A Systems Thinking Approach to Global Governance for Neglected Tropical Diseases

A SYSTEMS THINKING APPROACH TO GLOBAL GOVERNANCE FOR NEGLECTED TROPICAL DISEASES

JEFFREY D. GLENN

A DELTA Doctoral Thesis Submitted to the Faculty of

The Harvard T.H. Chan School of Public Health

in Partial Fulfillment of the Requirements

for the Degree of *Doctor of Public Health*

Harvard University

Boston, Massachusetts

May, 2018

Thesis Advisor: Dr. Thomas J. Bossert Jeffrey D. Glenn

A Systems Thinking Approach to Global Governance for Neglected Tropical Diseases

ABSTRACT

Neglected tropical diseases (NTDs) represent a major disease burden in sub-Saharan Africa and among the poorest of the poor in other regions around the world. A significant global effort is underway to deliver preventive chemotherapy (PC) medicines via mass drug administration (MDA) to people at risk the five PC-NTDs: lymphatic filariasis, onchocerciasis, schistosomiasis, soil-transmitted helminths, and trachoma. Despite the existence of an effective, low-cost, and seemingly simple solution of MDA aided by donations of free drugs, most countries will fall far short of the ambitious global NTD control and elimination goals targeted to be achieved by 2020. The host organization for this DELTA project, the END Fund, is a private philanthropic initiative that pools and directs resources to PC-NTD programs. This project used a systems thinking approach to better understand the complex challenges around addressing NTDs in order to make recommendations to the END Fund on how it can catalyze NTD systems change. The mixed-methods approach included 1) a quantitative survey with social network analysis of global NTD stakeholders and 2) in-depth interviews at the global level and in Nigeria to develop a qualitative model of the NTD system. A parallel work stream involving a group-based systems thinking process was facilitated with END Fund staff in order to inform the research component and help generate actionable recommendations. The research uncovered a number of structural issues impeding progress on NTDs and identified five key leverage points for systems change: 1) clarify potential for and assess progress towards elimination, 2) increase support for interventions besides drug delivery, 3) reduce dependency on donors, 4) address the issue of health worker incentives, and 5) create a more inclusive global NTD community. Each of these areas was accompanied by recommendations for how the END Fund and NTD community can influence each lever. The project is an example of using rigorous research methods in a practical, applied way to bridge the gap between the academic and practice sectors. This model also points to the need for more documented evidence of successful and failed attempts to use systems thinking to make progress on complex social problems.

TABLE OF CONTENTS

LIST OF FIGURES WITH CAPTIONS

LIST OF TABLES WITH CAPTIONS

LIST OF APPENDICES WITH CAPTIONS

LIST OF ACRONYMS

APOC	African Program for Onchocerciasis Control
BMGF	Bill and Melinda Gates Foundation
CDD	Community Drug Distributor
CDTI	Community Directed Treatment with Ivermectin
CWW	Children Without Worms
DALY	Disability-Adjusted Life Year
DFID	United Kingdom Department for International Development
DMDI	Disease Management, Disability, and Inclusion
FMOH	Federal Ministry of Health
GPELF	Global Program for the Elimination of Lymphatic Filariasis
ICTC	International Coalition for Trachoma Control
IDM	Intensive Disease Management
IRB	Institutional Review Board
ITI	International Trachoma Initiative
LF	Lymphatic Filariasis
LGA	Local Government Area
LSTM	Liverpool School of Tropical Medicine
MDA	Mass Drug Administration
MDP	Mectizan Donation Program
MOH	Ministry of Health
NGDO	Nongovernmental Development Organization
NGO	Nongovernmental Organization
NNN	Neglected Tropical Disease Nongovernmental Organization Network
NTD	Neglected Tropical Disease
OCP	Onchocerciasis Control Program
PC	Preventive Chemotherapy
PC-NTD	Preventive Chemotherapy Neglected Tropical Disease
SAFE	Surgery, Antibiotics, Facial Cleanliness, Environmental Improvement
SDG	Sustainable Development Goal
STH	Soil-Transmitted Helminth
TB	Tuberculosis
UN	United Nations
USAID	United States Agency for International Development
WASH	Water, Sanitation, and Hygiene
WHO	World Health Organization

ACKNOWLEDGEMENTS

I would like to sincerely thank the many people who contributed to this thesis and who have supported me through my time in the Harvard DrPH program.

Jeff Walker inspired me to learn more about systems approaches to social change, introduced me to the END Fund, and provided generous financial support to make this project possible.

Ellen Agler and the rest of the END Fund team opened their doors and facilitated an incredible opportunity for me to learn about their organization and programs. Alessia Frisoli, Heather Haines, Karen Palacio, Kimberly Kamara, Molly Anderson, Yayne Hailu, Jamie Tallant, Carlie Congdon, and Warren Lancaster all contributed significant time and valuable input throughout the project.

Franca Olamiju and Ijeoma Achu from MITOSATH and Rita Oguntoyinbo from the Amen Healthcare Foundation offered their time and support to arrange the logistics for my research in Nigeria. Zaiya Umar and Chukwu Okoronkwo at the Nigerian FMOH contributed to the research and went to great lengths to ensure the study protocol would be approved within the planned timeline. Many other dedicated public health professionals in Nigeria and across the globe were very generous with their time and insights to help me understand the challenges they face as they work towards ending NTDs.

My DELTA project committee – Tom Bossert, Anjali Sastry, Teresa Chahine, and Nils Daulaire – contributed significantly to the design and execution of the project at critical junctures and helped me feel supported throughout the process. I have learned much from them and from numerous other Harvard faculty members and DrPH program staff who taught and mentored me over the past three years.

I am part of a wonderful cohort of DrPH students who I am fortunate to consider my colleagues and friends. They have consistently been there helping me to make the most of this experience of professional and personal growth.

Finally, I will be forever grateful to my wife, Kathryn, and my children, Vivienne and Philip, for believing in me and strengthening me and sacrificing so much to make this adventure possible. I absolutely could not have done any of this without you.

I. INTRODUCTION

The term “neglected tropical diseases” (NTDs) encompasses 20 bacterial and parasitic infections that are found most commonly in tropical and subtropical environments (World Health Organization, 2017b). These diseases continue to represent a major disease burden in many parts of the world, particularly among the 2.7 billion people living on less than US$2 per day (P.J. Hotez et al., 2007). Together, these diseases are estimated to cause approximately 350,000 deaths and are responsible for 27 million disability-adjusted life years annually (D. H. Molyneux, Savioli, & Engels, 2017). NTDs are closely associated with poverty, with a particularly heavy burden in sub-Saharan Africa and at least half of the world’s NTDs occurring among the poor in higher-income countries (Peter J. Hotez, Damania, & Naghavi, 2016).

Many NTDs can be controlled and even eliminated through the use of well-established interventions. The focus of global NTD control and elimination efforts has largely been on five NTDs that can be prevented through preventive chemotherapy (PC) medicines distributed via mass drug administration (MDA) (Webster, Molyneux, Hotez, & Fenwick, 2014). These five disease, often known as the PC-NTDs, are: lymphatic filariasis, onchocerciasis, soil-transmitted helminths, schistosomiasis, and trachoma. One of the reasons NTDs have generated so much attention from aid agencies and philanthropists is because NTD control and elimination is widely seen as one of the best investments in global health, with effective MDA interventions in many circumstances costing less than US$.50 per person per year (D. H. Molyneux et al., 2017; Webster et al., 2014)

There is a strong global coalition of NTD organizations that has made significant progress over the past decade. At a 2012 meeting, representatives from major public, private, and nonprofit sector global health institutions joined together to sign the London Declaration on Neglected Tropical Diseases that resulted in significant commitments of drug donations to increase treatment opportunities for millions

of people (Cohen, Silva, Cohen, Awatin, & Sturgeon, 2016). The World Health Assembly then approved a resolution in 2013 that defined strategies with clear targets and milestones for 17 NTDs, and it endorsed the World Health Organization (WHO) NTD Roadmap goals for NTD control and elimination (D. H. Molyneux, 2014). Another major step forward came when NTDs were included – along with HIV, tuberculosis (TB), and malaria – in the Sustainable Development Goals (SDG) as target 3.3 (Engels, 2016).

Although NTDs are often portrayed as a simple problem with easily implementable solutions, many challenges remain as most countries appear to be falling far short of reaching the ambitious "end goals" set by WHO for 2020 (D. H. Molyneux et al., 2017). Despite significant financial and in-kind contributions, there is still an estimated US$200 million gap in annual funding to reach global NTD targets (World Health Organization, 2016b). The level of political priority afforded to NTDs remains relatively low, particularly at the country level, compared to many other global health issues (Iltis & Matthews, 2017). High-burden countries often lack the capacity to manage complicated supply chains and deliver available treatments, which has created a situation where the availability of drugs can outstrip country capacity to deliver them (Cohen et al., 2016; Zarocostas, 2017). Additionally, many NTD activities continue to be carried out in siloes rather than being integrated with country health systems and programs for other diseases (Meheus, Rijal, Lutumba, Hendrickx, & Boelaert, 2012).

Progress on NTDs will require learning on behalf of all stakeholders to generate political attention, secure resources, build capacity, find integrated solutions, and address other issues. These types of complex problems require systems solutions, i.e. those that address all the actors and components required to make progress on a challenge. This DELTA project takes a systems thinking approach to seek to better understand the complex issues, particularly those related to global health governance, around solving NTDs in order to identify levers for change and make recommendations to help my host organization refine its strategy to end NTDs.

My host organization for this project, the END Fund, is a private philanthropic initiative established in 2012 to pool private and philanthropic sector resources to invest in programs targeting the five PC-NTDs. The END Fund is the largest source of private funding for NTD programs globally, with over US$75 million raised since 2012 and approximately US$17 million granted in 2016 alone (The END Fund, 2017). It has also become a key voice among the network of global organizations advocating for more attention towards NTDs. The END Fund sees its role as that of a systems entrepreneur – a neutral broker that seeks to understand the interconnected components of a system and brings together diverse stakeholders to change the underlying system – working to improve the way global NTD system functions to end NTDs (Kirsch, Bildner, & Walker, 2016).

The first section of this thesis presents the analytical platform on which the project is based. This includes a detailed description of the global NTD problem, ongoing interventions, and the network of stakeholders working to solve the problem. It also includes a brief exploration of the relevant political economy and health systems literature, as well as the systems thinking literature that provides the primary theoretical framework for the project. The analytical platform concludes with a detailed description of the project design. The results statement section of the thesis walks through the five project phases and describes the activities completed and the results produced in each phase. This includes the primary research findings in Phase 3 and the key recommendations in Phase 4. This section concludes with a discussion of the project limitations, implications for the practice of public health, and reflections on how the DrPH enabling change competencies were incorporated. The thesis concludes with a summary of key takeaways and issues to consider for future NTD, public health, and systems change research and practice.

II. ANALYTICAL PLATFORM

The analytical platform for this project is based on an extensive, albeit non-systematic, review of the literature relevant to NTDs, health system integration, global health governance, agenda setting, and systems thinking. These topics were identified as important during the initial phase of the project, given its aim and objectives. I had already collected many of the articles through my previous work on these topics. I conducted a search for additional articles in PubMed and Web of Science using these topics as key search terms. I then reviewed titles and abstracts to identify articles that could contribute to strengthening the theoretical foundation of the project. Finally, I identified additional articles by looking for relevant or highly cited articles within the references of the new articles identified.

The analytical platform that follows presents the problem of NTDs, the public health response, and some of the theories helpful to understanding key elements of this response. A thorough knowledge of this background information is critical to fully grasping the complex issues that are raised in the research findings of this thesis. The analytical platform concludes with a discussion of the systems thinking approach upon which the project framework was designed, as well as a presentation of the project design itself.

A. NTD Problem

DISEASES

While the existence of many of the diseases now known as NTDs can be traced to ancient human history (P. Hotez, Ottesen, Fenwick, & Molyneux, 2006), it was not until the 21st Century that these diseases became integrated under a common "brand". The term, "neglected tropical diseases" first came into widespread use following two meetings hosted by the German Agency for Technical Cooperation and the World Health Organization (WHO) in 2003 and 2005, during which participants called for an

integrated approach towards intervention in order to realize efficiencies and catalyze advocacy (B. Liese, Rosenberg, & Schratz, 2010). Scientists and advocates recognized some key similarities between the 13 diseases originally designated as NTDs: they are bacterial or parasitic infections, require similar interventions, affect many of the same populations, are closely associated as both causes and effects of poverty, and were neglected by policymakers and donors (P.J. Hotez et al., 2007; D. H. Molyneux, Hotez, & Fenwick, 2005).

As of 2018, the term NTDs officially refers to 20 different diseases (see Table 1), including three that were added in 2017 (World Health Organization, 2017b). Five of the 20 – lymphatic filariasis, onchocerciasis, trachoma, schistosomiasis, and soil-transmitted helminths – are commonly referred to as the preventive chemotherapy NTDs (PC-NTDs) due to their amenability to treatment by preventive chemotherapy antibiotics distributed via mass drug administration (MDA) campaigns (Ortu & Williams, 2017). Since the five PC-NTDs are among the most prevalent NTDs and are those targeted by the END Fund, they will be the focus of this thesis. These diseases are described briefly below.[1]

Table 1. List of Neglected Tropical Diseases

Diseases Classified by the World Health Organization as Neglected Tropical Diseases	
Buruli ulcer	Lymphatic filariasis*
Chagas disease	Onchocerciasis (river blindness)*
Dengue and Chikungunya	Rabies
Dracunculiasis (guinea-worm disease)	Schistosomiasis*
Echinococcosis	Soil-transmitted helminthiases*
Foodborne trematodiases	Taeniasis/Cysticercosis
Human Africa trypanosomiasis (sleeping sickness)	Trachoma*
Leishmaniasis	Yaws (endemic treponematoses)
Leprosy (Hansen's disease)	
Added in 2017	
Mycetoma, chromoblastomycosis and other deep mycoses	
Scabies and other ectoparasites	
Snakebite envenoming	

*PC-NTD prioritized by the END FUND

Note. From the World Health Organization website: http://www.who.int/neglected_diseases/en/.

