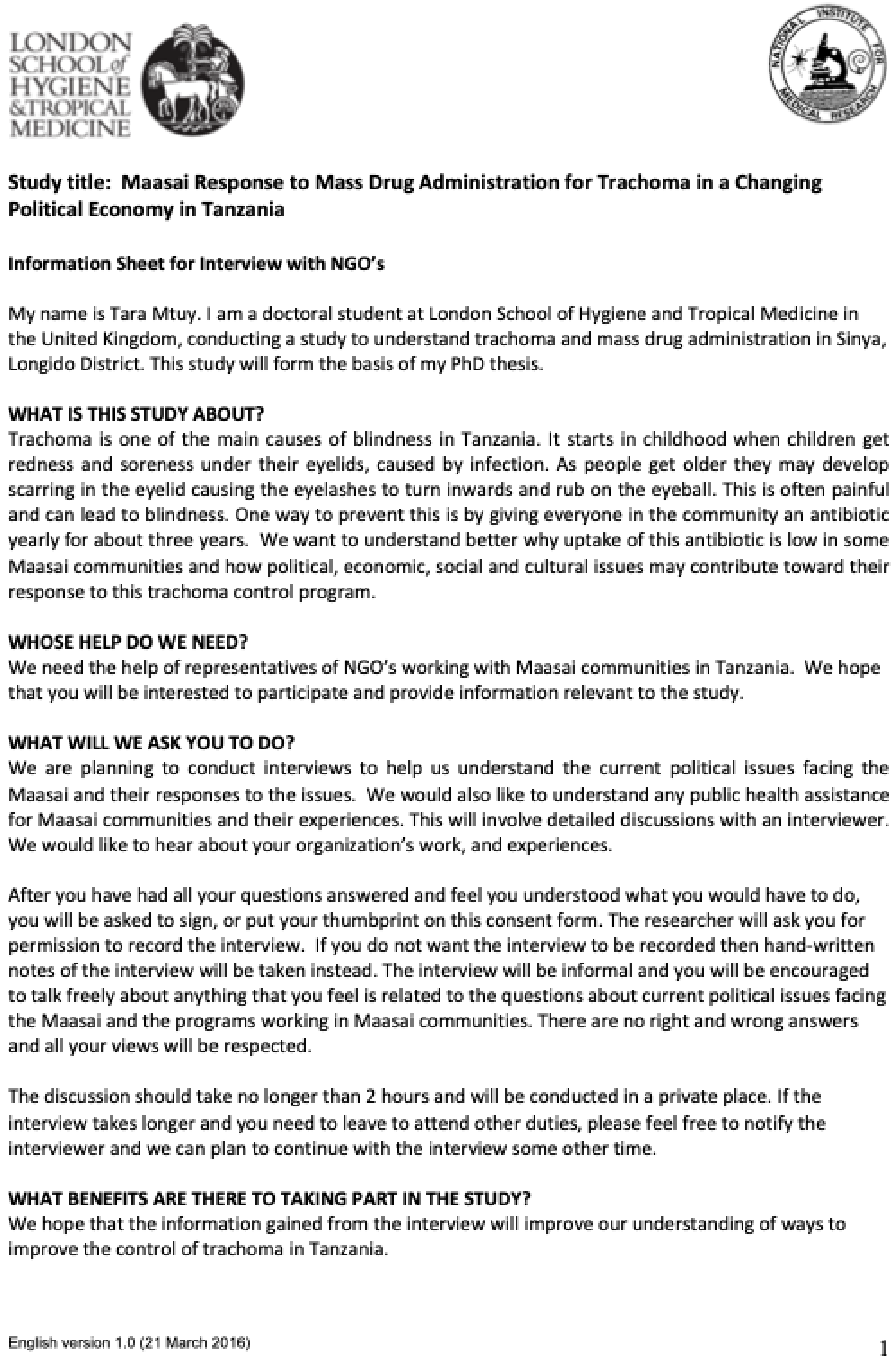
Information sheet for interviews with NGOs



LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

NATIONAL INSTITUTE FOR MEDICAL RESEARCH

Study title: Maasai Response to Mass Drug Administration for Trachoma in a Changing Political Economy in Tanzania

Information Sheet for Interview with NGO's

My name is Tara Mtuy. I am a doctoral student at London School of Hygiene and Tropical Medicine in the United Kingdom, conducting a study to understand trachoma and mass drug administration in Sinya, Longido District. This study will form the basis of my PhD thesis.

WHAT IS THIS STUDY ABOUT?

Trachoma is one of the main causes of blindness in Tanzania. It starts in childhood when children get redness and soreness under their eyelids, caused by infection. As people get older they may develop scarring in the eyelid causing the eyelashes to turn inwards and rub on the eyeball. This is often painful and can lead to blindness. One way to prevent this is by giving everyone in the community an antibiotic yearly for about three years. We want to understand better why uptake of this antibiotic is low in some Maasai communities and how political, economic, social and cultural issues may contribute toward their response to this trachoma control program.

WHOSE HELP DO WE NEED?

We need the help of representatives of NGO's working with Maasai communities in Tanzania. We hope that you will be interested to participate and provide information relevant to the study.

WHAT WILL WE ASK YOU TO DO?

We are planning to conduct interviews to help us understand the current political issues facing the Maasai and their responses to the issues. We would also like to understand any public health assistance for Maasai communities and their experiences. This will involve detailed discussions with an interviewer. We would like to hear about your organization's work, and experiences.

After you have had all your questions answered and feel you understood what you would have to do, you will be asked to sign, or put your thumbprint on this consent form. The researcher will ask you for permission to record the interview. If you do not want the interview to be recorded then hand-written notes of the interview will be taken instead. The interview will be informal and you will be encouraged to talk freely about anything that you feel is related to the questions about current political issues facing the Maasai and the programs working in Maasai communities. There are no right and wrong answers and all your views will be respected.

The discussion should take no longer than 2 hours and will be conducted in a private place. If the interview takes longer and you need to leave to attend other duties, please feel free to notify the interviewer and we can plan to continue with the interview some other time.

WHAT BENEFITS ARE THERE TO TAKING PART IN THE STUDY?

