# The Impact of Neglected Tropical Diseases (NTDs) on Health and Wellbeing in sub-Saharan Africa (SSA): A Case Study of Kenya

by

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**Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public

**Abstract**

Neglected Tropical Diseases (NTDs) remain endemic to many regions of sub-Saharan Africa (SSA) left behind by socioeconomic progress. As such, these diseases are a proxy for extreme poverty and inequitable access in the political, economic, social, and cultural systems which hinder the attainment of health and wellbeing. NTDs affect marginalized populations who are unable to lobby for their rights and thus have no 'political voice' to influence NTD control interventions. As countries embrace and work towards achieving the Sustainable Development Goals (SDGs), the needs of such vulnerable populations need to be addressed in the local and global arenas. Health is a universal right and is central to happiness, economic progress, and wellbeing. As such, it is important to measure the wellbeing of populations living in some of the poorest and most uneven settings and in so doing identify potential indicators for use in a Global Index of Wellbeing (GLOWING) that will capture the inequities represented by NTDs.

The research uses primary qualitative data collected from five NTD endemic counties of Kenya. The study interviews key informants (n=21) and focus groups (n=5) consisting of 7-8 people, involved in studying NTDs or infected / affected by NTDs, respectively. Informed by the capability and the political ecology of health theories, the following objectives were addressed: 1) to identify the political, economic, social, and cultural impacts of NTDs on health and wellbeing; 2) to investigate the capacity of local communities to address the burden of NTDs; 3) to identify potential indicators for use in a Global Index of Wellbeing (GLOWING), that will capture the inequities represented by NTDs.

The main findings of this research indicate that first, broad structural factors such as devolution of government services, competing interests, political climate; economic opportunity and productivity; marginalization, illiteracy, gender, cultural norms and practices; psychological

and behavioral practices; environmental activities, water, sanitation and housing status determine NTD transmission and subsequently the health and wellbeing of populations. Second, even though there are numerous ongoing control strategies for NTDs in the country guided by the World Health Organization (WHO), early physical examinations, proper diagnosis, universal health care, counseling services, and support groups for persons suffering debilitating NTDs are severely lacking. Third, the research reveals that persons living in NTD endemic areas are poverty-stricken, dependent, and reside in areas that have poor health infrastructure. As a result, their wellbeing or ability to live a good life is dependent on access to basic needs, and good spiritual and psychosocial health.

This thesis makes important contributions to knowledge, policy, and practice. Theoretically, the research extends social theory (structure and agency) in the largely biomedical field of NTDs to demonstrate that inequities are embedded within the broad political, socio-cultural, and economic systems which enhance NTD infection. Through the capability approach, the research acknowledges the role of human agency in providing context specific solutions to NTDs. Methodologically, the research contributes to the conceptualization and measurement of wellbeing in populations affected by NTDs in Low-Middle Income Countries (LMICs). Moreover, the research uses qualitative rather than quantitative methods (prevalence levels) to highlight the lived in experiences of persons infected and affected by NTDs. In terms of policy and practice, first, the research recognizes the challenges that exist within the broader political, socio-cultural and economic systems and suggests an equity lens in the distribution of basic resources such as water, sanitation and housing. Second, the research proposes poverty alleviation as a means of tackling NTDs for sustained economic opportunity and productivity at the local and national level. Third, the research finds that NTD stakeholders need to engage the

communities in/affected by NTDs in order to tackle issues of marginalization and discrimination as well as initiate community-driven interventions for NTD control for enhanced health and wellbeing.

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**Dedication**

This thesis is dedicated to my Mum and Dad (Florence and Pius Ochola), who were a source of inspiration, encouragement, and prayers. I sincerely thank you for your patience, love, and commitment over the years. I hope that this work is a proud moment for all the hard work, sacrifices, and devotion you made in raising me.

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**List of Abbreviations**

**AIDs** Acquired Immunodeficiency Syndrome

**CHVs** Community Health Volunteers

**CIW** Canadian Index of Wellbeing

**CLTS** Community-Led Total Sanitation

**DRC** Democratic Republic of Congo

**FDI** Foreign Direct Investments

**FGDs** Focus Group Discussions

**GDP** Gross Domestic Product

**GWD** Guinea Worm Disease

**GLOWING** Global Index of Wellbeing

**HAT** Human African Trypanosomiasis

**HIV** Human Immunodeficiency Viruses

**KII** Key Informant Interview

**LF** Lymphatic Filariasis

**LMICs** Low-Middle Income Countries

**MDA** Mass drug Administration

**MDGs** Millennium Development Goals

**NTDs** Neglected Tropical Diseases

**SDGs** Sustainable Development Goals

**SSA** Sub-Saharan Africa

**WASH** Water, Sanitation and Hygiene

**WHO** World Health Organization

# CHAPTER ONE INTRODUCTION

## 1.1 Research Context-sub Saharan Africa (SSA)

The region of sub-Saharan Africa (SSA) has a total area of 23.6 million square kilometres, which makes it larger than the United States, Canada, and the European Union combined. The United Nations predicts that the number of people living in SSA is likely to reach two billion by the year 2050 due to the young age structure, high fertility rates, and increasing life expectancy of many SSA countries (Berlin Institute for Population and Development, 2015; World Bank, 2015). Over the last decade, Foreign Direct Investments (FDI) have tripled in the region, making SSA the fastest growing economy in the world. However, economic performance still varies considerably among the African states, due to resources, conflict, governance,. As a result, the majority of the population lives on less than US$ 2 a day, with rampant unemployment on the rise due to low paying jobs (Freedom House, 2014) and poor infrastructure that limits economic growth (Overseas Development Institute, 2015). The region also experiences several health challenges such as Neglected Tropical Diseases (NTDs), HIV/AIDs, tuberculosis, and malaria; high maternal, infant and child mortality; and a rise in Non-communicable Diseases (NCDs) such as hypertension, diabetes, and cancers (Berlin Institute for Population and Development, 2015).

In sub-Saharan Africa, political and economic power manifest at different scales, for example, the national, the household and the individual which determine human-environmental interaction (Mayer, 2000), distribution of resources, and the transmission of infectious agents. A political ecology of health approach provides an avenue to understand disease transmission (Mayer, 2000), and since health and disease are socially constructed in place, this requires an understanding of the broader determinants of health (Dyck,1999, Elliott, 2018). Historically,

biomedicine and the distribution of services through the formal health care system was the sole channel through which the study of disease, health, and healthcare was possible but in recent times, health research has come to acknowledge the importance of socio-environmental factors in the transmission of disease both at the individual and community level (Elliott, 2018; Hayes, 1999). As a result, health geography has emerged as a powerful sub-discipline for examining infectious diseases due to its expanded definition of health that includes the physical, social, cultural and behavioural standards (Elliott, 2018). Additionally, health geographers conduct theoretically grounded research using a range of methodologies to understand the role of place and space in disease transmission ( Cummins, 2007). Presently, there has been an increased interest in the study of wellbeing and its measurement, with geographers positioning wellbeing as a desirable outcome in the evaluation of societal systems, government policies and community practices ( Schwanen and Atkinson, 2015). Health geographers such as Dorling (2011) have examined the effects of socio-spatial inequalities on wellbeing, with others such as Schwanen and Wang (2014) exploring the subjective experiences of wellbeing in place and space. However, wellbeing remains a versatile concept that varies with space, place, time, and individual experiences (Fleuret and Atkinson, 2007). Countries in the global north have shown an interest in developing indicators of wellbeing that combine economic indicators alongside other factors when determining a nation's performance (Aslam and Corrado, 2011). Unfortunately, there has been a limited focus in the measurement of wellbeing that reflect lived in experiences of individuals and communities in the global south (Kangmennaang and Elliott, 2019; Tomaney, 2015).

In Kenya where this research was carried out, half of the population live in extreme poverty, they survive on less than $2 USD a day which is not adjusted for Purchasing Power

Parity (PPP) with a rampant increase in infectious diseases due to poor leadership, corruption, inadequate numbers of health care workers and weak policies in the public health sector (World Bank, 2015; KNBS & ICF Macro, 2015). Kenya is in the eastern part of Africa and lies on the equator between the latitudes of $5^oN$ and $5^oS$; and longitudes $34^oE$ and $42^oE$. The country has a total area of $582,650km^2$ and borders the Indian Ocean to the east and south-east, Somalia to the northeast, Ethiopia to the north, Sudan to the north-west, Uganda to the west and Tanzania to the south. The population of Kenya as per the 2009 census was estimated to be 46 million people (Muthembwa, 2016) with the age group of 15-64 years, constituting 55.1% of the total population. The country's Gross Domestic Product (GDP) in the year 2017 was US $ 78.76B and currently, the country ranks position 125 out of 157 in the achievement of the Sustainable Development Goals (SDGs) (Index S. D. G., 2017) with persistent diseases of poverty such as NTDs negatively affecting the country's economic performance and wealth distribution.

Kenya's development structure is guided by Vision 2030, which aims to create a flourishing country with a desirable quality of life by the year 2030 (KNBS & ICF Macro, 2015). Over the years, the Kenyan economy has been growing steadily amid the global financial crisis and internal conflict. For example, Kenya experienced 7.0% economic growth in the year 2002, but this slipped to 5.3% by the year 2014. Even so, the recurrent spending on health services improved from 7% in the fiscal year 2003/04 to 7.9% in the year 2006/07 (KNSP, 2016). Despite this decline in economic performance, significant gains have been made in the health sector as shown by the improvement in core health indicators (Table 1.1) but, much more remains to be done to boost human capacity and enhance economic gains (KNSP, 2016).

**Table 1.1: A table showing National Health indicators in Kenya**

| Indicator | 2016 | 2018 | Trend |
|---|---|---|---|
| Birth rate/1000 | 30.49 | 28.60 | Neutral |
| Death rate/1000 | **5.96** | **5.52** | Positive |
| Population growth rate (%) | 2.45 | 2.33 | Neutral |
| Fertility rate (births per woman) | 3.74 | 3.52 | Neutral |
| Infant mortality rate (deaths/1000 live births) | **38.43** | **36.34** | Positive |
| Population 0-14 years (%) | 40.02 | 39.03 | Neutral |
| Population % age 15-24 years (%) | 19.15 | 19.61 | Positive |
| Population % age 25-54 years (%) | 33.91 | 34.27 | Positive |
| Population % age 55-64 years (%) | 3.92 | 4 | Neutral |
| Population % age 65> years (%) | 3 | 3.08 | Neutral |
| Life expectancy at birth male | 64.4 | 64.6 | Positive |
| Life expectancy at birth female | 68.9 | 69.0 | Positive |
| Life expectancy for both sexes | **64.88** | **66.18** | Positive |

Source: (Kenya National Strategic Plan, 2016; WHO, Key Country Indicators, 2018)

## 1.2 The evidence

In recent decades, academics across the social and behavioural sciences have recognized that Gross Domestic Product (GDP) is an inadequate measure of a country's progress (Deaton, 2013; Stiglitz, 2012). GDP accounts for the value of all goods produced within a country's border over time and forms the basis for calculating national income (Deaton, 2013). Additionally, GDP determines national policies such as the need to increase or decrease government spending, measure the success of current economic policies such as the effect of tax cuts on the economy and evaluate the quality of life (a subcomponent of wellbeing that includes health, work-life balance, education, personal security and civic engagement) in countries like Kenya, Egypt and Tanzania (Deaton, 2013; Giannetti *et al*., 2015). For all these purposes, economists use average figures to compute economic growth; hence, the assumption is, the higher the GDP, the better the living standards of a population within a country (Deaton, 2013).

In reality, an increase in GDP does not necessarily mean that the rewards of growth are shared equally (Stiglitz, 2012). First, GDP fails to indicate the wealth distribution on-'who gains

and who loses', which tends to leave the poor and vulnerable behind. Second, GDP does not detect inequalities that exist in wealth, resources, and opportunities. Third, GDP overlooks citizens' capabilities on relative wealth or things they can achieve. Fourth, GDP focuses on the quantitative aspects and ignores qualitative and contextual information that makes data meaningful in a population. Fifth, GDP excludes non-monetary work such as voluntary work, child care, and work done at home. Sixth, it does not consider the effect of depletion of resources in the natural environment (Allin & Hand, 2014; Deaton, 2013; Dicken, 2015; Elliott *et al*., 2017, 2018; Giannetti *et al.*, 2015; Stiglitz *et al*., 2009). These limitations render GDP inadequate as a measure of a country's progress since it excludes core aspects of what citizens deem to be important in life beyond wealth, finances or income, such as contentment, health, happiness (happiness is temporary, it describes how people feel from time to time) and job satisfaction (Allin & Hand, 2014). For this reason, scholars recommend better systems of measurements that go beyond income and wealth, better capture inequality, and reflect how all citizens of a country are doing (Giannetti *et al*., 2015; Stiglitz, 2012).

The World Health Organization (WHO) reports that Neglected Tropical Diseases (NTDs) compromise the health and wellbeing of populations by causing undesirable effects on personal, social and economic aspects of individuals and communities (Geary, 2016). NTDs are a diverse group of communicable diseases or conditions that globally infected/affect more than 2.7 billion of the poorest populations (Gyapong and Boatin, 2016). They are found in several Low to Middle-Income Countries (LIMC) in Africa, Asia, and Latin America (Herricks *et al*., 2017). Sub-Saharan Africa makes up 90% (WHO, 2013) of the disease burden (Figure 1.2) due to widespread poverty in the region and the distinct characteristics of some NTDs to thrive in specific climates (Gyapong & Boatin, 2016). Over 40% of the global burden of Lymphatic

Filariasis (LF) occurs in SSA, additionally, the region hosts all remaining cases of Guinea worm disease (GWD) (WHO, 2010) and NTDs such as loiasis and Human African Trypanosomiasis (HAT) are only found in the continent (Gyapong & Boatin, 2016) (Table 1.2).

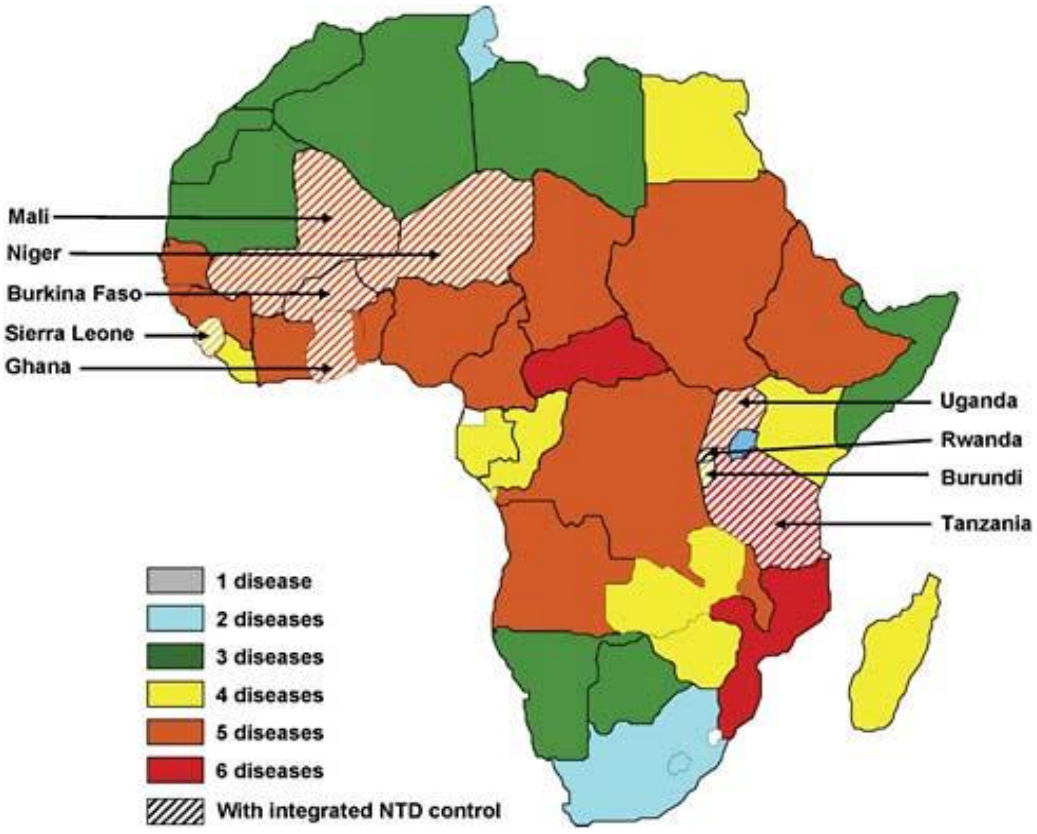


***Figure 1.2*: A map showing the distribution of NTDs in Africa.**

Source: (Fenwick *et al.*, 2009; Molyneux *et al.*, 2005).

**Table 1.2: A table showing the NTDs of priority as per World Health Organization (WHO)**

| | Disease/Condition | Alternative name | Common Symptoms | Causative agent | Suspected/Found in Kenya |
|---|---|---|---|---|---|
| 1. | American trypanosomiasis | Chagas disease | Localized swelling | Protozoa | No |
| 2. | Buruli ulcer | Bairnsdale ulcer | Nodules/swelling | Bacteria | Yes |
| 3. | Cystic echinococcosis | Hydatidosis | Cysts filled with fluids | Helminth | Yes |
| 4. | Dengue and Chikungunya | | High fever and joint pains | Virus | Yes |
| 5. | Dracunculiasis | guinea-worm disease | Painful blister | Helminth | Yes |
| 6. | Endemic treponematoses | Yaws/ endemic syphilis | Small crusted lesions | Bacteria | No |
| 7. | Foodborne trematodiases | | Pain in the abdominal region | Helminths | Yes |
| 8. | Human African trypanosomiasis | Sleeping sickness | Fever, poor coordination | Protozoa | Yes |
| 9. | Leishmaniasis | | Ulcers and enlarged organs | Protozoa | Yes |
| 10. | Leprosy | Hansen disease | Lumps and disfigurement | Bacteria | Yes |
| 11. | Lymphatic filariasis | Elephantiasis | Swelling of the limbs | Helminth | Yes |
| 12. | Mycetoma, and deep mycoses | Madura foot | Inflammatory disease of the foot | Fungal/ Bacterial | Yes |
| 13. | Onchocerciasis | River blindness | Severe itching and blindness | Helminth | Yes |
| 14. | Rabies | | Inflammation of the brain | Virus | Yes |
| 15. | Scabies and other ectoparasites | | Intense itching and rash | Parasitic | Yes |
| 16. | Schistosomiasis | Snail fever | Abdominal pain and organ damage | Helminth | Yes |
| 17. | Snake bite envenoming | | Life threatening | | Yes |

| | | | | | |
|---|---|---|---|---|---|
| 18. | Soil-transmitted helminths | Worms, STHs | Abdominal pain and anaemia | Helminths | Yes |
| 19. | Taeniasis/cysticercosis | | Abdominal pain | Helminth | Yes |
| 20. | Trachoma | | Inflammation of the eyelids | Bacteria | Yes |

Modified from: (WHO, 2017)

In general, NTDs cost developing economies billions of dollars every year in lost revenue by interfering with labour productivity (agricultural and industrial) and with the wage-earning potential of individuals who are already poor and surviving on less than US$ 2 a day (WHO, 2017). Similarly, NTDs limit educational opportunities for school-going children by interfering with cognitive development and causing undesirable effects on school attendance and child development. Moreover, NTDs trap individuals in a cycle of poverty, leading to social stigma at the family and community level (Hotez *et al.*, 2014) and provide underlying disease susceptibility mechanisms for cancers in SSA (De Martel *et al.*, 2012; Hotez and Daar, 2008).

The 'neglect' in NTDs occurs at three main levels: first, at the community level, NTDs arouse fear and inflict stigma to people infected in the community due to the physical impairments and disfigurements that they cause. Secondly, at the national level, these diseases exist in remote and rural areas, which translate to low priority for national health ministers and policymakers. Thirdly, at the international level, NTDs are not perceived as global threats compared to the 'big three'- malaria, tuberculosis, and HIV/AIDs (Hotez, 2013).

Currently, The World Health Organization (WHO) has an updated list of 20 NTDs that account for the highest health burden worldwide (WHO, 2017) (Table 1.2). Unfortunately, some of the NTDs missing on the list such as podoconiosis and Strongyloidiasis (Table 1.3) lack global attention in as much as they cause severe morbidity. This uneven representation contributes to limited NTD data (Herricks *et al*., 2017) and leads to an increase in the total NTD burden. For a long time, quantifying the impact of NTD infection was challenging because of focal clustering of diseases, under-reporting of prevalence levels, polyparasitism, varying morbidity symptoms, and social stigma (Bardosh, 2014). However, the 2013 Global Burden of Disease (GBD) study manages to systematically quantify the prevalence, morbidity, and mortality of about 300 diseases, injuries and risk factors including NTDs on a global scale (Herricks *et al*., 2017). The results of the study indicate that NTDs are among the world's greatest global health problems despite the recent gains made in health strategies (Herricks *et al*., 2017; Hotez *et al.,* 2016). The GBD 2013 also finds that most NTDs are profoundly disabling and account for 57 million Disability Adjusted Life Years (DALYs) (Herricks *et al*., 2017; Hotez, 2009). Even though DALYs are widely used to estimate the lasting impact of NTDs, they do not measure the complete political and socioeconomic implications of the diseases that often maim rather than kill (Hotez *et al.,* 2014*).* Hence, NTDs remain endemic to many regions left behind by socioeconomic progress and cause a heavy burden of disability that exceeds malaria and tuberculosis. Moreover, the long-term nature of NTD infection is complicated by the lack of healthcare access in many areas (Hotez *et al.,* 2006). As such, these diseases continue to limit educational opportunities, interfere with wage-earning potential, and compromise wellbeing.

**Table 1.3: A table indicating the NTDs that are missing from the WHO list**

| | Disease/Condition | Alternative name | Common Symptoms | Causative agent |
|---|---|---|---|---|
| 1. | Amoebisiasis | | Abdominal pain and diarrhea | Protozoan |
| 2. | Balantidiasis | | Diarrhea | Protozoan |
| 3. | Bartonellosis | | Organ damage | Bacteria |
| 4. | Bovine tuberculosis | | Lung damage and lymph nodes | Bacteria |
| 5. | Brucellosis | Crimean fever | Muscular pain and fever | Bacteria |
| 6. | Giardiasis | | Abdominal pain and diarrhea | Protozoan |
| 7. | Haemorrhagic fever | | Blood vessel and organ damage | Virus |
| 8. | Japanese encephalitis | | Fever and mental retardation | Virus |
| 9. | Leptospirosis | | Muscle pain and fever | Bacteria |
| 10. | Loiasis | | Lesions and itching | Helminth |
| 11. | Myiasis | | Severe irritation | Ectoparasitic infections |
| 12. | Paracoccidiomyosis | Brazilian blastomycosis | Painful lesions | Fungal |
| 13. | Podoconiosis | | Swelling of lower extremities | Irritant mineral particles found in volcanic soils |
| 14. | Relapsing fever | | Fever and joint aches | Bacteria |
| 15. | Rheumatic fever | | Painful joints | Bacteria |
| 16. | Strongyloidiasis | | Swelling and itching | Helminths |
| 17 | Yellow fever | | Fever and organ damage | Virus |

Modified from: (Hotez, 2009; WHO, 2010, 2016).

The diseases listed above fail to appear on the WHO priority list because they are considered less pathogenic or are encountered less frequently (Choffnes and Relman, 2010; Fenwick, 2011)

The current knowledge generated in years of research demonstrate that minimum diagnostic tools and strategies are available to assess the distribution of NTDs and inform control, elimination and eradication programs on a global, national/regional and local scale (Grepin & Reich, 2008; Gyapong & Boatin, 2016). As such, the World Health Organization recommends the following public health interventions for an integrated approach to NTD control: Preventive Chemotherapy (PCT); Intensified Case Management (ICM); provision of safe water, sanitation, and hygiene facilities; vector control; and veterinary public health. For the recommended programs to be effective, it is crucial that intervention activities focus along NTD 'hotspots' (Aagaard-Hansen and Chaignat, 2010) and obtain the necessary political, economic and social supports (Armah *et al*., 2015; Gyapong & Boatin, 2016). Furthermore, it is essential to harmonize and coordinate control activities among stakeholders to complement support from key donors beyond the initial commitments stipulated in the London Declaration (Gyapong & Boatin, 2016) (Table 1.4).

**Table 1.4: The 2012 London Declaration goals on Neglected Tropical Diseases**

| |
|---|
| The London Declaration was inspired by the World Health Organization's 2020 Roadmap on NTDs, to control or eliminate at least 10 of the NTDs. The Declaration commits to the coordination and collaboration of the public and private sectors to work together to enable the more than a billion people suffering from NTDs lead healthier and more productive lives. It aims to: |
| • Sustain, expand and extend programmes that ensure the necessary supply of drugs and other interventions to help **eradicate** Guinea worm disease, and help **eliminate** by 2020 lymphatic filariasis, leprosy, sleeping sickness (human African trypanosomiasis) and blinding trachoma. |
| • Sustain, expand and extend drug access programmes to ensure the necessary supply of drugs and other interventions to help **control** by 2020 schistosomiasis, soil-transmitted helminthes, Chagas disease, visceral leishmaniasis and river blindness (onchocerciasis). |
| • Advance R&D through partnerships and provision of funding to find next-generation treatments and interventions for neglected diseases. |
| • Enhance collaboration and coordination on NTDs at national and international levels through public and private multilateral organizations to work more efficiently and effectively together. |
| • Enable adequate funding with endemic countries to implement NTD programmes necessary to achieve these goals, supported by strong and committed health systems at the national level. |
| • Provide technical support, tools and resources to support NTD-endemic countries to evaluate and monitor NTD programmes. |
| • Provide regular updates on the progress in reaching the 2020 goals and identify remaining gaps. |

Modified from: (WHO, 2013)

As such, the objectives of this research was to:

a) To identify the political, economic, social, and cultural impacts of NTDs on health and wellbeing in Kenya.
b) To investigate the capacity of local Kenyan communities to address the burden of NTDs.
c) To identify potential indicators for use in a Global Index of Wellbeing (GLOWING) that will capture the inequities represented by NTDs in Kenya.

## 1.3 Index of wellbeing as an alternative to GDP

### 1.3.1 Beyond GDP measures

Gross Domestic Product (GDP) as an economic measure of development that misses many other aspects important in people's lives. In response to the shortcomings of GDP, countries such as Australia, Canada, the United Kingdom, and others (Table 1.5) have worked on broadening their measures and indicators to include wellbeing as an indicator of development and evaluate how well their citizens are doing. The mid-20$^{th}$ century saw a shift towards health and wellbeing rather than disease, illness, and death. Health is a resource for everyday living and a positive concept that emphasizes social and personal resources as well as physical capabilities (Allin & Hand, 2014) and psychosocial health. Medical researchers and doctors examining new treatments are currently interested in measuring outcomes such as improved health and wellbeing over time (Allin & Hand, 2014). Sometimes the terms 'health' and 'wellbeing' are used interchangeably in health-related literature to mean one and the same thing. However, Article I of the Declaration of Alma-Ata (1978) equates health to be a complete state of physical, mental, and social wellbeing and not merely the absence of disease or infirmity. Although this definition is broad, it gives a better understanding of health to include the action of

other processes such as the social for example, life experiences and collective action (Wilkinson and Marmot, 2003).

**Table 1.5: A table showing alternative measures of wellbeing**

| **'Measures beyond GDP'** | **Description** | **Examples** |
|---|---|---|
| **Indicators that correct the shortcomings of GDP for example GDP+ and GDP++** | GDP is the starting point in which other domains are added or subtracted, for instance, health, education, natural, social and human capital, adjustments. | Genuine progress indicator, genuine savings, ecological footprint, index of sustainable development, green GDP, welfare and genuine wealth |
| **Measures of subjective wellbeing** | The indices are from primary data, and the questions require individuals to reflect and evaluate their wellbeing, happiness or life satisfaction | Quality of life indices, world values survey and happiness index |
| **Composite measures of wellbeing** | | |
| **Subjective and objective indicators** | Examines a broad range of domains and indices that make use of subjective and objective measures captured from primary and secondary data | Happy planet index, Bhutan gross national happiness index |
| **Objective indicators solely** | Relies on a broad range of domains and indices that go beyond personal experiences, for example, education. Makes use of secondary data sources | Human Development Index (HDI), Canadian Index of Wellbeing(CIW), Australian index of wellbeing(AIW) |

Modified from (Costanza *et al.,* 2009; Vemuri & Constanza, 2006)

In contrast, wellbeing is a broad, complex, and multidimensional concept that has different definitions and interpretations (Atkinson, 2013). For example, Michaelson *et al*. (2012), define wellbeing as the way people feel and how they function on a personal and societal level. Nussbaum (2011), and Sen (1993), conceptualize wellbeing as the freedom to live a flourishing life depending on one's capabilities. Over the last decade, the concept of wellbeing

has received attention in the national arena with many seeing it as a goal or a factor shaping the quality of life, happiness, fulfillment, job satisfaction, spirituality, job productivity, environmental awareness, social inclusion and justice (Allin & Hand, 2014). For a broader and comprehensive definition of wellbeing, this research adopts Angus Deaton's definition, which refers to wellbeing

> as all the things that are good for a person that make for a good life. Wellbeing includes material wellbeing such as income and wealth; physical and psychological wellbeing, represented by health and happiness; education and the ability to participate in civil society through democracy and the rule of law. (Deaton, 2013, pg.24)

In other words, wellbeing is a concept that extends beyond health to include holistic and intersectoral experiences (Fleuret & Atkinson, 2007). This research argues that the Canadian Index of Wellbeing (CIW) (Figure 1.3) is an example of a 'beyond GDP measure,' which uses secondary data and can be used as a guide to provide simple and meaningful indicators of wellbeing in vulnerable populations, such as those living in sub-Saharan Africa (SSA) and affected by Neglected Tropical diseases (NTDs).

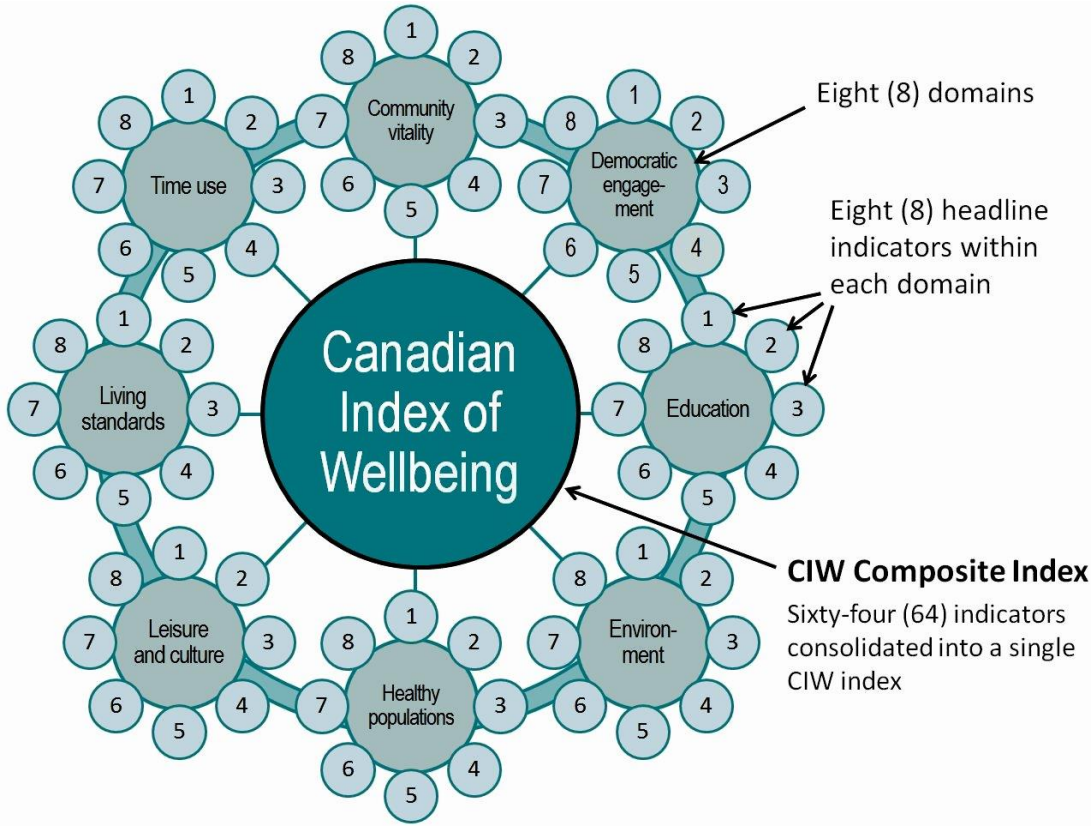


***Figure 1.3*: A figure showing the Canadian Index of Wellbeing (CIW) with the 8 domains and 64 indicators**

Source: (Michalos *et al.*, 2011).

It is important to measure wellbeing because relying solely on economic measures to assess the progress of a country may lead to the wrong assumption that citizens are doing well (Deaton, 2013). Furthermore, with economic growth come inequalities in the distribution of resources (Allin & Hand, 2014). Inequalities, especially in SSA, manifest in various dimensions such as wealth or income, gender, and ethnicity and may lead to exclusion from essential elements of life such as education and healthcare. For example, wealth inequality may not be unique to an individual, but the average measures of wealth in a population as measured by GDP

do not reflect such disparities. For this reason, it is essential to broaden the indicators of wellbeing, to capture inequalities that may exist in the political, economic, social, and cultural systems (Allin & Hand, 2014).

Measures of wellbeing can be either objective or subjective indicators or a combination of both. An objective measure is external to an individual but has an impact on their wellbeing or is an indicator of their wellbeing (Allin & Hand, 2014), for example, physical health, and education. Furthermore, objective indicators of wellbeing tend to take into consideration equity and sustainability (Allin & Hand, 2014). In contrast, a subjective measure of wellbeing is a self-reported state of a person's wellbeing. However, it is not the self reporting that makes the indicator subjective but rather the fact that it reports on an internal aspect of a person's condition. For example, happiness, and how a person evaluates his/her life based on things that are satisfactory to them (Michaelson *et al.*, 2012). For this reason, the sole use of subjective measures of wellbeing may introduce difficulties when making cross-national and cross-cultural comparisons because of the different ways people report their experiences (Allin & Hand, 2014).

The CIW is a measure of wellbeing that provides a foundational base for developing a Global Index of Wellbeing (GLOWING) because, firstly, it uses secondary data (Michalos *et al.*, 2011) from government agencies and other relevant data bodies, for example, the World Bank which has a strong reputation in data development. The use of secondary data in the CIW (Michalos *et al.*, 2011) makes it attractive for use in SSA because it eliminates the need for sampling and other field logistics involved in the collection of primary data in limited-resource settings (Elliott *et al.*, 2017). Secondly, CIW measures wellbeing across society and not just on an individual's account hence eliminating personal experiences of wellbeing that may vary from one person to the next leading to inconclusive responses (Graham *et al.*, 2010). Thirdly, CIW

measures wellbeing on a national scale, using objective indicators on multiple domains and reports it in a composite index. A composite index uses a single value to provide information on wellbeing, and this compressed data is comparable over time (Allin & Hand, 2014; Canadian Index of Wellbeing, 2012; Elliott *et al.*, 2017; Michalos *et al.*, 2011). Fifthly, CIW has domains and indicators that people value beyond GDP measures, which are agreed upon by policymakers and citizens following consultations and sustainable partnerships (Elliott *et al.*, 2017).

For these reasons, the CIW makes an excellent foundation for the development of a GIW that can measure wellbeing over time in areas where inequalities exist in the political, economic, environmental, social and cultural systems. As such, this dissertation explored the structural impacts of NTDs in Low to Middle-Income Countries (LIMCs) of Sub-Saharan Africa with Kenya as a case study.

### 1.3.2 Neglected Tropical Diseases (NTDs) as an inequity

People bearing the burden of NTDs predominantly reside in low-income countries, but surprisingly, as the economies of such countries improve to middle-income, NTDs continue to thrive among sub-populations of low socioeconomic status (Gyapong & Boatin, 2016). Hence, this observation suggests that not everyone shares in the economic boom, and because of this, NTDs continue to thrive (UNDP, 2013). As a result, NTDs have become a proxy for poverty, income inequality, and resulting development inequalities such as access to health services, proper housing, clean water, and sanitation.

In Kenya, 18 out of the 20 NTDs (Table 1.2) are suspected, confirmed, or endemic to the country. Even though they are not always a direct cause of mortality, they usually cause immense suffering (KNSP, 2016), impairment, disfigurement, and even permanent disability. For example, trachoma infection can lead to blindness if not treated in the early phase, and

leprosy causes deformity of the limbs once it gets to the chronic stage. Since people infected with NTDs are usually the poorest of the poor, and the most stigmatized or marginalized, they are often unable to gain access to services such as health, education, and infrastructure.