[1] Unless otherwise noted, the information on these five diseases was drawn from the book: Forgotten People, Forgotten Diseases: The NTDs and their Impact on Global Health and Development (Peter J. Hotez & American Society for Microbiology., 2013)

Lymphatic Filariasis

Lymphatic filariasis (LF) is a chronic infection caused primarily by the filarial parasite Wuchereria bancrofti that is transmitted to humans by the same mosquito species that transmit malaria (Peter J. Hotez & American Society for Microbiology., 2013). Once someone is infected, the adult worms typically grow in lymphatic or genital body tissue and can reach sizes of a meter or more. A person with LF can have no symptoms or can progress to the most severe symptom, a disfiguring and dramatic complication known as elephantiasis, which is thought to occur when the adult worms dilate the lymphatic vessels in which they reside. Patients can also develop large hydroceles, an accumulation of fluid in the sac surrounding the testicles, and lymphedema, edema, and swelling of the legs and scrotum with thickening and loss of skin elasticity. While it rarely causes death, LF has serious economic and social consequences due to the disability and stigma it provokes in working age adults. The public health response to LF includes 1) preventive chemotherapy using combinations of the drugs albendazole, Ivermectin, and diethylcarbamazine and 2) morbidity management in the form of hygiene, skin care, and simple surgery to address the symptoms described above. A new triple drug therapy for LF has been found to be superior to previous treatment protocols and is currently being piloted and rolled-out in some settings (Jacobson & Bush, 2017).

Onchocerciasis

Onchoceriasis is a filarial infection commonly known as river blindness because the blackflies that transmit the often blinding infection breed along fast-flowing streams (Peter J. Hotez & American Society for Microbiology., 2013). The infection is caused by Onchocerca volvulus, a filiarial worm that can grow up to 20 inches and coils up in fibrous nodules that form under the skin. The Onchocerca microfilariae cause intense itching and disfigurement as they migrate in the skin, eventually reaching the eye and over time causing severe visual impairment and blindness. In certain endemic areas in sub-

Saharan Africa there are communities where 10 percent or more of the adult population is blind, which results in devastating economic and social consequences that can include food shortages and even the abandonment of homelands in fertile river valleys. Onchocerciasis control programs originally focused on vector control until the discovery and subsequent donation of the drug Ivermectin, an anthelmintic drug originally developed for veterinary use but that was later found to be safe and extremely effective in reducing the density of Onchocerca microfilariae in humans.

Trachoma

Trachoma, a chronic infection caused by the bacterium Chlamydia trachomitis, accounts for approximately 3% of blindness cases worldwide (Peter J. Hotez & American Society for Microbiology., 2013). The infection is spread from person to person on dirty hands and clothing and can also be spread by flies that carry the bacteria from the eye discharges of an infected person. It is therefore common for trachoma to affect entire families with detrimental impacts on economic and educational opportunities. Trachoma occurs most often in dry and dusty environments with poor water and sanitation infrastructure. Blindness occurs as recurrent infections lead to scarring of the eyelids that eventually turn inward and begin scratching the surface of the eyeball, which then leads to inflammation and scarring of the cornea. Trachoma is addressed using an integrated approach known as the SAFE strategy, which stands for **S**urgery, **A**ntibiotics, **F**acial hygiene, and **E**nvironmental improvement. The surgery provides immediate relief of trichiasis to prevent scarring in patients with advanced stages of the disease while the antiobiotic azithromycin is used to prevent and treat infections in communities with high prevalence of infection.

Schistosomiasis

Schistosomiasis is a waterborne infection caused by parasitic flatworms known as flukes (Peter J. Hotez & American Society for Microbiology., 2013). Humans acquire schistosomiasis after coming into contact

with the larval stages, or cercariae, that swim in freshwater where they spend part of their development living inside aquatic snails. The cercariae have forked tails that allow them to swim and directly penetrate human skin. After a person is infected, the adult schistosomes become resistant to the human immune system and live in the bloodstream where they release eggs that make their way to the urinary tract, intestine, and liver. These eggs produce serious disease that include anemia, chronic inflammation, and organ damage. These conditions are associated with undernutrition, cognitive delays, chronic abdominal pain, poor school performance, and reduced work capacity. Those most at risk for schistosomiasis include poor rural populations who regularly fish, bath, swim, or work in or near schistosome-contaminated waters. The most effective means of controlling schistosomiasis is mass drug administration of the drug praziquantel; however, high rates of reinfection make the elimination of transmission unlikely without complementary strategies such as hygiene promotion and vector control (Fenwick & Jourdan, 2016).

Soil-Transmitted Helminths

Soil-transmitted helminths (STH), or intestinal worms, are nematodes that live in the human gastrointestinal tract (Peter J. Hotez & American Society for Microbiology., 2013). The three most prevalent STH infections include ascaris, hookworm, and trichuris. Humans acquire these infections through contact with soil contaminated with parasite eggs or immature larval stages that can directly penetrate exposed human skin. The rural poor are very susceptible to STH infections due to, among other reasons, inadequate sanitation, dirt floors in houses, and limited access to deworming drugs. Worm infections cause sickness due to intestinal blood loss and anemia. Children are the group most impacted by these infections, which are closely linked to stunted physical growth and cognitive development. While improved sanitation is important to STH control, evidence suggests that large scale control is possible only with substantial poverty reduction. Mass deworming programs using the

anthelmintic drugs albendazole and mebendazole are the most effective means of controlling STH infection.

GLOBAL BURDEN

Different studies have estimated the global burden of all NTDs to be between 23 and 56 million disability-adjusted life years (DALYs) annually (Peter J. Hotez, Fenwick, Savioli, & Molyneux, 2009; Kassebaum et al., 2016; Murray et al., 2012). While NTDs are generally low mortality, high morbidity conditions (Peter J. Hotez et al., 2016), global annual mortality for all NTDs is still estimated to range from 150,000 to 350,000 (D. H. Molyneux et al., 2017). Figure 1 shows DALY estimates for NTDs compared to other major conditions from the 2015 Global Burden of Disease Study. At 23 million annual DALYs, NTDs fall slightly below TB and malaria but above diseases like breast cancer and measles.

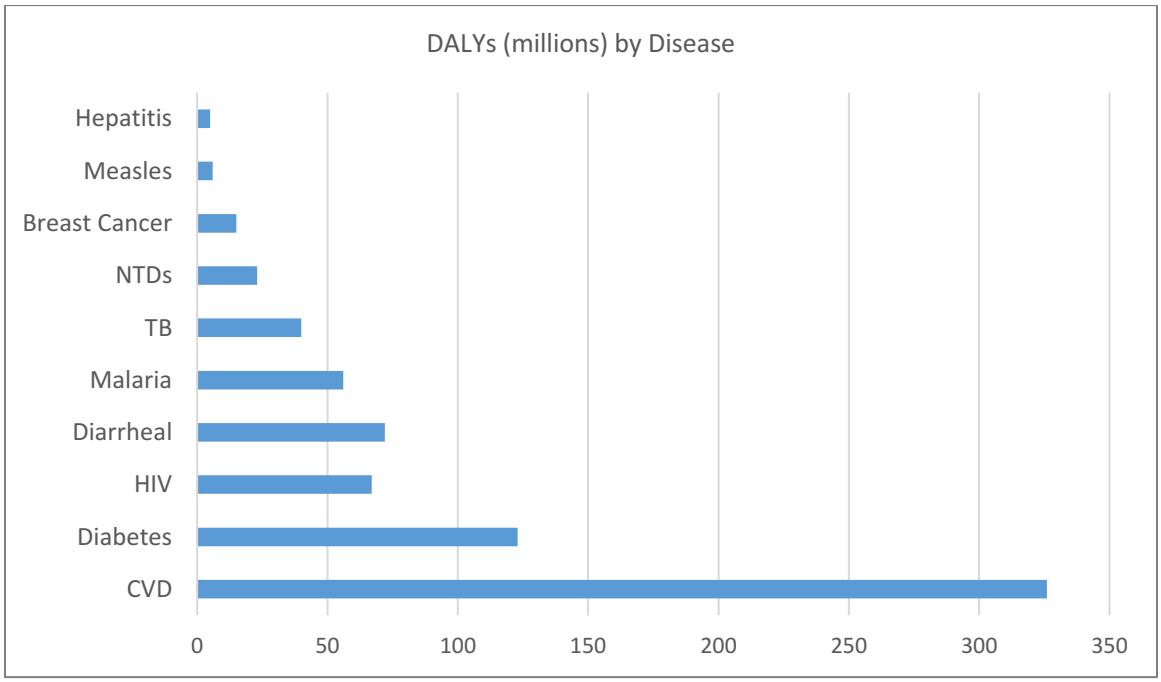

Figure 1. Global Burden of NTDs
From *Global, regional, and national disability-adjusted life-years (DALYs) for 315 diseases and injuries and healthy life expectancy (HALE), 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015* (Kassebaum et al., 2016).

Figure 2 shows the annual DALY estimates for the five PC-NTDs. Soil-transmitted helminths account for nearly 3.5 million DALYs compared to 2.6 million for schistosomiasis, 2 million for lymphatic filariasis, 1.2 million for onchocerciasis, and 0.3 million for trachoma.

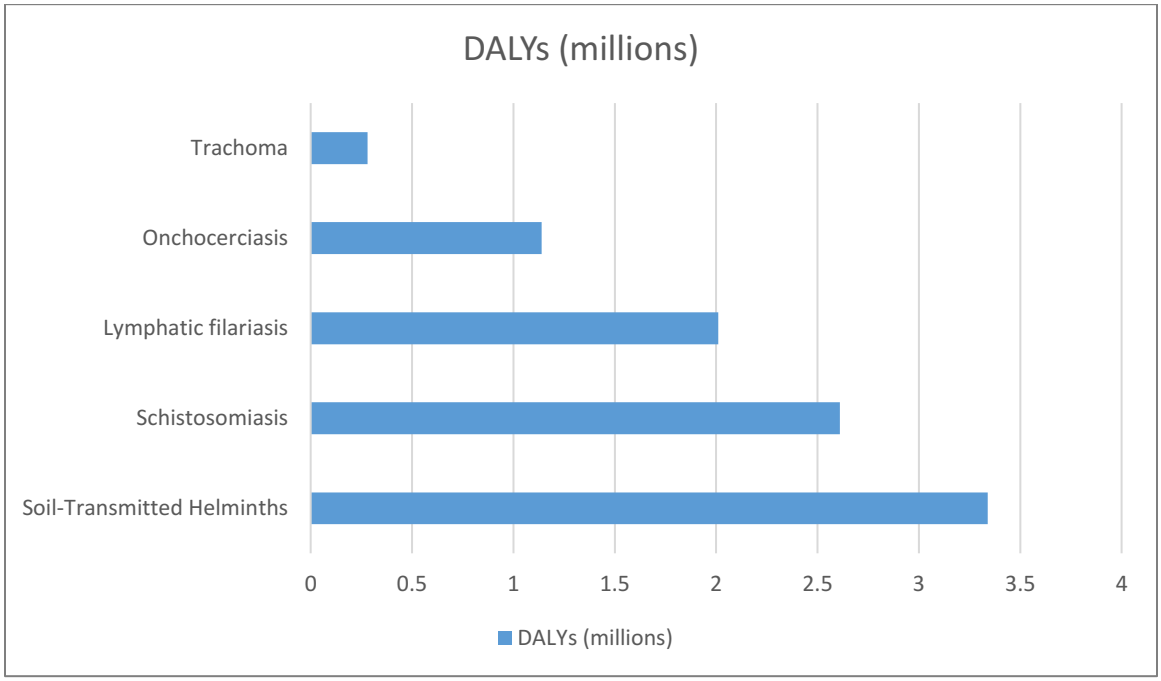

Figure 2. Global Burden of Five PC-NTDs
From *Global, regional, and national disability-adjusted life-years (DALYs) for 315 diseases and injuries and healthy life expectancy (HALE), 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015* (Kassebaum et al., 2016).

Figure 3 shows that the number of people requiring interventions against NTDs is much higher for the PC-NTDs compared to other NTDs, with those affected by lymphatic filariasis being the highest at nearly 1 billion in 2015. The number of people requiring interventions against NTDs dropped from 2 billion to 1.5 billion from 2011 to 2016 due primarily to the success of global treatment efforts (Uniting to Combat NTDs, 2017).

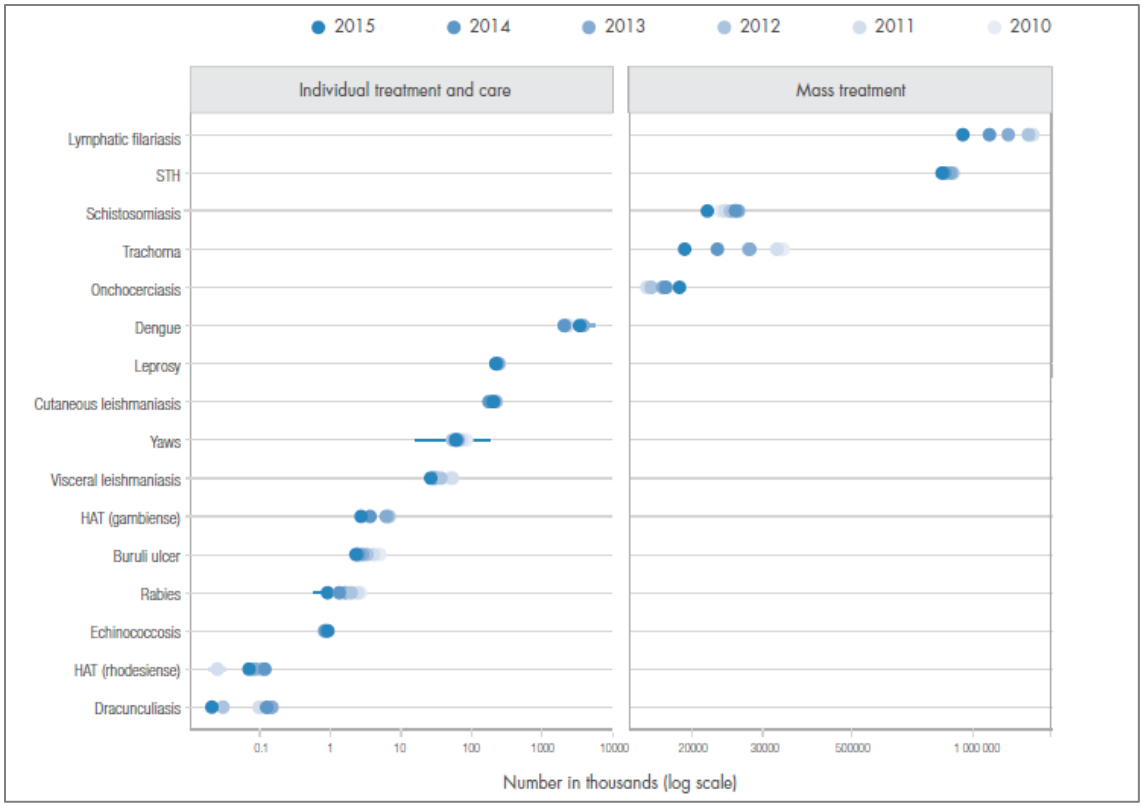

Figure 3. Number of People Requiring Interventions against NTDs
Reprinted from *Integrating neglected tropical diseases into global health and development. 4th WHO report on neglected tropical diseases* (World Health Organization, 2017a).