We hope that the information gained from the interview will improve our understanding of ways to improve the control of trachoma in Tanzania.

WHAT ARE THE RISKS, STRESS OR DISCOMFORT OF TAKING PART IN THIS INTERVIEW?

We do not expect that you will experience any harm by taking part in this interview. However, some of the questions may be sensitive and you may feel uncomfortable to discuss them. You can stop the interview or withdraw from the interview if you feel uncomfortable.

DO I HAVE TO TAKE PART IN THE STUDY?

You do not have to take part in this study; it is entirely voluntary.

HOW WILL THE INFORMATION I GIVE BE KEPT PRIVATE?

Your contact details will be confidential and only be available to the staff involved in the study. The copy of the recording will not have your name attached to it. All information collected in this study will be kept securely and confidential in a locked location. Your name and details will not be recorded on the notes written during the interview or in reports from the study and your identity will remain private and confidential. Reports about this study may quote some of the words you tell us. Any words that you have told us during the interviews will not have your name attached to them.

ARE THERE COSTS ASSOCIATED WITH PARTICIPATING IN THIS STUDY?

There are no direct costs to you for participating in this study.

HOW WILL I HEAR THE RESULTS OF THE STUDY?

After we have completed the research we will inform you of the outcomes of this study through a meeting which will be organized for NGO's contributing toward this research.

WHOM CAN I CONTACT IF I HAVE QUESTIONS OR NEED ADDITIONAL INFORMATION?

We would like to answer all your questions. If you have any questions now, please ask us. If you have any questions later, please contact:

Tara Mtuy- +255 755 162 677
Jeremiah Mepukori- +255 784 811 000

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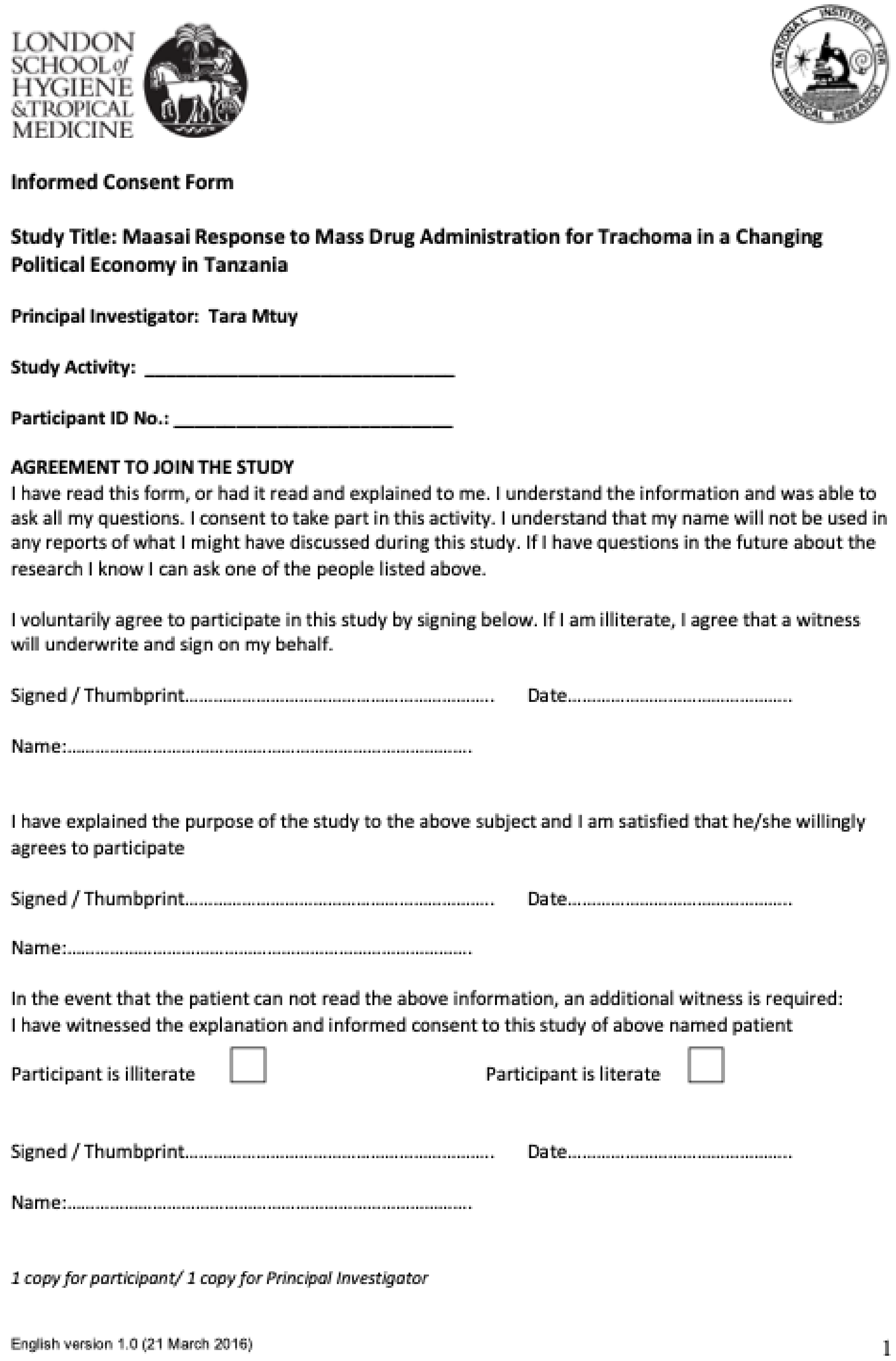
WHAT AM I REQUIRED TO DO?

If you agree to participate in this research, please sign below.

Consent Form



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HYGIENE
&TROPICAL
MEDICINE

Informed Consent Form

Study Title: Maasai Response to Mass Drug Administration for Trachoma in a Changing Political Economy in Tanzania

Principal Investigator: Tara Mtuy

Study Activity: _______________________________

Participant ID No.: ____________________________

AGREEMENT TO JOIN THE STUDY

I have read this form, or had it read and explained to me. I understand the information and was able to ask all my questions. I consent to take part in this activity. I understand that my name will not be used in any reports of what I might have discussed during this study. If I have questions in the future about the research I know I can ask one of the people listed above.