### 1.3.3 Terminology: control, elimination and eradication of NTDs

The control, elimination, and eradication of infectious diseases are desirable goals that many health systems aim to achieve as indicators of good public health practice. Over three decades ago, smallpox was eradicated in the public health arena and with it came long-lasting health benefits to the society. Recently, other diseases have been identified as eradication candidates, including NTDs like dracunculiasis, also known as guinea worm disease (GWD). The GWD eradication program has made great strides as witnessed by the decline in the global cases from 3.5 million in the mid-1980s to about 28 human cases in 2018 (CDC, 2018). Hence, it is important to understand what the terms ‘control’, ‘elimination’ and ‘eradication’ mean in the global health arena.

To begin with, ‘control’ refers to a reduction in disease incidence, prevalence, morbidity, and mortality to an acceptable level as a result of various intervention efforts. The success of control programs relies on continuous intervention strategies to maintain the already reduced prevalence levels. The next step after ‘control’ is ‘elimination,’ which means interrupting transmission and reducing the incidence of infection to zero within a defined geographical region (Cochi and Dowdle, 2011). Elimination carries with it a minimal risk of reintroducing the parasite to the locality because continuous actions and a series of documentation called ‘verification’ are carried out to ensure disease transmission does not occur. Finally, after a successful control and elimination process, ‘eradication’ comes next. Eradication is the permanent global reduction to zero; this means that a specific pathogen cannot be reintroduced

into a particular environment hence no further risk of infection, this process is often certified (Cochi and Dowdle, 2011). As such, most countries endemic for GWD are in the certification process, and it is projected that other NTDS such as cysticercosis and LF may soon make it to the eradication list.

### 1.3.4 NTD initiatives

The study of NTDs has a long and complicated past, but one historical event that stands out is when the German government under the current GIZ program co-sponsored two stakeholder conferences with WHO in the year 2003 and 2005 in Berlin, Germany to set the pace for global NTD initiatives (WHO, 2010). The meetings brought together key players from different organizations with a clear agenda of alleviating the misery and suffering brought about by NTDs. It is during this period that the term 'NTDs' was coined to refer to a group of communicable diseases and conditions that affect the poor and marginalized (WHO, 2004, 2006). The primary outcome of the meetings was the need to have an integrated approach towards NTD control and elimination efforts (WHO, 2004, 2006, 2010). Before the 'Berlin meetings,' several global initiatives had been launched to mobilize political and social capital and address specific infectious diseases of concern in various contexts (WHO, 2015). While there were success stories, most of the activities were happening at a rather slow pace. The success of the two meetings influenced the World Health Assembly (WHA) to come up with speedy resolutions towards resource mobilization and political capital to support drug donations and improve delivery mechanisms for integrated control programs (WHO, 2015). It is through this recommendation that pharmaceutical companies, governments, non-governmental organizations, and public health professionals saw the need for having a 'moral investment'

towards NTDs. 'Moral investment' involves a fundamental commitment of political and social systems for successful control and eradication measures. It also refers to putting in place measures that positively impact on the lives of many people which reflects on their choices in the kind of life they would like to live (Gyapong & Boatin, 2016; Hotez *et al.*, 2006). Moral investment further recognizes the importance of having a world that is free from the burden of diseases and inequity where good health is accessible to all.

In Kenya, the recently launched, National Strategic Plan for Control of Neglected Tropical Diseases (2016-2020) aligns with the Kenya Health Sector Strategic and Investment Plan (2014-2018); Kenya's Vision 2030, United Nations Sustainable Development Goals (SDGs) and The WHO guidelines, to implement universal access and coverage of NTD interventions. Key to this is the expansion of the 'PHASE' approach, which advocates for **p**reventive chemotherapy, **h**ealth education, **a**ccess to safe water, **s**anitation, and hygiene and **e**nvironmental improvements (KNSP, 2016).

### 1.4 Geographic context and practical importance of research

Health geographers recognize the role of place in shaping health and wellbeing (Gatrell and Elliott, 2015), where a person resides can be a risk factor for disease or ill health. Hence, geographic context matters in access to essential services such as health care, nutritious food, clean water, and decent housing. The emergence of geographies of health and healthcare from the biomedical approach of medical geography recognizes human agency and awareness in the study of health (Gatrell and Elliott, 2015). Furthermore, geographies of health acknowledge the social construction of health and socio-economic processes in determining resource allocation and

production of inequity (Gatrell, and Elliott, 2015). As such, there is a need to study how political, socio-economic, and cultural factors shape the distribution of resources and affect wellbeing.

Poverty and inequities are social determinants and consequences of NTD infection (Aagaard-Hansen & Chaignat, 2010). Hence for NTDs to be addressed, poverty needs to be alleviated, and this involves listening to the voices of the marginalised and vulnerable groups and exerting political influence in the local and global arena (Aagaard-Hansen & Chaignat, 2010). The sooner this is done, the faster SSA can accelerate progress in major areas of education, nutrition, water and sanitation and in doing so; improve the health and wellbeing of its populations. After all, the wellbeing of a nation is not dependent on one but several components (Deaton, 2013).

In the year 2013, the World Health Assembly adopted a resolution to intensify the efforts towards elimination and eradication of NTDs and this included integrating NTDs within primary health services and subsequently within the SDGs by providing a strong call for action (Sun and Amon, 2018). This research responds to this call by examining the inequities that are present in the broader political, economic, and socio-cultural systems which hamper access to preventive chemotherapy and morbidity management and gives rise to stigma and discrimination.

## 1.5 Organization of the dissertation

This dissertation is organized into seven chapters. Chapter two broadly reviews the current literature in the study of NTDs, health, and wellbeing. It begins explicitly with the historical evolution of the sub-discipline of health geography from medical geography, discusses the theoretical framework, and highlights the research gaps that inform this research. Chapter three provides a detailed methodology which includes the study context, ethical considerations, study design, and data collection procedures. Chapter four discusses the results of the first objective (the link between NTDs and structural inequities) and provides the research summary and next steps. Subsequently, chapter five and six discuss the results of the second (the capacity of local communities to address the burden of NTDs) and third objective (the potential indicators for use in the Global Index of Wellbeing that will capture the inequities represented by NTDs) respectively and also provides the research summary and next steps. The final chapter (seven) summarizes the conclusions drawn from the three objectives and provides substantive, methodological, and theoretical contributions as well as the limitations and recommendations for future research.

# CHAPTER TWO LITERATURE REVIEW

## 2.1 Introduction

This chapter reviews the current literature on the impact of NTDs on health and wellbeing. It begins by discussing the core concepts in health geography and provides the theoretical framework that guides this research (capability approach and the political ecology of health). It further highlights the existing research gaps that the three objectives aim to address which include: the political, economic, social, and cultural impacts of NTDs on health and wellbeing, the capacity of local communities to address the burden of NTDs and the potential indicators for use in a Global Index of Wellbeing (GLOWING) that will capture the inequities represented by NTDs respectively.

## 2.2 Geographies of Health

Health geography is a sub-discipline of human geography that applies geographical perspectives, information, and methods to study health, disease, and health care (Luginaah & Kerr, 2015). In the early 90s, Robin Kearns pioneered a debate that encouraged a shift from medical to health geography (Brown, Mc Lafferty, and Moon, 2011; Kearns, 1993). Medical geography was chiefly concerned with disease ecology (the relationship between disease and the environment), disease mapping, health service provision using positivist theory and quantitative methods (Kearns, 1993; Andrews *et al*., 2012). Robin Kearns proposed that geographers incorporate a place sensitive approach to health and healthcare delivery (Andrews *et al*., 2012). The debate encountered opposing views from Mayer and Meade (1994), who argued that Kearns proposal partially overlooked the theoretical and empirical perspective of disease ecology. Geographers like Dorn and Laws (1994), partly agreed with Kearns but criticized that the

proposed body of work was not extensive enough because it lacked engagement with social theory and scholars like Fiona Smyth noted that the proposed sub-discipline lacked effective policies to reduce inequalities in population health (Smyth, 2008). Hence, the merging of the new 'ideas' alongside the 'old approaches' gave rise to the sub-discipline of health geography.

Currently, health geography is a sub-discipline that appreciates methodological plurality with the choice of research question determining the selection of method (Elliott, 1999). The sub-discipline also engages with social theory to explain peoples' lived experiences. Equally, health geography is conversant with culture and difference, inequality and power, representation, and meaning. At the same time, there is an improvement in disease mapping and modelling using Geographic Information Systems (GISs), multilevel modelling, and advanced spatial analysis. This enrichment has broadened engagement with questions of health inequalities, population health, and environmental degradation. As a result, the subdiscipline of health geography currently speaks to broader audiences within and beyond geography (Andrews *et al*., 2012; Brown, Mc Lafferty, and Moon, 2011).

Place, health and wellbeing, and their interactions are key constructs of health geography. An exploration of health and wellbeing in place requires an epistemological approach that recognizes individual experiences as a way of knowing (Elliott, 1999). The concept of place in health geography is understood to be an operational living construct that matters and is not just a passive container (Kearns and Moon, 2002). Hence, Kearns (1997), calls for a place-sensitive approach to the study of health to reclaim health as a quality rather than a commodity. Health geographers perceive health to be more than the absence of medically defined ailments. This implies a shift in mindset from biomedical preoccupations to a broader commitment to social, cultural, political, and natural components of place-based communities. Health geographers

maintain that a holistic view of health is warranted: one with a socio-ecological model and actual orientation to support policy formulated ideas around empowerment, community action and capacity building (Kearns and Moon, 2002; Brown, Mc Lafferty, and Moon, 2011; Kearns, 1997).

Wellbeing is a product of the efforts to broaden the concerns of health beyond traditional concerns of disease and sites of care towards aspects of wellness (Fleuret and Atkinson, 2007). Developing countries face unique challenges in defining, establishing, and promoting health and wellbeing due to unequal distribution of resources (Luginaah & Kerr, 2015). As such, health geography strives to commit to social justice and equity by informing inquiries around barriers that may hamper equity in access to services (Barnett and Kearns 1996; Hayes, 1999). Hence, this research draws from two complementary theories namely: the capability approach and political ecology of health framework to demonstrate how large-scale structural factors propagate inequalities and how this affects opportunities and freedom of people infected with NTDs.

### 2.3 Theoretical Framework

The role of theory in health geography has taken centre stage over the past two decades (Kearns, 1993; Litva and Eyles, 1995; Krieger, 2011). A theory is a consistent, presumptive, testable set of ideas that enables researchers to describe, explain and predict features of a commonly shared biophysical reality in which a cause and effect relationship exists (Krieger, 2011). Ontology (ways of being) guides a researcher's theoretical approach and epistemology (ways of knowing) determines how we perceive and see the world and this informs how we formulate a research question to address a research problem.

The use of theory is essential in the research process because: Firstly, it helps us understand the world (Litva and Eyles, 1995). Secondly, theory informs our observation and shapes our data collection process (Litva and Eyles, 1995), because "data is not simply observed" (Krieger, 2011.pg17), much thinking goes behind the data collection process, which ultimately guides the data analysis and interpretation (Krieger, 2011). Thirdly, theory helps us to construct and test different representations of reality (Ziman, 2000), because, knowledge does not originate in a vacuum but is embedded in life's social practices (as cited in Sayer, 1992).

Human geographers use theory both implicitly and explicitly within the discipline, for example, Litva and Eyles (1995), report how medical geography was assumed to be atheoretical, but found to draw majorly on positivist theory using quantitative methods. Similarly, health geographers engage actively with social theory to sustain inquiries (Brown, Mc Lafferty, and Moon, 2011) on the progressive view of health. Considering the diverse societal contexts (Krieger, 2011), there is no 'one size fits all' thus, health geographers engage with a range of theoretical frameworks to address questions that arise from health and healthcare.

### 2.3.1 Capability Approach

This approach was developed by Amartya Sen to work out the conflicts that exist between objective and subjective wellbeing. Sen proposes the need to have a combination of objective descriptors alongside personal specifications (Fleuret and Atkinson, 2007). The core concepts of the approach are capability and functioning. Sen describes functioning as "various things a person may value being and doing" (Sen, 1999 pg.75) for example, nourishment, good health, happiness, and self-respect (Sen, 1992). He further adds that there is no definitive list of basic functioning because different sets are relevant to different people in different settings (Sen,

2005). A person's capability entails a combination of various functionings (a set of things that a person is or does-"being and doings") that the individual can achieve (Sen, 1992) as such functioning's depends on access to opportunities. Therefore, a person's capability is a set of all functionings that a person can achieve given resources. As such, a capability reflects freedom and real opportunities and is a robust concept to use when addressing issues around poverty, injustice, and wellbeing (Comim, Qizilbash and Alkire, 2008).

In addition to capability and functioning, Sen introduces a third concept, agency. Based on his account, an agent is someone who acts to bring about change (Sen, 1999). Agency is key because it evaluates " what a person can do and achieve in pursuit of whatever goals or values he or she regards as necessary" (Sen, 1995 pg. 203). The capability approach acknowledges that inequity can constrain freedom, choices, and agency (Nussbaum, 2011) in the enhancement of wellbeing. The limitation in the sole use of the capability approach is that it overlooks the role of broad political, economic, and social structures in people's ability to function (Binder, 2014). Hence this framework is deficient when it comes to generating broader policy recommendations beyond an individual.

In the context of NTDs, poverty causes a deprivation of freedom, capabilities and further impairs opportunities and choices in life (Franco-Paredes & Santos-Preciado, 2011). NTDs thrive in socially secluded areas that have high rates of illiteracy, malnutrition, poor living conditions, and unemployment. Individuals suffering from NTDs find themselves with few choices and opportunities regarding food security, political freedom, clean water, sanitation, social care and access to NTD treatments.

### 2.3.2 Political ecology of health

Human health is understood to be at the interface of social and ecological systems that intersect across spatial and temporal scales. Additionally, vulnerability and decision making play a role (King and Crews, 2013) in health and healthcare provision. A political ecology of health framework (Figure 2.3.2) interrogates health discourses as produced in society and demonstrates how political, economic, social-cultural and environmental systems influence human behaviour and transmission of infectious diseases (Janes *et al*., 2012; King and Crews, 2013; Manderson, 2009).

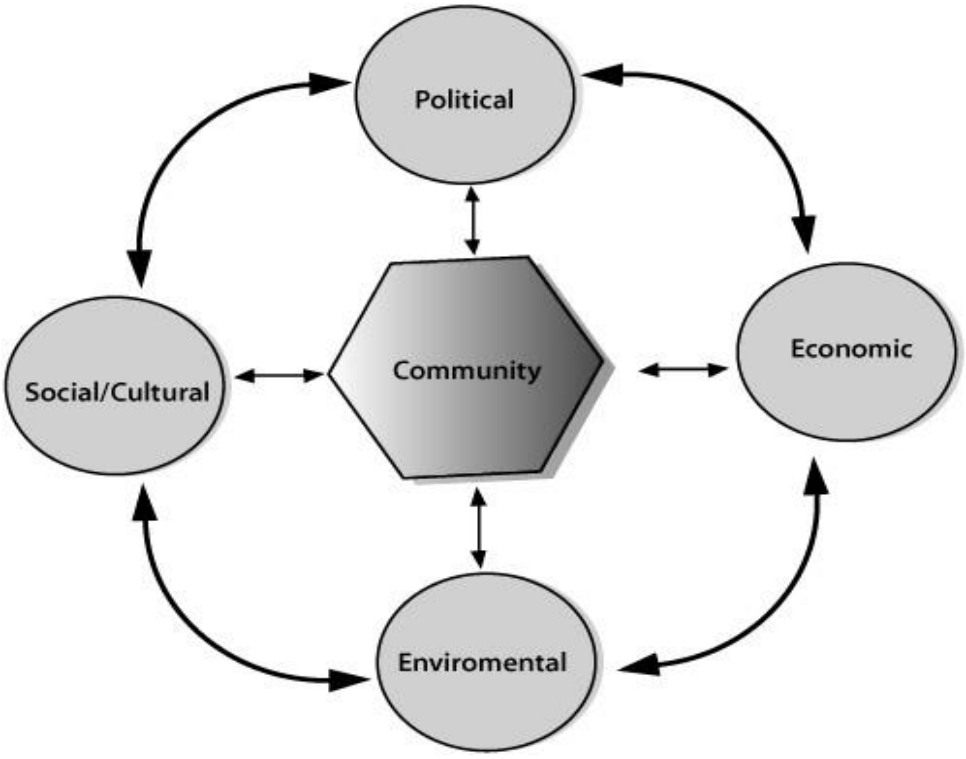


***Figure 2 .3.2*. A diagram showing the political ecology of health framework**

Source: (Adapted from Sanginga, Ochola & Bekalo, 2010)

Over the last two decades, alterations in the physical environment through agriculture, forestry, industrialization and urbanization have seen changes in human use of the environment, exposure to vectors and vulnerability to infection. Similarly, political instability and limited resources affect the way governments manage environments, control disease transmission and ensure proper health delivery (Manderson, 2009). As such, social, cultural, and economic factors interact and shape government response to infectious diseases (Manderson, 2009). Thus it is critical to acknowledge the role of political, social, cultural, and economic environments in exploring health and wellbeing (Elliott, 2017). Therefore, political ecology provides an avenue to examine the relationship between poverty and inequity as shaped by structural factors.

A few scholars use political ecology of health to study infectious diseases, for example, King (2010) uses political ecology of health to examine the effect of integrated health discourses and environmental systems on the delay of anti-retroviral (ARV) policies in post-apartheid South Africa during the HIV/AIDs pandemic. Similarly, he uses the theory to understand the underlying factors that propelled the cholera outbreak in Zimbabwe in the year 2008 (King, 2010). Hence, political ecology of health enables us to understand the dynamics of disease transmission and how governments and health care providers can efficiently and adequately respond to the health needs of its population (Gesler, 2002; Mayer 1996) in light of competing political preoccupations and decisions.

Scholars like Richmond *et al.,* (2005), use political ecology of health to capture how the Namgis (Aboriginal people of Canada) think about themselves, relate to each other and their environment. The study establishes that they define health and wellbeing in terms of political, economic, social, and cultural aspects of their lives and the ease with which they can access natural resources. Additionally, McSweeney and Pearson (2013), give an account of how

indigenous women in Latin America despite having poor physical health are satisfied with their families and at the same time concerned with the social, cultural and economic futures of their children and grandchildren. The authors recommend a fruitful inquiry on the role of socio-political and ecological factors in the study of health and wellbeing.

### 2.4 To identify political, economic, social and cultural impacts of NTDs on health and wellbeing

Human health exists at the interface of environment and society (King and Crews, 2013). Thus social and ecological systems define the health of populations. For this reason, it is vital to explore the sociopolitical, ecological and vulnerability aspects of health, and in so doing address issues of wellbeing, sustainability and equity. Human geographers recognize the fluidity and simultaneity of environmental, political, economic, and social aspects of health. For example, indigenous communities perceive land and resources to be inseparable from their health and wellbeing (King and Crews, 2013; Richmond *et al*., 2005). Similarly, poor communities who suffer from the socio-economic impacts of NTDs demonstrate poor health-seeking behaviour and wellbeing across age and gender (Tolhurst *et al*., 2012).

#### 2.4.1 Political factors

Political power influences government functions, and when power is unevenly distributed, it creates a loophole for the exploitation of the poor, which hinders an egalitarian economy and society and preserves inequalities (Stiglitz, 2012). Unequal power yields high poverty rates, illiteracy, health, and gender inequality, conflict, and war (Deaton, 2013). When this occurs, politics which is often seen as a means of improving the social and emotional wellbeing of citizens by advancing their economic circumstances fails to achieve this objective

(Wilkinson and Pickett, 2010). As such, disease and poor health are a measure of societies failure and political action provides an avenue for the control of infectious disease through poverty elimination, social cohesion, and economic development. Even though political action seems a sure way for enhanced health and wellbeing, there are obstacles in the implementation of interventions and policies in the form of powerful economic interests, inequitable distribution of social resources, and tension between national and local authorities (Mackenbach, 2008; Marmot *et al*., 2008). Under these circumstances, poverty and inequality persist among vulnerable populations and hinder societal wellbeing (Jaumotte *et al*., 2013).

Conflict disrupts government structures leaving citizens vulnerable and prone to bureaucracy with less effective governments and poor accountability (Global Peace Index, 2016). Moreover, conflict or warfare increases the prevalence of NTD infection because the resources assigned for public health programs are diverted to offset warfare costs. In sub-Saharan Africa, three out of six countries with the highest NTD prevalence have an ongoing violent conflict (Global Peace Index, 2016). This holds for the Central African Republic (CAR) which is endemic for HAT; South Sudan for visceral leishmaniasis and leprosy; and Ethiopia for trachoma (Table 1.2), therefore, it is generally concluded that conflict aggravates NTD infections as witnessed by the increasing cases of onchocerciasis in the Democratic Republic of Congo (DRC) (Herricks *et al*., 2017). Although successful control and elimination programs have eradicated dracunculiasis in most endemic countries of Africa, conflict regions like Chad, South Sudan, Ethiopia, and Mali are still endemic for the disease. Furthermore, violent conflict interrupts control efforts and increase NTD prevalence as observed in the rising cases of onchocerciasis in CAR and HAT in South Sudan and Uganda (Table 1.2). In other words, conflict interferes with control programs such as vector control and mass drug administration,

which compromises human health, increasing susceptibility to NTDs (Du, Stanaway and Hotez, 2018).

Moreover, violent conflict damages the physical environment through deforestation, destroys wildlife habitats, and pollutes water and soil sources which promote vectors, hosts and pathogenic environments leading to an increase in NTD transmission. In the same manner, conflict causes displacement of populations and leads to a decline in economic opportunity and productivity making it difficult to afford health care services and proper housing facilities which increases the risk of acquiring infectious diseases (Du, Stanaway and Hotez, 2018).

### 2.4.2 Environmental factors

Presently, humanity is facing a harsh reality of a quickly changing climatic landscape. As it is, temperatures are warming, and there are alterations in rainfall patterns, floods, and drought among other extreme weather events which are expected to intensify in the future. Climate change is linked to the viability, emergence or decline of NTDs because of species-specific differences and their interaction with other social determinants such as conflict, migration and urbanization influence NTD transmission patterns (Blum and Hotez, 2018). For example, hotter and drier conditions may reduce the incidence of schistosome infections by interfering with the population of the freshwater snail (intermediate hosts). However, not all species respond uniformly to new changes in the environment, and the different responses determine disease magnitude. In case of parasite decline, economic development through urbanization, expansion of MDA activities and possible development of a schistosomiasis vaccine may speed up elimination and eradication of schistosomiasis in the African continent (Blum and Hotez, 2018). A promising schistosomiasis vaccine may be preventive against schistosome infection or may

reduce parasite reproduction in the human body making it a useful addition to existing integrated programs such as chemotherapy and health education (McManus and Loukas, 2008).

Contrastingly, similar climatic conditions may influence the distribution of the LF parasite differently and interfere with MDA efforts. This is because expanded temperature ranges may extend parasite breeding seasons and possibly increase mosquito populations making it difficult to concentrate existing control efforts. Intermediately, hookworm populations respond differently to climate changes, for instance, high temperatures favour the development of *Ancylostoma duodenale* which thrives in extreme environmental conditions (Brooker, Clements and Bundy, 2006) while *Necator americanus* (the most dominant hookworm species) responds poorly to the same changes. Based on the examples above, it is evident that predicting and understanding the diverse outcomes of climate is complex, even though most research demonstrates that hotter temperatures and altered rainfall patterns enable or constrain the development of some vectors. Furthermore, infrastructural development, such as the construction of dams, can alter the local ecosystem and affect the vector habitat and population (Blum and Hotez, 2018). Thus the environment plays a vital role in the promotion or decline of vector-borne NTDs, and as such, it is essential to put that into consideration when planning NTD control strategies.

### 2.4.3 Economic factors

Poverty propagates NTD infection and NTD infection leads to poverty. Many communities affected by NTDs have low socio-economic status and minimal access to health services. Other than physical and psychological discomfort caused by NTDs, these diseases pose a tremendous economic burden to individuals, households, communities, and societies. Hence, an investment in NTD control activities may yield a high rate of economic return and positively impact on the quality of life. As such, NTD programs need to be integrated into the regular health care system to enable rapid diagnosis and treatment of infected individuals for the achievement of universal health access (Gyapong & Boatin, 2016). Previous studies conducted in SSA demonstrate that the economic impacts of NTDs such as LF are likely to be underestimated due to stigma. In instances where individuals abandon work, (Norris *et al.,* 2012) agricultural productivity is affected, and this decreases family income (Gyapong *et al.,* 1996b) leading to malnutrition. For example, in Ghana, patients suffering from Buruli ulcer, combined with their caregivers, lose an accumulated 535 productive days in the care and treatment of the disease. This is due to the patient and the caregiver inability to engage in paid work as a result of the devastating consequence of the disease. And infection often has ripple-on effects: school-going children can lose up to 365 days in cases where they are withdrawn from school due to non-payment of fees by a parent or guardian sick with Buruli ulcer (Amoakoh and Aikins, 2013). Buruli ulcer also accounts for up to 25% of household earnings going towards hospitalization costs in countries such as Cameroon with $21.88 being the cost of treating a single household member suffering from the disease in a household surviving on less than $2 USD a day (Grietens *et al.,* 2008).

Other conditions caused by NTDs such as dengue hemorrhagic fevers and clinical rabies require intensive care which is quite expensive. Even though the progression of rabies can be prevented through rapid immunization after exposure, the vaccine remains costly and unavailable in many countries of sub-Saharan Africa (WHO 2010a). As a result, there is a need for NTD endemic countries in SSA to increase their local investment and scale up interventions by making NTD control activities part of the national health budget allocation (WHO, 2015) to avoid overreliance on foreign donors. When NTDs are made part of the health budget, it is easier for the drugs to get to the people who need them the most.

The investment in drugs and vaccines for NTD interventions by renowned pharmaceutical companies remain critical in the light of accessibility and affordability given that most individuals affected by NTDs live in poverty which affects their economic power. It takes a substantial amount of time and money to develop new pharmaceutical products (Moran *et al.,* 2009) since for each product; there is basic research, product discovery, pre-clinical and clinical trials and initial product implementation costs. These costs are enormous and risky which compel pharmaceutical companies to only willingly manufacture and invest in diseases that are prioritized in the global health world such as the 'big three' which spurs a crisis for NTD interventions (Choffnes and Relman, 2010). When most drug companies abandon NTDs in favor of other diseases, then research and development are left to a handful of global partners who at the same time also commit over 75% of their budget to fund the big '3' leaving a small fraction of the funds directed towards NTD activities. This translates to a low level of investment into Research and Development (R&D), making it nearly impossible to move products through the pipeline to the patients (Moran *et al.,* 2009). Over the years, pharmaceutical companies such as GlaxoSmithKline and Merck have donated Albendazole and Ivermectin to the global NTD

program as part of their corporate social responsibility. The same companies have also supported the delivery of the drugs to the country level and built capacity in endemic areas which have been critical for the success of NTD programs. However, it remains unrealistic to over-depend on NTD interventions and control via global donations from western countries which are indirectly affected by NTDs. Even though developing countries have been seeking official development assistance (ODA) for NTD programs, countries such as Brazil and India through their Innovative Developing Country (IDC) have been aiming to fund at least 10% of their NTD budget (OECD, 2008; Ravishankar *et al.*, 2009). As such, it is important for local governments and organizations to invest in research and interventions for NTDs, which inflict disability and trauma to its citizens.

### 2.4.4 Social factors

Du, Stanaway, and Hotez (2018) argue that poor health is not only a problem to poor people, but the burden of poor health is significantly higher in poor populations that have insufficient social programs, corrupt policies, and conflict which enable poverty to obstruct health. NTDs are diseases of poverty, and they extend to other axes of disparities such as gender, ethnicity, and disability. Hence, these diseases affect populations that are least able to demand basic services, for example, women, children, ethnic minorities, displaced people and their effects are felt in health, agriculture, infrastructure, and education sectors (Gyapong & Boatin, 2016).

The social stigma attached to NTDs, particularly the highly disfiguring ones such as Buruli ulcer, leprosy, lymphatic filariasis, and onchocerciasis is devastating. For example, leprosy, which is a biblical NTD, is recorded in ancient Egyptian history, and these historians suggest that individuals suffering from leprosy were regarded as unclean and banished from

society (Hotez, 2008). As such, disease-related stigma encourages exclusion, rejection, blame, and social judgment (Weiss and Ramakrishna, 2006). Additionally, stigma fuels the disease burden and poverty levels. For example, women have a higher disease burden from leishmaniasis compared to men due to reduced health care access and gendered social isolation as a result of the lesions caused by the disease (Hotez, 2008). Furthermore, stigma leads to social exclusion, reduced quality of life, and poor mental health. As such there is a need to address the social underpinnings of NTDs to enhance the health and wellbeing of citizens in LMICs.

The third WHO report (2015) on 'investing to overcome the global impact of NTDs' has a major focus on equity. Likewise, the SDGs set the pace for goals related to shared prosperity and 'leaving no one behind' (WHO, 2015). For this purpose, enhanced and equitable distribution of resources seems to be the most appropriate way in which the most marginalized communities affected by NTDs can have an opportunity to lead improved lives (WHO, 2015). In Kenya, the poorest of the poor, the most stigmatized and marginalized communities infected and affected by NTDs, are still unable to gain access to services such as health, education, and infrastructure.

### 2.4.5 Cultural factors

Socio-economic activities such as fishing, crop farming, nomadism, and livestock rearing may predispose communities to NTDs such as schistosomiasis, HAT, and leishmaniasis, respectively due to the environments in which these livelihoods are pursued (Table 1.2). Most of the socio-economic activities in Kenya are influenced by culture and lifestyle factors. For example, pastoralism or nomadism involves the movement of people from one area to another in search of water and pasture for their animals which leads to new exposure to disease-causing

agents. When the migrating population advances into new areas they may also carry with them infectious organisms into the new environments (Aagaard-Hansen, Nombela, and Alvar, 2010). As such, pastoralism is associated with higher prevalence's of NTDs such as trachoma and dracunculiasis compared to the non-mobile populations due to proximity to cattle and unsafe water sources, respectively. Furthermore, such temporary movements may create new epidemics. For example, when a non-immune population temporarily migrates to a visceral leishmaniasis endemic area, upon their return they may introduce the parasite into a previously non-endemic area. Other contributing factors that may fuel the infection among the migrating population include high malnutrition, lack of diagnostic kits and treatment, and weak health systems leading to high mortality from the disease (Aagaard-Hansen *et al.*, 2010). Culture influences human activities, and the community's perception of the interaction between disease and the environment, because, it determines social behaviour, occupation and gender-specific knowledge on the impact of the interactions between hosts, parasites, and vectors (Rutto *et al.*, 2013). As a result, it is not unusual in African countries to find NTD infections attributed to 'charms' or 'witchcraft'. For example, in Benin, infection with Buruli ulcer is attributed to trespassing on another person's property (Grietens *et al*., 2012). Similarly, infection with lymphatic filariasis in Northern Ghana is attributed to witchcraft (Ahorlu *et al.*, 1999) which leads to stigma. Likewise, in Tanzania, Parker and Allen (2012), establish that communities attribute untreatable hydrocele cases to witchcraft. This happens when a person has conflict with another person in the village and he becomes 'bewitched' leading to accumulation of fluids in his male genitalia (hydrocele). Once this happens, it becomes impossible to access treatment in a hospital because it is commonly understood, even among African medical professionals, that

'witchcraft does not respond to conventional medicine' and such a person, if lucky, can only be cured using herbs which leads to social stigma due to the society's understanding of its origin.

Despite the cultural or religious diversity across multiple African countries, the experience of stigma seems to be similar in several settings. Stigma affects mobility, relationships, marriage, employment, and participation in leisure activities, religious and social functions. The magnitude, depth, and experience of stigma may be linked to gender roles, relations, and expectations (van Brakel, 2003). Vlassoff *et al.*, (2000), in a multi-country study examining the gender-related features of stigma due to lymphatic filariasis, onchocerciasis, and leprosy establish gendered differences in the manifestations of stigma. In men, stigma is perceived as a limitation to economic opportunities while in women, stigma is viewed as a limitation to getting married and starting a family (Vlassoff *et al.,* 2000).

### 2.4.6 Gender factors

A thriving society depends on the ability of individual members to adopt specific roles and responsibilities shaped by broader sociopolitical forces and defined by gender (Allotey and Gyapong, 2005). A gender difference, in this case, is not a significant problem, but it is the values placed on the various roles and responsibilities that bring inequities between the genders (Allotey and Gyapong, 2005). In many developing countries, certain gender-based factors support a wide range of social policies and practices which are biased against women. For example, domestic and sexual violence, child marriages, and labor limit developmental opportunities for women (UNOHCR, 2008) making them live in fear, compromising how well they take care of themselves, their children, and access healthcare services. Furthermore, gender roles, responsibilities, and relations influence how individuals interact in society and affect the

access and distribution of resources. Thus, it is paramount that research considers the dynamics of gender relations in NTD transmission cycles.

Women are the vast majority of the world's poor who live in extreme poverty (ILO, 2009; UN 2010c). As such, when a woman lacks the economic resources, education, political and social influence and is struggling to feed her family, she will not be in a position to accord NTD infections the urgency they require in the event that her health and that of her family is affected. Also, women tend to be at risk of acquiring NTDs such as HAT and leishmaniasis due to heightened occupational exposure to the vector compared to men (Choffnes and Relman, 2010). However, women tend to be more stigmatized compared to men from contracting the NTD infections, making them shy away from seeking treatment and later on suffering from complications such as amenorrhea, infertility, and miscarriages (WHO, 2010a).

Women in Africa are typically caregivers in the family, which predisposes them to NTDs such as trachoma because as they tend to family members who are sick, they risk transferring bacteria into their own eyes. Additionally, studies confirm that women are two to three times more likely to be permanently blinded from trachoma compared to men (Carter Center, 2009; Hotez, 2008) because of poor health-seeking behaviour. When a woman becomes blind, her educational opportunities and ability to earn a living are limited, and this promotes poverty (Choffnes and Relman, 2010). In the family context, women who suffer from disabling NTDs such as trachoma and lymphatic filariasis are barred from engaging in sexual relations and are forced to leave their matrimonial homes, while males seek companionship from other women for sexual relations (Mpanya *et al.*, 2012). Furthermore, women who experience stigma, social, and psychological distress associated with the chronic effects of lymphedema and elephantiasis find it hard to find a spouse because the swelling of the extremities interferes with mobility and the

inability to participate in social activities leads to hopelessness (Okwa, 2007; WHO, 2010a). For this reason, women must be empowered to access treatment in order to enhance their health and wellbeing, as well as prevent them from being disease reservoirs for NTD transmission in the community (Manderson *et al.*, 2009).

Both men and women suffer equally from schistosomiasis and soil-transmitted helminths, but women experience more negative health effects during pregnancy due to compromised immunity leading to substantial parasite infection, which causes iron deficiency (WHO, 2010a). Similarly, urogenital schistosomiasis, also known as female or male genital schistosomiasis, is prevalent in sub-Saharan Africa among adolescent girls, boys, women, and men. In women, the disease presents itself with lesions around the vagina, bleeding, unpleasant discharge from the vagina, and discomfort during sex for females. If left untreated, it can be a cause of infertility, miscarriage, and increased susceptibility to HIV and Human Papillomavirus (HPV) which has far-reaching economic and social consequence on livelihoods and wellbeing. The male version, Male Genital Schistosomiasis (MGS) occurs in adolescent boys and men; some of the symptoms associated with the disease include bleeding and presence of thick yellow egg deposits in semen. The health implications of MGS in males remain understudied (Mbabazi *et al.*, 2011), and thus, further studies are required to understand the community discourse around the disease and the realities of differential gendered experiences.

**2.5 To investigate the capacity of local communities to address the burden of NTDs**

The year 2012 saw the *London Declaration* (Table 1.4) established in line with the WHO 2020 Roadmap for control, elimination or eradication of at least 10 NTDs by the year 2020. The agreement provided a step towards sustainable health among the world's most impoverished populations (Du, Stanaway and Hotez, 2018). The 10 out of the 20 NTD diseases of priority as per the roadmap include dracunculiasis, LF, leprosy, HAT, trachoma, schistosomiasis, STHs, Chagas disease, Visceral Leishmaniasis (VL) and onchocerciasis (Table 1.2).