The majority of the NTD burden is in sub-Saharan Africa, with other hotspots falling in parts of Asia, Latin America, and the Pacific (P.J. Hotez et al., 2007). This can be seen in Figure 4 which shows a map of the countries requiring and implementing preventive chemotherapy for the five PC-NTDs. However, NTDs do not affect only the lowest income countries. At least half of the world's NTDs occur among the poor living in G20 countries and in Nigeria (Peter J. Hotez et al., 2016).

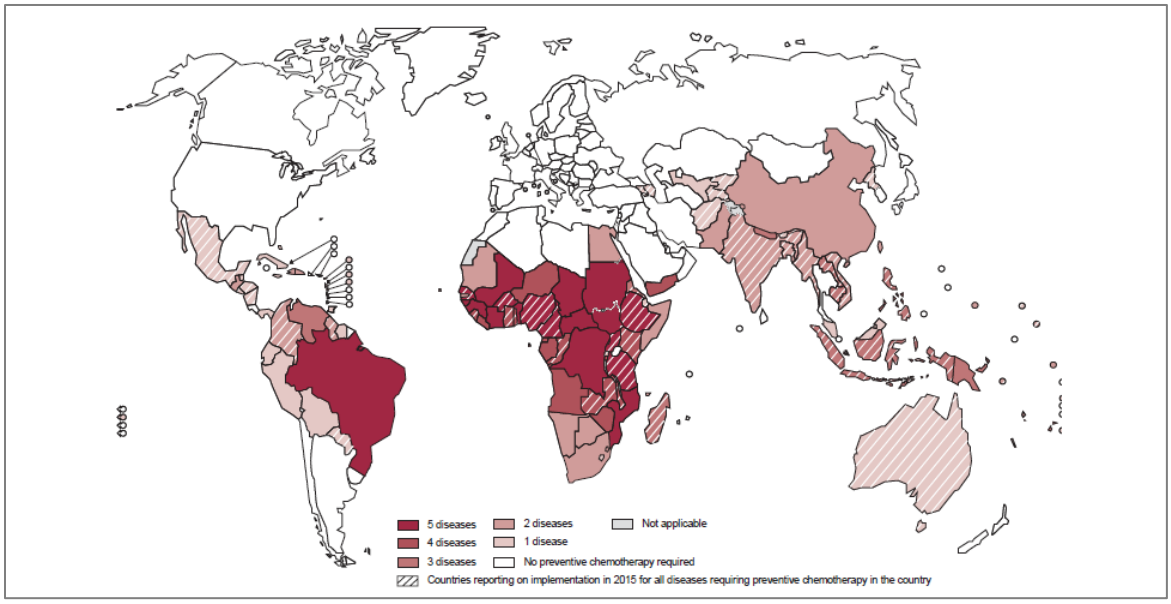

Figure 4. Countries Requiring and Implementing Preventive Chemotherapy for the 5 PC-NTDs, 2015
Reprinted from *Integrating neglected tropical diseases into global health and development. 4th WHO report on neglected tropical diseases* (World Health Organization, 2017a).

NTDs are closely associated with poverty, both as a cause and an effect. Almost all of the poorest "bottom billion" people on earth have at least one NTD, which, at the household level, reinforces the trap of poverty by negatively impacting child survival, educational achievement, agricultural productivity, and the cost of medical care (Bangert, Molyneux, Lindsay, Fitzpatrick, & Engels, 2017; Peter J. Hotez et al., 2009). For example, agricultural activity is impacted when infected people are unable to work and thus experience reduced harvests, poorer health, and lower incomes. These features make them and their families more susceptible to worse symptoms and risk factors for acquiring new NTD infections, which continues the cycle of NTDs and poverty across generations. Poverty can even affect the effectiveness of treatments, e.g., dissuading people from swallowing the antibiotics if they have insufficient food to mitigate the side effects (M Parker & Allen, 2011). At the aggregate level, the impact of NTDs is devastating on communities and national economies (Musgrove & Hotez, 2009).

As is often said, NTDs "persist in conditions of poverty, where they cluster and frequently overlap" (IOM (Institute of Medicine), 2011). A common argument used by the NTD community to advocate for

increased attention is that investment towards NTDs will go a long way towards helping "make poverty history" (Peter J. Hotez et al., 2009; D. H. Molyneux et al., 2005). On the other hand, it has also been argued that focusing primarily on treatment is misplaced as efforts to address NTDs should begin with strategies addressing the "root causes of suffering and vulnerability" (Allotey, Reidpath, & Pokhrel, 2010; Ross, Olveda, & Li, 2015).

B. Public Health Response to NTDs

NTD INTERVENTIONS

While each NTD is unique and requires its own control and elimination strategies, the backbone of the PC-NTD response includes four key interventions: preventive chemotherapy; intensive disease management; vector control; and water, sanitation, and hygiene (WASH) (World Health Organization, 2016b; World Health Organization, 2017a).

Preventive Chemotherapy

The use of preventive chemotherapy medicines distributed via MDA has had the greatest impact of any intervention on controlling the five PC-NTDs (World Health Organization, 2017a). In an MDA campaign, drugs are delivered to targeted populations in entire communities or schools in order to prevent future infections. The drugs are preventive but can also be curative in certain situations (Meheus et al., 2012; D. Molyneux, Malecela, Savioli, Fenwick, & Hotez, 2012).To prevent disease transmission, drugs typically need to be taken annually in at-risk communities (Jacobson & Bush, 2017). For some of the PC-NTDs, high enough coverage in a community for a long enough period of time can eventually break the cycle of transmission, after which time regular MDAs are no longer necessary (Simonsen et al., 2013). In these cases, disease surveillance systems must be in place in order to detect and treat any emergent cases (Ortu & Williams, 2017).

MDA is seen by many to be an “aggressively pro-poor,” “quick win” strategy that can be delivered safely and effectively (P.J. Hotez et al., 2007; D. H. Molyneux et al., 2005). It is widely considered one of the “best buys” in global public health because of the safety and effectiveness of the drugs combined with their relatively low cost (Peter J. Hotez et al., 2009; D. H. Molyneux et al., 2005). Since drugs for each of the five PC-NTDs have been donated on a large scale by pharmaceutical companies, funding is required only for delivery and not to purchase medicines. The per person annual cost estimate typically ranges from only around US$.40 to US$.79 (D. H. Molyneux et al., 2005).

An integrated MDA approach for the five PC-NTDs, in which interventions are implemented together for multiple PC-NTDs, has been pushed in order to increase efficiencies and synergies of control and elimination activities (D. H. Molyneux et al., 2005). Since integrated MDA programs were first advocated for around 2005, there has been a significant increase in the number of programs embedded as policy in endemic countries (D. Molyneux et al., 2012). Community engagement is particularly important to the success of NTD programs (Das, Salam, Arshad, Maredia, & Bhutta, 2014). MDA campaigns are often organized through an approach known as community-directed treatment, in which local community members determine the most appropriate treatment strategy for the particular community (Collins, 2004). This approach, developed initially for distribution of Ivermectin for onchocerciasis, has been found to be highly successful, even in areas with weak health systems (Haddad, 2008; Peter J. Hotez et al., 2009).

Despite the widespread belief in and apparent success of integrated MDA programs for the PC-NTDs, there are some researchers who argue that the benefits of MDA have been oversold. This faction claims that vertical MDA programs damage country health systems by creating parallel systems driven not by community ownership but by top down donor requirements, and that the figures purportedly demonstrating the success of MDA are exaggerated (T. Allen & Parker, 2012; Cavalli et al., 2010; Melissa Parker & Allen, 2014; Utzinger, Raso, Brooker, Savigny, & Tanner, 2009). They raise concerns about

relying on unpaid volunteers to distribute drugs, potential drug resistance, the sustainability of NTD programs that rely solely on MDA, and the lack of guiding evidence from the biosocial perspective (Dean et al., 2016; Meheus et al., 2012; M Parker & Allen, 2011). They also note that decisions to aggressively promote MDA programs are driven in part by the pharmaceutical companies' donations of the drugs (Melissa Parker & Allen, 2013).

In recent years some of the original evidence of the benefits of deworming through MDA has been reexamined and called into question (T. Allen & Parker, 2016; J. R. Andrews, Bogoch, & Utzinger, 2017). WHO recently issued a consensus statement reaffirming the policy supporting deworming via MDA, stating that the full body of evidence provides adequate scientific justification for the current strategy (World Health Organization, 2016c). Other scholars have similarly argued that the expected benefits of deworming are likely to greatly exceed the cost (Croke, Hicks, Hsu, Kremer, & Miguel, 2017). Despite the challenges and shortcomings of MDA, many argue that it would be unfair and unethical to withhold delivery of free drugs that have been proven to be effective in preventing and mitigating the effects of NTDs that afflict millions of the poorest of the poor (D. H. Molyneux & Malecela, 2011)

Intensive Disease Management

Intensive disease management (IDM), or morbidity management, is used as the primary approach to address diseases for which limited control tools exist (World Health Organization, 2016a). Thus, IDM constitutes the primary public health response for many of the non-PC-NTDs. It is, however, also important for the PC-NTDs. For example, LF patients benefit from IDM through simple surgeries, hygiene, and skin care due to the severe disability and disfigurement caused by advanced symptoms of the disease (Peter J. Hotez & American Society for Microbiology., 2013). Likewise, trichiasis surgeries are an essential element of the SAFE strategy for trachoma control (Musgrove & Hotez, 2009). IDM will

become a proportionately more important element of PC-NTD control efforts as MDA programs are successful in reducing the overall burden of disease (Macpherson et al., 2015).

Vector Control

Vector control involves different methods of killing the mosquitos, worms, and snails that harbor and transmit NTD infections. For years prior to the discovery of Ivermectin for onchocerciasis, vector control through aerial spraying was the only strategy used by the African-based Onchocerciasis Control Program to control the disease (Hopkins, Richards, & Katabarwa, 2005). While MDA is now the dominant approach, adding vector control to preventive chemotherapy programs can accelerate overall progress by reducing the overall numbers of existing parasites (Macpherson et al., 2015).

Water, Sanitation, and Hygiene

Lack of improved water and sanitation infrastructure is a major risk factor for NTDs due, for example, to transmission of disease that occurs through contaminated water or to mosquitos breeding near poorly constructed latrines (Bangert et al., 2017). While not as straight forward to implement as MDA, WASH interventions are seen by many as a key but all too often neglected component of sustainable NTD programs (Bangert et al., 2017; Campbell et al., 2017). Along with vector control, improved access to WASH has played a critical role in communities that have achieved interruption of disease transmission and is seen as an essential part of efforts to eliminate schistosomiasis and soil-transmitted helminths, in particular (J. R. Andrews et al., 2017; Campbell et al., 2017; Fenwick & Jourdan, 2016; Rollinson et al., 2013).

WASH interventions include water and sanitation infrastructure as well as behavior change related to hygiene (Campbell et al., 2017; Rollinson et al., 2013). Barriers to WASH integration include the high cost, longer timeline, and, perhaps, the overemphasis of MDA by donors and advocates (Kabatereine et al., 2010; Musgrove & Hotez, 2009; Ruxin & Negin, 2012).

Recent efforts by WHO and partners have attempted to spark increased efforts to integrate WASH and NTD programs (Campbell et al., 2017). WHO launched a global strategy and action plan for WASH integration in 2015, and in 2017 initiated an expert consultation process to develop WASH-related indicators for monitoring integrated NTD programs (Bangert et al., 2017; Waite, Velleman, Woods, Chitty, & Freeman, 2016). These efforts to design and implement sustainable and integrated WASH programs will continue to require intersectoral collaboration and community participation (Campbell et al., 2017; Rollinson et al., 2013)

Data

High quality data is important for various elements of NTD programs. Massive efforts to map the geographic disease burden of NTDs, which should be a first step for all country programs, have been crucial to progress (Hanson et al., 2012; Rollinson et al., 2013). Monitoring and evaluation of programs at the community level is critical to ensure treatments are well tolerated and effective, and to monitor changes in disease epidemiology and emerging cases of drug resistance (Peter J. Hotez et al., 2009; Humphries, Nguyen, Boakye, Wilson, & Cappello, 2012; Utzinger et al., 2009). At end stages of elimination programs, monitoring and disease surveillance systems are needed to identify and rapidly address any instances of disease resurgence (Fenwick & Jourdan, 2016; Ortu & Williams, 2017; Rollinson et al., 2013). At the global level, Uniting to Combat NTDs compiles a scorecard to follow country progress and provide a snapshot of multiple indicators (Uniting to Combat NTDs, 2017).

NTDS AND INTEGRATION

The degree to which NTD programs are integrated with each other and with other health and development programs is of central importance to NTD control and elimination efforts. Grepin & Reich put forward a framework for conceptualizing the different domains, levels, and degrees of NTD integration (Grépin & Reich, 2008). The domain refers to *what* is being integrated. This can include

activities (e.g., service delivery), policies (e.g., advocacy or guideline development), and organizational structure (e.g., merging organizations). The level refers to *where* integration is occurring, which can be at the global, national/regional, or local levels. Finally, the degree refers to *how* the integration is occurring, which ranges from communication to collaboration to consolidation. NTD integration can and does occur within each domain, at each level, and to each degree (Grépin & Reich, 2008).

Programs that integrate the PC-NTDs with each other have focused primarily on the domain of delivery of medicines (activity domain) and disease mapping (activity domain) (Ortu & Williams, 2017). These programs are purported to increase efficiencies and expand impact because there is so much overlap in the populations impacted, risk factors, treatment protocols, and other interventions required (P.J. Hotez et al., 2007; D. H. Molyneux et al., 2005). Some have urged caution in pointing out that, despite their similarities, each NTD has unique features that require intervention through carefully planned, disease-specific strategies (Kabatereine et al., 2010). As will be discussed later, there have also been major efforts towards integration in the policy domain at the global and national levels (Uniting to Combat NTDs, 2017). There is an increasingly recognized need for a higher degree of integration between MDA programs and behavioral change for WASH, intensive disease management, and vector control (Savioli, Fenwick, Rollinson, Albonico, & Ame, 2015).