I voluntarily agree to participate in this study by signing below. If I am illiterate, I agree that a witness will underwrite and sign on my behalf.

Signed / Thumbprint…………………………………………………………. Date……………………………………….

Name:……………………………………………………………………………….

I have explained the purpose of the study to the above subject and I am satisfied that he/she willingly agrees to participate

Signed / Thumbprint…………………………………………………………. Date……………………………………….

Name:……………………………………………………………………………….

In the event that the patient can not read the above information, an additional witness is required:
I have witnessed the explanation and informed consent to this study of above named patient

Participant is illiterate ☐ Participant is literate ☐

Signed / Thumbprint…………………………………………………………. Date……………………………………….

Name:……………………………………………………………………………….

1 copy for participant/ 1 copy for Principal Investigator

English version 1.0 (21 March 2016) 1

Appendix 3. Topic Guides

Interview Guide- Individual interviews

General Information:

- Date
- Location
- Name of interviewer
- Start time/ End time

Introduction:

- Aim of interview
- How long it will take
- What happens to the data
- Confidentiality
- Consent process

Demographic information:

- Gender
- Age
- Village/ sub village

1- Have you ever heard of trachoma? What do you know about it? (or show pics of people with trachomatis disease to elicit information)

2- What are some of the symptoms people with trachoma experience?

3- Who is at risk for getting this eye disease?

4- Do you know any children with discharge from the eye? Can you describe the eye problem or eye disease?

5- How does someone get this disease? What causes this?

6- Do you know of any ways to prevent the disease? How? (probe if know about facial cleanliness and environmental issues)

7- Do you recall when drug distributors have come to the village to give you a drug for trachoma? How does this drug help trachoma?

Treatment:

8- What do you do when you or your family members have eye problems?

9- What treatments are you aware of other people using

10- Perceptions of western treatment vs local medicine

11- Have you ever come across a disease where the eyelashes turn inwards and scratch the eyeball?

12- What is the treatment for ‘eyelash trachoma’/ trichiasis?

13- Can explain this is what people carry ‘olputetu’ for.

14- How is that children have the infection but ‘eyelash trachoma’ /trichiasis (what leads to being blind) occurs as adults?

Beliefs about blindness and its causes:

15- What causes blindness?

16- How is blindness perceived. Stigma.

17- What is it like for a blind person to be cared for/ burden on others in the boma.

Interview Guide- Household interviews I

Greetings and cultural respect.

Introduction:

- Aim of interview
- How long it will take
- What happens to the data
- Confidentiality
- Consent process

General Information to record:

- Date
- Location (name of village and boma)
- Name of interviewer
- Start time
- End time
- Boma- number of people (men, women, children <12 years of age)
- Male lead- age, education, occupation
- Female lead- age, education, occupation

Health Programmes:

1. The government dispensary does vaccinations regularly. I see they have posts in different parts of Sinya for vaccination days *(show them a picture of the map of Sinya with vaccination posts).*
    - Tell me about the vaccination programme in Sinya.
    - Do you go with your children?
    - How important is vaccinations for your children?
    - How often do they go for vaccinations? Do they tell you when you need to bring the children next? Do you follow that? Why/ why not?
        - Probe for rumours, beliefs, interactions with dispensary staff, information obtained, importance of getting vaccines

2. One of the ways to treat trachoma is by surgery *(explain in simple terms at what stage of trachoma surgery is done, how, success/complications)*. There is a government partner organization that is performing surgery called KCCO. They were just in Sinya in February.
    - Do you know anyone who has had the surgery this past February?
        - If yes Has anyone in this boma had it done? If yes, ask if they can join the discussion. If they are unavailable, carry on with discussion with women.
            - How was the patient identified? Who made the arrangements for surgery? Tell me about that process.

            - How did the surgery go?
                - Probe for challenges/positive experiences, success, interaction with surgery team, information obtained from programme
            - Would you recommend this for others in your community who have trichiasis?
        - *If no explain that it is a free service for anyone identified with trichiasis.* How would you or your family members feel about using such a service if it was needed? Why/ Why not?
            - Probe for comparison to experiences with other programmes/ services they've had (particularly government led programmes vs private or NGO).
    - Do you know anyone who has had the surgery in the past/ prior to this February visit?
        - If yes Has anyone in this boma had it done? If yes, ask if they can join the discussion. If they are unavailable, carry on with discussion with women.
            - How was the patient identified? Who made the arrangements for surgery? Tell me about that process.
            - How did the surgery go?
                - Probe for challenges/positive experiences, success, interaction with surgery team, information obtained from programme
            - Would you recommend this for others in your community who have trichiasis?
        - If no AND did not answer the questions above, explain that it is a free service for anyone identified with trichiasis. How would you or your family members feel about using such a service if it was needed? Why/ Why not?
            - Probe for comparison to experiences with other programmes/ services they've had (particularly government led programmes vs private or NGO).

3. There is a clinic run by an American NGO called Olmoti Clinic. Are you familiar with this place?
    - What do you know about it? What do they do there?
    - What are people's experiences attending that clinic?
        - Probe for rumours, beliefs, interactions with staff, information obtained
    - Are there differences in attending Olmoti vs the government clinic or other health facilities you or others in your boma attended? *Probe for issues of trust, treatment/relations, description of experiences*
    - When the clinic was set up, do you know how involved community leaders and members were in discussing the needs of the community with the funders?
        - Probe for challenges in this or positive experiences in working with the NGO.
    - Does the clinic serve the community well? Explain.

4. Last year there was a deworming programme at the school in Sinya.

   Were you aware of this?

   - *If yes,* what do you know about it? Why was it done?
     - Probe for rumours, beliefs, interactions with staff, information obtained
     - How was it done?
     - What information did you get about it? Were you satisfied with the amount of information you were given?
     - What were people's experiences with this deworming programme? Any challenges with the drug given?

   If no, Do you have any children in this boma that go to that school?
   - *If yes,* how do you feel about the dispensary doing a drug distribution programme at the school?
   - If no, end the questioning there.