Mapping studies conducted in SSA demonstrate that most countries have a geographic overlap of three or more NTDs (Figure 1.2) hence the need to have tools and interventions that can be used for more than one disease (Gyapong *et al*., 2010). Even though most NTDs have available interventions that work, the biggest challenge remains how to deliver interventions to affected populations in areas experiencing weak health systems (Gyapong *et al*., 2010). Despite the upward development trends in most countries in SSA, the healthcare worker to population ratio remains exceptionally high with some areas not served at all, thus, there is a need to involve other personnel for school and community-based healthcare approaches. Community Directed Treatment (CDT) approaches provide an avenue for health providers to work closely with community members for effective healthcare delivery in specific settings (Amazigo *et al.,* 2007; WHO, 2008). The CDT approach involves selection and training of Community Health Volunteers (CHVs) and enables community members to decide on the intervention locality, and how monitoring and supervision is done (Gyapong and Boatin, 2016). In as much as CHVs are shown to have a wealth of knowledge, are capable and reliable, they require incentives to remain motivated and support intervention strategies, hence, the focus of action needs to go beyond

health worker messaging towards collective action and responsiveness of health systems to the needs and realities of individuals (Gyapong and Boatin, 2016).

The persistence of NTD infection is attributed to uneven social arrangements such as poverty and inequity, which consequently affects the distribution of healthcare resources. Social policies and resources are connected to wealth, power, and prestige, which create barriers for marginalized populations. Whereas public health interventions require political action to have sufficient health policies in place, the role of collective action remains equally important. For example, Shiffman and Smith (2007), explore the role of collective action in harnessing the power to encourage action for global health initiatives. The authors assess power relations regarding people connected or affected by the issue, the power of ideas used to champion the cause and the political context of the situation to inspire action.

Similarly, Bisung *et al.* (2014), emphasize the importance of social capital to spur collective action in lobbying for common environmental rights among marginalized communities, since social capital predisposes people towards cooperative behaviour necessary to facilitate shared goals. However, for social capital to influence public health practice and interventions, it is essential that the underlying mechanisms extend beyond individual and community levels to include macro-structures such as politics and power relations (Kawachi, Subramanian, and Kim, 2008).

Grepin and Reich (2008), propose the integration of disease control programs on a global, national/regional, and local scale. Integration at the local level involving a district/ village/community using the Ministry of Health employees, community volunteers, and other partners. This form of mobilization offers an opportunity for the use of collective action in communities affected by NTDs since, intersocial networks increase information uptake through

community mobilization and solidarity, cultural change and disease prevention (Janes *et al*., 2012).

The success of large-scale public health interventions continues to rely on political commitment. For example, polio, GWD, and LF programs have benefitted from political and societal support. The challenge remains on how to sustain government level support for all NTDs given the issues that exist on the ground such as social perception, supervision, and surveillance. Hence there is need for consistent advocacy at the local level to maintain momentum ( Hotez *et al.,*2006; Molyneux *et al.*, 2005). As such, this study examined the role of collective action as a means in which community members can identify the kind of sustainable contributions they can make towards control of NTDs in their contexts.

### 2.6 To identify potential indicators for use in a Global Index of Wellbeing (GLOWING), that will capture inequities represented by NTDs

Many health policies are reliant on medical measures of morbidity and mortality in decision making and implementation at the expense of other social factors that produce and reproduce ill-health (Fleuret & Atkinson, 2007). Thus, proper measurements are required to help identify areas of strength and weakness in public policies and enable effort and resources to be directed towards sectors or domains that require improvement, hence measures of wellbeing. Wellbeing is a multidisciplinary and integrative concept that provokes thinking among statisticians, sociologists, economists, geographers, medical researchers, and others on how life can be made better for individuals and communities, sustain development and eradicate poverty (Allin & Hand, 2014). In simple terms, 'wellbeing' is regarded as measuring 'what matters.' For example, at a minimum, the use of objective indicators may provide information to policymakers on diseases or conditions that are overlooked (Fleuret & Atkinson, 2007) such as NTDs, or the

rise in Non-Communicable Diseases (NCDs) such as cancers, heart disease and diabetes in SSA. Furthermore, measuring wellbeing provides a comprehensive and progressive understanding of tendencies that justify practices (Schwanen & Atkinson, 2015) that undermine what makes for a good life and foster dialogue among multiple stakeholders on the implementation of socially inclusive policies.

Several countries have launched measures of wellbeing to determine how their citizens are doing (Table 1.5). For example, countries such as Australia have the Australian Unity Wellbeing Index which uses a combination of subjective and objective measures of wellbeing (Elliott *et al.,* 2017). Such measures combine subjective experiences and objective indicators to measure what matters to the society. A limitation to the use of such measures is that first, they require the use of primary data which may be inconsistent and expensive together, and second, they may measure people's happiness as opposed to wellbeing (Elliott *et al.,* 2017). Other countries such as New Zealand and Canada use the New Zealand Social Report (NZSR) and the Canadian Index of Wellbeing (CIW) respectively, which use domains and indicators that citizens' value beyond GDP, and which can be applied when measuring wellbeing in LMICs. The CIW provides a foundation for measuring wellbeing in LMICs because it uses objective indicators which eliminate the cost of collecting primary data. Secondly, studies by De Neve *et al*. (2013) suggest that subjective wellbeing has an impact on objective wellbeing in broad areas such as health, education, and productivity. The CIW consists of eight domains that focus on fundamental aspects of life that matter to Canadians (Michalos *et al.,* 2011) and recognizes the interconnectedness of the domains in informing public policies. Additionally, CIW regularly reports and implements social change at local, provincial, and national levels. The eight domains of the CIW are healthy populations, democratic engagement, living standards, environment,

education, community vitality, time use, leisure and culture (Canadian Index of Wellbeing, 2012; Michalos *et al.,* 2011).

### 2.6.1 Healthy populations

Health is a key aspect of wellbeing. The Universal Declaration of Human Rights asserts that all humans have a right to enjoy the highest level of health and wellbeing. The right to health is enshrined in numerous international and human rights treaties as well as in the constitutions of over 115 countries (Zuniga, Marks & Gostin, 2014). Surprisingly, the 'right to health' statement seem not to apply to the world's most impoverished and most uneven settings (Hall, 2014; Zuniga *et al.,* 2014) even though poverty is a structural determinant, and a consequence of NTD infection in the public health arena (Bardosh, 2014). Despite this realization, the suffering of more than two billion people seems to be forgotten (Hotez, 2013). Currently, the global burden of NTDs is almost equal to at least half the combined global burden of HIV/AIDS, tuberculosis and malaria (Choffness & Relman, 2011), yet the latter diseases continue to be given priority in the global health arena. NTDs have a dire impact on physical and intellectual development across generations due to the chronic nature of infections that persist for years and enhance the clinical progression of diseases such as HIV/AIDs, tuberculosis, malaria and cancers (Hotez, 2008a; Hotez *et al.,* 2009). As a result, people living in remote rural areas or urban slums continue to bear the majority of the health burden of NTDs (WHO, 2010).

Even though WHO released a report in the year 2008, advocating for global efforts to address social determinants of health by promoting health equity and prioritizing equitable distribution of power, money, and resources (WHO, 2008), a lot remains to be done to achieve

this goal. Thus, this research recognizes that health and wellbeing of populations depend on proper biophysical, social, economic, and political environments.

### 2.6.2 Democratic engagement

Democratic engagement provides a platform for people to take part in fair political processes through political organizations. A sound political voice and good governance permit individuals to have a say in the rule of law (Deaton, 2013). Comparatively, citizens who have a political voice can trust public institutions and keep their governments accountable for their needs. At the same time, proper administrative structures ensure that citizens can access resources with relative ease (Stiglitz, 2012; Allin & Hand, 2014). A compromised democratic engagement process leads to unfair economic arrangements and poor social policies that are responsible for breeding health inequalities which compromise the social and emotional wellbeing of citizens (WHO, 2008; Wilkinson & Pickett, 2010).

### 2.6.3 Living standards

Living standards represent the distribution of income and wealth, with necessities such as food and housing factored in. Populations most affected by NTDs are often left behind by socioeconomic progress because they are poor and live on less than USD$2 a day (WHO, 2017). NTDs promote poverty as they make people too sick to work and earn a living (Gyapong & Boatin, 2016). For this reason, it is pertinent that equity prevails in the allocation of public resources and considers certain groups facing the burden of NTDs and other obstacles in accessing health care (Braveman, Krieger & Lynch, 2000).

The Millennium Development Goals (MDG) (UNDP, 2010) were primarily set by countries in the global north for the countries in the global south as relevant benchmarks for poverty reduction, global health, and equity using quantitative indicators (Allin & Hand, 2014). Despite the goals listing NTDs in MDG 6 under 'other diseases,' these diseases were largely overlooked in favour of the 'big three' (HIV/AIDs, malaria and tuberculosis) due to non-existent performance indicators and targets assigned to NTDs. As a result, the broad and bold MDG goals failed to address in totality the issues of poverty and inequality by the close of 2015. On the positive, the MDGs highlighted other areas that require current global initiatives such as improvement of health and wellbeing for vulnerable populations suffering from NTDs (Mc Donald, 2011). Furthermore, the MDGs paved the way for the United Nations (UN) Sustainable Development Goals (SDG), goals one, three and ten of which seek to alleviate poverty, promote good health and wellbeing, and reduce inequalities respectively (Index S. D. G., 2017).

### 2.6.4 Environment

The environment is broadly comprised of the biosphere, geosphere, hydrosphere and atmosphere. Hence, the environment is a biosocial determinant (Aagaard-Hansen and Chaignat, 2010). Environmental conditions have an impact on day-to-day life as they influence the worldwide distribution of disease-causing organisms. As a result, most infectious disease-causing pathogens are found in the equatorial regions of the world, and the numbers decrease as the distance from the equator increases (Guernier *et al.,* 2004). Also, contaminated water sources provide breeding grounds for vectors such as snails that transmit schistosomiasis. Furthermore, water contact at the household level through drinking water contaminated with vectors increases the risk of contracting diseases such as dracunculiasis, and similarly, stagnant water bodies act as

habitats for mosquito vectors that transmit dengue fever and lymphatic filariasis (Aagaard-Hansen and Chaignat, 2010).

Physical and environmental factors also influence human migration patterns globally, and with the onset of urbanization in developing countries comes urban poverty and the rise of informal settlements (Kjellstrom and Mercado, 2008; UN, 2010b). Additionally, factors such as desertification and armed conflict carry with them risks of famine and displacement from rural farmlands, leading to clustering in informal settlements, substandard housing, and inadequate sanitation facilities, which are optimum conditions for the spread of NTDs (Choffnes & Relman, 2010). All these concerns are made worse in the face of global environmental threats such as climate change and related ecosystem disruption[1] (IOM, 2009).

### 2.6.5 Education

Education is a useful resource in the modern technological era, but more importantly, education breeds opportunity and gives people a considerable choice and control over their lives (Allin & Hand, 2014). A high level of education generally translates into better health, high employment rates, and greater economic and social engagement. Unequal access to education promotes various forms of inequality and hinders one's contribution to society. Unfortunately, most of the people living with NTDs are illiterate because they experience barriers to accessing education (UNESCO, 2008).

Poverty and illiteracy go hand in hand because an illiterate society cannot be an innovative society. Contrastingly, educated individuals can find their fulfillment in life even

[1] The localized or large-scale disturbances (the effects can be short-lived or long-term).

beyond retirement age (Allin & Hand, 2014). Thus poor educational attainment promote child poverty, child labour and child marriages, all of which limit access to education and exposes children to numerous health hazards including NTDs. Neglected diseases such as soil-transmitted helminths affect children's cognitive and physical development, and stunt their educational prospects, setting them on a life-long path of disability and poverty (Hotez, 2009).

### 2.6.6 Community Vitality

Community vitality is a measure of how social support networks influence people's lives across multiple scales. Previous studies show that at the individual level, there is a strong link between social networks and improved health and wellbeing (Allin & Hand, 2014). Similarly, solid social networks translate to an individual's access to higher levels of education and secure employment opportunities. Contrastingly, the social stigma of NTD infection compromises an individual's participation in community activities. As a result, alienated individuals find it challenging to get married or have children, leading to psychological stress, hopelessness and a negative impact on their social and emotional wellbeing (Okwa, 2007; Person *et al.*, 2009).

### 2.6.7 Time use

Time connects to social space or place (Taylor, 2005). How people choose to their time affects their wellbeing. Healthy time use comes with the freedom to choose one's interest (Allin & Hand, 2014). In this case, individuals infected with NTDs tend to have their work productivity impaired due to physical disability and disfigurement. For example, NTDs such as Chagas disease cause cardiac problems; lymphatic filariasis and Buruli ulcer cause skin lesions and ulcers; trachoma and onchocerciasis cause irreversible blindness and they all consequently deny individuals a choice on how they spend their time (Rodrigues & Lockwood, 2011).

Similarly, NTD infection makes individuals spend much time seeking health care services over other essential duties, such as earning a living or going to school. For example, surgeries for trachoma the treatment of Buruli ulcer, dengue hemorrhagic fever, and Chagas disease require extended hospital stays, and patients suffering from Buruli ulcer, leprosy, and lymphatic filariasis find themselves spending prolonged periods in rehabilitation centres (WHO, 2010; 2010a).

### 2.6.8 Leisure and culture

Some NTDs have distinct age-related manifestations; for example, Buruli ulcer, schistosomiasis, and soil-transmitted helminths mostly affect children. HAT primarily affects adults, and onchocerciasis and trachoma cause blindness in the elderly population because of the long-term progression of the diseases (Aagaard-Hansen and Chaignat, 2010). Individuals infected with NTDs tend to have limited sources of income. The resulting poverty and disadvantage breed food insecurity, malnutrition, and susceptibility to other infections (Perera, 2007). The lack of economic and social support prevents such individuals from taking part in leisure and cultural activities in their community, which in turn affects their health and wellbeing.

## 2.7 Chapter Summary

This chapter reviews relevant literature in the study of NTDs, health, and wellbeing. The review begins by situating the research within the sub-discipline of health geography emphasizing on the interconnectedness of place, health, and wellbeing, using two complementary theories that examine the broad structures in society and individual agency namely: the political ecology of health and the capability approach respectively. The chapter further discusses the political, economic, environmental, social, cultural, and gender-specific impacts of NTDs on health and wellbeing. Moreover, it reviews the capacity of local communities to collectively provide context specific interventions for NTD control. The chapter finally concludes with the importance of measuring wellbeing by highlighting the existing measures of wellbeing in the global north and discussing the advantages of using a CIW as a foundation for measuring wellbeing in LMICs.

The next chapter outlines the research methodologies used to address the research objectives, which includes: study context, ethical considerations, research design, data collection, analysis, and interpretations.

# CHAPTER THREE METHODOLOGY

## 3.1 Introduction

This dissertation explored the impact of neglected tropical diseases on health and wellbeing using the political ecology of health and capability approach theories. The thesis further used qualitative methods on a cross-sectional design to 1) identify the political, economic, social, and cultural impacts of NTDs on health and wellbeing; 2) to investigate the capacity of local communities to address the burden of NTDs; 3) to identify potential indicators for use in a Global Index of Wellbeing (GLOWING) that will capture the inequities represented by NTDs. This chapter explores the research design, methods, and gives a detailed structure of the data collection process.

## 3.2 Study context

The study was conducted in Kenya (figure 3.2), which has a tropical climate with 80% of the land consisting of arid and semi-arid zones. The zones define the agroecological areas that influence the focal endemicity of NTDs (KNSP, 2016). Despite only 20% of the land being arable, agriculture remains the main economic activity and practices such as irrigation and fishing are considered risk factors for the spread of NTDs such as schistosomiasis (KNSP, 2016). In reference to water and sanitation, only 61% of the total population has reasonable access to safe drinking water with a substantial disparity in the distribution between regions, urban and rural communities. At the household level, only 26% of urban homes have access to sanitation facilities; a rate which is slightly lower in rural areas. Such inadequacies contribute to the spread of NTDs, such as soil-transmitted helminths (STH) and trachoma (KNSP, 2016).

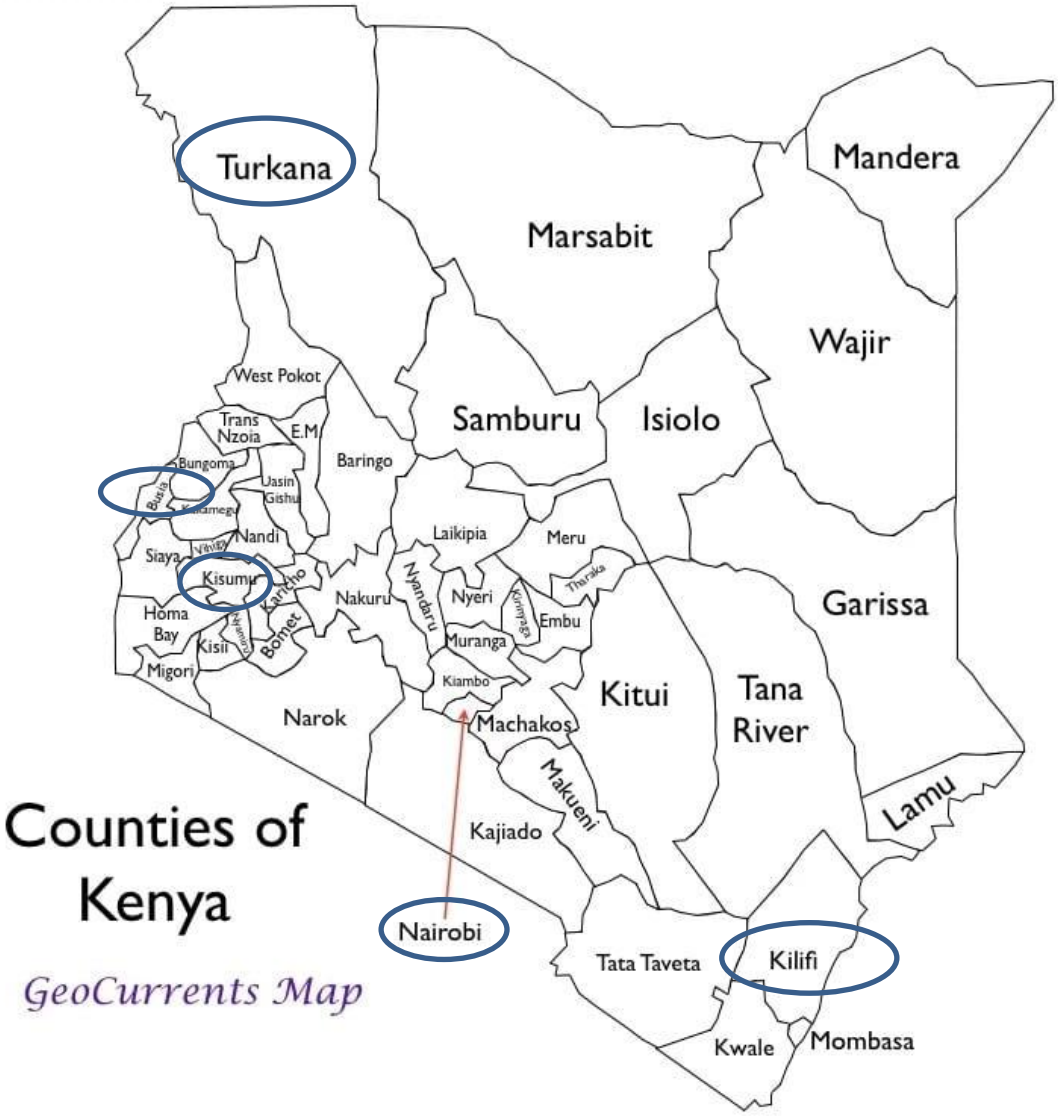


***Figure 3.2:*** **A map of Kenya showing the 47 counties. The circled areas are the study counties.**

Source: Google images

In the year 2010, the promulgation of the new constitution devolved Kenya into 47 administrative counties. Under this system of governance, most of the health functions were devolved to the county level which is the same for NTDs. However, the national NTD unit was made responsible for policy formulation, capacity building, monitoring and evaluation of NTD activities in the counties. The Ministry of Health first launched the National multi-year strategic plan of action for the control of NTDs (2011-2015) in November 2011. The plan prioritized control of Soil-Transmitted Helminths (STH), schistosomiasis, Lymphatic Filariasis (LF), trachoma and cystic echinococcosis (hydatid disease).

The conception of this roadmap saw promising steps towards the management of NTDs through the WHO recommended strategies for prevention and control. First, a major mapping exercise for schistosomiasis and STHs was conducted for people living in the 19 out of the 47 counties. Second, through the National School-Based Deworming Programme (NSBDP), a total of 6.1 million children were dewormed by the close of the year 2015. Additionally, 17 out of the 23 LF endemic sub-counties had received mass treatment using a combination of Di-ethyl Carbamazine (DEC) and Albendazole, and thirdly, the National NTD program in collaboration with other partners carried out a series of combined Preventive Chemotherapy (PCT) and Case Management (CM) interventions for other NTDs. The mapping of trachoma was completed in 12 of the endemic counties followed by Mass Drug Administration (MDA) in 8 out of the 12 counties using Azithromycin and 1% Tetracycline eye ointment. Fourth, safer and effective combination therapy for Visceral Leishmaniasis (VL) using Paramomycin and Sodium Stibogluconate (PSSG) to replace the monotherapy with Sodium Stibogluconate (SSG) was introduced.

The success of the programs outlined above rely on the accessibility of the regions of interest, political goodwill, and donations from global partners. Hence, the current 2016-2020 strategic plan aims to scale up access to interventions and treatment of populations at risk; enhance monitoring & evaluation activities; supervise surveillance and operational research activities; strengthen government ownership, coordination and partnership in line with the renewed global momentum towards elimination and eradication of (some) NTDs by the close of 2020.

### 3.3 Ethical consideration

The study protocol was reviewed and approved by the University of Waterloo Research Ethics Committee (ORE#22493) and the Maseno University Ethical Review Board (MSU/DRP/MUERC/00496/17) to satisfy the requirements of conducting research studies in Kenya. Before the study commenced, the researcher shared the aims of the study with the Ministry of Health representatives from the national and county governments. Research participants also gave informed consent before taking part in the study. The consent forms outlined the objectives of the study, the participation requirements of the consented individual, the expected outcomes of the study as well as the benefits of the research.

The participants were informed of their right to participation and withdrawal from the study at any time without penalty, and the researcher ensured that all the data collected was stored in a locked cabinet for the confidentiality and privacy of the study participants. Additionally, encrypted passwords were used to secure the data on the computer, and only the researcher and the academic supervisor had access to the data. All information gathered from the

study participants was treated as confidential, and no personal identifiers were used during data entry and analysis.

### 3.4 Research design

The objectives of the research were: 1) to identify the political, economic, social, and cultural impacts of NTDs on health and wellbeing; 2) to investigate the capacity of local communities to address the burden of NTDs; and 3) to identify potential indicators for use in a Global Index of Wellbeing (GLOWING) that will capture the inequities represented by NTDs. The research was framed within social constructionism which takes on a humanistic approach to capture and understand the lived in experience of people infected and affected by NTDs in Kenya. The research used qualitative methods to provide a deeper understanding of values, beliefs, and attitudes of participants in the context of NTDs (Hay, 2009), and it utilized country level NTD data to determine areas of NTD prevalence and interventions. Additionally, the use of qualitative methods allowed for the 'silenced voices' to be heard and in so doing, enabled a better understanding of the discourses around inequalities. The research was carried out in the NTD endemic counties of Kenya (Figure 3.2) and explored the meaning and experiences of how NTDs affect health and wellbeing of communities in Kenya to identify potential indicators for use in a Global Index of Wellbeing (GLOWING) that capture the inequities represented by NTDs. The methods used were Key Informant Interviews (KIIs) and Focus Group Discussions (FGDs).

### 3.5 Data collection

The study used purposive sampling to recruit participants from five NTD endemic counties, namely Turkana, Kilifi, Busia, Kisumu, and Nairobi counties of Kenya (Figure 3.2). The sampling of the regions was conducted as per the data published in the 2016-2020 NTD strategic plans (KNSP, 2016). All the selected counties were endemic for more than one NTDs and as such, the study enrolled participants who were infected or affected by NTDs aged 18 years and above; both male and female and excluded persons who were below 18 years of age, not infected/affected by NTDs and residing outside the study areas. The data collection took place for approximately two months from 7$^{th}$ December 2017 to 6th February 2018. Prior to the fieldwork, a reconnaissance trip was made in December 2016 for approximately one month to understand the study context and meet with key stakeholders carrying out NTD research in Kenya. In December 2017, just before the data collection process, there was a meeting with the officials and community leaders from the five counties of interest. The meeting was to introduce the research and seek formal permission to carry out the research. After the stakeholders meeting, the community leaders held a forum with the community members to discuss the general purpose and objectives of the research and relay any questions and concerns the community may have regarding the study.

### 3.5.1 Key informant interviews

A total of 21 Key Informant Interviews (KIIs) were conducted with participants from the national level, including NTD managers, policy makers and with participants from the community level, including community health volunteers, village elders, and local NTD partners (Table 3.6). The KIIs interviews addressed all the three objectives of the study and the data collected from this group of respondents is instrumental in informing decision making since it harnesses the suggestions and recommendations from the target populations and the policymakers.

Prior to the interviews, respondents were approached in any of the following ways: 1) face to face at the 12$^{th}$ Annual NTD conference in Nairobi, Kenya, 2) by email 3) or by a telephone call to book an appointment. Once they agreed to participate, the interviews were carried out face-to-face in their premises or any other neutral venue of their choice. An interview guide listing all the topics and issues of interest for the interviews was used, and subtle probes were applied to get detailed information (Appendix B). The interviews were carried out in either English/Swahili and lasted between 30 and 90 minutes. The interviews were concluded when no new information or themes emerged from the discussions (saturation). Field notes were taken to supplement the audio recordings, and all voice data was transcribed verbatim.

### 3.5.2 Focus group discussions (FGDs)

A Focus Group Discussion (FGDs) involves a small group of people discussing an issue defined by the researcher. The researcher guides, monitors, and records the discussion. (Kitzinger, 1994; Morgan, 1998). Focus groups generate information on collective views and analyses the meanings that lie behind those views. In this study, FGDs were used to: first,

understand participants' perception of wellbeing, second, identify group norms, meanings and processes towards structural inequities and third, investigate if the community members feel a moral obligation towards control of NTDs and finally, evaluate if the communities affected by NTDs have access to interventions and what more needs to be done to enhance control efforts. Focus groups complement other data collection methods; in this case, they complemented KIIs. The standard size for an FGD is between 6 to 8 participants. For this study, each group had 7-8 participants (Table 3.7) recruited to avoid having a limited discussion and steer from the chaos and insufficient opportunities to contribute associated with larger groups. The flow of the questions was from general to specific and linked to the research objectives.

The discussants represented various demographic categories, for example, the youth (18-35 years), middle-aged (36-60 years), and the old age (60 and above years). The participants' were both male and female, and the discussions took place in a venue that was neutral, accessible, and free from distractions. The lengths of the discussions were 45-90 minutes, in general, four focus groups (Krueger, 1998), are considered adequate for a set of research questions. In this regard, the study carried out five sessional groups to address the research objectives.

Most of the focus group discussions were conducted in the national language of Swahili because the study populations were heterogeneous and some resided in peri-urban areas. A structured FGD guide provided a general overview of the topics during the discussions. The discussions revolved around the participants' responses, and subtle probing was used in some cases. All the voice data from the FGDs was captured on audio recorders. Field notes taken by the researcher supplemented the audio recordings, and all voice data was transcribed verbatim.

### 3.6 Socio-demographics of the study participants

**Table 3.6: Characteristics of key informants**

| **Name** | **Number recruited (total 21)** |
|---|---|
| **Role in the community** | |
| Policymaker | 12 |
| Community leader | 3 |
| Researcher | 3 |
| Non-Governmental organizations (NGO) | 3 |
| **Gender** | |
| Male | 16 |
| Female | 5 |
| **Age** | |
| 18-35 years | 6 |
| 35-60 years | 13 |
| Over 61 years | 2 |
| **Years of work** | |
| 1-5 years | 15 |
| 5-10 years | 6 |

**Table 3.7: A table showing the demography of the focus group participants**

| **Name** | **Number recruited (total 46)** |
|---|---|
| **Place of birth** | |
| Born in the community | 32 |
| Born outside the community | 14 |
| **Length of stay in the community** | |
| Less than 5 years | 10 |
| 5-10 years | 12 |
| More than 10 year | 24 |
| **Economic activities** | |
| Casual Laborer | 6 |
| Salaried workers in the county | 2 |
| Small scale farmers | 11 |
| Small business operator | 13 |
| Unemployed | 14 |
| **Gender** | |
| Female | 21 |
| Male | 25 |

**Table 3.8 A table showing the sampling and sample sizes for the qualitative data collection**

| Counties | Province | # of FGDs | # of KIs |
|---|---|---|---|
| Busia | Western | 1 | 2 |
| Kilifi | Coast | 2 | 5 |
| Kisumu | Nyanza | 1 | 4 |
| Nairobi | Nairobi | None | 5 |
| Turkana | Rift Valley | 1 | 5 |
| Total | | 5 | 21 |

### 3.7 Analytical methods

A total of 21 key informants' interviews and five focus groups were conducted using interview guides (Appendix B) to explore the link between NTDs, health, and wellbeing. The interviews were audio-recorded and transcribed verbatim (Creswell, 2007), and later the transcripts were highlighted in Microsoft word version 2010 to identify emerging themes through coding, both deductively and inductively to create a coding manual (Appendix C2). Deductive codes captured themes that corresponded with the interview questions, existing literature, and concepts, while inductive codes considered issues emerging from the transcripts. Two transcripts were independently coded for each data source, first by the researcher and secondly by an independent researcher to establish the inter-rater reliability. The aim was to determine at least a 70% agreement for each source as described by (Miles and Huberman, 1994). The agreed upon thematic codes were subsequently uploaded on Nvivo version 12 and applied to the transcripts.

### 3.8 Reflexivity and rigour in qualitative data collection

Qualitative studies calls for researchers to understand their positionality and remain reflexive when carrying out their research for a rigorous outcome. The reflexivity process involves researchers becoming aware of their connection to the research by examining the power dynamics that may be present between them and the study participants (Hay, 2016). As such, the process involves recognizing previous knowledge of the research area, perceptions and embodying emotions which may accompany the research process (Hay, 2016). In this case, the research was conducted in Kenya, my country of origin and upbringing. It is possible that my preconceived knowledge of the country may have potentially affected the research process and to minimize the effects of such biases, I relied on evidence from existing literature to formulate open-ended questions which allowed the participants to answer questions based on their perspective with no right or wrong answer; hence all the participants' voices were heard.

To achieve rigour in qualitative studies and ensure trust worthiness of the research findings as proposed by Lincoln and Guba, (1985), I examined the credibility, dependability, transferability and conformability of the research ideas (Baxter and Eyles, 1997; Lincoln and Guba, 1985). To achieve this, each step of the research process, for example, the research design, data collection and analysis was carefully implemented as outlined in the research proposal to ensure dependability of the result findings. The research also employed triangulation of methods consisting of FGDs and KIIs and two complementary theories (capability approach and political ecology of health) to ensure dependability and conformability of the findings. Also, the study results provide transferability of research findings to other similar contexts of SSA due to the social construction of the linkages between NTDs, health and wellbeing in Kenya. The research also minimized bias by adhering to the data collection schedules and refining the

interview guide. Additionally, there was accuracy of the transcription process and efficient coding of the themes to enhance the analysis and interpretation of the data by accurately capturing the respondents' thoughts and lived in experiences (Creswell, 2014; Lincoln and Guba, 1985; Miles and Huberman, 1994).

## 3.9 Chapter Summary

The chapter describes the research methods used in this dissertation which includes: the study context, ethical considerations, research design, data collection, analysis, and interpretation. The purpose of describing the study context is to geographically situate the research and provide the place-based characteristics that are relevant to this research. The qualitative research design applied in this research allows for the 'silenced voices' to be heard in the understanding of perceptions and meanings, around NTD, health, and wellbeing in marginalized populations living in Kenya. Moreover, the chapter uses verbatim transcripts to develop emerging themes and codes for the data using MS word and Nvivo software. Furthermore, the chapter describes the deductive and inductive analysis used for themes of interest to be captured as well as allow for new ones to emerge. The identified themes are summarized by frequency of mentions and the number of participants mentioning the themes. The results of the research are presented in the subsequent chapter.

# CHAPTER FOUR NTDS AND STRUCTURAL INEQUITIES

## 4.1 Introduction

The aim of this dissertation is to 1) identify the political, economic, social, and cultural impacts of NTDs on health and wellbeing; 2) to investigate the capacity of local communities to address the burden of NTDs; 3) to identify potential indicators for use in a Global Index of Wellbeing (GLOWING) that will capture the inequities represented by NTDs. This chapter presents the findings on the first objective, which identifies the link between NTDs and structural inequities. The analysis reveals several factors associated with NTD infection namely: a) political factors; b) economic, social and cultural factors; c) psychological factors; d) behavioral factors; e) environmental factors, housing, water, and sanitation. The chapter presents the summarized findings in tables. The factors that matter most to the participants as per the objective is based on the frequency of mentions (number of times an indicator is mentioned within the categories) and the number of participants mentioning the category on both groups (key informants and the FGDs). The chapter concludes with a summary of findings and key messages from the results.

### 4.1.1 Political factors

Whereas clustering of NTDs has made it relatively easier for intervention strategies to be carried out, there exist barriers to effective prevention, diagnosis, and curative services for NTDs in the form of political, economic and social-cultural interests. The table 4.1.1 lists the political factors that affect NTD programs in Kenya.

**Table 4.1.1: A table showing the political factors that affect NTDs in Kenya**

| **Political Factors** | **Key informants (KIIs) (n=21)** | | **Focus groups (n=5) Total participants (46)** | |
|---|---|---|---|---|
| | **# of Key informants** | **# of mentions** | **# of FGDs** | **# of mentions** |
| • Devolution<br>• Jobs | 8 | 12 | 3 | 18 |
| • Health workers strikes | 6 | 16 | 5 | 16 |
| • 'Political appointments' | 2 | 7 | N/M | 0 |
| • Lack of political goodwill | 8 | 27 | 2 | 9 |
| • Denial of NTDs | 2 | 5 | 1 | 6 |
| • No budgetary allocations | 7 | 40 | 1 | 4 |
| • Other initiatives vs. NTDs | 4 | 6 | 1 | 3 |
| • 'Politicize essential resources | 1 | 2 | 3 | 3 |
| • Political tensions, violence and skirmishes | 3 | 7 | 3 | 5 |
| • Border tensions and conflicts | 3 | 12 | 1 | 3 |

The most frequently mentioned political factors among the key informants included: lack of budgetary allocations to address and implement NTD control strategies at the county level, lack of political will from the central government and the counties, and frequent health workers strikes (Table 4.1.1). On the other hand, the FGDs participants mention that devolution is a means by which residents have been able to access jobs but as mentioned by the key informants, the community members felt that the county governments have frustrated health workers leading to frequent strikes that interrupt provision of medical services in the hospitals. This is partly because devolution is a new and ongoing concept that involves the decentralization of government services with the aim of improving accessibility and job creation as mentioned by the respondents' below:

> *'When it comes to formal employment, devolution has supported the counties. It's after devolution that most of the employment opportunities have been made available to the locals'* (Jacklyn, female 40 years, **FGD**).

> *'Since devolution, there has been employment several health workers have been recruited, and therefore we have a good number of health care workers'* (Richard, male 38 years, **KI**).

> *'First of all, I would say that the devolution is still ongoing, the process is not yet complete. A number of times the nurses have been on strike, doctors have been on strike the clinical officers, the technicians and whenever there are strikes enrollment just crashes. No one is coming to the hospital'* (Mary, female 30 years, **KI**).

The key informants also mentioned that devolution led to the premature transfer of health services from the national government to the county government, leaving all health decisions to be made by 'political appointees' (Table 4.1.1) without appropriate training. This factor was not mentioned (N/M) by the FGs. This key informant had this to say:

> *'You find that when something comes from the assembly a technical person may give the direction but with them ('political appointees')they will come up with the final decision which suits them, so that's why you will find that most of the NTDs are not addressed because you know politicians are lay people they want to see something come out as an outbreak that's when they know a problem'* (Peter, male 34 years**, KI**).

This kind of arrangement creates an avenue for NTDs to spread due to lack of political goodwill (Table 4.1.1) as supported by the respondent from the FGDs:

> *'There is a lot of laxity from the government. They keep asking us back and forth our health concerns without any action, so for me I see that there is a lack of seriousness even in terms of follow up for these diseases [NTDs]'* (Fatuma, female 30 years, **FGD**).

The key informant added:

> *'Most of the times, there are no funds allocated just as the name suggests, these are neglected tropical diseases. So with the politician if you tell them that this is a neglected disease, they will tell you, do you want me to initiate the program if the Ministry itself has called it neglected?'* (John, male 32 years, **KI**).