The merits of so-called “vertical” and “horizontal” approaches is central to addressing NTDs and has been a prominent debate in global health for decades (Mills, 1983, 2005; Oliveira-Cruz, Kurowski, & Mills, 2003; Ooms, Van Damme, Baker, Zeitz, & Schrecker, 2008). Vertical approaches, or programs narrowly focused on a specific disease, became more common after scientific advances in the 1950s and 1960s enabled large-scale public health campaigns against diseases like smallpox and malaria (Mills, 1983; Oliveira-Cruz et al., 2003). Vertical approaches have largely dominated as they tend to be attractive for donors since the impact is usually easier to measure and time periods are more specific (Béhague & Storeng, 2008; Cairncross, Periès, & Cutts, 1997; Oliveira-Cruz et al., 2003). Proponents of a

more vertical approach for NTDs argue that this strategy is necessary due to weak or non-existent country health systems that lack the capacity to deliver the donated medicines to people who need them (D. H. Molyneux, 2014; D. H. Molyneux & Malecela, 2011). These programs claim to have been overwhelmingly successful in distributing medicines and reducing disease prevalence by organizing vertical programs around a laser focus of achieving specific drug distribution goals (D. H. Molyneux et al., 2017). Besides, some argue, vertical MDA campaigns ultimately strengthen existing health systems by building capacity of workers, adding interventions, improving systems for surveillance and monitoring, and strengthening operational research and laboratory services (Collins, 2004; Gyapong et al., 2010; Peter J. Hotez et al., 2009; D. H. Molyneux & Malecela, 2011).

Negative effects of purely vertical programs include the potential conflicts between local needs and top down targets, and the inefficient use of human and financial resources (Oliveira-Cruz et al., 2003). Opponents of the vertical approach for NTDs argue that parallel systems set up to distribute preventive chemotherapy drugs compete with health systems for scarce resources and prevent countries from establishing broader platforms for health service delivery (Cavalli et al., 2010; Dean et al., 2016; Marchal et al., 2011). According to this viewpoint, vertical programs mistakenly assume that diseases respond to interventions similarly everywhere and thus often ere in trying to transplant techniques from location to location without adequate consideration of the social and cultural context (T. Allen & Parker, 2011; Michael & Madon, 2017).

Horizontal approaches, or programs that bring together common functions within and between organizations to solve common problems, are more holistic and tend to be centered on the health needs of individuals and communities (Oliveira-Cruz et al., 2003). Horizontal approaches are said to carry a potential for delivering efficient services due to economies of scale (Oliveira-Cruz et al., 2003); however, full integration has the potential to dampen the effects of more focused programs (Gounder, 1998).

The evidence base for understanding how these approaches affect health and how to best integrate vertical programs into existing systems has progressed surprisingly little over the past decades (Balabanova, McKee, Mills, Walt, & Haines, 2010; Mills, 2005). Experimental methods have a limited ability to provide evidence about the complex nature of integration within health systems (Béhague & Storeng, 2008). While the quality of most studies addressing these issues is questionable, there is some evidence that vertical programs have had positive effects on the horizontal system, as with the case of a vertical Guinea worm program shown to have facilitated greater community mobilization (Oliveira-Cruz et al., 2003). Other vertical programs are reported to have strengthened managerial, surveillance, and laboratory capacities within health systems (Oliveira-Cruz et al., 2003). Despite these findings, a systematic review of the integration of vertical programs concluded that there is no strong evidence of the benefits of integration (Briggs & Garner, 2006). There are a few examples of vertical programs that have successfully been integrated into existing health systems, such as a schistosomiasis control program in Saudi Arabia (Oliveira-Cruz et al., 2003).

For NTDs and for other health issues, rather than being seen as an end in itself, it is useful to see and assess integration as a means to achieving a health objective (Mills, 1983). Vertical programs should take necessary measures to avoid setting up parallel systems that undermine the health system (Balabanova et al., 2010; Oliveira-Cruz et al., 2003). Integrated programs should be careful to avoid the dilution of program goals by relying on robust monitoring systems and pursuing thoughtfully sequenced, incremental approaches to integration based on careful planning (Balabanova et al., 2010; Oliveira-Cruz et al., 2003). The two approaches should not be seen as mutually exclusive but as complementary strategies (Mills, 2005; Oliveira-Cruz et al., 2003). Recently, some have argued for a “diagonal approach” that uses explicit priorities to drive broader improvements in health systems (Frenk, 2010; Ooms et al., 2008). A diagonal approach seeks to make full use of potential synergies by prioritizing programs that respond to multiple diseases (Knaul, Bhadelia, Atun, & Frenk, 2015). Many experts recognize that a

successful NTD program should align and combine the most promising elements from vertical and horizontal approaches (Utzinger et al., 2009). The proper balance depends largely on the intent of the program. While control measures depend on routine services that need to be maintained in a health system, elimination activities are often incompatible with integration as they are usually time limited, intensive, and targeted (Gyapong et al., 2010; Hopkins, 2009).

POLITICAL PRIORITY OF NTDS

As with any health issue, where NTDs sit on global, national, and local agendas has important implications for progress. The political economy literature provides a useful theoretical basis for analyzing what factors lead to political attention for NTDs. While some researchers make the distinction between 'agenda setting' (how an issue initially enters the agenda) and 'priority setting' (how an issue's priority changes once it is on the agenda), the focus of this analysis will incorporate both concepts into the idea of 'political priority', or "the degree to which international and national political leaders actively give attention to an issue, and back up that attention with the provision of financial, technical, and human resources" (Bump, Reich, & Johnson, 2013; Shiffman & Smith, 2007). The literature related to this topic has grown in recent years as scholars have applied theories to attempt to understand the level of political priority of various public health issues, including maternal health, polio, diarrheal diseases, and others (Bump et al., 2013; Shiffman & Smith, 2007).

Kingdon's multiple-streams framework is one of the most widely-used such theories and rests on the foundation of three key streams: problem, politics, and policy (Kingdon & Thurber, 1984). These three streams each unfold separately and, when all three streams are joined, a policy window is opened that can allow advocates to push their issue through. Policy entrepreneurs, "people willing to invest their resources in return for future policies they favor", play an important role in bringing the three streams together to facilitate the opening of policy windows (Kingdon & Thurber, 1984).

Shiffman & Smith propose another conceptual framework (see Figure 5) for identifying determinants of political priority specifically for global health initiatives, making it a helpful framework for understanding the political priority of global NTDs (Shiffman & Smith, 2007). While this framework cites Kingdon and incorporates many of his ideas, it adds additional dimensions by dividing key determinants into four categories: 1) the power of the actors involved, 2) the ideas they use to portray the issue, 3) the nature of the political contexts in which they operate, and 4) characteristics of the issue itself.

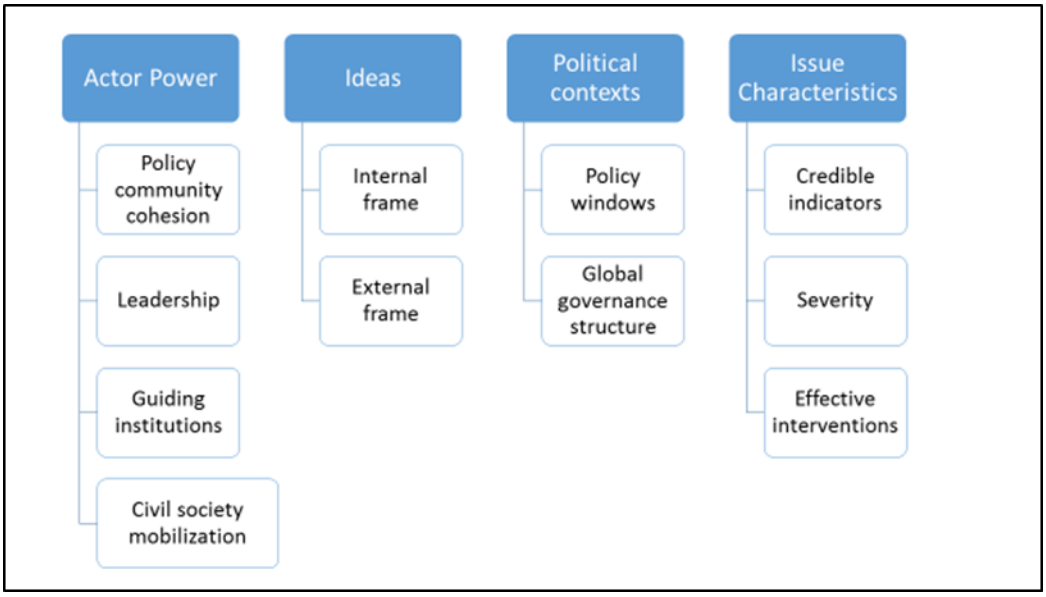

Figure 5. Shiffman & Smith's Political Priority Framework
Adapted from *Generation of political priority for global health initiatives: a framework and case study of maternal mortality* (Shiffman & Smith, 2007).

We see elements of both these frameworks when we trace over time the global political priority of NTDs. Despite the fact that global efforts to address NTDs represent some of the world's longest running public health programs, these diseases were nearly absent from global health and political agendas in the first few years of the 21st Century (Van Lieshout & Yazdanbakhsh, 2013). However, the PC-NTDs in particular have experienced a resurgence in attention since the mid-2000s with the establishment of the NTD classification and subsequent increase in advocacy for an integrated approach using preventive chemotherapy (P.J. Hotez et al., 2007; B. H. Liese, Houghton, & Teplitskaya, 2014; D. H. Molyneux et al.,

2017; Van Lieshout & Yazdanbakhsh, 2013). In Kingdon's framework, this repackaging under the NTD brand falls under the problem stream and helps to explain how NTDs have come to be perceived as a public health problem (Kingdon & Thurber, 1984). Using Shiffman & Smith, this touches on the external frame determinant, or the degree to which the issue is portrayed in a way that resonates with the public and policymakers, as well as the internal frame determinant, or the level of agreement about causes and solutions within the policy community (Shiffman & Smith, 2007). These frames have been shaped by what Shiffman & Smith refer to as the issue characteristics – credible indicators, severity, and availability of effective interventions – which for NTDs have all been positively impacting the trend towards receiving greater political priority.

Although the only reference in the Millennium Development Goals to the diseases now known as NTDs was the allusion to "other diseases" mentioned alongside AIDS, TB, and malaria, advocates began using this language as a way to advocate for inclusion of NTDs on the global health agenda (Smith & Taylor, 2013). After the NTD brand began to emerge in the mid-2000s, it was not long before WHO established a Department for NTDs in 2005 and the specialist journal PLOS NTDs was launched in 2007 (Smith & Taylor, 2013). In 2006, the US Congress committed specific resources for NTD control through the United States Agency for International Development (USAID), and then in 2008 the UK Department for International Development (DFID) did the same (D. H. Molyneux, 2014). The Bill and Melinda Gates Foundation (BMGF) began dedicating significant resources to establish NTD programs around the same time (P.J. Hotez et al., 2007). Legatum, a Dubai-based investment firm, also began funding NTD pilot programs during this time period, an effort that would eventually grow into the END Fund, a more permanent mechanism to channel philanthropic funding to NTD programs ("United Voices: The Story of the END Fund | The Legatum Group," 2016). Again, citing Shiffman & Smith's determinants, these organizations became the guiding institutions and many individuals working at these organizations

provided the leadership necessary to create a greater sense of policy community cohesion that has been essential to increasing the political priority of NTDs (Shiffman & Smith, 2007).

In January 2012, the WHO released what is now known as the WHO Roadmap on NTDs, a plan with specific control and elimination goals for each of the 17 NTDs to be achieved by 2020 (B. H. Liese et al., 2014; World Health Organization, 2012). The World Health Assembly approved these goals through World Health Assembly Resolution 66.17 in May 2013 (World Health Organization, 2016d). These actions led to further policy community cohesion and solidified both the internal and external frames of the issue (Shiffman & Smith, 2007). The global goals contributed to shaping Kingdon's policy stream by helping to present technically and politically feasible solutions (Kingdon & Thurber, 1984).

Another important milestone came during a 2012 meeting in which representatives from 77 major public, private, and nonprofit sector institutions joined together to sign the London Declaration on Neglected Tropical Diseases that resulted in significant commitments of drug donations to increase treatment opportunities for millions of people (D. H. Molyneux et al., 2017). These partners reunited in Geneva in April 2017 to mark the fifth anniversary of the London Declaration and renew their commitment to achieving the WHO NTD goals (Uniting to Combat NTDs, 2017). Another major step forward came when NTDs were explicitly included within the health targets of the Sustainable Development Goals (SDGs) in 2015 (Engels, 2016; D. H. Molyneux et al., 2017). SDG 3.3 states the goal of ending "the epidemics of HIV, tuberculosis, malaria and neglected tropical diseases" by 2030, with a corresponding indicator to track the number of people needing interventions against NTDs (Engels, 2016). The inclusion of NTDs in the SDGs was influenced by the advocacy of the network of NGOs working on NTDs (Rotondo, Harrison, Bush, Hopkins, & Koporc, 2015). Both the London Declaration and SDGs fall under Kingdon's politics stream that helps explain how the composition of elected officials combines with the strength of organized interests to influence which issues rise to the top of the agenda (Kingdon & Thurber, 1984). These events are also examples of Shiffman & Smith's global governance

structure determinant showing how the institutions created a platform for collective action, and the policy windows determinant showing how global conditions aligned to provide opportunities for advocates to bring attention to the issue (Shiffman & Smith, 2007).

The level of political priority NTDs experience at the country level has increased but generally not at the same pace as at the global level, particularly when it comes to allocation of domestic resources (Marchal et al., 2011). One potentially influential factor may be the lack of civil society mobilization for NTDs, which Shiffman & Smith cite as a key determinant of political priority (Shiffman & Smith, 2007). On the positive side, every endemic African country has developed a national plan for control of NTDs and many have started working towards implementation with a designated point person from the ministry of health (MOH) assigned to lead these efforts (Fenwick & Jourdan, 2016). The lack of country-level political commitment is frequently cited as a major barrier in NTD programs (Cohen et al., 2016; Rollinson et al., 2013). This lack of attention is not unexpected as national NTD policies compete for resources with many other priority issues, especially "the big three" of HIV/AIDS, and malaria (Iltis & Matthews, 2017; Linehan et al., 2011; D. H. Molyneux et al., 2005; Utzinger et al., 2009).