5. There is an organization called Marie Stopes that visits the village dispensary once every three months. Are you familiar with these people?
   If yes, what do you know about them? How do they assist at the dispensary?
   - What are people's experiences attending for their services?
     - Probe for rumours, beliefs, interactions with staff, information obtained, issues of trust, treatment/relations, more detail of experiences
   - Are you aware of Marie Stopes , doing any community education on family planning?
     - Probe for challenges in this or positive experiences in working with the NGO.

   If no, end the questioning there.

Non-Health Related Community Programmes:

6. There are a number of programmes in your community that are aimed at improving the lives of the people in Sinya, in particular around wildlife and how human wildlife interactions can improve the economic lives of the community. Sinya is part of the Wildlife Management Authority and other partners including Honey Guide Foundation and Big Life. In addition, Lion Guardians is doing work in Amboseli, which crosses into Sinya.
   - Tell me about these organizations. Do you have any stories of interacting with these programmes?
   - How so you see your community benefiting from their work?
   - What are the challenges of these organizations working in the community?
   - Part of the work of these organizations is related to anti-poaching. How has this issue effected your community?
   - How do you feel about their approach to improving the livelihoods of your community? / How might you suggest they better achieve their mission?

    - Probe for how cultural beliefs fits in, decision makers on these approaches, relationships with organizations, how it connects with other experiences with development work, trust in projects,

I also understand Lion Guardians who work in Amboseli use to work with the Sinya community up to three years ago. Were you familiar with them?

- *If yes,* what did you think of the programme?
    - Why are they no longer working in Sinya?
- If not familiar with them, end the questioning.

7. There are two tourist camps in or close to Sinya- Shumatta Camp and Kambi ya Tembo.
    - Do you know anyone who works at these camps? What are their experiences working there?
    - How do you feel about tourism in your community? Benefits/ Challenges
        - Probe for issues around economic benefit, land rent, land rights/grazing
    - Tell me about the relationships of these camps toward community development. How much do they involve the community in addressing community needs and development.
    - How might you suggest they work better to benefit the community?
    - (Depending on comfort and rapport, maybe discuss Ndarakwai Camp incident and discuss issues that come up related to that)

Ending:

- Thank them for their time and participation.
- Ask if it is ok to come back again. We'd like to visit again in July or August to ask more questions.

Interview Guide- Household interviews II

Greetings and cultural respect.

Introduction:

- Aim of interview
- How long it will take
- What happens to the data
- Confidentiality
- Reminder of consent process at previous visit

MDA Experience:

This past month drugs were distributed to all the residents of Sinya for eye problems. These are the red pills. Do you recall?

- Do you know what this was for?
  - Tell me more about trachoma.
  - Who is this programme for?
  - What information did you get from the CDD?

- Tell me about your experiences with the distribution.
  - Probe for interactions with CDDs, information obtained, importance of taking the drug
  - Did you see any benefits after you took it?

- I know some people were not around when the CDDs came. Some were out grazing, fetching water or fetching firewood. In many cases the CDDs left the drug with a mama to give to them later. Did this happen with people in your boma?
  - Did they take the drug when they returned that day?
  - Any of those people not take it? For what reasons?
  - What times of the day are best to find most people in your boma? *(ask for precise times)*

- I understand people who are pregnant or babies under 6 months should not take the drug. But did anyone in your boma not take it for other reasons?
  - Why didn't they take the drug?
    - If refusals, probe for rumours, beliefs, lack of information

- Who makes the decision that you and your family will take the drugs or not?
  - Do you consult elders? Husbands?
  - Do you mothers discuss among each other before deciding to take the drug?
  - Some mothers want their children to take the drug but they themselves don't. Why is this?
    - Probe for rumours, beliefs

        - Some mamas have said they think the drug may be family planning. What do you think of this?
    - Some *ilmurans* particularly refused the drug. Why?
        - Probe for cultural beliefs/traditions for this age group related to taking biomedicine or accepting things from people outside their age group etc.

- This was the third year that they gave this drug.
    - Did you receive the drugs last year? Why or why not.
    - Two years ago? Why or why not.
    - How was this years' experience any different from previous two years?
        - Probe for more or less side effects, information from CDDs, trust in CDDs, how it was organized

- In the last interviews we did, most people told me they trusted and supported the deworming drug given at Sinya Primary and the vaccination programme What about the trachoma drug? Do you have different feelings toward this programme compared to the others?

Migration:

- Did anyone in your boma not get the drug because they were out grazing or outside Longido when the CDDs came?
    - Who were these people? *(men/women, age group)*
    - Where were they?
    - What were they doing? (migrated, visiting people, participating in cultural traditions, at boarding school, working elsewhere)
    - How long were they away from home for?
- Was it of concern that they missed the drug?

Perceptions of Programme:

- Do you know who is organizing this drug distribution programme?
    - Who? Anyone else involved?
        - Probe for government and specifically what level of government; NGOs, international groups involved?
    - Why do you think they are putting a lot of resources into this programme?
    - If clarity needed on MDA programme- explain it's a programme coordinated at national level and carried out by districts with high prevalence of trachoma including Longido. Funding and support coming from international NGOs working with national level.
        - What do you think of this effort?
            - Probe for perceptions of government programmes and efforts to improve health in Maasai communities.
            - Probe for perceptions of the approaches government uses to help Maasai communities

- Have you talked about the MDA with other people in the community or with your neighbouring bomas?
    - What do people say?
    - Any positive experiences?
        - Probe as to why an experience was positive… what are characteristics of the programme people like.
    - Any negative experiences?
        - Probe for problems, rumours, beliefs

Prevention:

- Do you and the people in your boma do anything to prevent trachoma?
- What ways do you know of to prevent trachoma? Is it important to prevent it?
- *Explain how to prevent by facial cleanliness and environmental conditions.* Are these behaviours you can use in your boma? What are the challenges to change to these behaviours?