Another respondent added:

> *'Lack of political will. If the members of parliament are not interested or they lack awareness of how the disease is spread they will not talk about it in their meetings. And if they do not discuss it in their meetings, who else will share that information? No resource allocation because it is at their discretion. If they understand what an NTD is, it is them to mobilize and tell people at meetings that look here, this requires attention, and we need to allocate money. So lack of political will among the politician has fuelled the spread of NTDs in our community'* (Alan, male 42 years, **KI**).

Additionally, both the FGDs participants and the KI mention that some political leaders deny (Table 4.1.1) the presence of NTDs in their area because they do not want their areas to be associated with diseases of poverty, which creates stumbling blocks for research and interventions as observed by this respondent:

> *'Most politicians would not want their areas to be known to have jiggers because more or less you're exposing them that they are not doing much'* (John, male 34 years, **FGD**).

Moreover, many of the county governments have little or no budgetary allocations for NTD programs and have also failed to own donor-funded NTD intervention activity which has created a low priority for NTDs as mentioned in Table 4.1.1.

> *'The government has failed to allocate funds for NTD public health campaigns so the public awareness of the disease is very low. If these diseases remain neglected then chances of an outbreak are very possible'* (Sarah, female 36 years, **KI**).

Other political barriers include politicians preferring to implement certain initiatives (Table 4.1.1) over pressing NTD interventions, for example, constructing health facilities as opposed to performing facial cleanliness and environmental sanitation (F&E):

> *'So there is prioritization of resources at county level, most politicians would want to support programs or projects like the physically constructing health dispensaries, and during the next campaign, they will say you see Am behind this project. So they despise non-tangible issues like F& E' [facial cleanliness and environmental sanitation]* (Kanji, male 24 years, **KI**).

Furthermore, politicians tend to 'politicize' essential resources, for example, water in dry habitats. In such contexts, water is used as a weapon to entice or punish voters which leads to low political engagement, marginalization, and spread of infectious diseases.

> *'You know water here is a precious commodity. And most NGOs [non-governmental organizations] when they came in, they dug shallow wells, they assigned the shallow wells to certain individuals. The community itself appointed the chairman, the treasurer, and the secretary of the water users association. They formed the water users association so that they can take care of this water…water politics. So you find that this water point is accruing a lot of money at the same time it is also earning the interest of the politician. So during campaigns, it is used as a tool to punish those who do not vote for so and so'* (Pamela, female 44 years, **FGD**).

Other challenges, such as political tensions, skirmishes, and violence (Table 4.1.1) during the general elections, interfere with NTD activities, especially in hotspot areas such as western Kenya.

*'We live in an opposition strong-hold and, I would say politics really affects our activities. We just came from the general elections in August that was nullified and we had repeat presidential election- that's affected our activities, and I recall when the politicians even called for demonstrations against the independent electoral boundaries commission, we saw protests that were not really peaceful and people went into barricading roads, that means even if you were to drive to go out to reach out to the communities, that was not going to be possible, so we had to cancel most of our activities, especially during those political demonstrations. Even during campaigns many people want to go and attend those political rallies and to some extent it really affected our work, especially now when it turned out to be violent protest, of course, we take safety and security of our staff, our assets are very important so actually had to go slow during those events'* (Jeff, male 42 years. **KI**).

In counties that border neighbouring countries, for example, Turkana, tension, conflict, and insecurity are quite common, and this hampers NTD control efforts:

*'Let me say that when there is politics and when there is war, people tend to move. Let me say when we have tension like the recent politics, people tend to move with their animals towards the border. And within the borders, that's where people have no health facilities. That's where we have a lot of bushes which bring Kalazar [visceral leishmaniasis]. You understand what I mean, we have the anthills, we have bushes, and anyone suffering from Kalazar is not able to access the drugs and management. When it comes to hydatid…. open defecation, there are no toilets around the border* (Lawrence, male 32 years, **KI**).

*'We migrate as far as Ethiopia due to tension and conflict, we become a population that cannot access a health facility and we really suffer from many diseases especially Kalazar [NTD]'* (Kamara, male 40 years, **FGD**).

### 4.1.2 Economic factors

The focus group respondents engage in various economic activities to earn a living, and this includes running small businesses such as fish and milk vending, palm wine tapping, charcoal burning, and motorbike operation. Additionally, others practice small scale farming and pastoralism; casual labor in irrigation and fishing sectors; salaried work at the county governments, and the rest are unemployed (Table 3.7). The economic impacts of NTDs are diverse, and both the Key informants and the FG discussants mention that NTDs affect economic productivity and capacity to earn an income leaving the infected persons with little or no money to access health, education and other opportunities (Table 4.1.2).

**Table 4.1.2. A table showing the economic, social and cultural factors of NTD infection in Kenya**

| **Economic Factors** | **Key informants (n=21)** | | **Focus groups (n=5) Total participants (46)** | |
|---|---|---|---|---|
| | **# of Key informants** | **# of mentions** | **# of FGDs** | **# of mentions** |
| • Affect economic productivity | 21 | 57 | 5 | 80 |
| • Little or no income | 4 | 42 | 5 | 74 |
| • Lack of economic opportunity | 7 | 15 | 5 | 31 |
| • Loss of National revenue | 1 | 1 | 1 | 1 |
| **Social Factors**<br>• Marginalization in social affairs | 7 | 60 | 4 | 5 |
| • Low levels of literacy | 20 | 72 | 5 | 43 |
| • School absenteeism | 7 | 57 | 3 | 8 |
| • School dropouts | 4 | 12 | 3 | 10 |

| | | | | |
|---|---|---|---|---|
| • Gender specific exposures | 2 | 3 | 1 | 2 |
| • Desertion | 5 | 17 | 4 | 21 |
| • Poor advocacy | 6 | 26 | 2 | 15 |
| • Domestic and marital conflict | 3 | 14 | 5 | 12 |
| **Cultural Factors**<br>• Cultural norms and practices | 7 | 29 | 3 | 1 |
| • Curses | 2 | 5 | 2 | 4 |

The key informants and the FG discussants had this to say regarding economic productivity and income:

> *'The economic activity in the place where I work is mainly quarrying. So just focus on somebody whose fingers have been chopped because of leprosy. That person would not earn anything because of that disability. Somebody suffering from jigger infestation; he cannot work in a mining area because it is a manual work that would require this person to use his hands to get the daily bread. So that has an impact on the economy. So if that person has a family and is the one who is expected to go and work and he himself is suffering, the family is also suffering, and they become dependent on other family members. So it becomes a burden to other family members'* (James, male 28 years, **KI**).

Another respondent added:

> *'This disease affects us because of lack of money. When you are sick and do not have money at all, you can't take care of yourself at all. Hospitals are there but you can't go to hospital, so you are affected. Your economic activity becomes limited, and your earnings also decrease, and you can't work at all. That is what affects us. In this economy, if you do not have money you can't support yourself. You can't have an earning because you are sick'* (Halima, female 29 years, **FGD**).

A key informant observed the economic impact of NTDs at a national level:

> *'NTDs interfere with the people's output so at the individual level there's a huge impact on the economic productivity at a community level it's even bigger. It's a much bigger impact, we are estimating that annually we are losing about 200 billion Kenyan shillings every year to NTDs and that's a very conservative estimate as a country. Of course, there's a big impact on productivity, they also have a big impact in terms of bills incurred in treatment, so generally, there's a big dent that the NTDs are having on the economic situation. Not just at individual but also at a community level'* (Simon, male 40 years. **KI**).

Individuals suffering from disabling NTDs such as leprosy are heavily discriminated against because of their wounds and disfigured limbs, if they are involved in any form of economic opportunity, it is bound to be unsuccessful because prospective customers perceive their physical state as infectious:

> *'You know even if she wanted to sit in a 'kibanda'- [in a kiosk] or maybe be a fishmonger, people would not buy the fish because of the condition of the fingers even the ones with the jiggers. When one is down with it, they are not able to be productive in the community'* (Simon, male 40 years, **KI**).

NTD infections also lead to loss of jobs and incapacitation which translates to little or no income as mentioned by the hydrocele patient below:

> *'As for me, this disease has really incapacitated me. I can't walk; I can't farm, because of the disease. When I go to the hospital to be admitted they want KShs 10,000. The way you look at me, can I afford that amount'* (Jack, male 25 years, **FGD**).

Policymakers acknowledged that zoonotic NTDs such as rabies have severe effects which go beyond loss of income but they are not taken as trade sensitive hence they are neglected.

> *'Rabies is never going to be the top of the list, the reason being it's not a trade- sensitive disease. Among livestock you've got diseases like foot and mouth disease which means a lot to traders, so in a way it's neglected where the sources is…which is among animals and it's neglected where it has the greatest impact among humans* (Tom, male 41 years, **KI**).

### 4.1.3 Social factors

The social factors were explored in terms of family and community support; participation in social gatherings such as Baraza's (chiefs' meetings), church activities, volunteer activities, 'merry go rounds' and women groups. The results indicate that people infected with NTDs are unable to take part in communal events due to poverty, shame, and information distortion, which makes them marginalized in social affairs (Table 4.1.2), which was majorly mentioned by the KIs:

> *'Those infested with jiggers are peasant farmers and they're poverty-stricken families or communities, and are more or less neglected in social affairs, the current social affairs'* (Stella, female 27 years, **KI**).

Suppose the infected individuals have information on the communal gathering at hand, the physical challenges associated with the disease makes it difficult for them to attend and participate:

> *'Am not able to participate socially because my legs are swollen'* (Amina, female 54 years, **FGD**).

Even if they attend communal gatherings, they are not able to concentrate:

> *'When you participate in social gatherings, once the jigger starts to bite or itch while you are in the social gathering, you forget about the social gathering'* (Joyce, female 28 years, **FGD**).

Both the KI and the FG discussants agree that NTDs thrive in areas which have low levels of literacy which leads to ignorance as this Key informant mentioned:

> *'I think it's the lack of understanding of the means of transmission or the pre-disposing factors on how you acquire these diseases, because families are hiding cases of NTDs and not bringing them out so they are not getting solutions'* (Ken, male 42 years, **KI**).

The FG discussants mentioned that:

> *'In Turkana literacy level is a bit low. Once you are seen with Kalazar people think its HIV, you tend to be isolated'* (Selina, female 44 years, **FGD**).

Similarly, this respondent had this to say regarding transmission of chikungunya:

> *'The disease, I heard that it was in Rwanda from the news. It was in Rwanda then it was in Mombasa, but I was not aware how this disease is, till I got infected. The other day, I told people that I having Chikungunya and when I went to class everybody was like, do not give us Chikungunya. So I thought it was something like when you sit with someone you infect them'* (Janet, female 25 years, **FGD**).

In children, most of the KI mentioned that NTD infection leads to school absenteeism, dropouts, and increases the illiteracy rates (Table 4.1.2) as mentioned by this respondent:

*'I know what we look at greatly is school attendance. Two, you might have attendance, but you do not have the other bit of school attendance which is concentration in class. And the third would be cognitive development and being able to learn. I think that because of malnutrition and the growth of the worms, it impairs even the mental acuteness of the child and the child is not able to learn at a fast pace which delays their schooling*' (Caleb, male 36 years, **KI)**.

This FG participant mentioned:

*'My daughter has been absent from school for many days, she has jiggers and I think her nutritional status is deteriorating. She is very pale'* (Mary, female 38 years, **FGD**).

There are certain NTDs that are common in specific genders due to assigned gender roles in the community for example, among the Turkana community, women perform core duties compared to men for instance, they build houses, care for the home and rear animals among other tasks hence they are occupationally exposed to vectors such as sandflies which transmit visceral leishmaniasis (Kalazar). Similarly, women suffer from trachoma and hydatid cysts compared to men because they are in close contact with the vectors and parasites when they are executing their daily tasks.

*'Women in Turkana are at risk of more infections compared to other people mainly because of our duties. We are the ones who care for the children so in the process of caring for the children in a place that has scarcity of water; you find that, we are caring for our children in poor sanitation. So with the poor sanitation, we do not wash our hands so we contract diseases like trachoma'* (Anne, female 34 years, **FGD**).

Likewise, women lack access to health care services at their convenience due to time constraints, and they may also be required to seek permission from their husbands before accessing treatment or even taking part in communal NTD interventions within their locality as this respondent mentioned:

*'Sometimes your husband will say, 'no, you cannot be able to attend the clinic and that is the only day there is outreach in the community. So you have to wait for another time, and the disease progresses, the scarring of the tissues of the eye progresses until now it gets to the cornea and cannot be reverse, so you see there's that effect of the gender relations, the perceptions. Over time we have tried to come up with ways of including gender into our*

*programming. We were able to do a gender assessment in Baringo which we are now replicating in Turkana. And the issues that we got were around gender and trachoma and we are now just this sharing information with the case finders at the community level'* (Vanessa, female 33years, **KI**).

Additionally, NTDs such as Kalazar and hydrocele are common among men because of occupational and behavioural hazards. For example, the sandfly which resides in open spaces and transmits Kalazar will bite young boys when they go out to graze animals, while lymphatic filariasis which is transmitted by the Anopheles mosquito will mostly bite men who practice outdoor palm wine drinking in the evening hours. This FG discussant added:

*'Men spend their evenings outdoors drinking palm wine and that is where they are bitten by the mosquitoes. Also, when it comes to jigger infestation, the children get in while playing in the fields while the elderly men get in the drinking dens ' (*Juma, male 29 years, **FGD***).*

Similarly, social challenges associated with NTD infection include desertion, poor advocacy from the affected groups due to stigmatization and marginalization, domestic and marital conflict leading to divorce, abandonment, and collapse of the family structure:

*'These diseases have a lot of challenges because when they have not infected you, you will have friends. But the moment you get the disease, the friends will be few. This is because any time you are with them, you will be borrowing money to go to the hospital because you are now poor. Secondly, if you do not have the disease, and you have a wife, and you are not unfaithful to her then your wife has no stress but the moment you get sick, even your wife will start thinking you are a burden because you can't work and she will initiate other domestic problems in the household (sexual relations), so she goes away'* (Peter, male 27 years, **FGD**).

*'When a kid is bitten by a snake, they get maimed. The kid who is in school will be stigmatized just like a person having HIV. There is stigma in snakebites when you are bitten and maimed'* (Geoffrey, male, 37 years, **KI**).

*'I can say there is discrimination, because when I say am unwell, people do not take it serious when I say I need money to go to hospital. They take it lightly. I can't work and this forces me to stay home even for a whole month. But they do not take it serious so I see a lot of discrimination'* (Aisha, female 37 years, **FGD)**.

Another respondent added:

> *'These diseases really affect us even when you look at the domestic relations it is really affected because it slows down and this interferes with the marriage'* (Grace, female 22 years, **FGD**).

Another respondent affirmed that:

> *'My wife is not here. She went away to her home because I do not have the sexual urge at all'* (Andrew, male 40years, **FGD***).*

Interestingly, this respondent noted that women are more compassionate when men are infected with NTDs and not the other way round:

> *'In the community where I'm working, if a man is affected and infected, the woman has more passion and sympathy. But when it comes to a woman, men in many cases, they don't care. They leave the house and come back late. Women tend to have more sympathy than men. So if the NTD affects a woman, the woman suffers more'* (Brian, male 43 years, **KI**).

### 4.1.4 Cultural factors

The cultural factors that influence NTD transmission include norms and practices (Table 4.1.2) prohibiting the consumption of certain foods such as fish, eggs, and chicken in women and children, which lead to malnutrition. Malnutrition compromises the body's immunity to fight diseases and also makes it hard to carry out surgical interventions for NTDs such as visceral leishmaniasis (Kalazar).

> *'If the patient is anemic, it may take 2 days for their iron levels to pick up through blood transfusion. If the patients are malnourished it takes more time for them to be fed so they can recover. Otherwise if you have kalazar and all your health vitals are optimum, surgery and treatment is immediate, we don't wait' (Walter, male 52 years,* ***KI****).*

> *'In small children, their immunity is low, if they suffer from diseases like kalazar, they may die, if they are malnourished' (Florence, female 38 years,* ***FGD****).*

Furthermore, particular norms prohibit handwashing practices after eating foods such as meat which leads to susceptibility and infection with other diseases:

> *'You find that most of them, the issue of hand washing is not so much they say if you eat meat, it means you are a rich person. So after eating meat, you should just move around with that smell, people should know that you have eaten meat. So the issue of washing hands is not a priority'* (Helen, female 54 years, **KI**).

Among the pastoralists, cultural practices such as drinking fermented raw milk are risk factors for acquiring brucellosis (Table 1.3), which is a zoonotic NTD:

> *'Pastoralists have their old cultural practices that allow them to drink for instance fermented milk or just milk straight from the animal, from the camels or from the cows. And that increases the likelihood of transmission of brucellosis' (Tom, male, 41 years, **KI**).*

While certain communities consider NTDs such as jiggers and leprosy to be hereditary:

> *'A jigger is considered to be hereditary in that, if you are talking to those that are infested they will tell you that their parents have jiggers, the grandparents had jiggers, and the children and grandchildren have jiggers'* (John, male 32years, **KI**).

> *'My mother had leprosy, I have leprosy, so it's like I inherited it. My uncle also had the same case of leprosy'* (Sara, female 49 years, **FGD**).

Cultural norms also prohibit the sharing of toilets among in-laws and promote open defecation practices which are risk factors for schistosomiasis and STHs:

> *'Some things are very interesting. I went to Narok one time and we were making efforts to encourage communities to construct latrines and use, not only construct but make use of latrines. Ok, there are certain beliefs that hinder common use of the latrines like father and father-in-law cannot share a toilet with a daughter-in-law, similarly, a mother-in-law cannot share the same toilet with a son-in-law'* (Florence, female 38 years, **KI**).

*'Due to lack of latrine use, you'll find open defecation points. When digging wells you will find that shallow wells are already contaminated by feces and it increases the spread of the diseases'* (Joseph, male 37 years, **FGD**).

Additionally, cultural practices promote open defecation because latrines are equated to houses; hence using a latrine is an abuse of shelter. Also, there is the perception that using latrines depicts selfishness; meaning-denying pets their food as mentioned below:

*'Some believe that it's a house, it's abusing a house, a structure that looks like a house. You go and abuse it and even why they practice open defecation they say that if you bury your feces, you are depicting selfishness of the highest order by denying pets their food'* (Benjamin, male 50 years, **KI**).

Furthermore, others believe open defecation adds value to the soil and provides you with fresh air to breathe when relieving yourself:

*'We realized the rates of open defecation to be very high. We established that most of the community members because of the culture, they say when they go out to the land to defecate, they are adding value to the soil and getting free air to breath, which you cannot do in a latrine, so because of such beliefs you find that even in the households you walk over there, you find that they don't have a latrine' (*Vallary, female 35 years, **KI**).

An NTD such as leprosy is regarded as a curse (Table 4.1.2) in certain communities as this respondent mentioned:

*'It is believed that leprosy is a curse, so people delay seeking medical intervention; why do we go to hospital and it is a curse?'* (James, male 28 years, **FGD**).

*'For example, they believe that when someone has cultivated the farm and someone steals from the farm, they will get infected with the disease [leprosy] and you become cursed. You can't go to the hospital because it is a curse, you have to take a red and black hen to the owner and do a ritual with water'* (Makau, male 50 years, **KI**).

This KI had this to say regarding snake bites:

*'If you are bitten by a snake in the community, you are cursed; people just stop engaging with you even if they were your friends* (Geoffrey, male, 37 years, **KI**).

### 4.1.5 Psychological factors

The mentioned psychological impacts of NTDs include mistreatment, embarrassment, destitution, ridicule, dependence on other people/ incapacitation, and neglect (Table 4.1.3). The most mentioned psychological factors among the KI was destitution and neglect. The common factor that was mentioned by the FG was dependability and ridicule (Table 4.1.3). The commonly mentioned behavioural factor in both the KI and FGD was twilight discos.

**Table 4.1.3: A table showing the psychological and behavioural factors of NTD infection in Kenya**

| **Psychological factors** | **Key informants (n=21)** | | **Focus groups (n=5) Total participants (46)** | |
|---|---|---|---|---|
| | **# of Key informants** | **# of mentions** | **# of FGDs** | **# of mentions** |
| • Mistreatment | 1 | 4 | 1 | 1 |
| • Embarrassment | 4 | 4 | 2 | 3 |
| • Destitution | 7 | 9 | 2 | 7 |
| • Ridicule | 6 | 8 | 5 | 6 |
| • Dependence on other people Incapacitation | 5 | 7 | 5 | 10 |
| • Neglect(intentional/unintentional) | 7 | 10 | 3 | 9 |
| **Behavioural factors** • Twilight discos (disco matanga) | 6 | 23 | 1 | 5 |
| • Cultural dances like Edong'a | 3 | 10 | 1 | 1 |
| • Communal celebrations( topetoron) | 1 | 3 | N/M | 0 |
| • Traditional healers | 4 | 11 | 1 | 1 |
| • Occupational activities | 8 | 17 | 4 | 9 |
| • Household habits | 4 | 13 | 3 | 12 |
| • Poor investment in domestic animals | 2 | 5 | N/M | 0 |
| • Nomadic/pastoralists lifestyle | 5 | 8 | 1 | 2 |
| • Leisure activities | 2 | 4 | 1 | 2 |

The psychological impacts of NTDs often stem from a community's perception of the cause of the NTD which results to neglect (Table 4.1.3) and interferes with health-seeking behaviour as noted by the respondents below:

> *'With the soil-transmitted helminths, you find that the most who are infected are children. If a child is infested with STH, you find that the stomach will be protruding. Unfortunately, most of our communities cannot relate that to worms. The community will say that this child was bewitched or maybe the mother came with the child so maybe the other side of the child's family are doing something to make the child suffer. There's a lot of neglect and most children die, because of the minimal health attention'*(Catherine, female 38 years, **KI**).

> *'In our tradition, we women tend to blame it on the men; we say that men who have hydrocele get the disease because they have multiple female partners. We tend to dismiss the real reason why the disease is a problem. We don't consider the disease as vector infectious disease and that contributes to the disease burden'* (Salome, female 46 years **FGD**).

Other respondents noted that children were ridiculed (Table 4.1.3):

> *'When it comes to the jigger, the Tungiasis itself you find that most of these children are hidden when there are visitors around. Some are ridiculed, neglected and not allowed to eat with the people'* (John, male 32 years, **KI**).

> *'There is ridicule and discrimination by their peers even in the family set up. They are discriminated especially during meal times because when food is put together. No one wants to share a plate with them'* (Eva, Female 28 years, **FGD**).

The neglect of individuals infected with NTDs can also be unintentional. Unintentional neglect occurs when an infected person is left alone in the household as other family members go out to earn an income. As mentioned below:

> *'When it comes to jigger infestation, this time, it is a bit different because the person who is supposed to take care of the person with jiggers may have gone to tend to other activities or get daily bread. When they come back, they are too busy trying to prepare meals for the person, so the infestation of jiggers increases because of no medical attention. So sometimes a person may think that the person is left alone is discriminated. But again it is a matter of the household chores that makes this person not have time to look after the sick person'* (Juma, male 36 years, **KI**).

*'You have to stay at home when you have jiggers or even hydrocele, as others go and do work that you can't manage and you are not able to participate in anything'* (Hamisi, male 43 years, **FGD***).*

Persons infected with NTDs are forced to depend (Table 4.1.3) on other people for support in the family or in the community as mentioned by the respondents below:

*'If a person has NTD, he himself is suffering, the family is also suffering and they become dependent on other family members. So it becomes a burden to other family members'* (James, male 28 years, **KI**).

*'If a person becomes blind they will suffer a lot of stigma and discrimination both from the family level and even the community and having lost their ability to fend for themselves or take care of themselves, they have to depend on somebody else and it psychologically affects them'(*Brian, male 50 years, **KI**).

*'Am old and I have leprosy, I depend on other people for everything, Am not able to do anything for myself'* (Mercy, female 60 years, **FGD**).

### 4.1.6 Behavioural factors

The most mentioned behavioural factors by the KI was nightime activities such as twilight discos (disco matanga) and cultural dances like Edong'a (Turkana dance). The two practices happen outdoors at night when the vector biting habits are at their peak. During Edong'a dance, residents sit on anthills to watch dancers or take a break from dancing unaware that sandflies are active at that time of the evening; hence, they get bitten and infected:

*'There's this oneness that the community has, so like at night they have this dance they call it Edong'a. When they are busy with their dance or sitting on those anthills, they are not aware that sandflies are active between 6 in the evening that's the time when they are active. They are busy dancing and doing all these things so it pre-disposes them more'* (Leonard, male 31years, **KI**).

'*We practice our cultural values to strengthen our communal bonds, we have the night time dance, Edong'a and because it is dark, you can be bitten by the sand fly and you do not notice'* (Jemimah, female 37 years, **FGD**).

Regarding the twilight disco, another KI responded,

*'We have disco matanga when a person has passed on, men and women tend to take time to sleep outside. You do not ask for a mosquito net when we have a disco matanga and this disco matanga, it is done in preparation to receive a body for burial. So people take more time outside, to sleep outside without even thinking about how to protect themselves. So that behaviour of attending disco matanga, the other behavior of men staying in a drinking den for many hours that predispose them to infections, especially for the hydrocele and the elephantiasis'* (Allan, male 30 years, **KI**).

*'During funerals, most of the activities are outdoors and that is how you get mosquito bites for hydrocele and elephantiasis'* (Juma, male 27 years, **FGD**).

The KI also mentioned communal celebrations such as 'topetoron' among the Turkana community. During the ceremony, an animal is slaughtered and cooked to feed the community, and this can lead to consumption of improperly cooked meat which is a risk factor for hydatid disease.

*'NTDs could be caused by the lifestyle, which is the way of life. There are usually a lot of celebrations in Turkana and whenever there are celebrations we have the foods being prepared. We have the famous "topetoron" whereby the goat is roasted whole. And in such circumstances it may not cook properly and it is the main avenue for the spread of hydatid cysts'* (Jane, female 45 years, **KI**).

However, Topetoron was not mentioned among the FGDs. Another factor that was highly mentioned by KIs was the habit of visiting traditional healers before going to a health facility especially in the case of snake bites and visceral leishmaniasis but this factor was hardly mentioned in the FGDs. As such, this KI had this to say regarding children suffering from leishmaniasis:

*'In the management of leishmaniasis what I know is that in some communities and families they are very much aware of the disease and how it can be managed. They tend to go to the traditional healers to seek for help and as you know, most of those traditional healers are also looking for money. They will not tell you the truth that they will not be able to manage this; they will start managing you and once they are unable, that's the time that you realize that you need to take this child or these kids to the nearest hospital'* (Judy, female 26 years, **KI**).

The respondent further added:

*'Unfortunately someone may go to several healers, and by the time you realize that the healers are not healing you, it is very late. So by the time you go to the formal hospital, you may be at a very advanced stage, and even if you are given the drugs you may not end up getting healed. When you see marks on the body, those are signs that the patient has been taken to a traditional healer* (Judy, female 26 years, **KI**).

*Most of these communities visit traditional healers, where I work, if you are bitten by a snake, they will take you to a traditional healer who has their ways of removing the poison* (Geoffrey, male, 37 years, **KI**).

The KIs and the FG participants also mentioned that occupational activities (Table 4.1.3) such as fishing, irrigation, and car washing as well as daily tasks such as bathing and washing utensils in infected waters are risk factors for the spread of schistosomiasis.

*'You see, bilharzia (schistosomiasis) is brought by occupational hazards such as fishing and irrigation'* (John, male 47years, **FGD**).

Similar activities such as grazing animals and collecting firewood in forested areas predispose populations to sandfly and snake bites which spread leishmaniasis and kill respectively.

*'The pastoralists, send their children especially young boys to graze their animals in forested areas and this is where the sandfly breed too, so they end up being infected'* (Washington male 60 years, **KI**).

Additionally, rearing animals such as pigs close to humans are risk factors for acquiring for jiggers as observed below:

> *'If you take a look at the lifecycle of a flea or the Tunga penetrans it spends its lifecycle in animals. If human beings are in close proximity with animals, you find that those animals will urinate there, they defecate there and that is fertile ground for the Jiggers'* (John, male, 32 years, **KI**).

The transmission of NTDs such as dengue and chikungunya are dependent on behaviours that provide optimum breeding grounds for the mosquito. Household practices (Table 4.1.3) such as storing water in open containers, placing aesthetics items such as flower pots around the home; dumping wastes and accumulation of old tires around the neighbourhood provide ambient conditions for the vector:

> *'Just to mention that we put things like flower pots in and around our houses and have blocked rainfall water gutters which accumulate water and you wonder, where do mosquitos come from? Most of the things we do as human beings are breeding grounds. You have seen the dumpsites? It's more of human activities than anything else. In a place like Kondele, someone buys old tires and keeps so many like a hundred or so in his compound. So when it rains these tires accumulate water and when you go in there you find there's a lot of breeding'* (Brian, male 39 years, **FGD**).

Another behavioural factor that was mentioned solely by the KIs was poor investment in vaccinations for domestic animals which promotes NTDs like rabies as noted by this respondent:

> *'This is not limited to rural areas- people do keep dogs for various reasons. They keep dogs for security, for fun, others herd with them. I think the practice which is not cultural is the perception that there should not be much investment into your dog. We have an existing vaccine for dogs; people should vaccinate their dogs'* (Tom, male 41 years, **KI**).

The nomadic/pastoralists lifestyle was mentioned by the KIs but hardly with the FGDs. The lifestyle involves frequent migration in search of water and pasture which plays a role in NTD transmission. Due to the constant movement of people, it is challenging to construct permanent structures; hence there is limited, or no availability of WASH facilities for such groups and this encourages open defecation and contributes to poor environmental sanitation:

> *'Because they are nomadic in nature they practice a lot of open defecation. Human feces are all over in the bushes, around the homesteads, around the animal sheds, so it attracts a lot of flies that spread trachoma'* (Evans, male 50 years, **KI**).

The nomadic lifestyle also makes it challenging to provide NTD interventions because the population of interest is always on the move. Pastoralists keep numerous animals as a sign of wealth, and to protect their animals (wealth) they build houses around the animal pens, such designs encourage the breeding of flies which transmit trachoma:

> *'For instance, among the Maasai, you will find that they build households in a circle and at the centre is the animal shed which could be housing 3,000 heads of cattle. So you can imagine how many flies are there, especially after some rain there are millions of flies. Flies are the main transmitters of trachoma from person to person'* (Evans, male 50 years, **KI**).

Furthermore, the nomadic communities believe numerous flies landing on the face signifies riches, and it becomes difficult to prevent trachoma among people who hold this belief:

> *' The behavior of the pastoralists communities where trachoma and leishmaniasis are prevalent is strange. Flies transmit trachoma, but they think that if you chase flies that land on the face, you are chasing away your riches. They also believe in the physical removal eyelashes that have inverted and are causing damage to the cornea, to them it is a big thing to have a grandchild remove them. You know these are things that are causing sickness, but they are highly celebrated in such communities'* (Evans, male 50 years, **KI**).

The other mentioned behavioural factors in both KI and FGs are leisure activities (Table 4.1.3) such as children playing in the bushes which provides an environment for the sandfly to bite and transmit visceral leishmaniasis; equally walking bare feet in both children and adults are risk factors for jiggers and STHs infection.

### 4.1.7 Environmental factors, water, sanitation and housing

The KIs and FGs mentioned that NTD transmission is dependent on a host of environmental conditions such as hot, warm or dry climatic conditions, drought, dust, pollution, soil texture, and filth (Table 4.1.4). For example, warm soils provide an ambient environment for ova and cysts to incubate before transmission to the host; garbage offers a unique habitat for jigger transmission. Additionally, high temperatures, vegetation, and rainfall provide a habitat that favours the development of mosquitoes which transmit LF, dengue, and chikungunya.

**Table 4.1.4: A table showing environmental, water, sanitation and housing factors in NTD infection in Kenya**

| **Environmental factors** | **Key informants (n=21)** | | **Focus groups (n=5) Total participants (46)** | |
|---|---|---|---|---|
| | **# of Key informants** | **# of mentions** | **# of FGDs** | **# of mentions** |
| • Climatic conditions, rainfall, vegetation, soil structure and texture | 4 | 7 | 4 | 17 |
| • Garbage/filth | 2 | 5 | 3 | 14 |
| • Human-wildlife conflict | 1 | 5 | N/M | 0 |
| • Harsh terrain | 3 | 3 | 2 | 3 |
| **Water sources**<br>• Boreholes | 7 | 16 | 2 | 12 |
| • Lakes | 4 | 10 | 2 | 2 |
| • Dams | 4 | 4 | 4 | 7 |
| • Rivers | 6 | 7 | 5 | 28 |
| • Streams | 5 | 2 | 5 | 32 |
| • Earth pans | 3 | 2 | 3 | 21 |
| • Springs | 2 | 2 | 3 | 15 |
| • Rainwater | 1 | 5 | 1 | 4 |
| • Piped water | 1 | 6 | 2 | 8 |
| • ‘Leak it in’ or ‘tippy-tap’ | 4 | 1 | 3 | 17 |

| | | | | |
|---|---|---|---|---|
| **Challenges**<br>• Water rationing | 2 | 4 | 1 | 3 |
| • Water table | 3 | 5 | 1 | 2 |
| • Water quality | 4 | 10 | 5 | 30 |
| **Sanitation facilities**<br>• Toilets | 2 | 12 | 4 | 18 |
| • Latrines | 5 | 17 | 5 | 12 |
| • Open defecation | 7 | 21 | 5 | 23 |
| **Challenges**<br>• Open defecation | 3 | 29 | 5 | 40 |
| • Poor refuse collection and management | 1 | 3 | 1 | 2 |
| • Terrain | 2 | 2 | 1 | 1 |
| • Soil structure | 2 | 2 | 3 | 2 |
| **Housing status**<br>• Indecent | 4 | 17 | 5 | 29 |
| • Semi-permanent structures | 5 | 12 | 5 | 11 |
| • Poor lighting and ventilation. | 2 | 5 | 5 | 8 |

The KI mentioned climatic conditions in regards to the spread of dengue and chikungunya:

> *'Rainfall is an important cause; if there's a lot of water accumulating here and there it directly enhances breeding. The higher the temperature, the faster the mosquito goes through the development stage so we have an explosion of the mosquito population which can increase the risk of transmission if the virus is circulating within the community'* (Brian, male 50 years, **KI**).

This FG discussant had this to say:

> *'Kilifi is along the beach, we have pockets where water collects which enhance the breeding of mosquitoes, so you find even infection it's along these places where there are close pockets and that is why LF is just along the beach'* (Mark, male 50 years, **FGD**).

The abundance of sandy soils in an area provides the medium for the formation of ant and termite hills which harbour the sand fly that transmit VL. The human-wildlife conflict (Table 4.1.4) was a factor solely mentioned by the KI as the reason to the emergence of vectors in new areas; for

example, snakes are common around homesteads since humans have invaded areas that were previously occupied by wildlife.

> '*People are now spreading out to areas that had wildlife, causing the human-wildlife conflict. In this case, snakes will be in close proximity to the homestead and prey on chickens. Sometimes, they will slither inside the house to look for food or water and bite someone' (*Angeline, female 52 years, **KI**).

Another KI respondent added:

> *'People who farm here for such a long time expand and clear the forest to get better soil quality, which increases the interaction with the snakes… bites increase. The snakebite incidences over the past two years have been quite high' (*Geoffrey, male 37 years, **KI**).

The KI and FGDs agree that environmental conditions such as poor rainfall patterns and harsh terrain in arid areas especially for the nomadic communities determine food security and influence the course of treatment for specific NTDs such as visceral leishmaniasis:

> *'Because of the aridness, the dryness, the moving from one place to another is a contribution. When they lack water and food, it is a big factor in the management because most of these patients need support therapy which includes food and blood transfusion and haematinics'* (Brian, male 43 years, **KI**).

> *'The immunity in children is low; if they are infected with hydatid cysts or leishmaniasis they get very weak and die due to poor immunity'* (Anne, female 38years, **FGD***).*

The terrain plays a role in NTD transmission, for example:

> *'This area is very harsh and isolated, when we get bitten by snakes, it is hard to reach the health facility, in most cases you have to walk very many kilometers'* (Joseph, male, 56 years, **FGD**).

Additionally, terrain plays a role in promoting bruises in leprosy patients:

> *'I would want to refer to leprosy, as a leprosy patient, we stay in a hilly area. So the terrain of the place is not conducive. My digital fingers are gone, and I have to climb to reach where I stay. So that alone makes me get more wounds because I have to climb, and you know that grip puts me…a patient at risk of more bruises. So that is a threat to me as a leprosy patient'* (James, male 28 years, **FGD**).