RESOURCE MOBILIZATION

Funding is an important barometer of political priority and key driver of NTD control and elimination activities. International funding has been and remains critical to these efforts (P.J. Hotez et al., 2007). Despite that overall resources for NTD programs have increased significantly in the past decade, NTDs still only account for 0.6 percent of development assistance for health (DAH), representing a major funding disparity between NTDs and diseases like HIV/AIDS, which receives nearly 40 percent of official development assistance (ODA) (B. H. Liese et al., 2014; D. H. Molyneux et al., 2017). There is still an estimated US$200 - $400 million annual funding gap that needs to be bridged in order to meet the 2020 goals (Abt Associates, 2014; Uniting to Combat NTDs, 2017; World Health Organization, 2016b). This

estimate considers an almost exclusively MDA-focused strategy, which some argue is not sufficient to achieve the goals (Melissa Parker & Allen, 2013). Incorporating additional strategies such as vector control and WASH vastly increases the estimated funding gap (World Health Organization, 2016b).

Currently, donors invest approximately US$300 million per year towards implementation costs, with the bulk of this funding coming from USAID (~US$100 million), DFID (~US$90 million), and BMGF (~US$80 million) (Uniting to Combat NTDs, 2017). The END Fund is largest source of private funding for NTDs at ~US$17 million annually and over US$75 million since its inception in 2012 (The END Fund, 2017; Uniting to Combat NTDs, 2017). At the April 2017 NTD Summit in Geneva commemorating the 5th year anniversary of the London Declaration, an additional US$812 million was pledged by governments and private donors (Uniting to Combat NTDs, 2017). The vast majority of international NTD funding goes towards MDA for the five PC-NTDs (Kabatereine et al., 2010). Arguments that have helped encourage donors to increase support for NTDs include the fact that many NTDs are co-endemic with other NTDs, the availability of a readily available and relatively simple public health intervention in MDA, and the return on investment for dollars spent (Gustavsen & Hanson, 2009; D. H. Molyneux, 2010; Utzinger et al., 2009).

Thanks to the success of the drug donation programs, availability of drugs is no longer a barrier to achieving NTD goals (D. H. Molyneux et al., 2017). In 2016 alone, the pharmaceutical industry donated 1.8 billion treatments for NTDs (Uniting to Combat NTDs, 2017). Global public private partnerships for NTDs have been recognized in the Guinness Book of World Records for the most medication donated within 24 hours in an effort commemorating the 5th anniversary of the London Declaration ("Uniting to Combat NTDs program tackles infectious diseases with new world record | Guinness World Records," 2017).

At least part of the appeal of NTDs to international donors has been the opportunity to alleviate suffering among the world's poorest populations and the opportunity to completely eliminate a disease (Reidpath, Allotey, & Pokhrel, 2011; Utzinger et al., 2009). Concerns have been raised, however, regarding potential drying up of donor funding once initial goals are reached, which would severely hurt the ongoing effort needed to sustain progress (Linehan et al., 2011; Ortu & Williams, 2017). Thus, there is a widely recognized need to develop more sustainable sources of funding, particularly for NTD control programs that will require a sustained public health response even if goals should be met (Fürst et al., 2017). Mobilizing domestic funding from endemic countries themselves is a vital source of funding for sustainable programs (Gyapong et al., 2010; Hopkins et al., 2005; D. H. Molyneux et al., 2017; Ruxin & Negin, 2012). Domestic government funding has been scarce (see Figure 6), in part because communities affected by NTDs are often marginalized and hold little political power to advance their interests (B. Liese et al., 2010). There are, however, some examples of countries, such as Burkina Faso, that have established successful programs with significant contributions from their own budgets (Uniting to Combat NTDs, 2017).

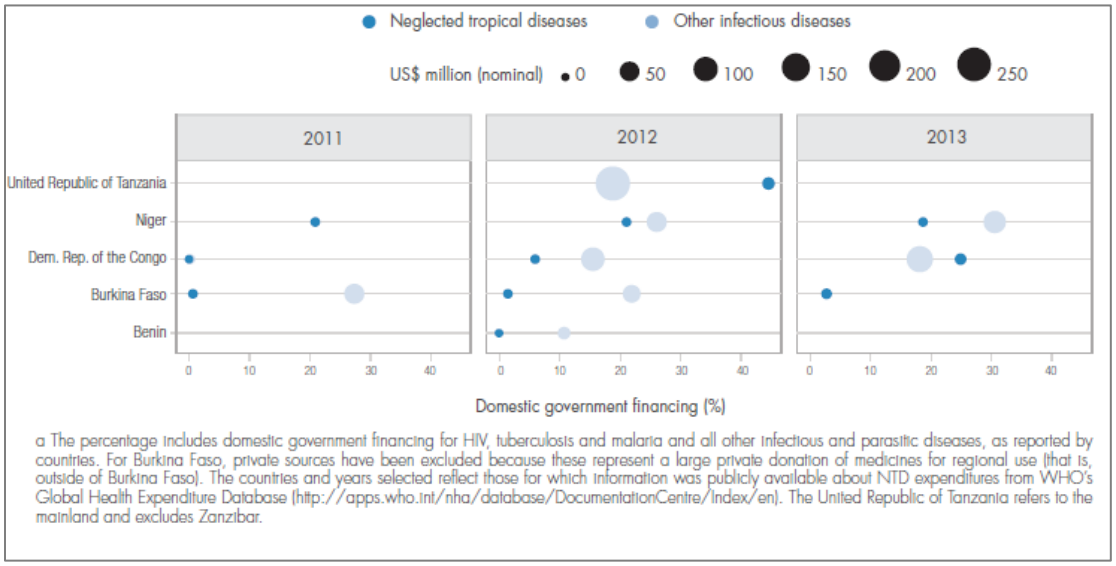

Figure 6. Domestic Financing as a % of Total Financing for NTDs and Other Diseases
Reprinted from *Integrating neglected tropical diseases into global health and development. 4th WHO report on neglected tropical diseases* (World Health Organization, 2017a).

CONTROL AND ELIMINATION GOALS

The 2012 WHO NTD Roadmap established a set of ambitious NTD control and elimination goals to be achieved by 2020 (World Health Organization, 2012). While the goals for the five PC-NTDs varied by region and target (see Table 2), the act of goal-setting represented a key milestone in the NTD movement that has served as a catalyst for mobilizing new resources and partners since their establishment (Fürst et al., 2017; World Health Organization, 2012). It has been estimated that meeting the WHO 2002 targets and the end of NTDs by 2030 would result in 600 million DALYs averted per year (Uniting to Combat NTDs, 2017). This includes 150 million cases of irreversible disease and 5 million deaths.

Table 2. PC-NTD Control and Elimination Goals

Disease	2015 Goal	2020 Goal
Lymphatic Filariasis	None	Global elimination as a public health problem
Onchocerciasis	Regional elimination – Latin America Country elimination – Yemen	Country elimination – Selected countries in Africa
Schistosomiasis	Regional elimination – Eastern Mediterranean, Caribbean, Indonesia, Mekong River basin	Control – 75% of school-aged children in need of treatment are regularly treated Regional elimination – Americas, Western Pacific Country Elimination – Selected Countries in Africa
Soil-Transmitted Helminths	Control – 50% of preschool and school-aged children in need of treatment are regularly treated	Control – 75% of preschool and school-aged children in need of treatment are regularly treated
Trachoma	None	Global elimination as a public health problem

Note. Adapted from *Accelerating Work to Overcome the Global Impact of Neglected Tropical Diseases: A Roadmap for Implementation* (World Health Organization, 2012).

The distinction is made in the Roadmap between eradication, elimination, and control, which remains a cause of ongoing heated discussion among many NTD partners (World Health Organization, 2012). The definitions for each of these terms is presented in Table 3. As shown in Table 2 above, some of the PC-

NTDs (lymphatic filariasis, onchocerciasis, schistosomiasis, and trachoma) have been targeted for elimination in certain locations and control in others, while soil-transmitted helminths have been targeted solely for control based on what is deemed feasible given disease characteristics, technology, and available resources (Fenwick & Jourdan, 2016). These differences largely reflect differences in ecologies of transmission of the diseases themselves but can vary according to local circumstances (King, 2017). The appropriate goal is not always clear cut, which is indicated, for example, by the long-standing debate regarding whether onchocerciasis programs should be targeted for control or elimination (Hopkins et al., 2005). WHO's ladder of control objectives suggests that a country's first goal should be to reduce morbidity by reduction and then elimination of heavy infections, followed by enhanced efforts to achieve elimination of transmission (King, 2017; World Health Organization, 2012).

Table 3. Definitions of Eradication, Elimination, and Control

Eradication
Reduction of the worldwide incidence of a disease to zero as a result of deliberate efforts, obviating the necessity for further control measures. True eradication usually entails eliminating the microorganism itself or removing it completely from nature.
Elimination
Refers to cessation of transmission of a disease in a single country, continent, or other limited geographic area, rather than global eradication (e.g., polio in the Americas). It is also theoretically possible to "eliminate" a disease in humans while the microbe remains at large (e.g., neonatal tetanus). Although a disease itself may remain, a particularly undesirable clinical manifestation of it may be prevented entirely (e.g., blindness from trachoma) or new transmission interrupted (e.g., infectious yaws). Control of a disease or its manifestations to a level that it is no longer considered "a public health problem," as an arbitrarily defined qualitative (e.g., onchocerciasis in West Africa) or quantitative (e.g., leprosy incidence below one case per 10,000 population) level of disease control.
Control
Reduced incidence or prevalence of a disease or condition; control measures are still required.

Note. Adapted from *The Allure of Eradication* (Hopkins, 2009).

Elimination for some of the PC-NTDs may be achievable with preventive chemotherapy alone; however, for others – particularly soil-transmitted helminths and schistosomiasis – alternative strategies need to be piloted and implemented (B. H. Liese et al., 2014; D. H. Molyneux et al., 2017; Melissa Parker & Allen, 2013). For example, a sustained reduction in transmission for these diseases will be possible only if

accompanied by achievement of WASH infrastructure and behavior change targets and significant poverty reduction (Bangert et al., 2017; Rollinson et al., 2013).

Much of the discussion around these terms revolves around varying definitions of elimination. The phrase, “elimination as a public health problem”, is associated with the NTD goals, but the definition is often unspecified (Hopkins, 2009). In practice, elimination as a public health problem does not always mean zero cases, or elimination of transmission (Zarocostas, 2017). Hopkins writes that, “crucial to the distinctions in the definitions of eradication, elimination, and control is whether control measures against the disease in question can be halted without the disease re-emerging in a population or not. Eradication and elimination should mean zero cases globally or in a defined geographic area, respectively” (Hopkins, 2009).

The target of elimination vs control can change the orientation of the entire program as elimination programs are typically more vertical, time limited, and intensive while control programs depend on the establishment of routine services over the longer-term (Gyapong et al., 2010). Local health system support and the development of sustainable programs is even more crucial for diseases “not suitable for elimination” (i.e., elimination of transmission) because they will require a sustained public health response even assuming the 2020 goals are met (B. H. Liese et al., 2014).

It appears that in most cases the 2020 goals will not be achieved (Uniting to Combat NTDs, 2017). Nevertheless, significant progress has been made across all the PC-NTDs. A number of countries have certified elimination of diseases over the past few years as summarized in Table 4.

Table 4. Progress towards Elimination

Disease	Country that has Achieved Elimination as Public Health Problem
Lymphatic Filariasis	Marshall Islands
	Thailand
	Togo
	Tonga
	Cambodia
	Cook Islands
	Maldives
	Niue
	Sri Lanka
	Vanuatu
Trachoma	Cambodia
	Laos
	Mexico
	Morocco
	Oman
	Country that has Achieved Elimination of Transmission
Onchocerciasis	Colombia
	Ecuador
	Guatemala
	Mexico

Note. Adapted from *5th progress report: Reaching a Billion* (Uniting to Combat NTDs, 2017).

GLOBAL GOVERNANCE FOR NTDS

As discussed in this section, a critical consideration for global NTD efforts is the nature and strength of global health governance, which is defined as the series of fluid partnerships and associations through which the organized social response for a health condition is managed (Frenk & Moon, 2013; Kruk, 2012). The END Fund operates as part of this structure of global governance for NTDs, which is one reason this project focuses primarily on issues at this level. Global governance includes core elements such as advocacy, strategic policy frameworks, oversight, coalition-building, regulations and incentives, and accountability (Mikkelsen-Lopez et al., 2011). An increasingly interconnected world due to forces of globalization has created a new global health system for which governance is no longer characterized by interactions between multilateral and bilateral institutions operating within interstate mechanisms; rather, the new, pluralistic system includes global health networks, public-private partnerships, civil

society organizations, and other actors that operate in an environment of fragmented decision-making and multiple health agendas (Kickbusch, 2005; Kruk, 2012). This is particularly evident among the global network of organizations working on NTDs.

In their work on the emergence and effectiveness of global health networks, Shiffman et al. define such global health networks as the web of "individuals and organizations linked by shared concern for a health condition" (Shiffman et al., 2016). Public-private partnerships and global health initiatives are important components of global health networks (Buse & Walt, 2000; Samb et al., 2009). The success of global health networks depends on their capacities to do things like attract attention, generate funding, develop interventions, and convince national governments to dedicate resources to the issues they address (Shiffman et al., 2016).

As mentioned above, innovative multisectoral partnerships have formed a cornerstone of NTD control efforts for decades and continue to play a major role in the success of the NTD movement (Bush & Hopkins, 2011; Grépin & Reich, 2008; Gustavsen & Hanson, 2009; Rotondo et al., 2015). A number of disease-specific coordination groups and alliances of various types exist for the five PC-NTDs individually and for NTDs collectively (see Table 5) (D. H. Molyneux et al., 2017; Rotondo et al., 2015). In 1991, two meetings in Geneva attended by endemic country representatives, NGOs, and Merck led to the establishment of the NGDO Coordination Group for Onchocerciasis Control (Bush & Hopkins, 2011). The Global Alliance for the Elimination of LF (GPELF) has worked closely with WHO since 1997 to manage the Global Program for the Elimination of LF (Kirby, 2010). Many NGOs involved in implementation of the SAFE strategy for trachoma grouped together to form the International Coalition for Trachoma Control (ICTC) (Bush & Hopkins, 2011). More recently, the Global Schistosomiasis Alliance and the Soil-Transmitted Helminths Coalition were created to coordinate efforts for the many partners focused on those diseases (Savioli et al., 2017). The work of these groups includes advocacy, communication,

technical assistance and other tasks important to global control and elimination efforts (B. Liese et al., 2010).