- Tell me about how eye problems are dealt with in your boma.
    - Probe for:
        - What are steps taken prior to attending to hospital?
        - biomedical and traditional medicine, trust in different types of medicine.
        - who makes decision to seek biomedical treatment, cost implications, where do you go

Ending:

- Explain the concept of MDA and how important it is for everyone to take the drug to lower the prevalence of trachoma in the community. Also explain importance of facial cleanliness and environmental cleanliness.
- Any comments or questions on this?
- Thank them for their time and participation & present gift of soap.

Interview Guide- Interviews with NGOs

General Information:

- Date
- Location
- Name of interviewer
- Start time
- End time

Introduction:

- Aim of interview
- How long it will take
- What happens to the data
- Confidentiality
- Consent process

Introductory questions:

- How long have you worked for the organization?
- What is your role in the organization?

Questions on the work of the NGO:

- Please explain the mission of your NGO
- What activities is the organization is involved in to achieve its mission?
    - ▪

Questions on social, economic, and larger context of the Maasai or marginalized communities you work in:

- Are you aware of the social context in which your NGO has to work with?
- Do you feel that it is important to understand the social context of the communities you work with?
- Since your organization is involved with the mobilization of resources and provide technical assistance, including logistics, how do you implement this?
- What is the economic context within these marginalized communities?
- What are some of the ongoing aspects in leadership in marginalised communities?
- What are some of the ongoing concerns within these marginalized communities that may effect their perception and/or uptake of health services?

Questions on health issues in the Maasai: *(if organization is addressing health)*

- What are some of the health issues facing the Maasai? How much of a priority is trachoma on a general level?
- How is your organization working on this? The approach?
- Can you describe the concerns of the Maasai community around the issue(s).

    - How do they feel about it?
    - What input have they given on approaches around the issue(s).
- Can you discuss the communities' response to your programme?
    - What are some of the challenges?
    - Why do think these challenges exist? How can an organization better tackle the issue or work with the Maasai community?

Questions specific to NGOs working on aspects of trachoma control:

- Do you know if there any factors about trachoma that makes the delivery of TCPs difficult?
- Do you think that trachoma-control programmes are more difficult to be implemented compared to programmes for other diseases? (NTDs or otherwise)
- Do you know whether the current understanding of trachoma in these populations affect the delivery of TCPs?
- Do you receive feedback on the interventions that you are using from the communities that receive it?
- Are you aware of the communities you work in do to deal with trachoma control themselves?
- How well are these programmes being taken up in these communities?

Ending Questions:

- What aspects have been beneficial to your organization in implementing health programmes?
- What are the most difficult aspects or barriers in your role in delivery of health programmes?
- What do you think your organization needs to do in order to improve the implementation of health programmes in these communities?

Appendix 4. Dissemination

American Society for Tropical Medicine and Health Conference, poster presentation

November 2017, Baltimore USA

No. 219

Understanding Perceptions and Experiences of Trachoma among the Maasai in Tanzania

Tara B Mtuy[1], Matthew J Burton[1], Upendo Mwingira[2,3], Jeremiah Ngondi[4], Shelley Lees[1]

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[2] Ministry of Health, Community Development, Gender, Elderly & Children, Dar es Salaam, Tanzania
[3] National Institute for Medical Research, Dar es Salaam, Tanzania
[4] RTI International, Tanzania

Introduction

- Trachoma remains the world's leading cause of preventable blindness. Repeated conjunctival infection by *Chlamydia trachomatis* during childhood can trigger chronic scarring in the eyelids. The eyelids eventually roll inwards so that the eyelashes scratch the surface of the cornea and blinding corneal opacification develops.
- Control of trachoma is based on the SAFE strategy (GET 2020), Surgery for trichiasis; Antibiotic treatment to eliminate the infection; Facial cleanliness; and Environmental improvement (WHO 2012).
- The Maasai are semi-nomadic pastoralists spanning the central border of Tanzania and Kenya. Lack of health facilities and schools in their communities, and the different views about their "development" have impacted on their experiences of health programs and services.
- WHO set a target for elimination of blinding trachoma by 2020. Despite decades of achievements in trachoma control worldwide, challenges remain in endemic communities including social issues.
- The aim of this study was to explore socio-cultural factors that may impact this disease and effective control among hyperendemic Maasai communities.

Methods

This study was situated in a larger ethnographic study of trachoma among Maasai. We used semi-structured interviews for an in-depth examination of the knowledge and understanding of the nature of trachoma. Stratified random sampling was used. Interviews were conducted in Maa. Transcripts were translated into English to conduct a framework analysis. This study was approved by the London School of Hygiene & Tropical Medicine and National Institute for Medical Research.

Fig. 1 Interviewer and a participant

Results

Interviews were carried out November- December 2016 among 15 women and 13 men ages 18-50 years. The Maasai translation for trachoma is *enaoji*, a term to describe a condition of eye irritation specific to the eyelids. Some mentioned white spots on the eye lids, possibly follicles. It was often reported to effect young children and some said it occurs within a few days after birth.

Causes and prevention of trachoma: Results show a poor understanding of trachoma. The causes of trachoma were attributed to pollen, dust, and smoke. When asked if facial cleanliness can prevent trachoma, responses were split between denial that it helps and "it helps" but unsure how. Water was seen as treatment and not prevention.

> *"We believe it happens because other people applied magic power or the patient is cursed. So we believe maybe the patient did wrong things and was cursed by his/her fellows. We believe that eyes and legs are among the most important body parts and life of the human are in his/her eyes and legs." [45 year old male]*

A link to flies was described by many participants but the mechanism was not clear. Only one participant mentioned bacteria and flies as a vector. There was little connection between childhood infection, trichiasis and related blindness.

> *"I think this is caused because there are those children with dead flies in their eyes and we take them to people who are able to remove those flies." [female in her 30's]*

Treatment: Traditional medicines from plants and roots were most often used for treating inflammation. The most common was a rough leaf used to scratch the inside of the eyelid until it bleeds. Veterinary medicines for cattle were also used to treat inflammation in children. Trichiasis was seen as a normal condition that comes with aging particularly among women. All were unaware that it can be treated by surgery. Most described the use of a U-shaped iron, *olputet,* for epilation of eye lashes.

Mass Drug Administration: Knowledge of MDA was inconsistent. Although many thought it helped the community, they perceived it as only for children and the sick. Many reported not taking the drug and some had no recollection of the previous MDA, six months earlier.