### 4.2 Water sources

The sources of water in the study areas ranged from boreholes, lakes, dams, rivers, streams, earth pans, springs, rainwater, piped water and 'leak it in' or 'tippy-tap' (this is a container filled with water and suspended on a tree. The container is perforated at the bottom using a sharp object to expose a hole in which water is released for use when required)(Table 4.1.4). Both KI and FGDs respondents agree that natural water bodies are the primary water sources compared to the availability of tap water.

> *'Water, water, water is a problem. We depend on natural water bodies and this area is an arid area so water is an issue. The Ministry of water is trying to come up boreholes so we have a constant supply but water is an issue. That's why there are nomads. They travel distances looking for water and pasture' (*Angeline, female 52 years, **KI)**.

> *'The water in the river and lakes are not safe; the quality is bad in most areas. When you look at the water that people are using, the quality is not good'* (Eva, Female 28 years, **FGD**).

The use of water from natural bodies promotes water-borne NTDs such as schistosomiasis.

> *'If you go to the lake to get water, you can get schistosomiasis; if you are somebody dealing with water you have a high risk of contracting schistosomiasis'* (Patrick, male, 47 years, **FGD**).

> *'The kids wash in the rivers, they wash in the lakes, they fetch water, and they do their chores at the lake barefoot. They also carry their younger brothers and sisters, they go swimming in the lake, they bathe in the lake, and all those are pre-disposing factors to schistosomiasis'* (Washington male 60 years **KI**).

The few residents, who have access to piped water, have questionable and irregular supply due to water rationing:

> *'This area in the coastal region is where fairly rich people stay but even here you find that water supply and reliability is the greatest challenge'* (Brian, male 43 years, **KI**).

> *'A few areas have tapped water but it is not evenly distributed there is a bit of rationing'* (Fatuma, female 30 years, **FGD**).

If a community decides to drill a borehole to access water, it depends on the water table (Table 4.1.4), if the aquifer is deep; it becomes expensive to drill the borehole. On the contrary, if the water table is shallow water, then it is easily contaminated by human wastes and accessed by wild dogs and livestock, which are risk factors for hydatid cysts and other zoonotic NTDs.

> *'It's very common to find most areas without piped water, most of them use water from shallow wells in the riverbeds so you find that even this water at night the wild dogs access this water, people do all sorts of activities in that water before morning and you know because of lack of awareness of the modes of transmission of these diseases this water is used for domestic use at the same time it's used for animals' (*Angeline, female 52 years, **KI).**

Additionally, Both the KIs and FGDs agree that water quality (Table 4.1.4) is a challenge.

> *'There is pollution of water sources, especially the boreholes and wells. If you go to the nomads they walk like 50 kilometers or 30 kilometers to access clean water and if they access the water, it's not clean, the water from open dams and open boreholes. When they get a water source, maybe the women can be able to carry 2-3 litres. They will give attention to drinking so when it comes to bathing, washing your eyes, that's not a priority and that's why you see trachoma is a problem in Turkana'* (Mark, male 50 years, **KI**).

> *'The water is dirty, its water that you will find in a trough or stream, the livestock have used it, and even us, as community members are going to collect it- that is the same water we are going to wash our faces with. You find that we are only adding germs to the face. Within a short time our eyes will be watery and infected' (*Aisha, female 37 years, **FGD)**.

Water quality also presents in the form of fluoride deposits in water which cause tooth fluorosis and impacts negatively on people's health. In an attempt to provide safe water, organizations involved with the distribution of water purification products have often fallen victims to circulating rumors that water treatment products are laced with contraceptives. Such unconfirmed statements affect safe water delivery in some areas:

> *'For instance, if you have a new product that you want to promote, people will have myths/misconceptions. Like I know for me it is promoting point of use water treatment,*

*when we started people were saying, 'now you're introducing a drug', that when we put in our water we will become infertile, and we cannot have children, so there are those rumours and misconceptions and some people did not want to use the water treatment products, saying that maybe it's laced with family planning products'* (Mark, male 50 years, **KI**).

*'I do not trust the tablets they give us to put in water. My neighbor told me that they are poisonous. One day her child drank that water and had stomach problems. There is no difference between those tablets and the water we collect from the river'* (Josephine, female, 32 years **FGD**).

### 4.3 Sanitation facilities

Sanitation facilities are a challenge in most parts of the country with cases of people practicing open defecation (Table 4.1.4) as highly mentioned by the KI and FGDs.

*'I would like to talk about sanitation and the culture of hand washing which is still a tall order here in Busia. People still practice open defecation and that is why we have a high prevalence of STHs. In schools the toilets are dilapidated and hand washing facilities are not even there'* (Richard, male 38 years, **KI**).

*'Here in western Kenya, we border Lake Victoria, but because of poor latrine coverage we have very many infections of schistosomiasis and STHs. People are still defecating in the open'* (Jacklyn, female 40 years, **FGD**).

Additionally, there is poor refuse collection and management in urban and peri-urban areas which provides an avenue for dengue transmission.

*'Here in the village we do not have a sewer system that is only in the city. So you dump your waste in a heap and wait for it to rot. This brings a lot of flies and other insects'* (Peter, male 34 years, **FGD**).

*'Waste disposal in this community is about you and your family. If you have generated waste in the family, you have to find a way to burn them, because we do not have those vehicles that come to collect waste'* (Janet, female 43 years, **KI**).

Even though several individuals and groups have constructed latrines and toilets, open defecation (Table 4.1.4) remains a common practice to many and a contributing factor for

schistosomiasis, STHs, and diarrheal infections. Part of the reasons for the practice of open defecation among the KI and FGDs are terrain and soil structure. Places which have loose or black cotton soil have a frequent collapse of latrines as mentioned below:

> *'Western Kenya, you'll find nearly 60% of the area is predominantly black cotton soil, and black cotton soil is quite unstable, so you want to encourage people to dig pit latrines but then they really face a challenge because this type of soil is very loose, so during wet season if you don't do proper lining, it tends to collapse. Or even during the dry season when you don't line that pit, then it tends to crack, and therefore you find that you put up a latrine and every other season it will collapse'* (Mark, male 50 years, **KI**).

> *'We were told to construct toilets by the public health officers. Many people constructed structures that resemble a toilet, it did not take long before the structures collapsed because of the soil'*(Judy, female, 57 years, **FGD**).

> Another respondent added that,

> *'Most of it is sand, and as such you find that even promotion of latrines becomes a very big issue. Because somebody digs 2, 3 feet, 5 feet deep it caves in. So it endangers the life of the person who's digging it becomes a very big issue. That's why most of them cannot build these toilets. The community says if you want us to build these toilets provide culverts. This is because when you put culverts in line with the soil, it can't cave in and kill someone. And also there was a time that somebody was killed. A latrine caved in on him, and he was killed. So the community keeps on referring to that thing year in year out, and it is something that happened somewhere in the 70s, but to date, that story is still on. So it really puts you off wanting to talk about latrines!'* (Jacklyn, female 40 years, **KI**).

Also, rocky areas make the construction of latrines difficult while zones that have high water tables are not feasible for latrine construction, as noted by the respondent below:

> *'There are places which are very rocky, so even digging a toilet is difficult, plus there is no sewage connection. If you decide to dig your pit at the household level or even the institutional level, then you have to deal with issues of hard rock. This makes it very difficult for people to put up latrines'* (Simon, male 40 years, **KI**).

> *'There are some places here in the community which have a high water table, that's a key factor. You find that you dig a pit 3 feet deep and you are hitting the water table so you can imagine if you are to put a toilet and at 3 feet you strike the water table, then it becomes very hard to put up a toilet'* (Joseph, male 50 years **FGD**).

### 4.4 Housing status

Both the KI and FGDs mentioned that the housing facilities in communities affected by NTDs are indecent due to poverty. The households have dusty floors consisting of top and loose soil which harbours vectors such as fleas and mosquitoes:

> *'Housing plays a major role in the transmission. These poor families they cannot afford decent housing or even the way they construct the houses are poor. When I was young, I used to see when someone was constructing a house or 'simba' they used to dig the top vegetable soil and throw it away. That top vegetable soil is ideal ground for a jigger to manifest or multiply in. So nowadays I do see most of the houses that are being constructed they just dig the hole for the posts, they put it in but they don't remove the top vegetable soil they just use it as a floor'* (John, male 25 years, **KI**).

Similarly, another respondent from the FGDs added:

> *'We have loose soil in our house and this alone contributes to the spread of the Jiggers infestation since the fleas are found there and there are children running barefooted in the house, if the neighbours children come to play, they share in the jigger infestation'* (Jack, male, 25 years, **FGD**).

In nomadic communities, the houses are small, semi-permanent dome-shaped structures with mud walls, crevices, poor lighting, and ventilation. Such homes harbour sandflies and are risk factors for respiratory infections such as TB due to poor ventilation and overcrowding (Table 4.1.4).

> *'In pastoralist's community, they build temporary houses; most of them are built with sticks, others have mud and you can see the crevices. That is where the sandflies that transmit leishmaniasis hide. At the same time, it is hard to spray these houses with insecticides'* (Evan, male 50 years, **KI**).

Regarding ventilation, this FGD had this to say:

> *'The houses are grass thatched and mud-walled with poor ventilation; if you live in a structure like that you get bitten by the sand fly or mosquito and you also get other infections like TB'* (Judy, female 26 years, **FGD**).

*'Poor housing promotes NTDs, the dome shaped structures are dark and mosquitoes like hiding in dome-shaped structures and that is how you end up with vector-borne NTDs'* (Brian, male 43 years, **KI**).

Poor housing also contributes to snake bites as mentioned by the KI:

> *'Have you asked yourself why most snake bites occur in remote areas? In remote areas, people like the pastoralists construct houses that have open spaces at the top (manyattas). Snakes find it easy to slither in such houses when they are looking for food'* (Tom, male 41 years, **KI**).

Furthermore, in areas like the coastal region, housing status contributes to NTD transmission as noted:

> *'There is a myth in the place that I work that NTDs for example, hydrocele is inherited. So in relation to housing structure, our houses are built in such a way that they do not have ventilation. And they are cladded with grass, so this grass harbours the mosquito. So if this mosquito being the vector carrying the parasite, it can stay in that house for many years. So it is only transferring the parasite from this person to the other person, so for the community, they say that this is a disease that has been inherited, not knowing that it is the housing structure that harbours this mosquito who carries the parasite to the other person. So surely the housing structure contributes to some of the NTDs' (Kanji, male 45 years, **KI**).*

Additional factors such as harsh environmental conditions characterized by high temperatures in arid areas influence accommodation or sleep options and determine NTD infection for leishmaniasis and snakebites:

> *'Housing in Turkana is determined by the harsh environment. You find that even those that are able to construct permanent houses, you find that most of them still end up sleeping outside. People end up sleeping outside because of the high temperatures. Some are more comfortable sleeping outside than sleeping inside the home and in relation to NTDs that exposes them, particularly leishmaniasis that being transmitted by the sandfly. Once they are out there sleeping not covered it becomes a failure and therefore they are vulnerable to the spread of leishmaniasis. There are also so many cases of snakebite. Most snake bite cases have been reported at night. I find that possible because at night it is a bit cooler, so the snakes are moving about as they are moving about they are able to enter the houses cause those houses are not quite intact, so they are able to get through and also some people are bitten because they are sleeping outside there, so the kind of housing in Turkana exposes people'* (Angeline, female 52 years **KI**).

### 4.5 Chapter Summary and take home messages

In summary, chapter four demonstrates that research participants report a wide array of inequities that they feel exist in the political, economic, social and cultural aspects of Kenya. First, the results reveal additional societal factors that propagate NTD infection such as environmental, psychological and behavioural factors; access to proper housing, water and sanitation. Second, NTDs affect economic opportunity and productivity both at the local and national level which determine income generation and economic growth respectively. Third, persons affected by NTDs remain marginalized and discriminated against in social affairs due to low levels of literacy.

# CHAPTER FIVE CAPACITY OF LOCAL COMMUNITIES TO ADDRESS THE BURDEN OF NTDS

## 5.1 Introduction

This chapter presents the findings from the second objective which is the capacity of local communities to address the burden of NTDs. The chapter begins by highlighting the current NTD programs in Kenya, information provided by the key informants and the focus group discussants. The chapter reveals that the current NTD programs in Kenya can be donor funded, government funded, or community-initiated. The chapter further discusses the proposed interventions from the community members and the key informants and finally concludes with the summary and take home message.

## 5.2 Current NTD programs in Kenya

Both key informants and FGDs mention that communities are using alternative measures to manage NTDs due to poverty, ignorance or the inability to access NTD control programs and medications. Table 5.1 summarizes, community initiated alternative measures mentioned by the KIs and FGDs which include: the use of sodom apple, urine, washing detergent (omo) and physical removal of the parasite to manage jigger infestation, individuals who are infected with visceral leishmaniasis visiting traditional healers to make cuts on the spleen to drain the Kalazar parasites, similarly, patients suffering from hydrocele, resorting to physical draining of accumulated fluids in the reproductive organs, the use of herbal remedies and cleansing ceremonies to manage hydrocele in the event that they are unable to access surgery. Additionally, patients who are infected with trachoma use hand tweezers to pluck eyelashes that have turned inwards to get temporary relief from scarring of the cornea.

Several NTD programs are currently being implemented in Kenya, the most common being the school-based deworming program carried out by the government of Kenya and its partners (Table 5.1).

*'We carry out periodic deworming to target school going children' ((*Peter, male 34 years, **KI**).

*'The Ministry of Health and Education coordinate the school health deworming activities which have really assisted the children to increase their level of participation in schools because most cases of the worm infestations have reduced'*(Richard, male 38 years, **KI**).

*'Our children get the medicines for worms in schools. It has been happening for some years now'* (Jacklyn, female 40 years, **FGD).**

There is also Community-Led Total Sanitation program (CLTS) which is currently being adopted by most counties in Kenya.

*'My county, Busia is aiming to be 100% CLTS compliant meaning everybody should have access to a toilet by the year 2020. I know there are relapses, here and there because some have constructed and it has collapsed but that is another question all together'* (Richard, male 38 years, **KI**).

*In our community, the Ministry came with the CLTS program to prevent open defecation and they said it also helps with reducing the transmission of worms.* (Jacklyn, female 40 years, **FGD**).

The CLTS program encourages communities to build and use latrines with counties such as Busia taking it a notch higher and adding a Financial Inclusion Improved Sanitation and Health (FIISH) component. The FIISH component encourages communities to use latrines as well as find innovative ways of turning wastes into fertilizer to earn income. The FGDs agree that there are WASH interventions (Table 5.1) at the community level, which includes the provision of safe drinking water through chlorine filters installed in water collection kiosks.

*'*We'v*e got WASH facilities… we've got water treatment at source and also point of use chlorine dispenser' (*Fatuma, female 30 years, **FGD**).

The WASH interventions at the school level include personal hygiene, face washing, and the 'Unilever School of 5' as mentioned by this KI:

> *'We are using the Unilever School of 5. Unilever has been for a long time dealing with school health WASH. Focusing on hand washing at 5 critical times: when somebody wakes up, before eating, after eating, after toilet, after blowing your nose or coughing –5 critical times using soap. They have been providing soap and water facilities to encourage children to wash their hands 5 times a day. So we riding on that approach we establish under the trachoma program, something we call Super School of 5'* (Brian, male 50 years, **KI**).

**Table 5.1 A table showing the current NTD programs in Kenya**

| | **Key informants (n=21)** | | **Focus groups (n=5) Total participants (46)** | |
|---|---|---|---|---|
| | **# of Key informants** | **# of mentions** | **# of FGDs** | **# of mentions** |
| **Current NTD Programs** | | | | |
| Community initiated alternative measures | 4 | 11 | 3 | 14 |
| School based deworming program | 7 | 27 | 5 | 25 |
| Community-Led Total Sanitation program (CLTS) | 9 | 15 | 3 | 17 |
| WASH interventions<br>• Chlorine filters<br>• 'Unilever School of 5' | 2 | 5 | 4 | 25 |
| Community sensitization | 5 | 6 | 4 | 7 |
| Community Mass Drug Administration (MDA) | 10 | 19 | 5 | 34 |

| | | | | |
|---|---|---|---|---|
| • Lymphatic filariasis<br>• Schistosomiasis<br>• STHs<br>• Trachoma | | | | |
| Morbidity Management and Disability Prevention Program (MMDPM | 2 | 2 | 1 | 1 |
| Indoor spraying | 4 | 5 | 1 | 2 |
| Outdoor spraying (fogging) | 3 | 7 | 1 | 3 |
| Mass dog vaccinations for rabies control | 2 | 4 | NM | 0 |
| Community level hygiene practices for wound management | 4 | 7 | 1 | 3 |
| Community outreaches | 6 | 5 | 2 | 6 |
| National school health policy | 4 | 3 | NM | 0 |
| Training of CHVs | 7 | 15 | 3 | 11 |
| Program assessment for onchocerciasis & Human African Trypanosomiasis | 1 | 3 | NM | 0 |
| Active case findings | 1 | 1 | NM | 0 |
| Training of medical personnel to carry out specialized services | 4 | 7 | 2 | 2 |
| SAFE strategy | 2 | 14 | 4 | 8 |
| Free surgeries and management services | 3 | 17 | 4 | 17 |

The other interventions that were mentioned by both the KIs and the FGDs include community sensitization on NTDs; community mass drug administration for lymphatic filariasis, schistosomiasis, STHs, and trachoma; surgical programs for hydrocelectomies and Morbidity Management and Disability Prevention Program (MMDPM) for lymphatic filariasis (Table 5.1). The MMDPM involves the provision of a minimum package of care to persons suffering from lymphedema, elephantiasis or hydrocele. Other NTD programs are indoor spraying and outdoor spraying (fogging) for vector control, mass dog vaccinations for rabies control, although this was not mentioned in the FGDs (at least once every three years) and community level hygiene practices (Table 5.1) for wounds caused by rabies, leprosy, and elephantiasis. In remote areas, there are community outreaches for trachoma patients, the community outreach programs involve mass screening of the community members, treatment of minor ailments, trachoma and cataract surgery.

Other ongoing programs (Table 5.1) include the establishment and review of the National school health policy, which was mentioned solely by the KI. The National school health policy has eight thematic areas that provide for WASH and guides deworming activities. There is the training of CHVs on intensive case finding for debilitating NTDs such as trachoma and lymphatic filariasis. The KIs also mentioned that in 2018, Kenya embarked on a program assessment for onchocerciasis & Human African Trypanosomiasis (HAT) to start off the certification process for the two NTDs as outlined by WHO, this was not mentioned by the FGDs. As such this KI had this to say:

> *'We are seeing that for conditions like onchocerciasis which we officially said had been eliminated, we still don't have a concrete scientific basis to demonstrate elimination, so we are actually ensuring that we come up with processes that are going to demonstrate that yes we don't have onchocerciasis and Human African trypanosomiasis'* (Simon, male 40 years, **KI**).

The KI also mentioned that, there is active case finding for leprosy and hydatid disease as well as plans to operationalize the NTD database to capture disease prevalence:

> *'NTDs like hydatid disease…..we are also looking at active case finding especially for leprosy-this one we just started so that we can pick up those cases. A big intervention is also data management. We have a lot of missing NTD data and we are trying to initialize data around NTDs and operationalizing our NTD database' (Simon, male 40 years,* ***KI****).*

Additional initiatives that were mentioned by both the KIs and FGDs include training of medical personnel to carry out specialized services such as trachoma surgeries and splenic aspiration of Kalazar parasites to avoid overreliance on foreign organizations. In trachoma-endemic areas, there is the implementation of the SAFE strategy, which includes **S**urgery, **A**ntibiotics, **F**acial cleanliness, and **E**nvironmental sanitation (Table 5.1). There are also free surgeries and management services for hydatid and Kalazar in static and outreach sites.

### 5.3 Proposed interventions from the communities

The community members acknowledge there is a gap in community sensitization for NTDs (Table 5.2). Several rural communities are still using alternative measures (Table 5.1) as opposed to conventional medicine manage NTDs due to high levels of poverty, ignorance and lack of access to health services.

**Table 5.2: A table showing the proposed NTD interventions from the communities**

| **Proposed Interventions from communities** | | |
|---|---|---|
| | **Focus groups (n=5) Total participants (46)** | **# of mentions** |
| Community sensitization | 4 | 4 |
| Political goodwill | 4 | 7 |
| Improvement in WASH facilities | 3 | 9 |
| Access to care, treatment, and UHC | 4 | 7 |
| Adequate patient health worker to patient ration | 4 | 9 |
| Proper diagnosis | 4 | 13 |
| Indoor spraying and vector control | 4 | 4 |
| Environmental sanitation | 4 | 9 |
| Early physical examinations | 5 | 7 |
| Counseling services &support groups | 5 | 15 |

As such, communities propose continuous sensitization to minimize ignorance. Additionally, the communities propose the use of political goodwill as a means of community empowerment in the counties.

> *'I would like as a member of this community to be sensitized because there are certain things we can do on our own to prevent these diseases. We need to live in a clean environment, we need to be educated, not to stay out very late or even sleep outside like is the norm with some of us, because that is where the mosquitoes find and bite you'* (Micah, male 52 years, **FGD**).

> *'For me, I think there is a lot of laxity from the government. They keep asking us back and forth our health concerns without any action, so for me I see that there is a lack of seriousness even in terms of follow up for NTDs* (Tina, female 43 years, **FGD**).

Another recommendation is an improvement in WASH facilities, which includes the provision of piped water, water treatment facilities, and construction of latrines up to the household level.

> *'I just want clean water, to say the truth; we do not have clean water here. The water that is here is shared by human beings and livestock. That is why we will continue getting sick if the government continues to marginalize us. Because we have asked for clean water and we have not received any till now. We get our water from the river which is also contaminated by livestock'* (Maureen, female 34 years, **FGD**).

*'Another thing that brings the disease is unhygienic conditions. So we have to have hygiene in our households. We need to have clean water and latrines'* (Linda, female 40 years, **FGD**).

At the health facility level, access to care and treatment (Table 5.2) needs to be made free or at an affordable rate as Kenya works towards providing universal health care to its citizens since the present National Health Insurance Fund (NHIF) is unaffordable to many:

*'For me it would be that anyone who has an NTD can access treatment and care at affordable price so that they can continue with their life and if possible the treatment should be free'* (Fridah, female 45 years, **FGD***).*

*'Myself and the other community health workers are covered by insurance and just a few who are employed by other sectors, but the majority here do not have an insurance cover, if you miss money, then you miss treatment, the government should provide insurance for poor people'* (Jack, male 24 years **FGD**).

The community members also felt the need to have an adequate ratio of a health care worker to patient ratio as well as the proper diagnosis of NTDs in the health facilities (Table 5.2).

*'We need adequate doctors in the health facilities so that we do not go very far for health services. We also need proper diagnosis so that people get treatment that is accurate'* (Tina, Female 42 years **FGD**).

Other proposed interventions include indoor spraying for vector control, environmental sanitation, and early physical examinations, especially for hydrocele patients (Table 5.2) as mentioned below:

Vector control and environmental sanitation,

*'There should be a program for indoor spraying of mosquitoes and fleas. As a community member, I think we should keep our environment clean. We can have the government help us to maintain cleanliness, so we avoid the bushes, raw sewage and flies everywhere*' (Jacklyn, female 40 years, **FGD)**.

Early physical examinations, especially for hydrocele patients,

*'When you get sick and go to hospital the charges are high. This makes people have alternative means such as temporarily draining hydroceles. If treatment was free or at an affordable price, we wouldn't have a lot of problems. We as men also need to have to have physical examinations from time to time to capture the disease at early stage'* (Fahim, male 30 years, **FGD**).

> *'I need my body to be checked, I need medical examination to find out if I have hydrocele before my reproductive parts get swollen'* (Jack, male 25 years, **FGD**).

The communities also noted that counselling services and support groups for people infected with long term disabling NTDs such as leprosy, elephantiasis, trachoma, and snake bites are lacking (Table 5.2). For example, this respondent noted that such support groups could be used to share information on what is expected on the conditions:

> *It will also be nice to have government initiate support groups for people infected with NTDs, just like there are support groups for people having HIV/AIDs* (Anne, female 38years, **FGD**).

> *Availability of counseling programs for people infected with NTDs so that they do not die of stress from stigma* (John, male 47years, **FGD**).

## 5.4 Proposed NTD interventions/policies from key informants

In as much as Kenya has made strides in NTD control activities, there are further improvements that need to be done. For example, NTD interventions are mostly coordinated through the Ministry of Health and sometimes the Ministry of Education hence the need for intersectoral integration (Table 5.3).

**Table 5.3: A table showing proposed interventions from key informants**

| **Proposed Interventions from Key informants** | **Key informants (n=21)** | |
|---|---|---|
| | **# of Key informants** | **# of mentions** |
| Intersectoral collaboration | 3 | 8 |
| **'**Bottom-up' capacity building | 5 | 12 |
| Sensitization and behaviour change | 4 | 17 |
| Counseling and support services | 6 | 22 |
| Enforcement of NTD legislative acts | 3 | 4 |
| Improved vaccination services | 4 | 5 |
| Enhanced water supply and storage in urban and rural areas | 3 | 7 |
| Infrastructure improvement and use of protective gear | 3 | 4 |
| Research on the climate on NTDs | 1 | 1 |
| Alternative economic activities and food policy | 2 | 3 |

This is to mean collaboration within the ministries themselves and also between the ministries and the affected populations, for example, the Ministry of Water working towards the provision of WASH facilities, the Ministry of Agriculture empowering communities on alternative economic activities that promote food security and livelihoods, the Ministry of Veterinary services providing sustainable vector control services to the communities, the Ministry of Public Works exploring ways in which infrastructure can be improved for example, building better roads and bridges, proper drainage systems and engaging the political class at the county government to oversee the implementation as noted by the respondent below:

> *'I feel there has to be integration of all NTD stakeholders and other sectors including housing, agriculture, veterinary- they should all be brought on board so that they can know their role in this. An NTD-infected or affected person, they require food. If we can bring in somebody who is an agriculturalist, who can tell them now that in Ganze you don't have, rain. Can you plant this for your benefit? So I feel that the interventions should be integrated. All other sectors are brought on board to address the problem of NTD'* (John, male 32 years, **KI**).

There is a need to engage communities through capacity building using the 'bottom-up approach' around NTD control. This should involve, forming active community committees comprising of health workers, CHVs, and individuals in the community for health education and NTD surveillance:

> *'I think one important area we need to take is a bottom-up approach and not thinking for the community but also getting the community to give their ideas especially when we are formulating this policy, engaging the communities to give their perception on what policy and what they want these policies to address'* (Mark, male 50 years, **KI**).

Similarly, NTDs need to be included in the school curriculum for sensitization and behavioural change among young adults:

> *'I think the education of diseases and neglected diseases, for instance, needs to be part of the curriculum for students. I think we should have an integrated curriculum that is able to take all this NTD information and put it together in a package that can actually be delivered to the to the students and to the communities holistically and cheaply and much more efficiently'* (Tom, male 41 years, **KI**).

Individuals suffering from a long term debilitating and disabling NTDs such as leprosy, elephantiasis, trachoma and snake bites require counselling services and support groups (Table 5.3) to help them deal with the psychosocial effects of NTDs:

> *'Because like HIV/AIDS they have a social group and they know each other, and they support each other just like diabetes they know each other. But for elephantiasis or leprosy, we've not started such as a county/country. Maybe we can, we can think of that as we have launched the MMDP, Morbidity Management and Disability Prevention Program. Maybe we can think of that so the people within a certain area can be meeting to socially support each other and give advice on the things they are supposed to be doing for example, how they are supposed to take care of their swollen legs'* (Mark, male 50 years, **KI**).

Another KI respondent added:

> *'As an intervention , we need to educate, counsel and support those who are having NTDs such as elephantiasis, to accept the situation and try to live with the disease because there is no further intervention once the legs are swollen. They have to know that once they take the medication the transmission will stop even though their legs will still be swollen' (Jemimah, female 50 years, **KI**).*

The interviewees indicated that the legislative acts (Table 5.3) around the treatment of NTDs need to be enforced to prevent passing on the infection, for example, public health act CAP 242 states that person's receiving treatment for leprosy need to be followed up to ensure that they adhere to the treatment regimen:

> *'If we can borrow and understand the constitution of Kenya, that everybody has a right to life, everyone has a right to health, then it can be emphasized and everyone sensitized to adhere to their treatment regimen. We have public health CAP 242 which focuses on those people suffering from NTDs, especially leprosy. There is an intervention so if that person does not come to take medication, by law, we have a right to follow and assist that person in taking up medication'* (Simon, male 40 years, **KI**).

There has to be improved vaccination services, with NTD vaccines such as rabies being part of the KEPI vaccines rather than on-demand vaccines when dog bites occur:

> *'If I was directly involved in passing of health policies for NTDs, I would move the rabies vaccines from being an on-demand vaccine and make it a part of the expanded program of immunization (compulsory vaccines). The reason for this is that, a child needs not to have money to get the measles vaccine; I think a family needs not to have money to be saved from the deadly virus rabies. So it's moving those vaccines to be completely free because they are lifesaving and they are too expensive for the people that are marginalized. Number two thing is that I would, put money to eliminate the disease at the source. In fact, rather than spend millions of shillings buying the vaccine on the human side, I would spend a bit of that money buying vaccines on the animal side and making sure that they are well funded because if they remove the disease in the dogs, then the humans are safe and it is cheaper, actually much cheaper'* (Tom, male, 41 years, **KI**).

Additionally, regular mass dog vaccination (Table 5.3) programs need to be made free or affordable to prevent transmission as Kenya works towards providing Universal Health Care (UHC) to its citizens, the same respondent added:

> 'In terms of government structures that could enable control and elimination of NTDs such as rabies within the country, I think what might work best is the universal health care. A county like Makueni has been trying that for the last one year–A family pays 500 then they're able to access health services at a subsidized rate. For instance, if you are a member of the universal health care system within a county like Makueni county and you're bitten by a dog, then there's an availability of PEP for you to get' (Tom, male 41 years, KI).

Other proposed interventions include enhanced water supply in urban and rural areas, in case of water rationing is to have proper water storage both indoors and outdoors to prevent the breeding of vectors such as mosquitoes which transmit dengue, chikungunya and lymphatic filariasis:

> *'You find that we tend to store water out of panic, we are not sure if we'll have water tomorrow, we tend to store water and we don't store it well- we store it uncovered or we store it for long in tanks, as long as you store water for a long period of time, this is where you enhance breeding of the mosquitos. In Msambweni, I remember there was one bathroom we went to just check, there were about 10 buckets, and I may show you a photo towards the end. They keep the water so that when you want to shower, you just need to grab your soap and towel and all these were breeding areas for the vector. So to them, yes they have stored water which is available when they need it, but so long as it stays for more than a week a lot of breeding is happening'* (Brian, male 50 years, **KI**).

On the use of infrastructure improvement and protective gear, communities need to be educated and empowered on the use of protective gear such as gumboots when carrying out certain economic activities such as rice farming in stagnant water.

*'Let's teach the community the importance of using protective gears such as gumboots in stagnant water. The water gets to the knee level which can lead to infections with schistosomiasis* (Jeff, male 42 years. **KI**).

Likewise, classrooms need to have cemented floors for jigger control because children spend most of their time in school.

*'We need to do spraying in those schools with the jiggers. As public health officials, we know that children are getting infected in the schools (because they do not have cemented floors) we need to get those classrooms cemented and it is easy to do this, since schools are organized structures* (Richard, male 38 years, **KI**).

The research gap on the influence of climate and habitat on NTD infection (Table 5.3) needs to be addressed.

> *'The climate is changing which is a big issue, which means the vectors can now expand their territories when it warms up. We need more research on climate, habitat and so on.. to really understand what happens and for the government to put the systems in place'*(Richard, male 38 years, **KI**).

There is need to have brainstorming sessions with community members on alternative economic activities that provide less exposure to NTDs.

> *'In terms of economic empowerment, that is currently way above the NTD unit, but it is something to think of in the future. The government of Kenya, has goodwill and is trying to transform the quality and living standards of every Kenyan, we need to propose and adopt a multi-sectoral approach to deal with these NTDs. For now I can assure you that the NTD unit is willing to pass across community education and in future brainstorm with community members on alternative economic prospects. These people know how they acquire these diseases and most of them do so when carrying out their main livelihood… their main source of livelihood' (Simon, male 40 years,* ***KI)***.

Furthermore, an establishment of a food policy around NTDs will help address issues of malnutrition and anemia which contribute to the long wait times associated with the treatment of certain NTDs. For example, malnourished and anemic individuals suffering from Kalazar and hydatid cysts require a blood transfusion before they can begin treatment.

> *'We need to have a comprehensive food policy that is crafted in a way that it is able to take care of issues to do NTDs such as kalazar, hydatid cysts and malnutrition, When you tackle the issue of food, there are several things, you can be able to cover such as hygiene, sanitation, and water. That's where I could prioritize most, the issue of water. Yes, cause minus water, there is no life and no food. However much we talk of the sanitation and all those other things unless you provide water, at the end of the day you will still not get anywhere. So that's where I could prioritize most' (Walter, male 52 years,* ***KI).***

## 5.5 Chapter Summary

The chapter highlights some of the gaps that are missing in NTD control programs with key take home messages. The top three recommendations that emerge from this research that NTD stakeholders should implement include: early physical examinations, proper diagnosis and treatment, universal health care, counseling services and support groups for persons suffering debilitating NTDs.

The importance of early physical examinations, proper diagnosis and treatment cannot be over emphasized because most of the NTDs present as febrile (showing signs of fever) illnesses at their onset for example, dengue, chikungunya, lymphatic filariasis and schistosomiasis and progress to cause physical disability and even death. As such, communities living in NTD endemic areas need to have access to proper diagnosis and treatment from their nearest health facilities as recommended by WHO policy document on primary health care.

Currently, the cost of accessing health care is out of reach for many people, especially those living in marginalized areas. As such, the government of Kenya should strive to provide universal health care services to all its citizens regardless of their socio-economic status. Finally, there is need for the establishment of counseling and support groups for individuals suffering from NTDs that cause long term disability such as leprosy, lymphatic filariasis and trachoma. Support groups will help such individuals to share their experiences and coping skills which will reduce stigma and discrimination against them, improve their self-esteem, enhance their coping mechanisms and provide adherence to care and medication.

# CHAPTER SIX POTENTIAL INDICATORS FOR USE IN A GLOBAL INDEX OF WELLBEING (GLOWING)

## 6.1 Introduction

This section presents the results of the third objective, which identifies the potential indicators for use in a Global Index of Wellbeing (GLOWING) that will capture the inequities represented by NTDs. It begins with the descriptions of wellbeing in both the key informants and the focus group discussants and the mentions of each indicator across the groups. The results capture the meanings of wellbeing across the population health domain as per the Canadian Index of Wellbeing (CIW). In the CIW framework, the healthy population domain combines societal health outcomes and other determinants that examine whether the aspects of health are improving or deteriorating (CIW, 2016). Thus, the GLOWING project is founded on the CIW framework and adopts the healthy population domain to identify the descriptors of wellbeing in populations affected by NTDs and further more highlight the relevant indicators that capture the inequities of NTDs in Kenya.

## 6.2 The meaning(s) and indicators of wellbeing across the healthy population domain

The indicators of interest were selected based on what mattered most to the participants, the frequency of mention and the number of KI and FGs mentioning the indicator. This criterion enabled the identification of the indicators that made sense to the community members and the policy makers. The community members who took part in this study were infected or affected by NTDs and as such they were regarded as marginalized members of the community. The table 6.1 summarizes the research context and characteristics of persons infected by NTDs.