Table 5. Global Partnerships for NTD Elimination and Control

Disease	Partnership(s)	Pharmaceutical Donor	Preventive Chemotherapy Drug
Lymphatic Filariaisis	Global Alliance for the Elimination of LF	GlaxoSmithKline Merck & Co, Inc Eisai Sanofi	Albendazole Mectizan (Ivermectin) Diethylcarbamazine
Onchocerciasis	Mectizan Donation Program	Merck	Mectizan (Ivermectin)
Schistosomiasis	Global Schistosomiasis Alliance	Merck KGaA	Praziquantel
Soil-Transmitted Helminths	Children Without Worms Soil-Transmitted Helminths Coalition	Johnson & Johnson GlaxoSmithKline	Mebendazole Albendazole
Trachoma	International Coalition for Trachoma Control International Trachoma Initiative WHO Alliance for Global Elimination of Trachoma by 2020 (GET 2020)	Pfizer	Zithromax (Azithromycin)

Note. This information was compiled from various articles, websites, and conversations.

Public private partnerships have long been central to NTD control efforts and, by some estimations, "have led to the biggest single health venture in the history of disease control" (Bush & Hopkins, 2011). Collaboration around onchocerciasis is a good example of the long-running coordinated efforts to address one NTD. The highly successful Onchocerciasis Control Program (OCP) ran in West Africa from 1974 – 2002 with the goal of eliminating onchocerciasis transmission through aerial spraying of fly breeding sites in disease-endemic countries (Hopkins et al., 2005). The Mectizan Donation Program (MDP), a public-private partnership drug donation program established by Merck and various NGO partners to distribute Mectizan (Ivermectin) for onchocerciasis control, was launched in 1987 after

Ivermectin was shown to be effective in humans (Collins, 2004). This unprecedented move by Merck to donate the drug for free "to anyone who needed it for as long as it was needed" was a critical moment for NTD control and became one of the first instances of a program initiated by a pharmaceutical company's decision to develop and donate a drug, and then to engage public sector organizations to distribute it on a large scale (Collins, 2004). In 1995, the African Program for Onchocerciasis Control (APOC) was initiated to help strengthen Ivermectin MDA programs (Hopkins et al., 2005). This program lasted until 2015 and helped to continue the development of the community-directed treatment method now used widely across MDA programs (Hopkins et al., 2005). The legacies of these programs are still felt by current-day NTD programs.

Drug donation programs, such as Merck's MDP, exist for each of the five PC-NTDs and have been key to the success of global MDA programs (Gustavsen & Hanson, 2009; B. H. Liese et al., 2014; B. Liese et al., 2010; Linehan et al., 2011). For LF, GlaxoSmithKline has been donating albendazole since 1997 (P.J. Hotez et al., 2007; Kirby, 2010). Pfizer has donated azithromycin for trachoma since 1998 and works through the International Trachoma Initiative (ITI) to coordinate distribution of the drug (P.J. Hotez et al., 2007; B. Liese et al., 2010). Johnson and Johnson established what is now known as Children Without Worms (CWW) in 2006 to coordinate distribution of mebendazole for soil-transmitted helminth control (Bush & Hopkins, 2011). Merck KGaA began donating praziquantel for schistosomiasis in 2007 and later expanded the program in 2010 (Fenwick & Jourdan, 2016). The Task Force for Global Health, based in Atlanta, has contributed to the coordination efforts among NTD partnerships by assuming responsibility for a number of these collaborative initiatives, including the ITI, CWW, and the MDP (Gustavsen & Hanson, 2009; B. Liese et al., 2010).

An entity known as the Global Network for Neglected Tropical Diseases was formed in 2006 and was an important force in NTD planning and advocacy efforts until it later dissolved with the emergence of other structures, such as Uniting to Combat NTDs, to fill a similar role (P.J. Hotez et al., 2007; B. Liese et

al., 2010; Musgrove & Hotez, 2009). An umbrella organization to help coordinate and enhance planning and advocacy for NTDs, Uniting to Combat NTDs, was formed through support from BMGF and others as a result of the London Declaration meeting in 2012 (Uniting to Combat NTDs, 2017).

NGO's have played an important role in establishing and strengthening NTD programs. In addition to being able to react quickly and adapt to different country contexts, NGO roles include bridging gaps between formal health systems and communities, brokering relationships across sectors, developing innovative program delivery models, and mobilizing resources (Bush & Hopkins, 2011). The Neglected Tropical Disease Nongovernmental Development Organization Network (NNN) was formed in 2009 after several existing disease-specific coordination groups decided to combine forces to enhance integrated NTD control and elimination efforts (Rotondo et al., 2015). Now the NNN comprises nearly 80 NGO member organizations that have formed coordination groups for the five PC-NTDs (soil-transmitted helminths and schistosomiasis are combined) as well as leprosy. There are also two cross-cutting thematic working groups on WASH and Disease Management, Disability and Inclusion (DMDI) (Rotondo et al., 2015).

On the research and development side, the Drugs for Neglected Diseases Initiative (DNDi) and the Foundation for Innovative Diagnostics (FIND) were both formed in 2003 to address the ongoing need for new drugs and effective diagnostics (Fürst et al., 2017; D. H. Molyneux & Malecela, 2011). In 2013, BMGF and USAID organized the Coalition for Operational Research on NTDs (COR-NTD), a mechanism that convenes international researchers, practitioners, and donors to work together address knowledge gaps needed to overcome challenges in global NTD programs (Toledo, Jacobson, Wainwright, Ottesen, & Lammie, 2015).

At the country level, many NTD programs are managed by NTD Steering Committees, led by the MOH and including nongovernmental partner organizations, to harmonize partner and MOH interests into a

coherent strategy (Linehan et al., 2011; Means, Jacobson, Mosher, & Walson, 2016). Despite the successful collaboration to date, it is widely acknowledged that these efforts must continue and be enhanced – particularly in the area of intersectoral collaboration between the health, WASH, and education sectors – in order to reach NTD control and elimination goals (Campbell et al., 2017; Kabatereine et al., 2010; Rollinson et al., 2013; Waite et al., 2016) Similarly, researchers acknowledge a lack of adequate collaboration between NTD programs and programs for "the big three" diseases of AIDs, TB, and malaria (P.J. Hotez et al., 2007; Macpherson et al., 2015).

How to assess a network's effectiveness, or the extent to which the network is able to move the world in a direction that meets its members collective preferences, is a critical question for global health (Shiffman et al., 2016). Much of the literature that addresses this question focuses on coalitions at the community level and has found important factors for community coalition effectiveness to include cohesion around a shared goal, active member participation, and strong leadership (Roussos & Fawcett, 2000; Zakocs & Edwards, 2006). At the level of global health networks, Shiffman et al. propose a framework for understanding network effectiveness that considers three main categories of factors: network and actors features, the policy environment, and issue characteristics. The authors applied the framework to six in-depth case studies of different global health networks though which they found that networks are most likely to be effective when they construct compelling framings of an issue and establish multisectoral coalitions beyond health (Shiffman et al., 2016). This framework provides a useful reference point for understanding how the global NTD network collaborates on the systemic issues important to network effectiveness. As mentioned earlier, the global NTD network has been very successful in constructing a compelling external frame around NTDs but has fallen short in expanding the strong NTD partnerships to sectors beyond NTDs.

One method used to study networks is social network analysis, which can be used to quantitatively measure and visually map partnerships characteristics and collaboration within networks (Honeycutt &

Strong, 2012; Schoen, Moreland-Russell, Prewitt, & Carothers, 2014). Doing so can enhance our understanding of how networks operate and how they might be strengthened to increase their effectiveness (Provan, Veazie, Staten, & Teufel-Shone, 2005). The most informative measures used in network analysis include the proportion of possible links in the network that actually exist (density), the extent to which a network is dependent on one or a few nodes that are not otherwise connected (betweenness centralization), and the distance from one node to the other nodes (closeness centrality) (Luke & Harris, 2007; Provan et al., 2005; Schoen et al., 2014). Network analysis can also look at things like the types of interactions between organizations, the strength of each relationship, and the level of trust each organization has with other organizations in the network (Provan et al., 2005; Schoen et al., 2014). Network analysis has a long history of use in public health (Luke & Harris, 2007). For example, it has been used to understand collaborative relationships among public health funding programs in the United States (Schoen et al., 2014), in state tobacco control networks (Harris, Luke, Burke, & Mueller, 2008), and in networks of researchers and practitioners promoting physical activity in Brazil and Colombia (Brownson et al., 2010; Parra et al., 2011). Network analysis has not been used extensively to look at governance for NTDs.

ORGANIZATIONAL STRATEGY

As a major objective of this project is to provide actionable recommendations for the END Fund, it is useful to consider guidance offered by the management literature around organizational strategy. In their seminal Harvard Business Review article from 1996, Porter and Roach define strategy as "the creation of a unique and valuable position, involving a different set of activities" (Porter & Roach, 1996). While there are stark differences between competitive strategy in the corporate sector and strategy for impact in the social sector, the overarching idea of strategy as a decision regarding which activities should be done and how they should be done is a useful one. Leonard offers a tool for strategic analysis that is helpful in identifying the key strategic questions for public sector organizations (Leonard, 2006).

This framework allows us to take the perspective of any organization and build a strategy by asking three key questions: 1) Do we have the capacity to carry out this work? 2) Do we have the support of the people or organizations whose support is relevant to our carrying it forward? 3) Would the operation of this action, program, or initiative create public value? This "Value, Capacity, and Support Model" serves as a basis for inquiry that allows an organization to improve its strategic setting as it seeks to "produce greater overlap between value, capacity, and support" (Leonard, 2006).

C. Systems Thinking

The overall approach used for this project is rooted in the theoretical foundation of systems thinking and complexity theory. Systems thinking provides an approach, toolkit, and set of values that increase the ability of stakeholders to influence durable change in complex contexts. This section explores the ideas and methods that constitute systems thinking and discusses the relevance of this approach for public health and NTDs.

DEFINING A SYSTEM

At its core, a system is an interconnected set of parts that, through their interactions, form a whole beyond the component parts (Cavana & Maani, 2000; Checkland, 1981; Meadows, 2008). Complex adaptive systems are systems that adjust or adapt in dynamic and often unpredictable ways to changes that occur in other system parts (Atun, 2012; National Cancer Institute, 2007; Swanson et al., 2012). While the study of complex systems largely originated in the biological and physical sciences, it is it becoming increasingly common to apply these learnings to the understanding of social systems in order to try to solve complex societal challenges (Birney, 2014; Meadows, 2008).

A first step to defining the boundaries of a social system of interest is articulating the problem situation that is being targeted for intervention (Checkland, 1981; Foster-Fishman, Nowell, & Yang, 2007). Since

the problems and solutions of complex social problems are often ill-defined or unknown, it is essential that the various stakeholders who represent a range of perspectives are involved in the process of problem articulation (Checkland, 1981; Foster-Fishman et al., 2007; Midgley, 2000). After clarifying the problem situation, system boundaries are further defined by determining who and what is contained within the system given the targeted problem (Foster-Fishman et al., 2007).

A social system includes the relevant actors, but it also includes the events, behaviors, and systems structure – the resources, regulations, operations, pressures, norms, values, goals, perceptions, attitudes, beliefs, etc. – relevant to the targeted problem (Foster-Fishman et al., 2007; Kim, 1999; Stroh, 2015; USAID, 2016). Gaining a thorough understanding of a system that one is seeking to change by exploring these system parts and the interconnected patterns of relationships among them is crucial to successfully intervening in a complex system (Foster-Fishman et al., 2007; Kim, 1999).

COMMON SYSTEM CHARACTERISTICS

Research on complex living and social systems has identified common system characteristics that help explain system behavior (Homer & Hirsch, 2006; Sterman, 2006). For example, we know that systems seek to maintain stability through feedback, or the transmission and return of information (Kim, 1999; Sterman, 2000). The balancing and reinforcing feedback loops that govern system behavior illustrate that systems are made up of interconnected sets of circular relationships, rather than the unidirectional cause-and-effect relationships that represent typical linear thinking (Homer & Hirsch, 2006; Kim, 1999; Sterman, 2006). Thus, intervening in a system can have unintended consequences when little is understood about how decisions will circle back to impact the context and other variables within a system (Sterman, 2006; Stroh, 2015). A phenomenon known as policy resistance, in which a system responds to our actions in ways that dilute them to make the policy ineffective, is a common occurrence in complex systems (Meadows, 2008; Sterman, 2000). In fact, there are many examples of policy

resistance in which actions intended to solve a problem resulted in making the problem worse than it was originally (Meadows, 2008; Sterman, 2000).

Another important system characteristic is that complexity is a result of stocks, or variables that accumulate, and flows, or rates of accumulation (Homer & Hirsch, 2006; Kim, 1999; Sterman, 2006). This central tenet of system dynamics is often described using the analogy of a bathtub in which the water in the tub represents a stock and the water entering and leaving the tub represents flows (Homer & Hirsch, 2006; Sterman, 2000). Understanding how stocks and flows of people, assets, information, etc. are changing within a social system is key to assessing how a system functions. The idea that there are time delays between causes and their effects within a system is a third common feature of complex systems with critical implications (Kim, 1994; Sterman, 2000). These delays can be physical, transactional, informational, and perceptual (Kim, 1999). Other common characteristics are that systems are constantly changing, tightly coupled, nonlinear, history-dependent, self-organization, adaptive and evolving, characterized by trade-offs, and counterintuitive (Sterman, 2006; World Health Organization, 2009).

COMPLEX PROBLEMS

It can be helpful to distinguish between three different types of problems: simple, complicated, and complex (Glouberman, Ph, & Zimmerman, 2002). Simple problems, such as following a recipe to bake a cake, are those that require a basic level of knowledge and technique but that, once mastered, carry with them a high probability of replicating success each time. Complicated problems, such as sending a rocket to the moon, require more coordination and expertise but still portend high levels of certainty of consistent outcomes. Complex problems, which are also sometimes known as adaptive challenges (Heifetz, 1994) or wicked problems (Pritchett, 2012), in contrast, are each unique and require learning in order to make progress. A metaphor for a complex problem is raising a child, since there are no recipes

or sure-fire formulas that guarantee a particular outcome. Complex social problems are nested within complex systems and have causes and solutions rooted in the work of many stakeholders (W. Allen, 2016). Many of society's most pressing challenges fit the criteria of complex problems as described above and as further detailed in Table 6.