> *"We just use them and the story ends there. We are not sure if they gave us drugs to stop us from getting pregnant. We had the same drugs given to us in 2015 and we used them too. And to the adult like me we took two tablets. And we feared about those drugs that maybe they are given to us purposely to stop pregnancy." [38 year old female]*
>
> *"I don't know [how MDA helps trachoma] because people are ignorant. So some took drugs but they didn't use them due to fear and lack of knowledge about what these drugs are for." [36 year old female]*

Conclusions

- Results show a poor understanding of trachoma, prevention and control measures.
- These findings can help guide approaches to SAFE in Maasai communities.
- The design of control programs in hard to reach communities needs to be tailored based on the socio-cultural issues of those communities.
- Targeted education programs are a critical precursor to effective control programs.

References

WHO (2012) WHO Alliance for Elimination by 2020. Weekly Epidemiological Record 87:161-68

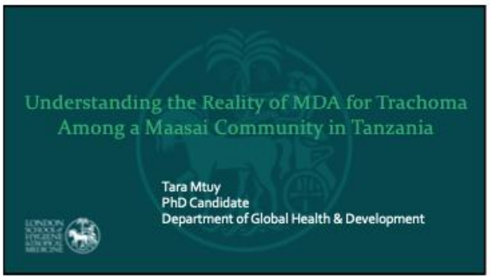
Funding

Chadwick Trust, UK

Improving health worldwide **www.lshtm.ac.uk**

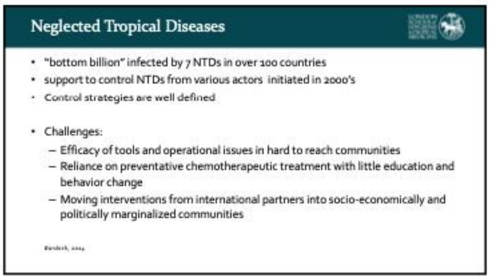
American Society for Tropical Medicine and Health Conference, oral presentation

November 2019, Washington DC USA



Understanding the Reality of MDA for Trachoma Among a Maasai Community in Tanzania

Tara Mtuy
PhD Candidate
Department of Global Health & Development

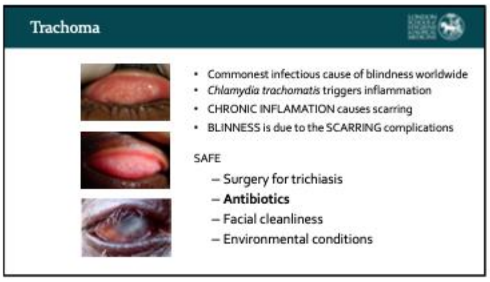


Neglected Tropical Diseases

- "bottom billion" infected by 7 NTDs in over 100 countries
- support to control NTDs from various actors initiated in 2000's
- Control strategies are well defined

- Challenges:
  - Efficacy of tools and operational issues in hard to reach communities
  - Reliance on preventative chemotherapeutic treatment with little education and behavior change
  - Moving interventions from international partners into socio-economically and politically marginalized communities

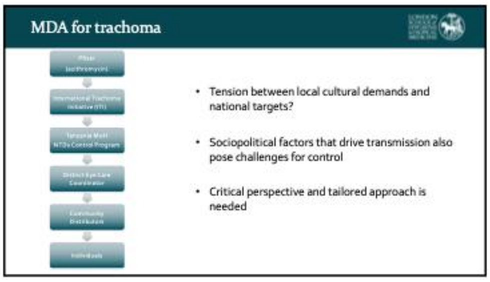
Bardosh, 2014



Trachoma

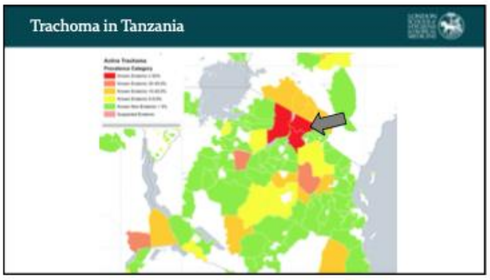
- Commonest infectious cause of blindness worldwide
- *Chlamydia trachomatis* triggers inflammation
- CHRONIC INFLAMATION causes scarring
- BLINNESS is due to the SCARRING complications

SAFE
- Surgery for trichiasis
- **Antibiotics**
- Facial cleanliness
- Environmental conditions



MDA for trachoma

- Tension between local cultural demands and national targets?
- Sociopolitical factors that drive transmission also pose challenges for control
- Critical perspective and tailored approach is needed

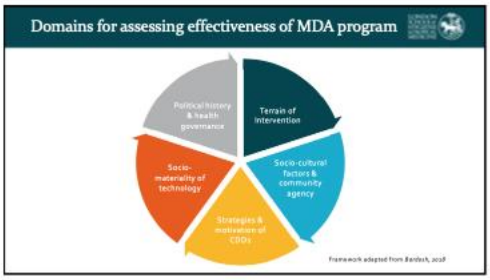


Trachoma in Tanzania

Ethnographic research

Aim: To understand the context of and the Maasai response to MDA against a backdrop of unique livelihoods and a changing political economy

- Lived in Sinya Ward for 16 months
- MDA- 2017, 3rd round



Domains for assessing effectiveness of MDA program

Political history & health governance

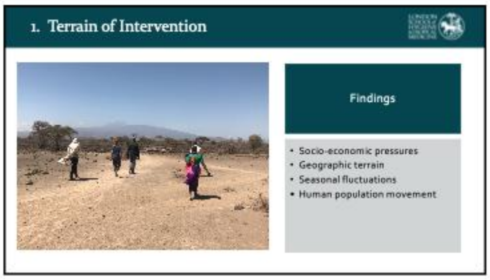
Terrain of intervention

Socio-cultural factors & community agency

Strategies & motivation of CDDs

Socio-materiality of technology

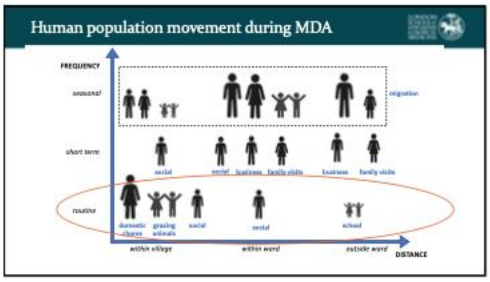
Framework adapted from *Bardosh, 2018*



1. Terrain of Intervention

Findings

- Socio-economic pressures
- Geographic terrain
- Seasonal fluctuations
- Human population movement