**Table 6.1 A table showing characteristics of people infected by NTDs**

| **Characteristic** | **Key informants (n=21)** | | **Focus groups (n=5) Total participants (46)** | |
|---|---|---|---|---|
| | **# of key informants** | **# of mentions** | **# of FGDs** | **# of mentions** |
| Dependent | 4 | 7 | 4 | 25 |
| Found in poor resource settings | 11 | 30 | 5 | 29 |
| Have poor health infrastructure | 7 | 22 | 5 | 23 |
| Illiterate/semi-illiterate | 6 | 14 | 5 | 19 |
| Live in areas with poor road networks | 2 | 6 | 5 | 15 |
| Marginalized | 3 | 9 | 5 | 17 |
| Neglected in social affairs | 2 | 5 | 5 | 12 |
| Poverty stricken | 8 | 7 | 5 | 7 |
| Vulnerable | 3 | 5 | 5 | 5 |

The respondents' classified people infected with NTDs into nine broad categories namely: dependent, found in poor resource settings, have poor health infrastructure, illiterate/semi-illiterate, live in areas with poor road networks, marginalized, neglected in social affairs, poverty stricken and vulnerable (Table 6.1). The highest mention in the focus group discussions was that people infected with NTDs are most likely or found in poor resource setting, are dependent on others and live in areas with poor health infrastructure respectively. Similarly, the key informants mentioned that persons infected with NTDs are found in poor resource settings, have poor health infrastructure and are illiterate or semi-illiterate (Table 6.1). The common theme across the groups as demonstrated by the responses is that persons infected with NTDs are found in poor resource settings. Based on this context we explored the meanings of

wellbeing, and the participants across the groups had varied responses on what wellbeing meant to them across the healthy population domain as shown in table 6.1 below:

### 6.3 The meaning(s) of wellbeing

**Table 6.2 A table showing the description of wellbeing from the respondents on the healthy populations domain**

| **Descriptions** | **Key informants (n=21)** | | **Focus groups (n=5)** | |
|---|---|---|---|---|
| | **# of Key informants** | **# of mentions** | **# of FGDs** | **# of mentions** |
| Absence of disease | 7 | 68 | 2 | 23 |
| Access to basic needs | 4 | 64 | 2 | 17 |
| Access to medications and health | 2 | 35 | 1 | 13 |
| Culture | 0 | 0 | 1 | 4 |
| Education | 2 | 32 | 2 | 21 |
| Environment | 1 | 8 | 1 | 7 |
| Good life | 3 | 51 | 2 | 24 |
| Good roads | 2 | 31 | 2 | 19 |
| Happiness | 3 | 45 | 2 | 18 |
| Love and support | 2 | 38 | 1 | 11 |
| No suffering | 5 | 43 | 1 | 6 |
| Presence of food | 5 | 40 | 1 | 10 |
| Psychosocial | 4 | 42 | 1 | 17 |
| Social engagement | 1 | 4 | 1 | 2 |
| Spiritual | 3 | 22 | 2 | 27 |
| Water and sanitation | 2 | 17 | 1 | 16 |

The highest mention in regards to the meaning (s) of wellbeing among the key informants was: wellbeing as the absence of disease, ease of accessing basic needs, leading a good life and happiness (Table 6.2). As for the community members, wellbeing was regarded in terms of spiritual nourishment; the ability to lead a good life, absence of disease and access to education (Table 6.2), below are some of the responses from the KIs and FGDs.

Wellbeing was regarded as an abstract construct as mentioned by this FGD respondent who lacked the proper vocabulary to define it:

> *'Wellbeing is the general…. Should I say wellness? You can say the general outlook on life of an individual I think, and you'll correct me if I'm wrong? I know in my mind what it is, but I don't know how to explain it* (Sabina, female 28 years old, **FGD**).

Wellbeing was also conceptualized within the definition of health to include the spiritual and psychosocial:

> *'Wellbeing is a term which is used to ensure that somebody is physically, mentally, socially, and probably spiritually stable. So this is encompassed, it is coined in the definition of health'* (Calvin, male 42 years**, FGD**).

Most of the KI respondents referred to wellbeing as a term that examines all aspects of human life:

> *'Maybe they might not be having any disease but you consider the psychologically or economically so I would say it's all round but to me so long as someone is not presenting any symptom of a disease we can assume the person is well and is able to carry on his or her daily activitie*s' (Brian, male 50 years, **KI**).

This KI respondent added:

> *'My perception of the term wellbeing, I think it is the holistic ability of a human being to be able to access all of his necessities, inclusive of decent foods and nutritional foods, a close distance to healthcare , decent access to information also education and perhaps social justice and human rights'* (Tom, male 41 years, **KI**).

Another participant emphasized:

> *'My perception of wellbeing, its looks at 3 things: 1… your mental capacity …2 is your health, health is part your wellbeing and 3 is your relationship with others….the way your body is working- which doesn't rule out an infection. It could be there, but it has not been diagnosed. Also, generally, it's how you associate with other people'* (Christine, female 35years **FGD**).

Wellbeing also includes proper mental capacity and a good relationship with others:

> *'Because if you are well, there is no infirmity, so wellbeing is in totality the aspect of how mental you are, how physical you are, how you are socially relating to others. That is how I understand wellbeing' (*Gabriel, male 36 years, **KI**).

This was further affirmed by the FGD below:

> *'For me well-being is a situation where you do not have an illness that will maybe deter you from doing anything, economically or engaging in certain activities, and well-being is not necessarily from the health point of view but also economic, social, and, to a large extent, spiritual nourishement. If you have those you regard yourself as someone who is well, and for me that's the way I could attribute to the meaning of wellbeing* (Jeff, male 30 years, **FGD**).

Wellbeing as everything you want to do without suffering:

> *'Wellbeing is when a person is able to do everything he wants to do and doesn't suffer, any ailment, I mean his system is working well, that's the extent of wellbeing. I mean his mind is ok, he is able to reason out issues and make decisions for himself, yeah he's accepted in the community, and he has no any physical ailment'* (Mark, male 50years, **KI**).

Wellbeing as being free from diseases, access to food, shelter, education and engaging in

activities that brings happiness:

> *'My perception would be wellbeing is free from disease, free from physical disease and you are able to meet the basic demands of life such as food, shelter, education and engaging in some activities that bring happiness'* (Stella, female 33 years, **KI**).

Wellbeing as a construct that includes good socioeconomic status, literacy, and access to information:

> *'My perception is that it is a state that, I'm able to talk about socioeconomic status up to date, my literacy is also good enough that I can access information and understand'* (Joyce, female 33 years, **FGD**).

Wellbeing as access to all necessities:

> *'When you talk of wellbeing, I think it's all round. It has to be psychologically, physically, socially, economically and it has to be all round. Yeah because you if you're economically well and mentally not well you are useless, it will not help, you're not healthy because you're not useful to yourself and useful to others at the same time. And you will not even serve your family or do whatever services you are supposed to do in the right way because, you have the money resources and everything, yes, but if you're mentally sort of handicapped, it is a problem. Socially if you maybe suffer from certain condition then you are socially stigmatized. Now that stigma will eat into you, and you will not function, there is something which is missing because of the stigma, and I mean segregation and all this. You know its discrimination and all that then you're not well'* (Jim, male 43 years, **FGD**).

This was affirmed by this respondent:

> *Wellbeing is everything, it's not just health, its food it's, you know its environment'* (Emmanuel, male 27 years, **KI**).

The above responses from the KI and FGDs summarize the perceptions of wellbeing among populations affected by NTDs and provide an avenue through which we can inductively capture the indicators that matter in their context. The interconnected construct that resonates from the responses above on wellbeing among the KIs and FGDs is the absence of disease and the ability to live a good life which fit within the CIW domain of healthy populations'. The healthy populations' domain of the CIW measures health status, lifestyle and behaviour and health care system factors. The dimensions of health status are: personal wellbeing, physical health conditions, life expectancy / mortality, mental health and functional health. The other dimensions include lifestyle and behaviour, public health and health care measure which are external factors that affect the health status of individuals and communities (CIW, 2016).

As per the geographic context of Kenya, personal wellbeing was captured by social engagement which corresponds to relationships and sense of community in the CIW. Social engagement was hardly mentioned by the FGDs and the KIs (Table 6.2). The physical health conditions corresponded with absence of disease, which was mentioned by both the KI and the FGDs (Table 6.2). Mental and functional health corresponded to psychosocial health and no suffering in the Kenyan context which was mentioned by both the KIs and FGDs. The other indicators that were important in the Kenyan context but were under a different domain in the CIW are: access to basic needs, education and infrastructure (good roads) (Table 6.2).

## 6.4 Chapter summary

The chapter highlights the meanings of wellbeing from the KI and the FGDs. It further identifies the indicators that matter to people infected or affected by NTDs in Kenya. The findings reveal that wellbeing can be described as the absence of disease, access to basic needs and presence of food. Wellbeing can also be based on spiritual health, the ability to live a good life, and presence of good roads. The common construct across the responses from the KIs and FGDs is that wellbeing is the absence of disease and the ability to live a good life which fit within the CIW domain of healthy populations'. As such, the findings capture the absence of disease as a physical health condition that affects wellbeing, psychosocial health and no suffering as an indicator of mental and functional health. Furthermore, social engagement corresponds to a sense of community. The results also find other indicators that are important in the Kenyan context such as access to basic needs, education and infrastructure (good roads).

# CHAPTER SEVEN DISCUSSIONS AND CONCLUSIONS

## 7.1 Introduction

The goal of this thesis was to examine the link between NTDs, health, and wellbeing. To achieve this, two social theories (capability approach and political ecology of health) and qualitative methods were used to: 1) to identify the political, economic, social, and cultural impacts of NTDs on health and wellbeing; 2) to investigate the capacity of local communities to address the burden of NTDs; 3) to identify potential indicators for use in a Global Index of Wellbeing (GLOWING) that will capture the inequities represented by NTDs.

This chapter presents a summary of key findings, contextualized within the current literature of NTDs, health, and wellbeing. Furthermore, the chapter identifies the main contributions of the research as well as the limitations; it concludes with a discussion of the policy implications for these findings as well as directions for future research.

## 7.2 Discussions

The results in this dissertation were informed by the capability approach and the political ecology of health to demonstrate that Neglected Tropical Diseases (NTDs) are diseases of the poor which contribute to a cycle of poverty, decreased productivity and long term disability. The research finds that NTDs are a proxy for inequities in the structural systems since people infected and affected by NTDs are unable to lobby for their human rights, possess limited finances, lack access to health care, live in areas that have polluted water sources with poor sanitation.

Politically, devolution informs the provision of services and directs the course of NTD activities in Kenya; for example, a health workers strike affects the diagnosis and treatment of NTDs in the health facilities. Additionally, a lack of political goodwill, political appointments,

and inadequate budgetary allocations frustrate control activities and impact negatively on policy formulation for NTDs. Hence, an unstable political climate characterized by political tensions and conflicts interfere with community outreaches making it difficult for health workers to provide interventions. These findings are consistent with the results from Ottersen *et al.* (2014), who acknowledge that the delivery of essential health care services may sometimes fall on non-state actors who may use their power and influence to create structural inequities. As such, this research finds that power and politics do not only affect governance, but are key factors in the delivery of public health care. Even though, the greatest responsibility for NTD programs lies with the international community, governments in NTD endemic regions must make a political commitment towards NTDs if the greatest impact is to be achieved (Narain *et al.*, 2010).

The study also establishes that NTDs affect the economic opportunity and productivity of infected persons. This is because persons affected by NTDs are unable to work, thus their income earning capacity is affected on a local and national level. Likewise, NTD infection contributes to school absenteeism and dropouts in school age children which later on manifest as low levels of literacy in adulthood, and consequentially poor advocacy and marginalization in social affairs. NTDs continue to be a cause of domestic and marital conflict as well as desertion which disproportionately affect women than men. These observations are consistent with findings from a report by Hunt *et al.* (2007), who establish that NTDs inflict a substantial economic burden to individuals, households, communities, and society through loss of productivity, school abseeitism, and high costs of inpatient hospital stays all which promote poverty and ill health for the populations. Similarly, studies by Hotez (2009) and Person *et al.* (2009), suggest that even though the economic impacts of NTDs are realized across generations, women tend to suffer more of the effects due to isolation and marginalization.

Cultural practices play a role in NTD transmission, because, the prohibition in the consumption of highly nutritious foods such as fish, chicken, and eggs in women and children compromises the body's immunity to fight diseases and make it hard for surgical interventions for NTDs in diseases such visceral leishmaniasis due to malnutrition. A similar observation by Hall *et al.* (2012), acknowledge the direct relationship between under nutrition and NTDs since, a lack of proper nutrition increases the risk of infection, the severity of disease, impairs host response to the pathogen and is a cause of death. There is still poor community perception on the causes of NTD transmission with community members attributing infections such as leprosy and jiggers to curses and hereditary transmission respectively. These findings are similar to the results by Ahorlu *et al.* (1999), who report that the cultural perceptions on the causes of lymphatic filariasis infection hamper health seeking behaviour. Furthermore, this dissertation establishes that cultural practices hinder essential sanitation practices. For example, the norms which prohibit construction and sharing of toilets among in-laws promote environmental hazards such as open defecation.

This research establishes that the psychological aspects of NTD infection such as destitution, ridicule, and neglect interfere with health-seeking behaviour. Regarding behavioural factors, communal events that take place at night provide an avenue for vectors to bite and infect community members. Consequently, upon infection, community members initially visit traditional healers for treatment and only proceed to health facilities when the condition worsens. Due to limited resources, they seek help immediately from the least expensive, closest and most trusted places before going to a health facility (Gyapong and Boatin, 2016).

Environmental conditions such as the soil structure and texture are ambient for the incubation of ova and cysts for soil-transmitted helminths. Additional climatic conditions such as

high rainfall and temperatures favour the development of mosquitoes which transmit LF, dengue, and chikungunya. Comparatively, human encroachment in areas previously occupied by wildlife has led to an increase in snake bites in Kenya, and this corresponds with WHO's recent report which indicates that snake bites are arguably the world's biggest hidden health crisis which kills between 81,000-138,000 annually and cause permanent disability to 400,000 others (WHO, 2019). As such, the structural inequities identified in this study are consistent with the findings from Aagaard-Hansen *et al*. (2010), which state that for health care systems to be responsive to the needs of all people, they must be sensitive to the local political, socio-cultural and environmental combinations.

Piped water remains a limited commodity in NTD endemic regions of Kenya, and as such, the research established that communities rely on natural water bodies such as rivers, lakes, and streams for their daily use which unfortunately may be contaminated with vectors. Piped water is expensive to connect and maintain and in areas where it is available, there are incidences of water rationing and poor quality. Sanitation facilities are also wanting in both urban and rural areas with problems such as open defecation becoming a risk factor for schistosomiasis and STHs. Furthermore, housing facilities present as indecent, semi-permanent structures with poor lighting and ventilation which harbor parasitic NTDs. Nomadic communities who reside in arid areas find that they have to construct semi-permanent structures or sleep outdoors at night risking snake bites.

The current NTD control activities in Kenya include community-run programs such as CLTS and WASH and national level interventions such as vector control practices and surgeries. The WHO 2020 strategy on accelerating progress in the control and elimination of NTDs, lays emphasis on integrated approaches to NTDs. As such this study applies human agency to finding

context specific solutions to NTDs and propose the need for intersectoral collaboration at the national level. This is to mean integration within and between ministries and also with the affected populations. A case example being, the ministry of water providing WASH facilities, the ministry of agriculture empowering communities on alternative economic activities that promote food security and livelihoods, the ministry of veterinary services providing sustainable vector control practices to the communities, the ministry of public works exploring ways in which infrastructure can be improved by building better roads, bridges and proper drainage systems at the same time engaging the political class at the county government for implementation and supervision. Similarly, the authors, Gyapong et al. (2016), advocate for intra and inter-sectoral action towards NTD control activities for the achievement of holistic benefits that extend beyond health. The second recommendation for NTD control strategy includes using the 'bottom-up' approach for capacity building, sensitization and behaviour change. This approach involves forming active community committees comprising of health workers, CHVs and individuals in the community for the purposes of health, education and NTD surveillance. Third, is the enforcement of legislative acts, for example, public health act CAP 242 which state that person's receiving treatment for leprosy need to be followed up to ensure that they adhere to the treatment regimen. At the local level, first, there is need to have early case finding and proper diagnosis to capture NTDs such as leprosy in their early phase and avoid the disability associated with the disease in the chronic stage. Second, is the establishment of support groups and provision of counseling services to help persons suffering from debilitating and permanent effects of NTDs such as leprosy, elephantiasis, trachoma and snake bites to cope with the psychosocial effects of NTDs, such groups have been successful in offering support for persons living with HIV/AIDs (Kabore *et al.*, 2010). Third, is the provision of universal

healthcare to include rapid diagnosis and treatment of NTDs at affordable costs or no costs to the citizens of Kenya. Fourth is that policy action needs to go beyond community messaging to ensure that health systems improve to cater to the needs and realities of citizens (Gyapong and Boatin, 2016).

The definition and measurement of wellbeing are two sides of the same coin (Allin & Hand, 2014) which are desirable goals for the evaluation of societal systems (Schwanen & Atkinson, 2015). However, the concept of wellbeing is multi-dimensional and varies with time, place and personal experiences (Fleuret and Atkinson, 2007) as such; people living in NTD endemic regions find themselves to be poverty-stricken, dependent and residing in areas with poor health infrastructure. As a result, they conceptualize their wellbeing to include aspects of their lives such as spiritual and psychosocial health, mental capacity, and good relationships with others. Additionally, wellbeing refers to being free from diseases, good socioeconomic status, literacy, access to information and the ability to engage in activities that bring happiness.

## 7.3 Conclusion

### 7.3.1 Objective 1: The political, economic, social, and cultural impacts of NTDs on health and wellbeing.

This dissertation acknowledges the inequities that exist in the political, economic, social and cultural systems. First, this research calls for an equity lens in the distribution and access of essential services such as housing, water and sanitation. Secondly, this research proposes poverty alleviation as a means of tackling NTDs for sustained economic opportunity and productivity at the local and national level. Third, this dissertation proposes that efforts should be made to engage persons affected by NTDs so as tackle issues of marginalization and discrimination.

### 7.3.2 Objective 2: The capacity of local communities to address the burden of NTDs.

This research recommends that NTD stakeholders align advocacy efforts with suggestions from the affected community members to enhance efficiency in the delivery of such programs. As such, these programs should include early physical examinations, proper diagnosis and treatment which should be made available from the closest health facility to prevent cases of physical disability and even death caused by NTDs such leprosy, dengue and chikungunya. Secondly, the county and national governments should strive to provide universal health care services to all its citizens regardless of their socio-economic status. Finally, the research proposes the establishment of counseling and support groups for individuals suffering from NTDs that cause long term disability such as leprosy, lymphatic filariasis and trachoma. The establishment of such groups will help individuals infected or affected by NTDs to share their experiences and coping skills, which will ultimately reduce stigma and discrimination against them, improve their self-esteem, enhance their coping mechanisms and provide adherence to care and medication.

### 7.3.3 Objective 3: The potential indicators for use in a Global Index of Wellbeing (GLOWING) that will capture the inequities represented by NTDs.

The research findings reveal that populations affected by NTDs perceive their wellbeing as the absence of disease, access to basic needs and presence of food. Additionally, their wellbeing is based on spiritual health, the ability to live a good life, and the presence of good roads. As such, this dissertation establishes the importance of place in conceptualizing wellbeing and reveals that inequities caused by NTDs compromise the wellbeing of persons living in endemic areas.

## 7.4 Research contributions

The study provides knowledge on the link between NTDs, health and wellbeing among populations living in endemic areas of Kenya. Framed within the social constructionists approach using qualitative methods, the research examines the complex relationships between people and places (Andrews *et al.*, 2014) to understand lived in human experiences of marginalized populations infected or affected by NTDs.

Substantively, the research provides alternative measures of wellbeing beyond the traditional economic measures of GDP in populations infected/affected by NTDs using indicators that captures the inequities represented by the diseases in the context of SSA. The use of such measures provides a step towards the development of a Global Index of Wellbeing (GLOWING) which is theoretically informed and can be transferred to similar contexts within LMICs.

Theoretically, the research uses two complementary social theories to provide explanatory power away from the tendency to have "blind observation" (Krieger, 2011) in the largely biomedical field of NTDs. The two theories, namely the capability approach and political ecology of health (structure and human agency) inform the research design, data collection and analysis and demonstrate that broad structural factors such as devolution of government services, economic activities, culture, behavior, water and sanitation influence NTD infection and subsequently the health and wellbeing of Kenyans. The intersection of the political, economic, social, and cultural systems reveal that first, NTDs are a proxy for inequities in the structural system and recommends an equity lens (Aagaard-Hansen *et al*., 2010) in the distribution of basic resources such as water, sanitation, housing and health. Second, poverty alleviation as an avenue of tackling NTDs for sustained economic opportunity and productivity

at the local and national level. Even though political ecology addresses the broad structures within society, it overlooks individual agency. Hence, the research uses the capability approach to complement political ecology of health to encourage human agency and collective action among community members for the initiation of context specific solutions to NTDs in Kenya. The capability approach acknowledges the deprivations of freedom and opportunities for persons infected and affected by NTDs and recommends community engagement as a means of tackling marginalization and discrimination (Gyapong *et al.*, 2016). Since, community engagement fosters collaboration and ensures that suggestions from the affected community members are aligned with the broader structural goals for efficiency in the delivery of NTD interventions such as proper diagnosis and treatment as well as fast track the provision of universal health care. The research also extends human agency in the proposed establishment of counselling and support services which have solely been used in HIV/AIDs programs (Kabore *et al.*, 2010) to disabling NTDs such as leprosy, trachoma and lymphatic filariasis. The use of such programs will encourage collective action, enhance shared goals in reducing stigma and discrimination by providing coping skills and mechanisms for self-esteem.

At the sub-discipline level, the research incorporates constructs of health geography: place, health and wellbeing, since, health geographers acknowledge that place based experiences shape health and wellbeing (Gesler, 2002) in addition to advocating for a shift in mindset from biomedical preoccupations to a broader commitment to social, cultural, political, and natural components of place-based communities (Brown, Mc Lafferty, and Moon, 2011). Furthermore the research responds to the call within the sub-discipline to reduce inequalities in population health (Smyth, 2008) by identifying the root cause of inequities in the political, economic and social-cultural systems and proposing intersectoral partnerships and collaborations that ensure

inclusive policies are formulated around empowerment, community action and capacity building (Kearns and Moon, 2002).

In regards to policy implications, at the local level, the research acknowledges that NTD infection in Kenya is a major problem that needs to be addressed as the world works towards achieving the WHO, 2020 goals of elimination and eradication of at least 10 NTDs by the year 2020. The formation of the Kenya National Strategic Plan (KNSP) 2016-2020 is a start but it is essential that policy makers work with communities to establish context-specific solutions that are sensitive to culture and behaviors, (Ahorlu *et al.*,1999) if the goals outlined in KNSP 2016-2020 are to be achieved. At the Global level, the research fits within the Sustainable Development Goals (SDGs) one, three and ten, which seek to alleviate poverty, promote good health and wellbeing and reduce inequalities respectively by formulating geographically relevant evidence-based policies. Methodologically, the study uses qualitative methods in a largely biomedical field of NTDs to provide a first-hand account of how the 18 out of the 20 NTDs affect health and wellbeing at the local and national level in Kenya using Focus Group Discussions (FGDs) and Key Informant Interviews (KIIs).

## 7.5 Research limitations

Despite the study having substantive and theoretical contributions, it had certain limitations as well. Firstly, the study was conducted when the country was experiencing political turmoil after the 2017 elections which lasted from August 2017 to March 2018 when the two national leaders from the government and the opposition side put their differences aside in the interests of serving the citizens of Kenya. During the turmoil period, it was difficult to reach certain areas due to demonstrations but the areas that were assessed provided a comprehensive picture of the NTD situation in Kenya.

Secondly, the qualitative methods used in the study were partially informed by prevalence data obtained from the latest copy of the Kenya National Strategic Plan for Control of Neglected Tropical Diseases (2016-2020) booklet. However, the prevalence data that was reported in the booklet was incomplete due to mapping challenges and underreporting of NTDs through the DHIS system. This set back was acknowledged by the officials from the National unit who were actively mobilizing funds to conduct a national wide mapping exercise to capture the most recent NTD prevalence in the country.

Thirdly, the study was qualitative and based on self-reported data which is susceptible to social desirability. In this case, participants could overstate or understate their experiences depending on expectations. To minimize such effects, the participants were asked follow up questions and subtle probes were used to enhance the experience and perception.

Fourthly, the study was cross-sectional which collected data on a single time point and did not allow for the examination of potential changes over time in regards to the ongoing country-wide intervention strategies. However, the use of triangulation of methods in this case, minimized bias and ensured similarity in the emerging themes between the FGDs and the KIIs.

## 7.6 Future Research recommendations

The research provides an understanding of the link between NTDs, health and wellbeing in sub-Saharan Africa. However, it identifies the research gaps in the methodology and policy. First, the research proposes the use of mixed methods in subsequent researches. This is because, in as much as qualitative methods provide a better understanding of the lived in realities of communities affected by NTDs as well as the challenges they face in accessing health systems, the use of quantitative data may accurately provide a perspective on the much required NTD prevalence at the country and county level, enhance the interpretation of the spatial distribution of NTDs, provide an opportunity to compare multiple perspectives and triangulate the observed research findings. Secondly, the study recommends subsequent longitudinal research since vulnerability to NTDs and the ability to access care and treatment are influenced by the political, social, economic, and cultural systems that affect populations in a multitude of pathways depending on contextual factors. As such, the use of longitudinal studies will analyze the relationships between systems and other factors over space and time as well as provide insights into other factors that were not examined in this research such as ethnicity and disability to ensure policy makers formulate health inclusive policies in the rapidly developing region of sub-Saharan Africa.

## 7.7 Chapter Summary

The chapter discusses the research findings as per the three study objectives. First, it establishes that NTDs are diseases of the poor that contribute to a cycle of poverty, decreased productivity and long term disability. Additionally, NTDs are a proxy for inequalities in the structural systems since people infected and affected by NTDs are unable to lobby for their human rights, possess limited finances, and lack access to health care, live in areas that have inadequate housing, polluted water sources and poor sanitation.

Secondly, the research establishes the need for intersectoral collaboration at the national and local level among other interventions such as early case finding and proper diagnosis and the provision of universal healthcare to include rapid diagnosis and treatment of NTDs at affordable or no costs to the citizens of Kenya. Third, the research establishes that wellbeing is a multi-dimensional concept that varies with place and personal experiences. As such, people living in NTD endemic regions are poverty-stricken, dependent and reside in areas with poor health infrastructure. As a result, they conceptualize their wellbeing to include aspects of their lives such as spiritual and psychosocial health, mental capacity, and good relationships with others. Also, their wellbeing means being free from diseases, having good socioeconomic status, literacy, access to information and the ability to engage in activities that bring happiness.

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# APPENDICES

## Appendix A1: Local ethics clearance letter

**MASENO UNIVERSITY ETHICS REVIEW COMMITTEE**

Tel: +254 057 351 622 Ext: 3050
Fax: +254 057 351 221

Private Bag – 40105, Maseno, Kenya
Email: muerc-secretariate@maseno.ac.ke

**FROM**: Secretary - MUERC

**DATE**: 4th January, 2018

**TO**: Elizabeth Akinyi Ochola
Department of Geography and Environmental Management
University of Waterloo
200 University Avenue West, Waterloo, Ontario
N2L3G1

**REF**: MSU/DRPI/MUERC/00496/17

**RE: Capturing the Impact of Structural Iniquities on the Prevalence and Experience of Neglected Tropical Diseases (NTDs) and How this Affects Health and Wellbeing in Sub-Saharan Africa (SSA) – A case Study of Kenya. Proposal Reference Number MSU/DRPI/MUERC/00496/17**

This is to inform you that the Maseno University Ethics Review Committee (MUERC) determined that the ethics issues raised at the initial review were adequately addressed in the revised proposal. Consequently, the study is granted approval for implementation effective this 4th day of January, 2018 for a period of one (1) year.

Please note that authorization to conduct this study will automatically expire on 3rd January, 2019. If you plan to continue with the study beyond this date, please submit an application for continuation approval to the MUERC Secretariat by 15th December, 2018.

Approval for continuation of the study will be subject to successful submission of an annual progress report that is to reach the MUERC Secretariat by 15th December, 2018.

Please note that any unanticipated problems resulting from the conduct of this study must be reported to MUERC. You are required to submit any proposed changes to this study to MUERC for review and approval prior to initiation. Please advice MUERC when the study is completed or discontinued.

Thank you.

Dr. Bonuke Anyona,
Secretary,
Maseno University Ethics Review Committee

DIRECTORATE OF RESEARCH PUBLICATION & CONSULTANCIES 04 JAN 2018 MASENO UNIVERSITY

Cc: Chairman,
Maseno University Ethics Review Committee.

**MASENO UNIVERSITY IS ISO 9001:2008 CERTIFIED**

**Appendix A2 General Information session for use in community meetings and/with local authorities**

**Study title**: *Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*

**Study Location**: Western, Coast, Eastern, Nyanza and Nairobi

The Purpose of the research project is to identify political, economic, social and cultural impacts of NTDs on health and wellbeing in communities living in endemic regions of Kenya, to investigate the capacity of local communities to address the burden of NTDs and to evaluate the effectiveness of existing NTD campaigns

**Introduction:**

My name is *Elizabeth Ochola*, a PhD Student of health geography, in the Faculty of Geography and Environmental Management at the University Of Waterloo, Ontario, Canada. My supervisor is **Prof. Susan J. Elliott (University of Waterloo, Department of Geography and Environment Management*, (519) 888-4567 Ext. (31107).*** This study will focus on the impact of Neglected Tropical Diseases (NTDs) on health and wellbeing. This study, is for my (Elizabeth Ochola's) PhD training in health geography under the academic supervision of Prof. Susan Elliott. The title of my research is **"Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya".**

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE# 22493). If you have any questions for the committee, contact the Chief Ethics Officer, Office of Research ethics, at + 1-519-888-4567 ext. 36005 or ore-ceo@ uwaterloo.ca and Maseno University Ethics Review Committee (MUERC) at muerc-secretariate@maseno.ac.ke, +254 57 351 622 ext. 3050. The County Government and its ministries, department, and authorities including the Ministry of Health, Devolution and Planning, and their sub-county offices have been notified about this study, and they have given permission for the study to be conducted. I have also visited the offices of the local authority leaders (chiefs and the assistant chiefs) who have organized for this meeting today. In this meeting, I would like to seek your permission to conduct my study in your community. However, before agreeing or failing to agree, I would like to take the opportunity to explain to you the study details.

**Information about the study**

Neglected Tropical Diseases (NTDs) are a diverse group of communicable diseases and conditions with distinct characteristics that affect the poorest populations. These diseases affect more than 1.4 billion people and cost developing economies billions of dollars annually in lost revenue (WHO, 2015; 2010). NTDs remain endemic to many regions left behind by socioeconomic progress and cause a heavy burden of disability that exceeds malaria and tuberculosis. In Kenya, 15 out of the 17 NTDs are suspected, confirmed, or endemic. Even

though most of the NTDs are not a direct cause of mortality, they cause immense suffering, (KNSP, 2016) impairment, disfigurement and even permanent disability.

The long-term nature of the infections is made worse by a lack of health care access. (Hotez *et al.,* 2006). Global improvements in healthcare have eliminated NTDs in developed countries, whereas in sub-Saharan Africa and Kenya, people infected with NTDs still lack access to basic preventative and diagnostic services (Deaton, 2013). This kind of disparity leads to exclusion from important aspects of life such as education, governance and health care which are crucial for wellbeing.

The association between poverty and NTD infection seems to be well documented. However, it remains unclear how structural inequities contribute to the prevalence and experience of NTDs within the broader context of health and wellbeing. Considering this, the proposed research will use a mixed method approach to assess the link between NTDs, health and wellbeing. The quantitative section of the research will use data from the Kenyan Neglected Tropical Disease Division. This aspect of the data will focus on the prevalence data collected by the organization over five years. The qualitative aspect of the data will be collected through focus group discussions, key informant interviews and photovoice. The focus group discussions will be conducted with middle age men and women, older adults of both genders and youths who have resided in the area for a least one year. The sessions will be organized by gender, age and will have approximately 7-8 people to discuss issues about the study. Participation in this study is voluntary. It involves key informant interviews (KIIs) of 30 minutes and Focus Group Discussions (FGDs) of approximately 60-90 minutes in length. The discussions will take place in a neutral location. The participants may decline to answer any of the questions if they wish.

Further, they may decide to withdraw consent from the study at any time without any negative consequences by advising the researcher to destroy the data available. It is not possible to withdraw consent once papers and publications have been submitted to publishers. The interviews will be audio recorded to ensure accurate collection of responses, which will be later transcribed for analysis. The analyzed data will be published and the information presented in scientific presentations and conferences.

All information that will be provided will be considered completely confidential; the names will not appear in any thesis or report resulting from this study, but with the participant's permission, anonymous quotations may be used. The researchers will ask that all participants keep the study discussions confidential, but there is a minimal risk that participants may not keep information disclosed in the sessions private.

Data collected in this study will be retained for at least three years in a locked office at the University of Waterloo, Canada. Only researchers associated with the study will have access. There will be a community appreciation meeting after the research results have been analyzed. All community members will be invited to the meeting at an agreed date, time and venue. In the meeting, the summary of the study findings shall be presented and discussed.

If you would like to take part in these sessions, I will ask you to register and leave behind your contact information. Once again your participation in the study is voluntary, and you can take your time to decide to participate. Once you decide, please alert your local leader or the researcher on telephone number +254 798 40 69 10

**Appendix A3: Invitation letter for an information session for community members and/with local authorities**

To potential participant: …….

**Project Title:** *Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya.*

You are at this moment invited to an information session for the project mentioned above, which shall take place on (insert date) at (insert the venue) as from (insert the time). During the meeting, the details of the proposed research that will be conducted in your community will be discussed. The study aims to identify political, economic, social and cultural impacts of Neglected Tropical Diseases (NTDs) on health and wellbeing in communities living in endemic regions of Kenya. Thus, the study will explore the lived-in experiences of people infected and affected by NTDs. You have been identified as a potential participant in this study and are therefore invited to attend the forth coming meeting. In this meeting, more details on the study shall be discussed. This letter is also accompanied by the information sheet summarizing the study objectives and methodologies. Your attendance is highly appreciated.

Yours sincerely,

Elizabeth Ochola
Ph.D. student,
University of Waterloo, Ontario, Canada

**Appendix A4: Information Sheet (Recruitment Letter) for Focus Group Participants**

**Date: ……...**

**Project Title:** *Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*

**Organizers:** Prof. Susan J. Elliott
University of Waterloo, Canada
Department of Geography and Environment Management
*(519) 888-4567 Ext. (31107)*

Elizabeth Ochola (Ph.D. Student)
University of Waterloo, Canada
Department of Geography and Environmental Management
(519) 888-4567 Ext. 37037

This session focuses on exploring the link between Neglected Tropical Diseases (NTDs), health and wellbeing, and it will be facilitated by Elizabeth Ochola, a Ph.D. student at University of Waterloo, Canada. My supervisor is Prof. Susan J. Elliott. This study is for the Ph.D. training for Elizabeth Ochola.
Participation in this session is voluntary and involves a 60-90 minutes discussion in a neutral location on issues relating to how NTDs affect your health and wellbeing. The main objective is to identify political, economic, social and cultural impacts of NTDs in communities living in endemic regions of Kenya. Every focus group will have a homogenous group of approximately 7-8 participants who will be categorized by gender and age. There is minimal risk to your participation in this session. You may decline to answer any questions you feel you do not wish to answer and may decline contributing to the session in other ways if you so wish.

Further, you may decide to withdraw consent from the study at any time without any negative consequences by advising the researcher to destroy the data available. However, it is not possible to withdraw consent once papers and publications have been submitted to publishers. The interviews will be audio recorded to ensure accurate collection of responses, which will be later transcribed for analysis. The analyzed data will be published and the information presented in scientific presentations and conferences. All information you provide will be considered confidential, and your name will not be identified with the input you give to this session. Furthermore, you will not be identified by name in the report that the facilitator will produce from this session. Given the group format of this session, we will ask you to keep in confidence information that identifies or could potentially identify a participant and/or his/her comments and to also respect the privacy and confidentiality of other individuals during the discussion. Although the researchers may keep what is said confidential, there is a risk that other participants may not. To ensure appropriate data collection, only those individuals who agree to be audio recorded will be invited to participate in the study. The information collected from this session will be kept for at least three years at the ***University Of Waterloo, Canada in Prof. Susan J.***

***Elliott's office in a locked cabinet***. Only researchers associated with the study will have access to the study documents. There will be a community appreciation meeting after the research results have been analyzed.

Following the completion of the research, all community members will be invited for an appreciation meeting at an agreed date, time and venue. In the meeting, the summary of the study findings shall be presented and discussed.

You can let me know if you are interested in receiving a copy of the executive summary of the session outcome.
I want to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#22493). However, the final decision about participation is yours. Should you have comments or concerns resulting from your participation in this study, please contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca and Maseno University Ethics Review Committee (MUERC) at muerc-secretariate@maseno.ac.ke, +254 57 351 622 ext. 3050.
Thank you for your assistance with this project. We will provide feedback to the community once the research is completed.

Yours sincerely,
Elizabeth Ochola
Ph.D. student,
University of Waterloo, Ontario, Canada

**Appendix A5: Informed Consent Form for focus group participants**

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

_____

I have read the information presented in the information letter about the session being facilitated by Elizabeth Ochola and supervised by Dr. Susan J. Elliott, Department of Geography and Environmental Management, University of Waterloo. I have had the opportunity to ask the facilitator any questions related to this session and received satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the session without penalty at any time by advising the facilitator of this decision.