Table 6. Signs of Complex Problems

Problem is chronic and has defied efforts to solve it
Diverse stakeholders find it difficult to align their efforts
Stakeholders try to optimize their part without understanding impact on the whole
Short-term efforts might actually undermine intentions to solve the problem
People are working on a large number of disparate initiatives at the same time
Promoting particular solutions comes at the expense of engaging in continuous learning

Note. Adapted from *Systems Thinking for Social Change* (Stroh, 2015).

Complex problems require different approaches than complicated or simple problems. Attempts to apply rational planning approaches or technical solutions to complex problems are often unsuccessful because they fail to take into account many of the counterintuitive features of complexity discussed above (Glouberman et al., 2002; Heifetz, 1994). Making progress on complex problems that are part of complex adaptive systems requires different skillsets that incorporate relationship building, convening, and, most importantly, learning (W. Allen, 2016; P. Senge, 1990).

SYSTEMS THINKING

Systems thinking is a conceptual framework or analytical lens that helps us see the world as a complex system in order to make progress on complex problems (National Cancer Institute, 2007; P. Senge, 1990; Sterman, 2000). By helping us understand and see through complexity, it makes systemic patterns clearer and assists us in identifying high-leverage actions to change systems effectively (P. Senge, 1990). Systems thinking involves an iterative learning process in which we substitute a holistic, dynamic view

for a reductionist, static view of the world (Sterman, 2006). The act of systems thinking often changes our perceptions of what the problems are, where their boundaries lie, and who ought to decide how to approach them (Leischow & Milstein, 2006).

The systems thinking iceberg shown in Figure 7 is a tool for thinking systemically about complex problems (Stroh, 2015). In this diagram, the iceberg represents the entire complex problem, some of which is visible above the surface but the majority of which is out of sight below the surface. It is typical for us to attempt to solve complex problems by reacting to events and trends – i.e., *what* is happening – since this is more easily apparent. However, failing to grasp the systems structure – or the interdependent relationships among the pressures, policies, power dynamics, perceptions, etc. that drive the system behavior – commonly results in policy resistance and a continuation of the problem we are hoping to solve. Uncovering the systems structure helps us understand not just *what* is happening but *why* it is happening (Kim, 1999). Systems thinking also assists by seeking to make explicit stakeholders' mental models that form the foundation of the deep structure of a system (Sterman, 2000; Stroh, 2015; The World Bank, 2014).

Since root causes of complex problems can be found in the underlying systems structure, changing this structure is critical to solving complex problems (Stroh, 2016). Because this structure is usually not readily apparent, systems thinking emphasizes the need to elicit multiple perspectives from diverse groups of stakeholders in order to understand the structure and co-create potential solutions (Foster-Fishman et al., 2007).

Figure 7. Systems Thinking Iceberg
Reprinted from Systems Thinking for Social Change (Stroh, 2015).

In practice, systems thinking includes a diverse set of methods and tools that range from the mostly qualitative to the highly quantitative (see Figure 8). On the qualitative side, soft systems methodology uses the idea of a complex system as an interrogative tool for stimulating debate, building relationships, and galvanizing people into action (Abercrombie, Harries, & Wharton, 2015; Checkland, 2011; Foster-Fishman et al., 2007). On the quantitative side, system dynamics modeling incorporates data into simulations of system behavior in order to describe a system and its operations (Sterman, 2000). Causal loop diagrams and stock and flow diagrams are tools that are essential components of system dynamic models but that can also be used to build qualitative models of complex systems that then form the basis of discussions across stakeholder groups in order to understand the problems and explore

potential leverage points for change (Abercrombie et al., 2015; Stroh, 2015; USAID, 2016). Social network analysis is another quantitative method that, as mentioned earlier, holds the potential for understanding linkages between stakeholder groups within a system (National Cancer Institute, 2007; Schoen et al., 2014).

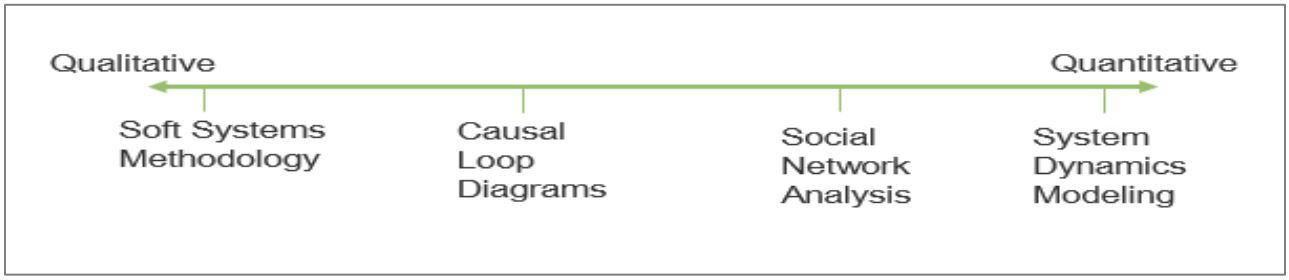

Figure 8. Examples of Systems Thinking Methods and Tools

Systems thinking has been used for a range of settings and purposes, including as a strategic planning and evaluation tool to address many types of business and societal challenges (Morecroft, 2010). On the organizational level, using systems thinking to identify and map feedback loops can be a valuable tool in helping an organization develop a core theory of success that takes into account the interconnectedness of the various processes at play in a system (Kim, 1999).

SYSTEMS THINKING IN PUBLIC HEALTH

Systems thinking is gaining an increased amount attention across a variety of fields, including in public health. Its value for public health is to help make explicit our mental models and assumptions, identify and test hypotheses, and calibrate our models against real data (Peters, 2014). Systems thinking in public health can also enhance our ability to generate and learn from evidence and catalyze effective change (Sterman, 2006). Public health interventions often ignore features of dynamic complexity that make public health challenges so difficult to solve, but studies grounded in systems thinking can increase

understanding of “how such systems are organized, how they behave over time, and how they can be better governed” (Leischow & Milstein, 2006).

In 2009, the WHO published a report, Systems Thinking for Health Systems Strengthening, that made the case that, since health systems are complex adaptive systems, “every intervention, from the simplest to the most complex, has an effect on the overall system, and the overall system has an effect on every intervention” (World Health Organization, 2009). Thus, the report argues, systems thinking has enormous potential to help decipher health system complexity and to design and evaluate health system strengthening interventions that seek to account for the unpredictability of operating within a complex system. A handful of subsequent publications have made similar arguments (Atun, 2012; Mutale, Balabanova, Chintu, Mwanamwenge, & Ayles, 2016; Swanson et al., 2012; USAID, 2016). Quantitative and qualitative systems thinking approaches have been applied to improve public health responses for tobacco control, cardiovascular disease, diabetes, polio, maternal health, and many other conditions (Hirsch, Homer, Evans, & Zielinski, 2010; Jones et al., 2006; Levy, Bauer, & Lee, 2006; National Cancer Institute, 2007; Rwashana, Nakubulwa, Nakakeeto-Kijjambu, & Adam, 2014; Thompson & Duintjer Tebbens, 2008).

SYSTEMS CHANGE

Systems change is a phrase that is often used, especially in the nonprofit sector, to refer generally to different types of big picture initiatives intended to solve social problems. However, some scholars and practitioners have offered more precise definitions that help to move towards a shared understanding of what the term means. Foster-Fishman et al. suggest that systems change “refers to an intentional process designed to alter the status quo by shifting and realigning the form and function of a targeted system” (Foster-Fishman et al., 2007). In other words, systems change focuses on transformational changes in the systemic structure, or the “below-the-surface” portion of the iceberg diagram (Stroh,

2016; Abercrombie 2015). Kim uses the metaphor of an airplane to explain that systems change involves not working “in the plane” like a pilot or flight attendant, rather it involves working “on the plane”, like the engineers who designed and built it (Kim, 1999).

Because the root causes of complex problems are found below the surface in the systems structure and touch the work of many stakeholders, changing such systems requires both convening and thinking systemically (Stroh, 2015). Convening systemically, or engaging multiple stakeholder groups with a range of perspectives, is generally agreed to be a necessary step to constructing a holistic understanding of what the problem is, what change is needed, and who needs to be involved in solving it (Abercrombie et al., 2015; Foster-Fishman et al., 2007; Sterman, 2006; World Health Organization, 2009). While convening is essential, it is not usually sufficient in and of itself to catalyze change in complex systems, and many systems change efforts ignore the systemic nature of the contexts they are targeting for change (Foster-Fishman et al., 2007). Thus, systems change also requires stakeholders to think systemically, or to engage in a joint learning process to understand the systems structure and identify potential solutions that take into account the complexities of the problem (P. Senge, 1990; Stroh, 2015).

A number of frameworks, each of which informed my overall DELTA project framework, offer a path forward for engaging in systemic change efforts. Each of the three frameworks presented below follows the same general pattern of beginning with understanding the system, identifying leverage points for change, and mobilizing action to generate the desired change. Stroh’s framework (Figure 9) places a heavy emphasis on helping stakeholders experience the gap between the current reality and the aspired state of the system (Stroh, 2015).

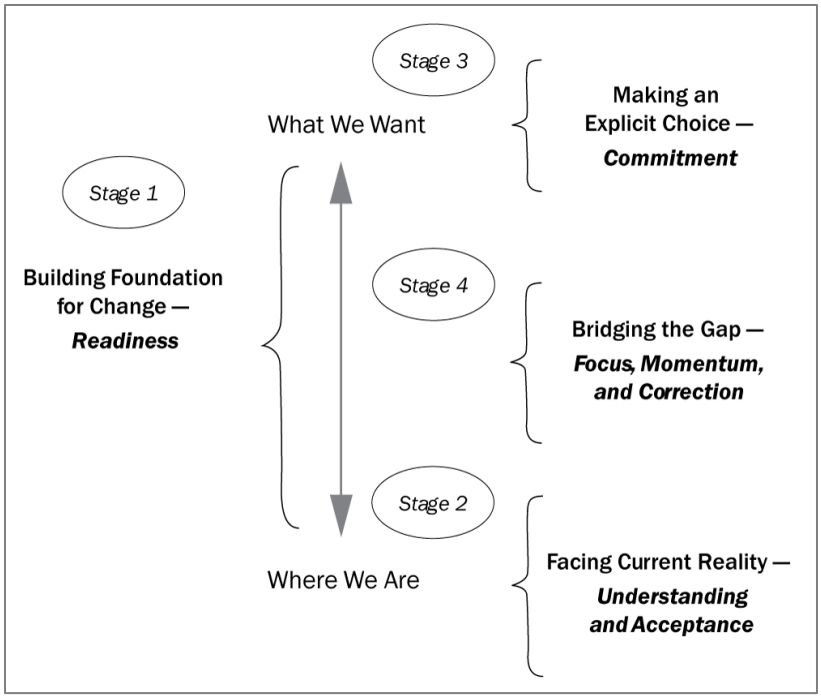

Figure 9. Stroh's Framework for Systems Change
Reprinted from *Systems Thinking for Social Change* (Stroh, 2015).

Foster-Fishman et al. draw on insights from their work in community development to outline detailed steps (Figure 10) for defining and assessing the systemic nature of a problem (Foster-Fishman et al., 2007). These steps culminate with a process for identifying feasible levers for change within the patterns that have been uncovered.

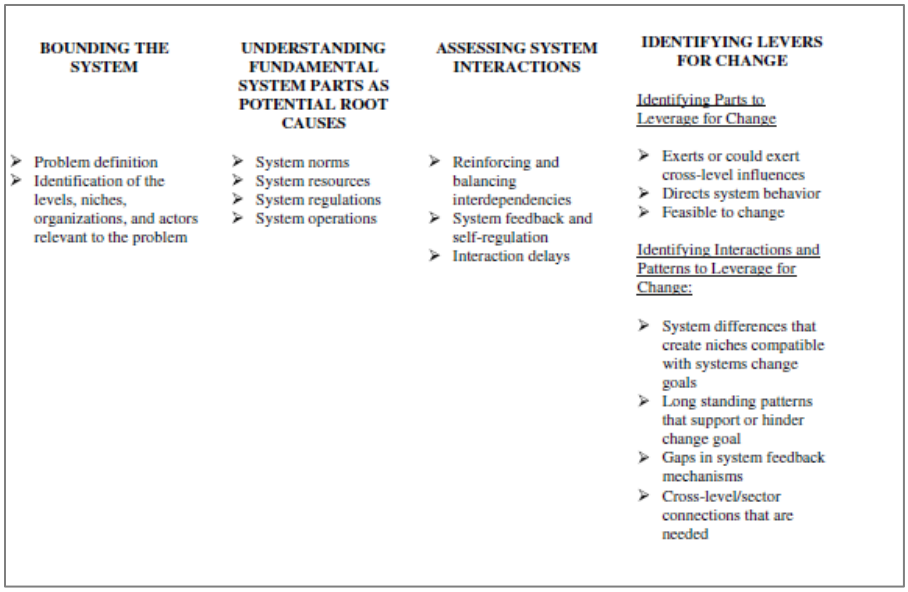

Figure 10. Foster-Fishman et al.'s Components of Transformative Systems Change
Reprinted from *Putting the system back into systems change: A framework for understanding and changing organizational and community systems* (Foster-Fishman et al., 2007).

Birney's six steps to significant change (Figure 11) trace the systems change process through an s-curve in which tipping points for systemic change occur after experiments and prototypes of pioneering practices are shown to be promising (Birney, 2013). It is essential to remember that systems change is usually a long, difficult, windy road, and thus changing systems often happens through the joint learning process than through reaching a finished end state (Abercrombie et al., 2015).

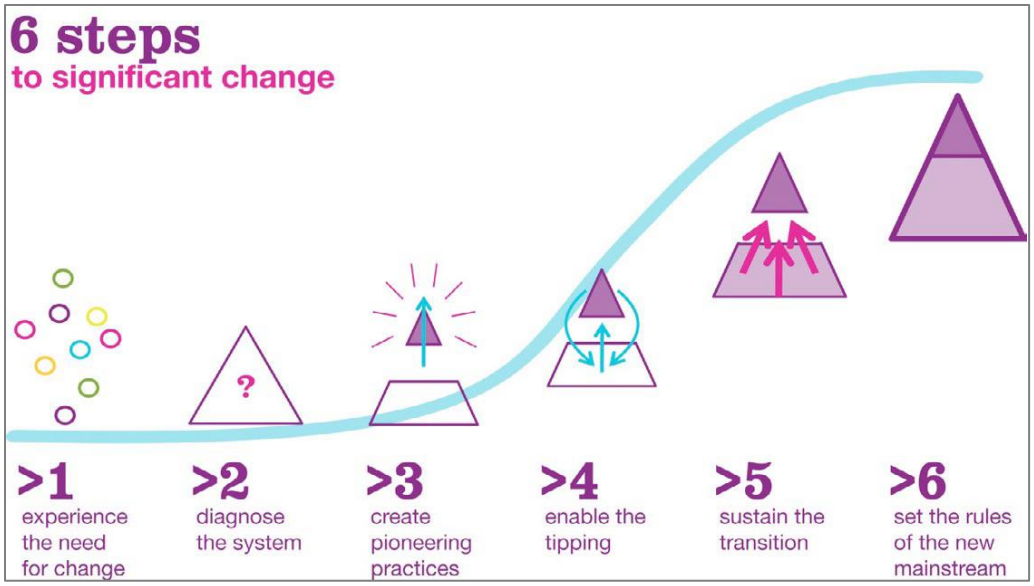

Figure 11. Birney's 6 Steps to Significant Change
Reprinted from Cultivating System Change: A Practitioner's Companion (Birney, 2014).