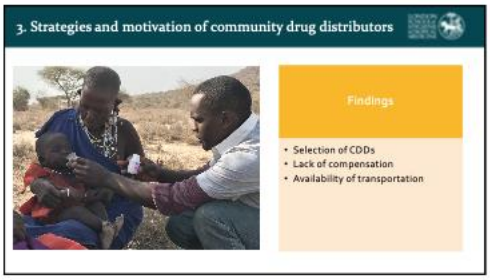


Human population movement during MDA

2. Socio-culture factors and community agency

Findings

- Disclosure of pregnancy
- Decision making
- Challenges in engaging *ilmurrani*
- Conforming to cultural norms
- Priorities of livelihoods
- Mistrust based on experiences with other programs



3. Strategies and motivation of community drug distributors

Findings

- Selection of CDDs
- Lack of compensation
- Availability of transportation

4. Socio-materiality of technology

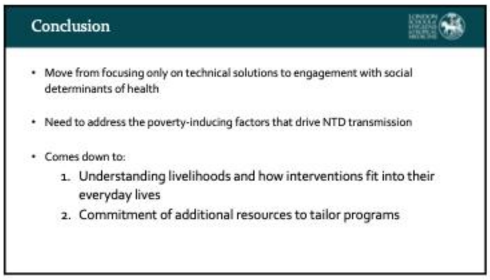
Findings

- Side effects
- Restrictions for post-partum women
- Access to water for swallowing drug
- Restrictions for *ilmurrani*

5. Political history and health governance

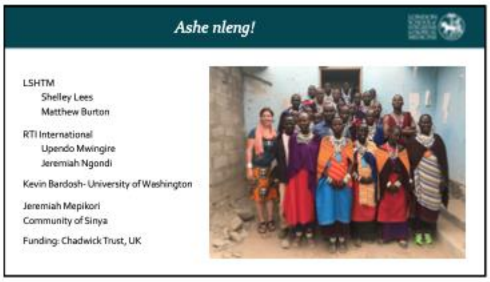
Findings

- Mistrust in government
- Misalignment of government and local community's priorities (access to water, health services and education)
- Community specific concerns not addressed (ie. Human- animal conflict)



Conclusion

- Move from focusing only on technical solutions to engagement with social determinants of health
- Need to address the poverty-inducing factors that drive NTD transmission
- Comes down to:
  1. Understanding livelihoods and how interventions fit into their everyday lives
  2. Commitment of additional resources to tailor programs



Ashe nleng!

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Community of Sinya

Funding: Chadwick Trust, UK

Qualitative Health Research Network Conference, recorded poster presentation

March 2021, *virtual*

Exploring cultural safety and ethical space in understanding health care access among Maasai in Northern Tanzania

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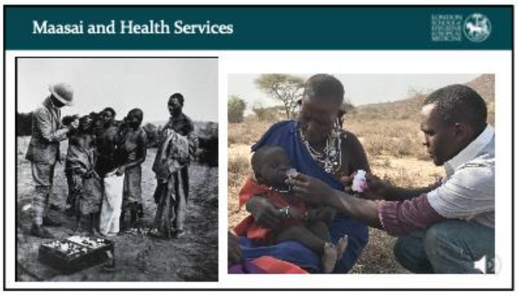


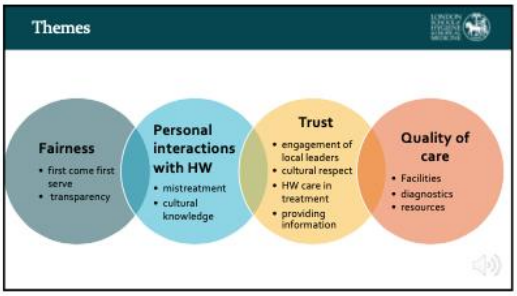
Maasai and Health Services

1

Cultural Safety and Ethical Space

Visual representation of Wood and Schwass' (1993) model of cultural safety and cultural risk

2



Themes

Fairness
- first come first serve
- transparency

Personal interactions with HW
- mistreatment
- cultural knowledge

Trust
- engagement of local leaders
- cultural respect
- HW care in treatment
- providing information

Quality of care
- Facilities
- diagnostics
- resources

3

Conclusion

- Historical, political and social influences on power imbalances impedes on health care access , practices and outcomes
- Recognizing barriers AND facilitators to engage in health care.
- Recommendation: Incorporating cultural safety and ethical space into training for health care workers in Tanzania

4

Thank you!

Please comment or ask questions on the presentation.

or email:
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5

BMC Bugbitten Blog, July 2021

https://blogs.biomedcentral.com/bugbitten/2021/07/30/putting-maasai-women-behind-the-camera-to-take-control-of-trachoma-control/

International Coalition for Trachoma Control, International Women's Day, March 2022

https://www.trachomacoalition.org/news-blogs/international-women's-day-how-photography-empowering-maasai-women-and-supporting-efforts

International Women's Day: How photography is empowering Maasai women and supporting efforts to eliminate trachoma

05 MAR 2022

by Tara Mtuy | Research Fellow, London School of Hygiene & Tropical Medicine

Trachoma, the world's leading infectious cause of blindness, disproportionately affects women. Research suggests women are twice as likely to require surgery to treat trachomatous trichiasis, the late blinding stage of trachoma, than men. In part, this is due to increased exposure to Chlamydia trachomatous, the causative bacteria of trachoma, from gender-related roles, such as childminding. Gender inequality is exacerbated by inequitable access to health services in many settings.