This project has been reviewed by and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#22493). However, the final decision about participation is mine. I understand that if I have any comments or concerns for the ethics committee resulting from my participation in this study, I can contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca and Maseno University Ethics Review Committee (MUERC) at muerc-secretariate@maseno.ac.ke, +254 57 351 622 ext. 3050. I have full knowledge of all preceding, I agree, of my own free will, to participate in this session and to keep in confidence information that could identify specific participants and/or the information they provided.

Print Name _____
Signature _____
Date _____
Witness_____

**Appendix A6: Information Sheet (Recruitment Letter) for Key Informants**

**Date: ……...**

**Study Title:** *Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*

**Organizers:** Prof. Susan J. Elliott
University of Waterloo, Canada
Department of Geography and Environment Management
*(519) 888-4567 Ext. (31107)*

Elizabeth Ochola (Ph.D. Student)
University of Waterloo, Canada
Department of Geography and Environmental Management
(519) 888-4567 Ext. 37037

Dear Sir/Madam (insert participant's name):
……
This letter is an invitation to consider participating in a study I am (Elizabeth Ochola) conducting as part of my Ph.D. degree training (health geography) in the Department of Geography and Environmental Management at the University of Waterloo under the supervision of Professor Susan J. Elliott. I would like to provide you with more information about this project and what your involvement would entail if you decide to take part.

**Study information:**
Neglected Tropical Diseases (NTDs) are a diverse group of communicable diseases and conditions with distinct characteristics that affect the poorest populations. These diseases affect more than 1.4 billion people and cost developing economies billions of dollars annually in lost revenue. NTDs remain endemic to many regions left behind by socioeconomic progress and cause a heavy burden of disability that exceeds malaria and tuberculosis. In Kenya, 15 out of the 17 NTDs are either suspected, confirmed, or endemic. Even though most of the NTDs are not a direct cause of mortality, they cause immense suffering, impairment, disfigurement and even permanent disability.

The long-term nature of the infections is made worse by the lack of health care access. Global improvements in healthcare have eliminated NTDs in developed countries, whereas in sub-Saharan Africa and Kenya, people infected with NTDs still lack access to basic preventative and diagnostic services. This kind of disparity leads to exclusion from important aspects of life such as education, governance, and health care which are crucial for wellbeing.

The association between poverty and NTD infection seems to be well documented. However, it

remains unclear how structural inequities contribute to the prevalence and experience of NTDs within the broader context of health and wellbeing. The results of this study will advise policy makers on how best governments can achieve equity in systems for improved health and wellbeing of vulnerable populations. Since your organization is directly involved with NTD activities within the country. It is in a better position to highlight the pertinent issues at hand.

Participation in this study is voluntary. It will involve an interview of approximately 40-60 minutes in length to take place in a mutually agreed upon location. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw consent from this study at any time without any negative consequences by advising the researcher. It is not possible to withdraw consent once papers and publications have been submitted to publishers. To ensure appropriate data collection, only those individuals who agree to be audio recorded will be invited to participate in the study. All the information you provide will be considered completely confidential. There is minimal risk to your participation in the study, while I will not identify you by name or position in final reports or publications, given the small number of individuals who occupy positions like yours, it may be possible for a motivated individual to attempt to discern your identity. Data collected during this study will be retained for at least three years in a locked office cabinet in my supervisor's lab. Only researchers associated with the project will have access. There will be a community appreciation meeting after the research results have been analysed. Following participation in the research, all participants will be invited for an appreciation meeting at an agreed date, time, and venue. In the meeting, the summary of the study findings shall be presented and discussed.

I want to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#22493). However, the final decision about participating is yours. If you have any comments or concerns for the ethics committee resulting from your participation in this study, please contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca and Maseno University Ethics Review Committee (MUERC) at muerc-secretariate@maseno.ac.ke, +254 57 351 622 ext. 3050. I hope that the results of my study will be of benefit to the disadvantaged populations of Kenya by giving them the opportunity to have their voices heard on issues relating to NTDs health and wellbeing.
I very much look forward to speaking with you, and thank you in advance for your assistance in this project.

Yours sincerely,

Elizabeth Ochola
Ph.D. student,
University of Waterloo, Ontario, Canada

**Appendix A7: Recruitment Email – Key Informant Interviews**

Dear ***(insert name of Key Informant)***,

My name is Elizabeth Ochola and I am a Ph.D. Candidate working under the supervision of Dr. Susan Elliott in the department of Geography and Environmental Management at the University of Waterloo. I am contacting you because we are conducting a study to understand the link between Neglected Tropical Diseases (NTDs), health and wellbeing. We are interested in your experiences in the study of Neglected Tropical Diseases.

Participation in this study involves a 40-60-minute interview (In person or over the phone depending on your availability) about your experiences with NTDs. Further information about the study is included in the attached information letter for key informants. This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision about participation is yours. If you have any comments or concerns resulting from your participation in this study, please contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca and Maseno University Ethics Review Committee (MUERC) at muerc-secretariate@maseno.ac.ke, +254 57 351 622 ext. 3050.
If you are interested in participating, please contact me at eochola@uwaterloo.ca to schedule an interview.

Sincerely,

Elizabeth Ochola
Ph.D. Candidate
School of Geography and Environmental Management

**Appendix A8: Consent Form for Key informants**

**Study Title:** *Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*

By signing this consent form, I understand that I am not waiving my legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

_____

I have read the information presented in the information letter about a study being conducted by Elizabeth Ochola, PhD Student and supervised by Dr. Susan J. Elliott, Department of Geography and Environmental Management, University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I have been informed orally and in writing about the aims and the procedures of the study, the advantages and disadvantages as well as potential risks. I am aware that my interview will be audio recorded to ensure an accurate collection of my responses. I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous. I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#22493). I understand that if I have any comments or concerns resulting from my participation in this study, I may contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca and Maseno University Ethics Review Committee (MUERC) at muerc-secretariate@maseno.ac.ke, +254 57 351 622 ext. 3050. With my signature, I certify that I will fulfill the requirements for the study participation and I understand that my participation is voluntary, and I can withdraw consent at any time without any negative consequences. Am aware it is not possible to withdraw consent once papers and publications have been submitted to publishers. I will inform the investigators about the link between NTDs, health and wellbeing

With full knowledge of all preceding, I agree, of my own free will, to participate in this study.

YES NO

I agree with the use of anonymous quotations in any thesis or publication that comes from this research.

YES NO

Participant Name: _____ (Please print/write)
Participant Signature: _____
Witness Name: _____ (Please print/write)
Witness Signature: _____
Date: _____

**Appendix A9: Invitation letter for all study participants to participate in the community appreciation meeting**

To the research participant: …….

**Project Title:** *Study Title: Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*

Date

Dear ***(Insert Name of Participant),***

I would like to thank you for your participation in this study entitled [*Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*. As a reminder, the purpose of this study is to identify how structural inequities contribute to the prevalence and experience of Neglected Tropical Diseases (NTDs) within the broader context of health and wellbeing. The data collected during interviews, focus group, and photovoice sessions will contribute to a better understanding on the link between NTDs, health, and wellbeing.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE file # 22493). If you have questions for the Committee contact the Chief Ethics Officer, Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca and Maseno University Ethics Review Committee (MUERC) at muerc-secretariate@maseno.ac.ke, +254 57 351 622 ext. 3050.

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with your community and also through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study or would like a summary of the results, please provide your email address or telephone contacts and when the study is completed, anticipated by [insert date], I will send you the information. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email or telephone as noted below.

Yours sincerely,

Elizabeth Ochola, Ph.D. student researcher,
University of Waterloo
Department of Geography and Environmental management
eochola@uwaterloo.ca
+254 798 40 69 10

**Appendix B1: Focus Group Discussion Schedule with Women (middle age 36-60)**

**Study Title:** *Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*

**Purpose of the checklist:**
This checklist will be a guide in the collection of data relating to the meaning of NTDs, health, and wellbeing. The research discussions will be audio-recorded to ensure accurate collection of responses. There are minimal risks to your participation in this session as researchers will not identify participants and are asking participants to keep the information confidential. You may decline to answer any questions you feel you do not wish to answer and may decline contributing to the session in other ways if you so wish. All information you provide will be considered confidential, and your name will not be identified with the input you give to this session. You will also not be identified by name in the report that the facilitator will produce from this session.

| **Construct** | **Question** | **Probes** |
|---|---|---|
| Neglected Tropical Diseases (NTDs) | Tell me about life in your community<br><br>What about the health in your Community<br><br>What are some of the diseases that are prevalent in your community?<br><br>Neglected Tropical Diseases (NTDs)? | Give me an example of an NTD<br>What NTDs are present in this community? |
| How NTDs affect health | What sorts of health issues affect families in this community?<br>What makes for a healthy community?<br>What do you think of when I say the word wellbeing?<br>Please let me know how NTDs affect you?<br>What do you think are some of the health issues caused by NTDs towards women and girls in this community?<br>What are some of the health challenges you encounter in your day to day life as a woman infected with NTDs?<br>How does NTD affect child health? What do you think are | Considering what you have described, do you consider NTDs to be a hindrance to your life?<br>If so, how?<br>How do you overcome such challenges? |

| | | |
|---|---|---|
| | some of the health issues facing children infected with NTDs in the community?<br>How would you like your children's life to be different from yours? | |
| **Assessment of health and wellbeing** | | |
| Social factors | Ok, thank you for such an excellent overview. I am now going to ask you questions relating to your community and daily life.<br>What are some of the social factors you think are important in your community? How does infection with NTDs affect such activities over time?<br>Are there any emerging social issues that women, girls, and children infected with NTDs face in this community? | How does NTDs affect family ties in this community? Have you experienced any changes over time?<br>Are there social networks and support within your community?<br>Are there opportunities and time for engagement in volunteer or church activities or local associations?<br>How does this relate to women's, girls, and children's health?<br>How have you overcome such limitations? |

| | | |
|---|---|---|
| Economic factors | Ok, great! Thank you for such a great discussion. I will now ask to discuss how NTDs affect the economic functions that matter to women.<br>Please, let me know the economic functions matter to you?<br>Can you tell me more about your housing status?<br>How has the free primary education policy impacted your community? What would you | How does this relate to the health of women, girls, and children?<br>How have you adapted to these? |

| | | |
|---|---|---|
| | like to be done differently in the education system?<br>Can you tell me more about employment and income? How does this relate to women, girls, and children? | |
| Cultural factors | Can we now talk about the cultural values and norms in your community?<br>Can we comment on cultural discrimination or segregation of people infected with NTDs?<br>What are some of the cultural issues associated with NTDs that you can say most affect the health of women, girls, and children? | How are these related to the health of women and children?<br>How have you adapted as women in this community? |
| Political context | We will now focus our discussion on politics. What are some of the political factors that influence women and girls in this community?<br>Are women and girls infected with NTDs in your community engaged in political issues?<br>If you were in the position of policy maker, what are some of the solutions to NTDs that you would recommend? | How has this impacted your health?<br>How are they engaged? If not, why? |
| Physical environment | Let us now discuss our physical environment. What do you think are some of the environmental issues that help spread NTDs to children, women, and girls in the community? | How is this related to the health and wellbeing of women and children? |
| Lifestyle and behaviour | What kinds of behaviours do you think make a person healthy? Why? | Relate this to the health of the community. Which one matters to you the most? |
| Health services | Thank you for such a great discussion. Can we now discuss health care services? What do you think are some of the most important issues concerning health care services? | Considering what you have described, would you consider the health care system effective? If yes/no why?<br>Can we also talk about accessibility, drug availability, |

| | | |
|---|---|---|
| | What are some of the challenges regarding health care services that persons infected with NTDs experience? | health insurance, specialized care and waiting time? How have you adapted? Are there alternatives? |
| Public health programs | Can we now discuss public health activities in the community? Please, let me know of the public health programs that matter to you?<br>Can we discuss the availability of potable water and sanitation in this community?<br>What are some of the challenges that persons infected with NTDs face in relation to public health programs in this community? | Which one matters to you the most?<br>How has water and sanitation impacted on your health? And how have you adapted?<br>Can we also comment on waste management, immunization, awareness creation, and health |
| **Existing interventions** | | |
| | Thank you for such a great discussion! We will now discuss if you are aware of any existing NTD interventions in your community.<br>Can you comment on the NTD interventions that are available in your community? Has this changed over time?<br>Are the NTD interventions adequate? | Please name some of the NTD interventions that are present in your community. |

**Thank you for your time and the information given**

**Appendix B2: Focus Group Discussion Schedule with men (middle age 36-60 years)**

**Study Title:** *Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*

**Purpose of the checklist:**
This checklist will be a guide in the collection of data relating to the meaning of NTDs, health, and wellbeing. The research discussions will be audio-recorded to ensure accurate collection of responses. There are minimal risks to your participation in this session as researchers will not identify participants and are asking participants to keep the information confidential. You may decline to answer any questions you feel you do not wish to answer and may decline contributing to the session in other ways if you so wish. All information you provide will be considered confidential, and your name will not be identified with the input you give to this session. You will also not be identified by name in the report that the facilitator will produce from this session.

| **Construct** | **Question** | **Probes** |
|---|---|---|
| Neglected Tropical Diseases (NTDs) | Tell me about life in your community<br><br>What about the health in your Community<br><br>What are some of the diseases that are prevalent in your community?<br><br>What are Neglected Tropical Diseases (NTDs)? | Give me an example of an NTD<br>What NTDs are present in this community? |
| How NTDs affect health | Please let me know how NTDs affect you?<br>What do you think are some of the health issues caused by NTDs towards men in this community?<br>What are some of the health challenges you encounter in your day to day life as a man infected with NTDs?<br>How does NTD affect child health? What do you think are some of the health issues facing children infected with NTDs in the community?<br>How would you like your children's life to be different from yours? | Considering what you have described, do you consider NTDs to be a hindrance to your life?<br>If so, how?<br>How do you overcome such challenges? |

| **Assessment of health and wellbeing** | | |
|---|---|---|
| Social factors | Ok, thank you for such a great overview. I am now going to ask you questions relating to your community and daily life.<br>What are some of the social factors you think are important in your community? How does infection with NTDs affect such activities over time?<br>Are there any emerging social issues that women, girls, and children infected with NTDs face in this community? | How does NTDs affect family ties in this community? Have you experienced any changes over time?<br>Are there social networks and support within your community?<br>Are there opportunities and time for engagement in volunteer or church activities or local associations?<br>How does this relate to men and children's health?<br>How have you overcome such limitations? |

| | | |
|---|---|---|
| Economic factors | Ok, great! Thank you for such a great discussion. I will now ask to discuss how NTDs affect the economic functions that matter to men.<br>Please, let me know the economic functions that matter to you?<br>Can you tell me more about your housing status?<br>How has the free primary education policy impacted your community? What would you like to be done differently in the education system?<br>Can you tell me more about employment and income? How does this relate to men and children? | How does this relate to the health of men and children?<br>How have you adapted to these? |
| Cultural factors | Can we now talk about the cultural values and norms in your community?<br>Can we comment on cultural discrimination or segregation of people infected with NTDs?<br>What are some of the cultural issues that you can say most | How are these related to the health of the men and children?<br>How have you adapted as men in this community? |

| | | |
|---|---|---|
| | affect the health of men and children? | |
| Political context | We will now focus our discussion on politics. What are some of the political factors that influence men in this community?<br>Are men infected with NTDs in your community engaged in political issues?<br>If you were in the position of policy maker, what are some of the solutions to NTDs that you would recommend? | How has this impacted your health?<br>How are they engaged? If not, why?<br>Why? |
| Physical environment | Let us now discuss our physical environment. What do you think are some of the environmental issues that help spread NTDs to children and men in the community? | How is this related to the health and wellbeing of men and children? |
| Lifestyle and behaviour | What kinds of behaviours do you think to make a person healthy? Why? | Relate this to the health of the community. Which one matters to you the most? |
| Health services | Thank you for such a great discussion. Can we now discuss health care services? What do you think are some of the most important issues concerning health care services?<br>What are some of the challenges concerning health care services that persons infected with NTDs experience? | Considering what you have described, would you consider the health care system effective? If yes/no why?<br>Can we also talk about accessibility, drug availability, health insurance, specialized care and waiting time? How have you adapted? Are there alternatives? |
| Public health programs | Can we now discuss public health activities in the community?<br>Please, let me know of the public health programs that matter to you?<br>Can we discuss the availability of portable water and sanitation in this community?<br>What are some of the challenges that persons infected with NTDs face in relation to public health programs in this community? | Which one matters to you the most?<br>How has water and sanitation impacted on your health? And how have you adapted?<br>Can we also comment on waste management, immunization, awareness creation, and health |

**Appendix B3: Focus Group Discussion Schedule with Women (old age 60 and above)**

**Study Title:** *Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*

**Purpose of the checklist:**
This checklist will be a guide in the collection of data relating to the meaning of NTDs, health, and wellbeing. The research discussions will be audio-recorded to ensure accurate collection of responses. There are minimal risks to your participation in this session as researchers will not identify participants and are asking participants to keep the information confidential. You may decline to answer any questions you feel you do not wish to answer and may decline contributing to the session in other ways if you so wish. All information you provide will be considered confidential, and your name will not be identified with the input you give to this session. You will also not be identified by name in the report that the facilitator will produce from this session.

| **Construct** | **Question** | **Probes** |
|---|---|---|
| Neglected Tropical Diseases (NTDs) | Tell me about life in your community<br><br>What about the health in your Community<br><br>What are some of the diseases that are prevalent in your community?<br><br>What are Neglected Tropical Diseases (NTDs)? | Give me an example of an NTD<br>What NTDs are present in this community? |
| How NTDs affect health | Please let me know how NTDs affect you?<br>What do you think are some of the health issues caused by NTDs towards older women in the community?<br>What are some of the health challenges you encounter in your day to day life as an older woman infected with NTDs?<br>How does NTD affect child health? What do you think are some of the health issues facing children infected with NTDs in the community? | Considering what you have described, do you consider NTDs to be a hindrance to your life?<br>If so, how?<br>How do you overcome such? |

| | | |
|---|---|---|
| | How would you like your children's life to be different from yours? | |
| **Assessment of health and wellbeing** | | |
| Social factors | Ok, thank you for such a great overview. I am now going to ask you questions relating to your community and daily life.<br>What are some of the social factors you think are important in your community? How does infection with NTDs affect such activities over time?<br>Are there any emerging social issues that women, girls, and children infected with NTDs face in this community? | How does NTDs affect family ties in this community? Have you experienced any changes over time?<br>Are there social networks and support within your community?<br>Are there opportunities and time for engagement in volunteer or church activities or local associations?<br>How does this relate to women's, girls, and children's health?<br>How have you overcome such limitations? |

| | | |
|---|---|---|
| | | |
| Economic factors | Ok, great! Thank you for such a great discussion. I will now ask to discuss how NTDs affect the economic factors that matter to women.<br>Please, let me know the economic factors that matter to you?<br>Can you tell me more about housing status? | How does this relate to the health of older women, girls, and children?<br>How have you adapted to these? |

| | | |
|---|---|---|
| | How has the free primary education policy impacted your community? What would you like to be done differently in the education system?<br>Can you tell me more about employment and income? How does this relate to older women, girls, and children? | |
| Cultural factors | Can we now talk about the cultural values and norms in your community?<br>Can we comment on cultural discrimination or segregation of people infected with NTDs?<br>What are some of the cultural issues that you can say most affect the health of older women, girls, and children? | How are these related to the health of older women and children?<br>How have you adapted as older women in this community? |
| Political context | We will now focus our discussion on politics. What are some of the political factors that influence older women and girls in this community?<br>Are older women and girls infected with NTDs in your community engaged in political issues?<br>If you were in the position of policy maker, what are some of the solutions to NTDs that you would prioritize? | How has this impacted your health?<br>How are they engaged? If not, why?<br>Why? |
| Physical environment | Let us now discuss our physical environment. What do you think are some of the environmental issues that help spread NTDs to children, older women, and girls in the community? | How is this related to the health and wellbeing of older women and children? |
| Lifestyle and behaviour | What kinds of behaviours do you think make a person healthy? Why? | Relate this to the health of the community. Which one matters to you the most? |
| Health services | Thank you for such a great discussion. Can we now discuss health care services? What do you think are some of the most | Considering what you have described, would you consider the health care system effective? If yes/no why? |

| | | |
|---|---|---|
| | important issues regarding health care services?<br>What are some of the challenges concerning health care services that persons infected with NTDs experience? | Can we also talk about accessibility, drug availability, health insurance, specialized care and waiting time? How have you adapted? Are there alternatives? |
| Public health programs | Can we now discuss public health activities in the community? Please, let me know of the public health programs that matter to you?<br>Can we discuss the availability of potable water and sanitation in this community?<br>What are some of the challenges that persons infected with NTDs face in relation to public health programs in this community? | Which one matters to you the most?<br>How has water and sanitation impacted on your health? And how have you adapted?<br>Can we also comment on waste management, immunization, awareness creation, and health |
| **Existing interventions** | | |
| | Thank you for such a great discussion! We will now discuss if you are aware of any existing NTD interventions in your community.<br>Can you comment on the NTD interventions that are available in your community? Has this changed over time?<br>Are the NTD interventions adequate? | Please name some of the NTD interventions that are present in your community? |

**Thank you for your time and the information given**

**Appendix B4: Focus Group Discussion Schedule with men (old age men 60 and above years)**

**Study Title:** *Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*

**Purpose of the checklist:**
This checklist will be a guide in the collection of data relating to the meaning of NTDs, health, and wellbeing. The research discussions will be audio-recorded to ensure accurate collection of responses. There are minimal risks to your participation in this session as researchers will not identify participants and are asking participants to keep the information confidential. You may decline to answer any questions you feel you do not wish to answer and may decline contributing to the session in other ways if you so wish. All information you provide will be considered confidential, and your name will not be identified with the input you give to this session. You will also not be identified by name in the report that the facilitator will produce from this session.

| **Construct** | **Question** | **Probes** |
|---|---|---|
| Neglected Tropical Diseases (NTDs) | Tell me about life in your community<br><br>What about the health in your Community<br><br>What are some of the diseases that are prevalent in your community?<br><br>What are Neglected Tropical Diseases (NTDs)? | <br><br><br><br><br><br>Give me an example of an NTD<br>What NTDs are present in this community? |
| How NTDs affect health | Please let me know how NTDs affect you?<br>What do you think are some of the health issues caused by NTDs towards older men in this community?<br>What are some of the health challenges you encounter in your day to day life as a man infected with NTDs?<br>How does NTD affect child health? What do you think are some of the health issues facing children infected with NTDs in the community?<br>How would you like your children's life to be different from yours? | <br><br>Considering what you have described, do you consider NTDs to be a hindrance to your life?<br>If so, how?<br>How do you overcome such? |

| **Assessment of health and wellbeing** | | |
|---|---|---|
| Social factors | Ok, thank you for such a great overview. I am now going to ask you questions relating to your community and daily life.<br>What are some of the social factors you think are important in your community? How does infection with NTDs affect such activities over time?<br>Are there any emerging social issues that women, girls, and children infected with NTDs face in this community? | How does NTDs affect family ties in this community? Have you experienced any changes over time?<br>Are there social networks and support within your community?<br>Are there opportunities and time for engagement in volunteer or church activities or local associations?<br>How does this relate to older men and children's health?<br>How have you overcome such limitations? |

| | | |
|---|---|---|
| Economic factors | Ok, great! Thank you for such a great discussion. I will now ask as to discuss how NTDs affect the economic factors that matter to men.<br>Please, let me know the economic factors that matter to you?<br>Can you tell me more about housing status?<br>How has the free primary education policy impacted your community? What would you like to be done differently in the education system?<br>Can you tell me more about employment and income? How does this relate to older men and children? | How does this relate to the health of older men and children?<br>How have you adapted to these? |
| Cultural factors | Can we now talk about the cultural values and norms in your community?<br>Can we comment on cultural discrimination or segregation of people infected with NTDs?<br>What are some of the cultural issues that you can say most | How are these related to the health of older men and children?<br>How have you adapted as older men in this community? |

| | | |
|---|---|---|
| | affect the health of older men and children? | |
| Political context | We will now focus our discussion on politics. What are some of the political factors that influence older men and girls in this community?<br>Are men infected with NTDs in your community engaged in political issues?<br>If you were in the position of policy maker, what are some of the solutions to NTDs that you would recommend? | How has this impacted your health?<br>How are they engaged? If not, why?<br>Why? |
| Physical environment | Let us now discuss our physical environment. What do you think are some of the environmental issues that help spread NTDs to children and older men in the community? | How is this related to the health and wellbeing of older men and children? |
| Lifestyle and behaviour | What kinds of behaviours do you think make a person healthy? Why? | Relate this to the health of the community. Which one matters to you the most? |
| Health services | Thank you for such a great discussion. Can we now discuss health care services? What do you think are some of the most important issues regarding health care services?<br>What are some of the challenges concerning health care services that persons infected with NTDs experience? | Considering what you have described, would you consider the health care system effective? If yes/no why?<br>Can we also talk about accessibility, drug availability, health insurance, specialized care and waiting time? How have you adapted? Are there alternatives? |
| Public health programs | Can we now discuss public health activities in the community? Please, let me know of the public health programs that matter to you?<br>Can we discuss the availability of potable water and sanitation in this community?<br>What are some of the challenges that persons infected with NTDs | Which one matters to you the most?<br>How has water and sanitation impacted on your health? And how have you adapted?<br>Can we also comment on waste management, immunization, awareness creation, and health |

| | | |
|---|---|---|
| | face in relation to public health programs in this community? | |
| **Existing interventions** | | |
| | Thank you for such a great discussion! We will now discuss if you are aware of any existing NTD interventions in your community.<br>Can you comment on the NTD interventions that are available in your community? Has this changed over time?<br>Are the NTD interventions adequate? | Please name some of the NTD interventions that are present in your community? |

**Thank you for your time and the information given**

**Appendix B5: Focus Group Discussion Schedule with Youths (18-35 years)**

**Study Title:** *Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*

**Purpose of the checklist:**
This checklist will be a guide in the collection of data relating to the meaning of NTDs, health, and wellbeing. The research discussions will be audio-recorded to ensure accurate collection of responses. There are minimal risks to your participation in this session as researchers will not identify participants and are asking participants to keep the information confidential. You may decline to answer any questions you feel you do not wish to answer and may decline contributing to the session in other ways if you so wish. All information you provide will be considered confidential, and your name will not be identified with the input you give to this session. You will also not be identified by name in the report that the facilitator will produce from this session.

| **Construct** | **Question** | **Probes** |
|---|---|---|
| Neglected Tropical Diseases (NTDs) | Tell me about life in your community<br><br>What about the health in your Community<br><br>What are some of the diseases that are prevalent in your community?<br><br>What are Neglected Tropical Diseases (NTDs)? | Give me an example of an NTD<br>What NTDs are present in this community? |
| How NTDs affect health | Please let me know how NTDs affect you?<br>What do you think are some of the health issues caused by NTDs towards older women in the community?<br>What are some of the health challenges you encounter in your day to day life as an older woman infected with NTDs?<br>How does NTD affect child health? What do you think are some of the health issues facing children infected with NTDs in the community?<br>How would you like your children's life to be different from yours? | Considering what you have described, do you consider NTDs to be a hindrance to your life?<br>If so, how?<br>How do you overcome such? |

| **Assessment of health and wellbeing** | | |
|---|---|---|
| Social factors | Ok, thank you for such a great overview. I am now going to ask you questions relating to your community and daily life.<br>What are some of the social factors you think are important in your community? How does infection with NTDs affect such activities over time?<br>Are there any emerging social issues that women, girls, and children infected with NTDs face in this community? | How does NTDs affect family ties in this community? Have you experienced any changes over time?<br>Are there social networks and support within your community?<br>Are there opportunities and time for engagement in volunteer or church activities or local associations?<br>How does this relate to women's, girls, and children's health?<br>How have you overcome such limitations? |

| | | |
|---|---|---|
| Economic factors | Ok, great! Thank you for such a great discussion. I will now ask to discuss how NTDs affect the economic factors that matter to women.<br>Please, let me know the economic factors that matter to you?<br>Can you tell me more about housing status?<br>How has the free primary education policy impacted your community? What would you like to be done differently in the education system?<br>Can you tell me more about employment and income? How does this relate to older women, girls, and children? | How does this relate to the health of older women, girls, and children?<br>How have you adapted to these? |
| Cultural factors | Can we now talk about the cultural values and norms in your community?<br>Can we comment on cultural discrimination or segregation of people infected with NTDs?<br>What are some of the cultural issues that you can say most | How are these related to the health of older women and children?<br>How have you adapted as older women in this community? |

| | | |
|---|---|---|
| | affect the health of older women, girls, and children? | |
| Political context | We will now focus our discussion on politics. What are some of the political factors that influence older women and girls in this community?<br>Are older women and girls infected with NTDs in your community engaged in political issues?<br>If you were in the position of policy maker, what are some of the solutions to NTDs that you would prioritize? | How has this impacted your health?<br>How are they engaged? If not, why?<br>Why? |
| Physical environment | Let us now discuss our physical environment. What do you think are some of the environmental issues that help spread NTDs to children, older women, and girls in the community? | How is this related to the health and wellbeing of older women and children? |
| Lifestyle and behaviour | What kinds of behaviours do you think make a person healthy? Why? | Relate this to the health of the community. Which one matters to you the most? |
| Health services | Thank you for such a great discussion. Can we now discuss health care services? What do you think are some of the most important issues regarding health care services?<br>What are some of the challenges concerning health care services that persons infected with NTDs experience? | Considering what you have described, would you consider the health care system effective? If yes/no why?<br>Can we also talk about accessibility, drug availability, health insurance, specialized care and waiting time? How have you adapted? Are there alternatives? |
| Public health programs | Can we now discuss public health activities in the community? Please, let me know of the public health programs that matter to you?<br>Can we discuss the availability of potable water and sanitation in this community?<br>What are some of the challenges that persons infected with NTDs | Which one matters to you the most?<br>How has water and sanitation impacted on your health? And how have you adapted?<br>Can we also comment on waste management, immunization, awareness creation, and health |

| | | |
|---|---|---|
| | face in relation to public health programs in this community? | |
| **Existing interventions** | | |
| | Thank you for such a great discussion! We will now discuss if you are aware of any existing NTD interventions in your community.<br>Can you comment on the NTD interventions that are available in your community? Has this changed over time?<br>Are the NTD interventions adequate? | Please name some of the NTD interventions that are present in your community? |

**Thank you for your time and the information given**

**Appendix B6: In-Depth Interview Guide with Key Informants**

**Study Title:** *Capturing the impact of structural inequities on the prevalence and experience of Neglected Tropical Diseases (NTDs) and how this affects health and wellbeing in sub-Saharan Africa (SSA) - A case study of Kenya*

**Purpose of the checklist:**
This checklist will be a guide in the collection of data relating to the meaning of NTDs, health, and wellbeing. The research discussions will be audio-recorded to ensure accurate collection of responses. There are minimal risks to your participation in this session as researchers will not identify participants and are asking participants to keep the information confidential. You may decline to answer any questions you feel you do not wish to answer and may decline contributing to the session in other ways if you so wish. All information you provide will be considered confidential, and your name will not be identified with the input you give to this session. You will also not be identified by name in the report that the facilitator will produce from this session.

| Construct | Question | Probes |
|---|---|---|
| **health and wellbeing** | Tell me about life in your community<br><br>What about the health in your Community<br><br>What are some of the diseases that are prevalent in your community?<br><br>To start off our discussion today, can you please tell me about your county/ organization/ministry and its involvement with NTDs, health and wellbeing issues<br>Please, let me know what makes for a healthy community free from NTDs? | Considering what you have described, do you consider this community as one that is healthy and free from NTDs? Why or why not?<br>What is the<br>From your experience working in the community, what aspects of a healthy community matter to the community you serve? |
| **Specific theoretical determinants of health and wellbeing** | | |
| Social factors | Ok, thank you for such a great overview. I am now going to ask you questions relating to the daily life of the community members infected with NTDs<br>What are some of the social factors you think are important in this community? Has these changed over time?<br>Are there any emerging social issues relevant to the health of this community? | How are family ties in this community? Have you experienced any changes over time?<br>Are there social networks and support within the community?<br>Are there opportunities and time for engagement in volunteer or church activities or local associations?<br>How does this relate to the health and wellbeing of the community? |

| | | |
|---|---|---|
| Economic factors | Ok, great! Please, let me know the economic factors that matter to this community?<br>Can you tell me more about employment, income? How does this relate to of the community?<br>Can you tell me more about housing status?<br>What would you like to be done differently in the education system?<br>How has the free primary education policy impacted your community? | How does this relate to the health of the community?<br>How has this community adapted to these? |
| Cultural factors | Can we now talk about the cultural values and norms in this community?<br>Can you comment on cultural discrimination or segregation of persons infected with NTDs?<br>What are some of the cultural issues that affect the health of the people that you serve? | How are these related to the health of the community?<br>How has the community adopted? |
| Political factors | What are some of the political factors that influence this community?<br>Comment on actively political engagement by the community members?<br>How is women leadership viewed in this community?<br>As a decision-maker or policymaker, what are some of the NTD policy issues that you would prioritize in this community? | How has this impacted your health?<br>How are they engaged? If not, why?<br>Why do you feel that is important? |
| Physical factors | What do you think are some of the environmental issues facing this community with respect to NTDs?<br>What are some of the challenges in relation to the physical environment that this community faces? | How is this related to the health and wellbeing of the community members?<br>What are your thoughts about soil quality, water quality, air |

| | | |
|---|---|---|
| Lifestyle and behavior | What are some of the lifestyle and behavior issues that confront this community? | Relate this to the health of the community. Which one matters to you the most?<br>How is the community adapting to such challenges? |
| Healthcare services | Thank you for such a great discussion. Can we now discuss health care services? What do you think are some of the most important issues with reference to health care services?<br>What are some of the challenges with reference to NTD health care services that we experience? | Considering what you have described, would you consider the health care system effective? If yes/no why?<br>Can we also talk about accessibility, drug availability, health insurance, specialized care and waiting time? How has the community adapted?<br>Are there alternatives that the community has opted for? |
| Public health programs | Please, let me know of the public health programs that matter to the community?<br>Can we discuss the availability of potable water and sanitation in this community?<br>What are some of the challenges that NTD infected people experience in relation to public health programs in this community? | Which one matters to this community the most?<br>How has water and sanitation impacted on your health? And how has the community adapted?<br>Can we also comment on waste management, immunization? |

**Appendix C1: Theme codes for focus group participants**

Study areas

- Dabaso-SA1
- Jaribuni-SA2
- Lodwar-SA3
- Magarini-SA4

Geographical regionsSemi-arid-GR1

- Arid-GR2

The health of the community

- Common flu-HC1
- Many diseases-HC2
- Poverty linked to the diseases-HC3

Common diseases and conditions in the study areas

- Cholera-CD1
- Diarrheal diseases-CD2
- Epilepsy-CD3
- Hernia-CD4
- High blood pressure-CD5
- HIV/AIDs-CD6
- Malaria-CD7
- Malnutrition (Kwashiorkor)–CD8
- Tuberculosis-CD9
- Typhoid-CD10
- Ulcers-CD11
- Others-CD12

Common NTDs in the study areas

- Dog bites-rabies-CN1
- Hydatid cysts-CN2
- Jiggers-CN3
- Leprosy-CN4
- Lymphatic filariasis-CN5
  -Elephantiasis-CN5_1
  -Hydrocele-CN5_2

- Snakebites-CN6
- Soil transmitted helminths-CN7
- Trachoma-CN8
- Urinary schistosomiasis-CN9
- Visceral leishmaniasis (Kalazar)-CN10

Populations at risk of NTDs

- Adult female-PR1
- Adult male-PR2
- Children under 5years-PR3
- Old men-PR4
- Old women-PR5
- Young boys-PR6
- Young girls-PR7

Causes of NTD infection

- Curses-CNI_1
- Drinking too much alcohol outdoors-CNI_2
- Hereditary-CNI_3
- Ignorance-CNI_4
- Lack of clean water-CNI_5
- Lack of medications in health facilities-CNI_6
- Lack of preventive items such as mosquito nets-CNI_7
- Multiple partners-CNI_8
- Unsanitary environment-CNI_9
- Vectors for example mosquitoes-CNI_10
- Witchcraft -CNI_11

Health problems associated with NTDs

- Blindness-HP1
- Blood in urine-HP2
- Death-HP3
- Deformity-HP4
- Extreme pain-HP5
- Flu-HP6
- Fluid retention-HP7
- General fatigue-HP8
- Hernia-HP9
- Itching-HP10
- Lowered immunity-HP11

- Poor quality of life/wellbeing-HP12
- Swelling of the lower extremities-HP13
- Swelling of the stomach-HP14

Other challenges

- Alcoholism-OC1
- Child labor-OC2
- Child/early marriages-OC3
- Food insecurity-OC4
- In access to education-OC5
- In access to health services-OC6
- Polygamy-OC7
- Rise in NCDs such as cancers-OC8
- Selling personal assets to cater for basic needs-OC9

Wellbeing

- Absence of diseases-W-1
- Presence of food, environment, water, and good roads-W-2
- When you get the appropriate medicine-W-3
- Live a good life W-4
-

Effectiveness of the health care system

- Yes-ES1
- No-ES2
- Maybe-ES3
- I do not know-ES4

Challenges in health services in regards to NTD infection

- Corruption of health workers-bribes-CH1
- Cost-CH2
- Lack of specialists to carry out interventions such as surgeries-CH3
- Long wait times-CH4
- Low suspicion index-CH5
- No health insurance-CH6
- No transport services to health services-CH7
- NTDs as ‘cold cases’-CH8
- Poor access to referral hospitals-CH9
- Poor curative services-CH10
- Poor diagnostic services-CH11

- Shortage of drugs-CH12

Availability of drugs in the health facilities

- Yes-AD1
- No-AD2

Water sources

- Boreholes-WS1
- Lake-WS2
- Piped water-WS3
- River-WS4
- Stream-WS5

Sanitation facilities

- Bushes-SF1
- Latrine-SF2
- Toilets-SF3

Housing risks

- Dusty floors-HR1
- Loose soil-HR2
- Mud houses-HR3

Political factors

- Devolution-Jobs-PF1
- Lack of political goodwill from counties-PF2
- Marginalization-PF3

Physical impacts

- Disfigurement-PI_1
  -Reproductive parts-PI_1_1
  -Extremities-PI_1_2

- Disability-PI_2
  -Blindness-PI_2_1
- Infected wounds PI_3

Economic activities

- Casual laborers-EA1

- Charcoal burning-EA2
- Salaried employment by the county government-EA3
- Farming-EA4
- Fish vending-EA5
- Milk vending-EA6
- Motor bike operator-EA7
- Unemployed-EA8
- Rearing goats, sheep, camels-EA9
- Small business-EA10
- Wine tapping-EA11

Economic impacts of NTDs

- Little or no productivity-EI_1
- Meager/ no earnings-EI_2
- No money to access health facilities-EI_3
- Poor educational opportunities-EI_4
- Lack of customers-wounds-EI_5
- Lack of other opportunities-EI_6
- Loss of jobs-EI_7
- Incapacitation-EI_8

Social factors

- Family support-SF1
- Community support-SF2
- Participation in:SF3

-Baraza's-SF3_1
-Church activities-SF3_2
-Volunteer activities-SF3_3
-Women groups-SF3_4

Social impacts of NTDs

- Domestic & marital conflict-SIN1
- The collapse of the family structure-SIN2
- Education-Absenteeism-SIN3
- Illiteracy-SIN4

Cultural impacts of NTDs

- Early marriages-CIN1
- Polygamy-CIN2

Psychological impacts of NTDs

- Not being taken seriously-PIN1
- Stigma-PIN2
- Discrimination-PIN3
- Ridicule-PIN4
- Desertion from significant other, friends &family-PIN5
- Dependability on other people-PIN6
- Incapacitation-PIN7

Environmental risks

- Proximity to natural water bodies-ER1

Rivers-ER1_1
Lakes-ER1_2
Streams-ER1_3

- Stagnant water in broken pots & open basins-ER2
- Harsh climatic conditions- hot and dry, cold-ER3
- Floods-ER4
- Drought-ER5
- Dust-ER6
- Pollution-ER7

Free Primary Education

Advantages

- Well received by the community-FPEA1
- School health programs for NTDs, i.e. deworming-FPEA2
- Increased enrollment-FPEA3
- School feeding programs in some areas-FPEA4

Disadvantages

- Decreasing quality of education-FPED1
- 'Hidden costs'-water, electricity, first aid equipment-FPED2
- Poor teacher to child ratio-FPED3
- Child truancy & drop outs-FPED4

Recommendations

- The scrapping of ‘other’ fees-FPER1
- Expansion of the school feeding programs-FPER2

Available interventions for NTDs

- Surgery- CH8
- Annual MDA and deworming programs-AIN2
- Distribution of mosquito nets-AIN3
- None-AIN4

Successful interventions

- Free eye surgeries for trachoma-SI_1
- Guinea worm eradication campaigns-SI_2

Temporary measures

- Draining of hydroceles-TM1
- Use of herbal remedies-TM2
- Cleansing ceremonies-TM3

Public health programs in the community

- Health education by the community health volunteers (CHVs)-PH1
- Use of chiefs Baraza’s to rely on the information on outbreaks such as cholera, dengue-PH2
- KEPI vaccinations-PH3
- Mosquito net distribution program-PH4

Challenges in NTD interventions

- Seasonal donor funded interventions for-CINN1
  -Jigger-CINN1_1
  -Trachoma-CINN1_2
  -Visceral leishmaniasis-CINN1_3
- Re-infection-CINN2
- Access of MDA programs to remote populations –CINN3
- Untreated community members-‘disease reservoirs’-CINN4
- Lack of appropriate funds for NTD public health campaigns from the counties-CINN5

Proposed interventions

- Community education-POI_1
- Health insurance-POI_2
- Counseling services & support groups for people infected with long term disabling NTDs such as leprosy, elephantiasis, trachoma, and snake bites-POI_3
- Access care and treatment for free/affordable rates-POI_4
- Indoor spraying for vectors-POI_5
- The building of latrines- POI_6
- Early physical examinations especially for hydrocele- POI_6
- Establishment of piped water- POI_7
- Provision of tablets for treating drinking water- POI_8
- Political goodwill- POI_9
- Proper diagnosis- POI_10
- Adequate number of health care workers- POI_11
- Environmental sanitation- POI_12
- Community empowerment- POI_13
- Clean drinking water POI_14

**Appendix C2: Theme codes for Key Informant Interviews**

NTD Endemic counties

- Baringo-NE1
- Busia-NE2
- Embu-NE3
- Isiolo-NE4
- Kajiado-NE5
- Kilifi-NE6
- Kisumu-NE7
- Kitui-NE8
- Kwale-NE9
- Laikipia-NE10
- Marsabit-NE11
- Meru-NE12
- Mombasa-NE13
- Nakuru-NE14
- Narok-NE15
- Nyandarua-NE16
- Samburu-NE17
- Turkana-NE18
- Wajir-NE19
- West Pokot-NE20

Study areas

- Busia-SA1
- Kilifi –SA2
- Kisumu-SA3
- Nairobi-SA4
- Turkana-SA5

Geographical regionsSemi-arid-GR1

- Arid-GR2
- Equatorial-GR3

Designation of key informants

- Chikungunya Patient-DK1
- Chronic Schistosomiasis Patient-DK2

- Community Health Volunteer (CHV)-DK3
- Country Director for WASH-DK4
- County NTD Laboratory Officer-DK5
- County Disease Surveillance Coordinator-DK6
- County Neglected Disease Coordinator-DK7
- County NTD Pharmacist-DK8
- County Public Health Officer/Epidemiologist-DK9
- National Trachoma Coordinator-DK10
- Pharmacist/ Schistosomiasis & STH Program Manager-DK11
- Pharmacists/ Program Head at the Kenya NTD unit-DK12
- Program Coordinator for Fred Hollows Foundation-DK13
- Program Manager for Leishmaniasis-DK14
- Program Manager- National School Deworming program-DK15
- Senior Research Scientist at KEMRI-DK16
- Veterinarian/ Program lead at Kenya Snakebite Research and Intervention center-DK17
- Veterinarian /Zoonotic Research Scientist-DK18

Work Experience

- 1 year-WE1
- 1.5 year-WE2
- 2 years-WE3
- 3 years-WE4
- 4 years-WE5
- 5 years-WE6
- 6 years-WE7
- 7 years-WE8
- 9 years-WE9

Involvement with NTDs

- Sensitization: IN1

-Staff-IN1_1

-Community-IN1_2

-Stakeholders-IN1_3

- Identification of cases-IN2
- Capacity building-IN3
- Disease surveillance-IN4
- Coordination of prevention & control activities for NTDs-IN5
- Follow up of NTD cases for treatment purposes-IN6
- Disease prevention, & health promotion to prolong life-IN7
- Research based evidence on control of zoonotic diseases such as rabies-IN8
- Pilot counties for the elimination of rabies-IN9
- Improving health and economic status of communities-IN10
- Implementing health programs and research-IN11
- Capacity building on social behavior change-1N12
- Hygiene education-1N13
- Door to door visitation of community members-1N14
- Implementation of research oriented and tried programs that are cost effective & can be scaled-IN15
- Technical guidance, proposal development and financial management to the Ministry of Health-IN16
- Monitoring and evaluation of NTD programs i.e. deworming-IN17
- Development of strategies and policies for NTDs-1N18
- Designing and planning research aspects of the program i.e. designing surveys-IN19
  -Baseline surveys-IN19_1
  -Impact assessment surveys-IN19_2
  -Surveillance surveys-1N19_3
  -Operational research-IN19_4
- Research mobilization of program requirements-1N20
- Drug procurement from WHO and facilitating their entry into the country-IN21
- Mapping of NTDs-IN22
- Examining the burden of NTDs in Kenya-morbidity &mortality, socioeconomic burden-IN23
- Allocating required resources to NTD activities-IN24
- Improvement on the current therapies for certain NTDs, i.e. anti-venom-1N25
- Improvement on context specific diagnosis for context specific & treatment –IN26
- Establishing a center of excellence in research, attract funding and build capacity-IN27
- Management of NTD conditions-IN28
- Impact assessment for NTDs-IN29

Sector:

- Public sector-S1
- NGO-S2

Stakeholders:

- Ministry of Health-ST1
- County governments-ST2
- Ministry of Education-ST3
- Local Research institutions-ST4
- International research institutions-ST5

The health of the community

- Average health-HC1
- Fair health seeking behavior-HC2
- High morbidity and mortality of infectious diseases-HC3
- Malnourished-HC4
- Poor access to water and sanitation-HC5
- Poor health indices-HC6
- Poor health seeking behavior-HC7
- Vulnerable-HC8

Reason for the good health of the community

- Community strategy-RC1
- Presence of various partners  both local and international–RC2
- An improvement in health seeking behavior-RC3
- Improvement in reporting of NTDs-RC4
- Urbanization-RC5
- Presence of community Health Volunteers (CHV)-RC6
- Devolution- more health facilities-RC7
- Health research in some counties-RC8
- Improvement in women empowerment, i.e. a third majority rule, small groups (switis), microfinance , basic rights, environmental rights, training and allocation of funds-RC9
- Free health services in level two  facilities-dispensary-RC10

Diseases / conditions that are prevalent in the community

- Amobiasis-D1
- Cancer of the esophagus-D2
- Cholera-D3
- Conjunctivitis-D4
- Diabetes-D5
- Diarrhea-D6
- Giardiasis-D7
- Hernia-D8

- HIV/AIDs-D9
- Hypertension-D10
- Malaria-D11
- Measles (sometimes)-D12
- Meningitis-D13
- Other respiratory infections-D14
- Pneumonia-D15
- Skin conditions (Rashes/Fever)-D16
- Tuberculosis-D17
- Typhoid-D18

NTDs that are prevalent in the community

- Jiggers/Tungiasis-N1
- Urinary schistosomiasis-N2
- Intestinal Schistosomiasis-N3
- Soil transmitted Helminths (worms)-N4
  -Hookworm-N4_1
  -Trichuris trichiura-N4_2
  -Ascaris lumbricoides-N4_3
- Lymphatic filariasis-N5
- Snake bite-N6
- Hydrocele-N7
- Leprosy-N8
- Dengue-N9
- Chikungunya-N10
- Dog bites-rabies-N11
- Trachoma-N12
- Cutaneous leishmaniasis-N13
- Visceral leishmaniasis (Kalazar)-N14
- Cystic regional echinococcosis (Hydatid cysts)-N15
- Mycetoma (Madura foot)-N16
- Scabies-N17

Characteristics of people infected by NTDs

- Dependent-C1
- Found in poor resource settings-C2
- Have poor health infrastructure-C3
- Illiterate/semi illiterate-C4

- Live in areas with poor road networks-C5
- Marginalized-C6
- Neglected in social affairs-C7
- Poverty stricken–C8
- Vulnerable-C9

Other health challenges in the community

- A rise in NTD associated NCDs such as diabetes retinopathy-OT1
- AlcoholisM-OT2
- Cataracts-OT3
- Child headed households due to HIV/AIDs-OT4
- Early marriages-OT5
- Female Genital Mutilation-OT6
- Fluorosis-OT7
- Food insecurity-OT8
- Glaucoma-OT9
- Gunshot wounds-OT10
- Infant, child and Maternal mortality-OT11
- Lack of adherence to HIV/AIDs and TB medication-defaulters ( MDR)-OT12
- Poor menstrual hygiene management-OT13
- Poor nutrition-OT14
- Poor sources of energy-OT15
- Rape-OT16
- Scorpion bites-OT17
- Sparganosis-OT18
- Teenage pregnancies-OT19
- Wife inheritance-OT20

Causes of NTD infection

- The close proximity of humans and animals-C1
- Curse-C2
- Drinking a lot of palm wine-C3
- Eating a lot of cashewnuts-C4
- Flies-C5
- Hereditary-C6
- Mosquito bites-C7
- Multiple sexual relations-C8
- Poor water and hygiene services (hardware and software)-C9

- Sandfly bites-C10
- Shared items, i.e. basin, towels, beddings-C11
- Witchcraft-C12

Are community members aware of the burden of NTDs

- Yes-A1
- No-A2
- Partially-A3
- Other-A4

The burden of NTDs on the healthcare system

- A reduction of infestations, i.e. trachoma and STHs-BH1
- An increase in the burden of NTDs such as leprosy that was thought to have been eliminated-BH2
- Focal nature of some NTDs, i.e. Leishmania, & Chikungunya-BH3
- Ignorance of communities-BH4
- Inconsistency in NTD programs/activities-BH5
- Reports of NTDs spreading to new areas, i.e. Lymphatic filariasis-BH6
- Some NTDs cause outbreaks, i.e. dengue & chikungunya-BH7
- STH is prevalent all over the country, but only 27 counties qualify for MDA-BH8

Lessons learnt

- Counties are diverse, and there is need to tailor NTD programs in line with the county objectives-L1
- Different health priorities across the counties-L2
- It is import to regularly re-assess prevalence levels for programs such as deworming to adequately cater to communities in need-L3
- It is important to allocate funds to strengthen weekly surveillance of NTDs-L4
- It is important to interrupt transmission by destroying inactive termite/ant hills where sandflies breed-L5
- It is important to educate the pastoralist community on the importance of investing in their health, i.e. hesitancy to buy nets or take family members to hospital-L6
- It is important to empower communities economically for them to be independent-L7
- It is important to have school health programs running during the entire school year for a lasting impact on schools and communities-L8
- It is important to have social scientists in NTD control activities to address issues of cultural practices and behavior change-L9
- It is important to establish the best way to sensitize communities in the digital age i.e. use of radio and text messages, documentaries, cartoons etc.-L10

- Malnutrition complicates treatment and management of NTDs such as leishmaniasis-L11
- Migration plays a role for NTD infection especially for nomadic communities-they move away from health facilities to look for pasture and water in very remote areas-L12
- NTD control activities need to be complimented by WASH programs-L13
- Resources and intersectoral partnerships are key to NTD control-L14
- Some approaches for NTDs work best using community based approaches over hospital based approaches –L15
- Some NTDs present with febrile symptoms similar to malaria i. e. dengue, chikungunya etc.-L16
- The government needs to invest more on NTD activities-L17
- The presence of community based interventions, information or awareness, does not always translate to health seeking behavior in some communities L18
- There are still knowledge gaps in community awareness of NTDs L19
- There is a need for collaboration & partnership in the changing political context-L20
- There is a need for consistent use of mosquito nets for NTD vector control-L21
- There is a need for identification of permanent settlement for communities to do away with 'no man land syndrome' where there is no responsibility-L22
- There is a need to increase cost effectiveness and efficiency in all NTD programs-L23

Target populations for NTD programs

- 1-9 years-T1
- 40 years and above-T2
- 5-14 years-T3
- 6-14 Years-T4
- 8-15 years-T5
- 9-12 Years-T6
- All age groups-T7
- Children below 15 years-T8
- Children from 2years-T9
- Females-T10
- Males-T11
- Pregnant women-T12
- School aged children-T13
- The elderly-T14
- Under 5 years-T15

Health problems associated with NTDs

- Absenteeism-H1
- Amputation-H2
- Anemia-H3
- Bleeding-H4
- Blindness-H5
- Blood in urine-H6
- Confusion & aggressiveness-H7
- Death-H8
- Decreased cognitive function & participation in activities-H9
- Decreased concentration-H10
- Disability-H11
- Discomfort-H12
- Disfigurement-H13
- Fatigue-H14
- Fear of light-H15
- Fever-H16
- Flu like symptoms headache, fever & profuse sweating-H17
- Hepatomegaly-H18
- Hydrophobia-H19
- Intestinal obstruction-H20
- Inward turning of eye lashes-H21
- Malnutrition-H22
- Pain and tingling sensation at the site of infection-H23
- Paralysis-H24
- Protruding stomach-H25
- Splenomegaly-H26
- Wounds-H27

Wellbeing

- Encompasses the whole human being-W1
- Everything you want to do without suffering-W2
- Free from disease, access to food, shelter, education and engaging in activities that bring happiness-W3
- Generally fine in all aspects-W4
- Good health in all manners-W5
- Good socioeconomic status, literacy, and access to information-W6
- The holistic ability of human beings to access all necessities-W7
- Mental capacity & relationship with others-W8
- Not just the physical wellbeing but spiritual & psychosocial-All round wellness –W9

- Physical, mental, social, economically and spiritual stability-W10
- A holistic state of an individual/group of people/ community-W11

Family ties:

- Yes-F1
  -Short term-F1_1
  -Long term-F1_2
- No-F2

Political Engagement

- Yes-P1
- No-P2
- I don't know-P3

Political factors

- Lack of political goodwill in some counties-PF1
- Devolution is a new concept, and it is still ongoing-PF2
- Little or no budgetary allocations for NTD programs on the health budget-PF3
- Denial of the presence of NTDs from the area politicians-PF4
- Devolved health functions from the National government-decision makers are not technical people (political appointees) –PF5
- Low political engagement of NTD patients because of marginalization-PF6
- Poor link between research and policy/practice-PF7
- Leadership, control and stumbling blocks placed on research by the political class-PF8
- The failure of the county government to own NTD intervention programs after devolution-PF9
- Political interference of NTD programs during General Elections and the associated skirmishes/violence-PF10
- Politicians prefer to implement certain NTD initiatives, i.e. physically constructing health facilities, providing surgery and antibiotics compared to implementing Facial cleanliness & Environmental sanitation-PF11
- Tension, conflict, and insecurity in border counties which hamper NTD control efforts-PF12
- The politicization of water resources in arid-semi-arid areas- water is used for enticement/punishment for votes in an area-PF13

Success

- Some counties, i.e. Turkana realize that trachoma is a public health issue hence the county is investing in water and sanitation, i.e. sinking two boreholes in each of the 47 wards-S1

Economic activities

- Peasant farmers-E1
- Animal rearing-pigs, poultry, sheep, goat & cattle-E2
- Quarry mining-E3
- Motor bike operator-E4
- Wine tapping-E5
- Salaried employment in the public service-E6
- Small business-E7
- Formal employment in the county-E8
- Fishing-E9
- Irrigation-E10
- Rice farmers-E11
- Casual laborers-E12
- Pastoralism-sheep, goat, camel & donkeys-E13

Economic impacts of NTDs

- Little or no productivity-EI1
- Meager/ no earnings-EI2
- Loss of jobs-EI3
- Loss of revenue-billions of shillings every year-EI4
- Incapacitation-EI5
- Lack of customers-because of visible wounds-EI6
- Lack of other opportunities-EI7
- Some Zoonotic NTDs are not taken as trade sensitive, i.e. rabies-EI8

Social factors:

- Family support-SF1
- Community support-SF2
- Participation in: -SF3
  -Baraza's-SF3_1
  -Church activities-SF3_2
  -Volunteer activities-SF3_3

-Women groups-SF3_4
-Merry go rounds-SF3_5

- Low levels of literacy-SF4
- Gender inequality-SF5
- Poor advocacy from the affected groups-SF6
- Divorce, abandonment & collapse of the family structure-SF7
- Some religions do not allow the taking of medication-SF8
- School drop outs-SF9

Free Primary Education

Advantages

- Improved literacy rates-F1
- Easy to change mindset (behavior change) regarding NTD control-F2
- Easy access for school health programs because of the structures, i.e. deworming-F3
- Increased enrollment in the primary and improved transition to secondary schools-F4
- School health education programs, i.e. hand & face washing, school feeding programs, personal &mental hygiene-sensitization done using fun activities such as pictures, songs, cartoons, etc. –F5
- There are four times as many schools as we have hospitals-F6
- Deworming is a simple exercise that can be done by teachers, therefore more teachers than health workers-F7
- Teachers are parents themselves-comfortable with providing medication to children-F8
- Through the school structures, it is cost-effective to administer one pill compared to the community model-F9
- Preschool children (2-5 years) and non-enrolled children are able to access deworming programs through the schools-F10
- Deworming in schools improves health and academic output of the kids-F11
- Government increased financial allocation per child from KShs 1020 to KShs 1420-F12
- Introduction of specific vote head on environment and sanitation-F13
- Increased deworming coverage>80%-F14

Disadvantages

- The strain on available school infrastructure, i.e. classrooms and sanitation facilities-D1
- Poor teacher to child ratio-decreased quality of education-D2

Recommendations

- School ownership of NTD programs (continuity)-RE1

- Deworming drugs to be included in the first aid kits-RE2
- Curriculum to move from exam oriented to talent/skill oriented-RE3
- Expansion of the school facilities-ensure enrollment matches facilities-RE4

Cultural factors

- Norms prohibiting the consumption of certain foods for women & children-malnutrition-CF1
- Norms prohibiting hand washing-no washing hands after eating meat-CF2
- Norms prohibiting sharing of toilets among in-laws-CF3
- Women are required to seek permission from husbands to access NTD treatments-CF4
- Latrines are equated to houses-abuse of houses-CF5
- Hiding of NTD affected persons-CF6
- Polygamy-CF7
- Norms around the practice of open defecation-burying faces depict selfishness (deny pets their food), adds value to the soil and provide you with fresh air to breathe-CF8

Psychological impacts of NTDs

- Dependability on other people-P1
- Incapacitation-P2
- Not being taken seriously-P3
- Mistreatment-P4
- Stigma-P5
- Segregation/ discrimination-P6
  -Yes-P6_1
  -No-P6_2
  -I don't know-P6_3
- Neglect-P7
- 'Unintentional' neglect-being left alone as other family members go out to earn an income-P8
- Domestic & marital conflict-P9
- Embarrassment-P10
- Devastation-P11
- Destitution-P12

Behavioural factors

- Twilight discos (disco matanga) and cultural dances like Edong'a enhance vector bites-B1
- Outdoor drinking in the evenings-vector bites-B2
- Occupational activities such as fishing, irrigation, and car washing-B3
- Domestic activities such as grazing, collecting firewood, bathing, and washing utensils-B4

- Poor water storage practices in households-B5
- Flower pots around the home-breeding grounds for mosquitoes-B6
- Dumpsites-B7
- Accumulation of old tires- breeding grounds for mosquitoes-B8
- Poor investment in domestic animals, i.e. vaccinations-B9
- Nomadic life/Pastoralists-migration-B10
  - Contributes to poor environmental sanitation- no WASH facilities (open defecation) - B10_1
  -Nomadic practices make it hard for NTD interventions-B10_2
- Building houses around the animal shed for security-Presence of flies for transmission-B11
- Walking bare feet-B12
- Allowing flies to land on the face-sign of riches-B13
- Social activities, i.e. children playing in the bushes-B14
- Gender roles-women do more duties compared to men, i.e. building houses, caring for the home-B15
- Communal celebrations ('topetoron') improperly cooked meat as a risk factor for hydatid disease-B16
- Visiting traditional healers for NTD medication before going to health facilities-B17

Environmental factors

- Warm climatic conditions-EN1
- Filth-EN2
- Drought-EN3
- Topography-EN4
- Loose soil-EN5
- Black cotton soil-EN6
- Rainfall- Dengue & Chikungunya-EN7
- High temperature-Dengue & Chikungunya-EN8
- Vegetation-habitat for mosquitoes-EN9
- Peak biting hours for vectors such as mosquito-EN10
- Climate change-EN11
- Floods-stagnant water for vector breeding site-EN12
- Blocked drainages & water gutters-EN13
- Proximity to natural water bodies, i.e. lakes-EN14
- Stagnant water in broken pots & open basins-EN15
- Pollution-EN16
- Hot and dry-EN17
- Harsh terrain-EN18
- Soil contaminated with ova and cysts-EN19

- Forested areas for sand flies-EN20
- A lot of sand-EN21
- Termite /anthills-EN22
- Increase in wildlife human conflict-EN23

Water

Sources of Water

- Piped water-WA1
- Bore holes-WA2
- Earth pans-WA3
- Rivers-WA4
- Streams-WA5
- Rain water-WA6
- Springs-WA7
- Dams-WA8
- Wells-WA9
- Leak it in / Tippy tap-WA10

Challenges

- Water rationing-CH1
- Few hand washing facilities in schools-CH 2
- Poor maintance of hand washing facilities in schools, i.e. old, breakdown, need replacement-CH3
- Water treatment products associated with infertility-CH4
- Deep aquifers-expensive to draw water-CH5
- Water sources with too much fluoride-negative impact on people's health-CH6
  Scalability of some water sources-CH7
- Shallow water wells that can be accessed by animals, i.e. wild dogs and livestock-CH8

Success

- Establishment of water kiosks with filtration membranes-ES1
- Establishment of chlorine water points-ES2
- Establishment of solar disinfection facilities for households-ES3
- A reduction in diarrheal infections in some counties-ES4

Sanitation

- Diarrheal disease outbreaks caused by lack of sanitation-SA1

- Loose soil/Black cotton soil- the frequent collapse of latrines-SA2
- Rocky areas-makes construction of latrines difficult-SA3
- High water table-not feasible to dig latrines-SA4
- Poor refuse management in urban and rural settings-SA5

Recommendation

- Sand lining or the use of culverts in building latrines with loose/black cotton soils-RC1
- Provision of portable toilets in flood prone areas-RC2

Housing status

- Pathetic/Indecent housing-HS1
- Use of topsoil on the floors-HS2
- Poor ventilation-HS3
- Poor lighting-HS4
- Grass thatched-HS5
- Dome shaped structures-HS6
- Semi-permanent structures-HS7
- Mud walled-HS8
- Small houses-overcrowding-HS9
- Crevices-HS10
- Preference to sleep outside at night due to high temperatures-HS11

Available health care services

- Family planning-AH1
- Management of worms-AH2
- Management of skin conditions-AH3
- Medication for leprosy-AH4
- Ambulance services-AH5

Challenges in health services

- Minimal health attention to patients-CHS1
- Poor surgical facilities-CHS2
- Poor staffing-CHS3
- Limited health insurance-CHS4
- Poor access to health facilities –CHS5
- Poor road networks to health facilities-CHS6
- No remuneration to CHVs-CHS7

Public health programs

- Immunization programs-PH1
- HIV/AIDs programs-PH2
- Mass bed net distribution for specific NTDs –PH3
- Continuous health education-PH4
- WASH programs-PH5
- Nutrition programs-PH6
- Use of chiefs Baraza's/ dialogue days to rely on information on outbreaks such as cholera, dengue, etc. –PH7
- Community strategy-PH8
- Training of CHVs-PH9

Current NTD programs

- School-based deworming programs-CNP1
- CLTS-CNP2
- Financial Inclusion Improved Sanitation and Health in some counties-CNP3
- WASH-CNP4
  -Water treatment at the source-CNP4_1
  - Point of use (chlorine dispensers) -CNP4_2
  -School health programs-Unilever School of 5 in selected areas-CNP4_3
  -Personal hygiene, hand washing & face washing-CNP4_4

- Community sensitization-CNP5
- Management of wounds-CNP6
- Mass drug administration, i.e. ELF and trachoma program-CNP7
- Planned surgical intervention programs, i.e. hydrocelectomies-CNP8
- Launch of Morbidity Management and Disability Prevention Program-CNP9
- Indoor spraying-CNP10
- Fogging-outdoor spraying-CNP11
- Mass dog vaccinations-CNP12
- Community level practices, i.e. hygiene around NTD infected sites for rabies and elephantiasis-CNP13
- Community outreaches for Trachoma programs –CNP14
  -Mass screening–CNP14_1
  -Treating of minor ailments–CNP14_2
  -Trachoma surgery–CNP14_3
  -Cataract surgery–CNP14_4

- Establishment and review of the National school health policy that has eight thematic areas such as WASH that guides activities such as deworming–CNP15
- Training CHVs on case finding and counseling skills for NTDs–CNP16
- Program assessment of Onchocerciasis & Human African trypanosomiasis to lead certification as outlined by WHO–CNP17
- Intensified case management for lymphatic filariasis–CNP18
- Active case finding for leprosy–CNP19
- Operationalizing the NTD database in Kenya–CNP20
- Availability and use of trained personnel to carry out trachoma surgeries and perform splenic aspirates for diagnosis of Kalazar–CNP21
- SAFE ( Surgery, antibiotics, facial cleanliness & environment) strategy for trachoma in static and outreach sites–CNP22
- Free surgeries and management for trachoma, hydatid cysts, and Kalazar–CNP23

Partners working on NTDs

- WHO-NTP1
- FIND-NTP2
- Queen Elizabeth Trust-NTP3
- DNDi-NTP4
- UNICEF-NTP5
- CBM-NTP6
- Evidence Action-NTP7
- Children Investment Fund Foundation-NTP8
- Fred Hollows-NTP9
- Sight savers-NTP10
- AMREF-NTP11
- World vision-NTP12
- Child fund-NTP13
- Red cross-NTP14
- SWAP-NTP15
- Save the children-NTP16
- Diocese of Lodwar and Spanish doctors-NTP17

Success in NTD programs

- Free STHs drugs in health facilities-SNP1
- CLTS – 100 % ODF in some villages and counties-SNP2
- Certification stage for the Guinea worm campaign-SNP3
- A reduction in the burden of intestinal worms on school going children-improved growth-SNP4
- Government provision of free test kits during Dengue and Chikungunya outbreaks-SNP5

- Training of school teachers to carry out deworming exercises in schools-SNP6
- Establishment of technical working groups for some NTDs, i.e. schistosomiasis, trachoma, and snake bites-SNP7
- Launch of an integrated NTD unit with strategic plans (2011-2015; 2016-2020) –SNP8
- Establishment of the Kenyan zoonotic disease unit-SNP9
- Establishment of the Kenyan one health policy-SNP10
- Increased efficiency in school deworming programs-cost per child dropped from $0.6 to $0.46-SNP11
- Political commitment at the National level (cabinet secretary)- key indicators in the performance contract-SNP12
- Enhanced coordination of NTD activities in trachoma and school deworming programs to avoid duplication of activities-SNP13
- Improved community mobilization using Information Education and Communication (IEC) materials, i.e. posters, leaflets, and vernacular radio station-SNP14
- Urban development & lifestyle changes have eliminated NTDs such as trachoma in selected counties in Eastern and Nairobi provinces-SNP15
- Establishment of a National trachoma task force that has been devolved to 12 endemic counties-SNP16
- Free diagnostic kits and medication (SSG) for leishmaniasis-SNP17
- Long term Pharmaceutical commitment (Pfizer) toward NTDs, i.e. trachoma-SNP18
- Early advocacy for jiggers & snakebite envenoming in Kenya before WHO recognized it as category A NTD in 2017-SNP19
- Certain MDA programs have additional health benefits, i.e. treating trachoma using Zithromax helps with the treatment of chest problem & urinary tract infection-SNP20
- Use of motorcycle ambulance to transport people bitten by snakes in remote areas to hospitals-SNP21
- Some counties, i.e. Turkana have an NTD budget to cover some activities such as treatment in health facilities-SNP22

Challenges in NTD control programs

- The school deworming programs has specific needs, i.e. schools, ages (5-14 years)-CCP1
- Difficult to determine the prevalence of some NTDs, i.e. jiggers-CCP2
- Poor research on some NTDs, i.e. jiggers-CCP3
- Poor mindset-Hard to change behavioral & cultural practices (may take generations) –CCP4
- NTDs as ‘cold cases’ in health facilities-CCP5
- Poor reporting –CCP6
- Stock outs of drugs and other supplies-CCP7
- Poor management of NTDs-CCP8

- Relapses in community programs such as CLTS-CCP9
- Reinfection with NTDs-CCP10
- Delayed diagnosis of arboviral NTDS-CCP11
- Low suspicion index-misdiagnosis is real-CCP12
- Ignorance of affected communities-CCP13
- Competing interests with other diseases 'ATMs' (Aids, TB & malaria) –CCP14
- Certain NTDs not perceived as threats because of few deaths at a time-CCP15
- Poor funding- sometimes zero budget-CCP16
- Poor access to drugs for some NTDs-CCP17
- Some NTD intervention measures are expensive, i.e. vaccines, Kalazar-CCP18
- Poor NTD knowledge among the health workers (scanty information) –CCP19
- No uniform measures for NTDs such as jiggers-CCP20
- No clear policies on some NTDs such as jiggers-CCP21
- Frequent health care workers strikes-CCP22
- Poor drug accessibility for leprosy patients-CCP23
- Over-reliance on donor funded programs-no sustainability-CCP24
- The high cost of drugs, vaccines, and immunoglobins-CCP25
- Lack of anti-venom & anti-rabies vaccine in health facilities-CCP26
- Long wait times for surgical procedures-CCP27
- Failure to achieve MDA targets due to poor social mobilization-CCP28
- Untreated community members-'disease reservoirs'-CCP29
- Slow information uptake by the health workers and the community-CCP30
- Inappropriate response to an NTD outbreak, i.e. bed nets during dengue outbreak-CCP31
- Poor disease surveillance-action only happens during an outbreak-CCP32
- No cure for certain NTDs- only management, i.e. elephantiasis and TT-CCP33
- Co-endemicity of NTDs-CCP34
- No public health programs for certain NTDs just research- Dengue and Chikungunya-CCP35
- Poor delivery of NTD vaccines, i.e. snakebite vaccine can cause a violent response-CCP36
- Geographical inaccessibility of some areas during NTD interventions, i.e., islands, hilly and rocky terrains in Arid &semi-arid counties-CCP37
- Adverse side effects from certain NTD medications, i.e. PZQ and VL-CCP38
- Donor conflict regarding intervention strategies-who the target population should be-CCP39
- Chronic nature of some NTDs take many years to manifest, i.e. trachoma and hydatid cysts-CCP40
- Treatment of some NTDs requires hospital stays, i.e. SSG treatment for 30 days-CCP41

Alternative management of NTDs

- Use of sodom Apple-AN1
- Urine-AN2
- Detergent (OMO) –AN3
- Physical removal of the parasite using sharp objects, i.e., jiggers-AN4
- Cuts to the spleen to remove Kalazar parasites-AN5
- Use tweezers to pluck eyelashes that have turned inwards because it is an old age disease-AN6

Proposed NTD interventions/policies:

- Capacity building for staff working on NTDs-PNP1
- Counseling services & support groups for people infected with long term disabling NTDs such as leprosy, elephantiasis, trachoma, and snake bites-PNP2
- Intersectoral integration, i.e. water, agriculture, veterinary, public works, county government, etc.–PNP3
- Enforcement of public health act CAP 242–PNP4
- Enforcement of mass dog vaccination –PNP5
- All classrooms to have cemented floors for jigger control–PNP6
- Engagement with the political class at the county level–PNP7
- The building of more health facilities in some counties–PNP8
- NTDs to be included in the school curriculum for sensitization and behavioral change–PNP9
- Free/affordable vaccines for NTDs–PNP10
- Proper storage of water both indoors and outdoors–PNP11
- Reliable water supply–PNP12
- Formation of active community committees comprised of health workers and CHVs for active NTD surveillance–PNP13
- Research towards the influence of climate, habitat, etc. on NTD infection–PNP14
- Universal health care in counties–PNP15
- The rabies vaccine should be part of the KEPI vaccines and not an on-demand vaccine–PNP16
- Bottom up approach-engaging communities on policy changes they would like to see on NTD control–PNP17
- Provision of protective wear such as gumboots–PNP18
- Brainstorming on alternative economic activities that provide less exposure to NTDs–PNP19

Establishment of a food policy around NTDs to address issues of malnutrition and anemia leading to blood transfusion before treatment of Kalazar and hydatid cysts–PNP2