In East Africa, trachoma remains a public health problem in areas inhabited by the Maasai. In 2016 the prevalence of trachoma in predominantly Maasai districts in Northern Tanzania was estimated to be more than 50%. Women living in these communities often faced increased disadvantages accessing health services due to the remoteness of their communities, in addition to social, economic, and environmental barriers. For example, a recent study looking at MDA in a Maasai community in Tanzania found that pregnant women often accepted the antibiotic but did not swallow the drug due to their norms and beliefs.

Tara Mtuy, Research Fellow, London School of Hygiene & Tropical Medicine

To improve knowledge and to empower Maasai women as health educators in their communities, a recent project assessed the use of Photovoice - a method that provides participants with cameras to visually document a specified topic in order to improve knowledge, reflection and stimulate dialog on an issue and facilitate social change.

The project included a workshop providing trachoma education to Maasai women, who were tasked with sharing that information back with their communities. Towards the end of the workshop, women were given disposable cameras to document their efforts as trachoma ambassadors. They were taught how to use the cameras, what types of images they can capture, and the ethics of photography. Women were asked to photograph people, activities and things that can convey their efforts as trachoma elimination ambassadors including successes and challenges.

What was taught?

During the workshop, women were taught about the causes of trachoma, its transmission, symptoms, prevention and treatments. Stuffed *sorbens* (flies) were used to show transmission of chlamydia trachomatis from flies to eyes. Workshop facilitators used baby powder, representing chlamydia trachomatis, around the eyes of women to show how easily the disease can be transmitted through flies or other items. This highlighted the importance of facial cleanliness to prevent transmission. A storytelling session was also held to convey lessons around trachoma infection and treatment. This was followed by a short video by The END Fund and Sightsavers, "Leaky Tin: A Simple Solution", which was translated into Maasai language to show a simple and effective way to wash faces and hands using minimal amounts of water.

What we found

When photographs were reviewed, the most commonly shared photos were of children either washing their faces or displaying clean faces with no flies. Women shared photos of individuals cleaning up trash or human and animal faeces, cleaning clothes and displays of 'leaky tins' at their enkang (homestead). Some women shared photos of themselves conducting meetings with other women in their village to educate them on trachoma. However, very few women shared photos of challenges but of those that did, the photos showed traditional practices of treating trachoma-like symptoms and of animal carcases. The workshop only mentioned faeces as a source of flies and despite this, women reasoned that animal carcases were a source of flies. This is a very real source of flies in this community with a lot of carcases of wildlife and donkeys close to their enkang.

Photovoice as a tool for trachoma elimination

Women gained important knowledge about trachoma from the workshop. Photovoice provided a means to share how women transferred knowledge from the workshop to their community and the response from the community. This was evident from the follow-up visit to their homes as well as the photos they shared, particularly those taking action to reduce risk factors in their homes, such as cleaning up animal faeces, erecting leaky tins for hand and face washing and increased face washing for children and adults.

Impact on women

Throughout this project, women felt proud to be selected by male community leaders to take on the responsibility of representing their sub-village and acquiring new knowledge. They felt valued as experts within their community when they disseminated their newly acquired knowledge. Women were agents of change in their community by spreading the trachoma education they received to other women in their communities. Conversations and photographs demonstrated participants effectively stimulated social change.

Access to and use of resources

All women in the intervention reported that it was their first time using a camera. When first given the cameras, they were unsure which way to hold them or what the mechanism was to capture an image. Through demonstrations and practice they proudly improved locating an image, focusing on it, and pressing the shutter-release. The women were being trusted to provide information with cameras which added additional value for them. Through gaining knowledge to control trachoma, women were trusted by husbands to utilize household resources to aid in control measures such as containers for leaky tins, purchasing soap for washing bodies and clothes, and use of limited water for preventive techniques.

What next?

Photovoice provided a personalized perspective that researchers or NGOs would not otherwise experience - images inside people's homes, engaging in social activities, and documenting behaviours that words could not fully capture. It should be considered for future interventions as a communication tool on health issues and to empower women to be ambassadors for health promotion.

Final words

The intersection between gender and ethnicity exacerbates challenges for Maasai women to receive the interventions they need to achieve the elimination of trachoma as a public health problem. This intervention demonstrates what can be achieved through the empowerment of women in the community. The global trachoma program has a unique opportunity to improve women's health while dismantling harmful gender-based practices. Interventions like photovoice should therefore be considered in future programs to ensure that women's participation is systematic and that trachoma programs maximize their contributions to the achievement of Sustainable Development Goal 5: Gender Equality.

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International Coalition for Trachoma Control, oral presentation

30 March 2022, London

Photography as a Tool for Trachoma Control

A Public Engagement Activity with Maasai Women

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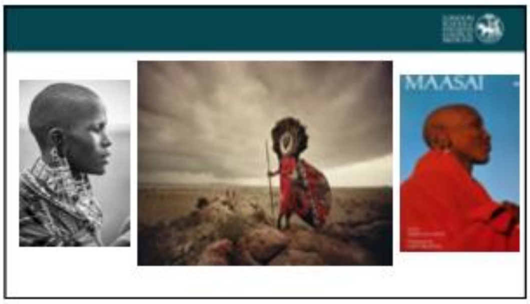
Background to this project



The Intervention

1. Workshop
   - Education on trachoma
   - Demonstration with stuffed *M. sorbens*
   - Storytelling
   - "Leaky tin" demonstration
   - Break out groups
2. Photography

Sharing photos

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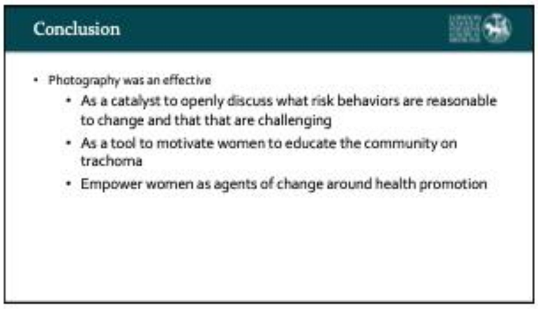

Conclusion

- Photography was an effective
  - As a catalyst to openly discuss what risk behaviors are reasonable to change and that that are challenging
  - As a tool to motivate women to educate the community on trachoma
  - Empower women as agents of change around health promotion

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Thank you!

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