Finally, Rwashana et al.'s revised dynamic synthesis methodology (see Figure 12) offers a framework with research strategies for approaching systems change (Rwashana et al., 2014). This six stage framework begins with a qualitative approach that involves using interviews and surveys to describe the problem and gain a deeper understanding of key issues. Stage 3 calls for building and validating a qualitative descriptive model of the system before moving on to a dynamic simulation model in the subsequent stages.

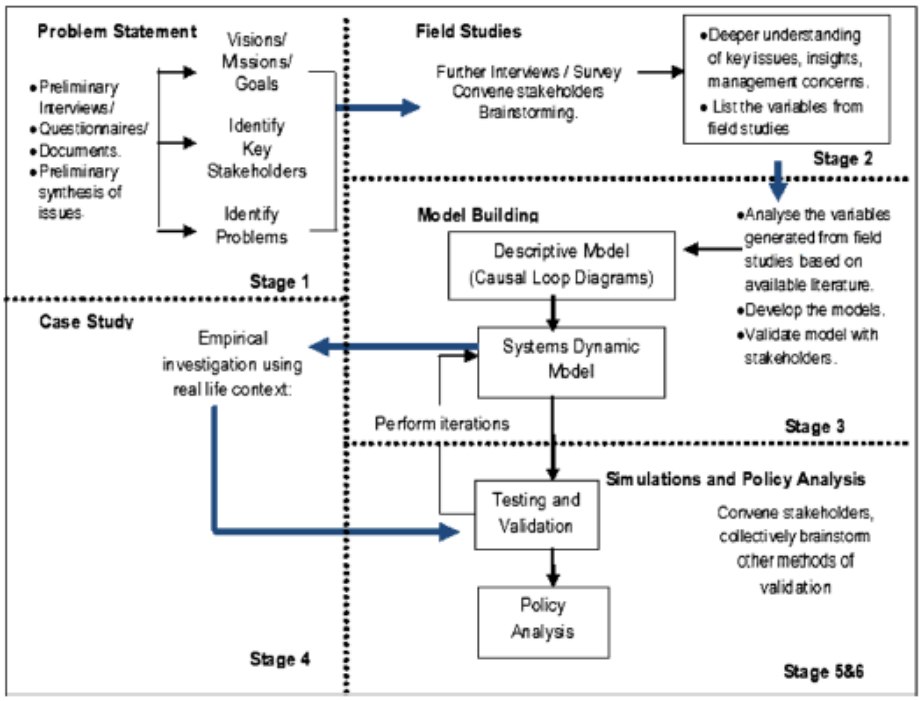

Figure 12. Dynamic Synthesis Methodology
Reprinted from Advancing the application of systems thinking in health: understanding the dynamics of neonatal mortality in Uganda (Rwashana et al., 2014).

SYSTEMS ENTREPRENEURSHIP AND LEADERSHIP

Systems change can be accelerated through the efforts of individuals and organizations, sometimes referred to as “system stewards” or “system entrepreneurs”, who seek to understand whole systems and are skilled in coordinating systematic approaches to problem solving (Walker, 2017). System entrepreneurs act as the “connective tissue” between parts of an ecosystem by serving as neutral brokers to help like-minded individuals join forces to catalyze innovative systems change (Abercrombie et al., 2015; Kirsch et al., 2016; Love & Sinha, 2015; Walker, 2017).

Making progress on systemic problems requires a kind of leadership different from typical ideas of leadership (Heifetz, Kania, & Kramer, 2004; P. Senge, Hamilton, & Kania, 2015). Rather than attempting to provide easy answers, those who successfully lead systems change try to create the conditions through which stakeholders can learn together and take responsibility for addressing their own

challenges (Heifetz et al., 2004; P. Senge et al., 2015). The heart of this type of “adaptive leadership” is getting people to pay attention to tough problems (Heifetz et al., 2004). Three roles suggested for those who lead in systems include 1) cultivating a shared vision for change, 2) empowering widespread innovation and action, and 3) enabling mutual accountability for progress (Nelson & Jenkins, 2016).

COMPLEXITY AND NTDS

In a sense, NTDs appear to represent a simple problem since the global network of organizations working to control and eliminate NTDs has been very successful in reducing the number of people affected through scaling up evidence-based programs to deliver preventive chemotherapy drugs to millions of individuals in at-risk communities. However, despite the advocacy message that often gets communicated that MDA is an easy solution that can rid the world of NTDs once and for all if we can just get more funding, MDA is not a cheap fix for poverty or a ‘magic bullet’ to achieve health for all (T. Allen & Parker, 2011; Dean et al., 2016; Jacobson & Bush, 2017; Michael & Madon, 2017). As with many social problems, NTDs are a complex issue for which systems thinking approaches can offer valuable insight (Michael & Madon, 2017).

At the disease level, transmission of infections in human communities is an inherently complex phenomena that is influenced by the interconnections between ecological, social, political, and economic processes (T. Allen & Parker, 2011; Allotey et al., 2010; Michael & Madon, 2017). Factors such as conflict or climate change can influence each of these processes, making it not only difficult to access and establish programs in certain communities, but also making it imperative that MDA campaigns are adapted to take into account the unique and complex socio-ecologic contexts (T. Allen & Parker, 2011; Dean et al., 2016; Haddad, 2008; Hanson et al., 2012).

At the governance level, NTDs are part of an intricate web of complex systems. For example, NTD programs can be thought of as being nested within country health systems that are nested within a

broader global health system (Hill, 2011; Peters, 2014). At each level there are large numbers of non-linear relationships and other common characteristics of complex systems, including unintended consequences, feedback loops, time delays, policy resistance, etc. (Adam & De Savigny, 2012; Atun, 2012; Peters, 2014; World Health Organization, 2009). Identifying and attempting to understand where and how these features exist within the global NTD system can be helpful in planning intervention strategies. The complexities of governance for NTDs at the global and country levels further add to the need for a more holistic, systems thinking approach (Swanson et al., 2012; World Health Organization, 2009).

The strong history of multisectoral partnerships is seen by many as one of the unique success factors in the NTD sector (Bush & Hopkins, 2011; Rotondo et al., 2015). While likely true, collaboration also adds complexity (Hill, 2011). In addition to the logistical challenges of coordinating efforts across many partners, the fact that there are large numbers of stakeholders involved ensures that at some point there will be differences in values, attitudes, or opinions regarding how critical issues should be addressed (Heifetz et al., 2004). This is true at the global, national, and community levels.

Many of the other major challenges facing the NTD community in its quest to reach the end goals are inherently complex, and thus require learning rather than blueprint approaches. For example, as mentioned earlier, while drug companies have donated billions of dollars' worth of NTD drugs, the supply of these drugs is often greater than the capacity to deliver them (Cohen et al., 2016; D. H. Molyneux, 2014; Zarocostas, 2017). New resources must be mobilized to fill the estimated US$200 million annual global funding gap in order to meet the delivery need (Abt Associates, 2014). In many countries and even still at the global level, NTDs receive minimal attention from policymakers, which represents the enormous challenge of convincing people to prioritize something about which they care little and have limited knowledge (Jacobson & Bush, 2017). Another example of complexity is the ongoing debate discussed above regarding the proper balance between vertical, top-down approaches

that focus on a particular disease and horizontal approaches in which disease-specific programs are integrated into the broader health system.

Making progress on NTDs can be accelerated by convening systemically and thinking systemically to engage stakeholders in a collective learning process to better understand the complex systems in which these complex problems exist and to catalyze systems change. To be successful, these efforts must include diverse perspectives, and they must not shy away from asking and seeking answers to the hard questions that surface as a result of this process. It is often these questions that hold the keys to transformative systems change. The following section describes how I designed my DELTA project to better understand the NTD system and identify leverage points for change.

D. DELTA Project Design

The project incorporated the five key components of the Maxwell model for interactive qualitative research design: goals, conceptual framework, methods, validity, and research questions (Maxwell, 2013). It also explicitly considered an enabling change component based on the competencies emphasized in the DrPH program. Each of these is discussed below.

GOALS

This project was designed with the aim of using a systems thinking approach to help inform the END Fund's systems change strategy to end NTDs. Drawing on key principles from the systems change literature, the project's four main objectives were as follows:

1) Understand the global NTD system from a systems perspective
2) Identify levers for NTD systems change
3) Engage stakeholders in a systems change process
4) Build capacity for systems thinking among internal and external stakeholders

The global NTD system being studied includes both who is in the system (i.e., people and organizations) as well as what is in the system (i.e., the relationships, events, patterns of behavior, apparent and deep structures, and interactions).

PROJECT CONCEPTUAL FRAMEWORK

The project conceptual framework was developed based on the systems thinking literature review. It draws heavily on Foster-Fishman et al.'s and Stroh's frameworks for systems change, as well as elements of the dynamic synthesis methodology framework used by Rwashana et al. (Foster-Fishman et al., 2007; Rwashana et al., 2014; Stroh, 2015). The project framework includes five phases, beginning with the development of the theoretical foundations of the project and then developing a logical justification for how the project could lead to change in addressing the problem of NTDs. The phases are: 1) develop conceptual framework, 2) bound the system, 3) assess dynamic interactions, 4) identify levers for change, and 5) mobilize for systems change. Each phase is described briefly in

Figure 13 but is also discussed in greater depth in the results statement section of the thesis.

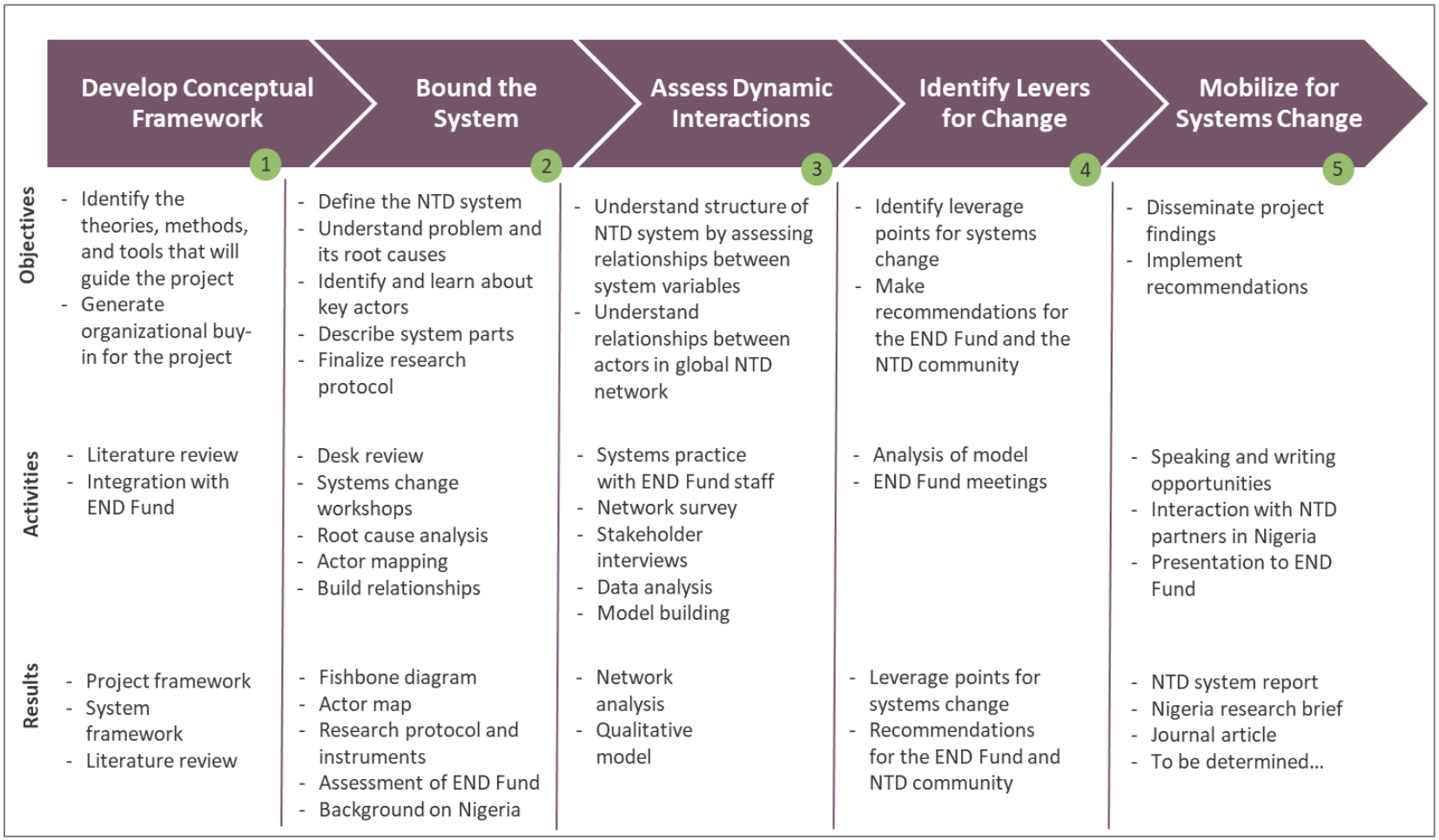

Figure 13. Project Framework

RESEARCH QUESTIONS

During Phase 1, I identified and refined the research questions that would guide the rest of the activities in the project. The two primary research questions were:

1) Why, despite the significant efforts of stakeholders, do NTDs persist as a major public health problem?
2) What would constitute NTD systems change and what are the key leverage points for change?

These first two questions are intended to frame the project from a systems thinking perspective. Question 1 serves as a useful systems focusing question (Stroh, 2015) that leaves space for the research to uncover new questions in the process of exploring the system elements and their interactions. Question 2 provides a launching point for the study's findings to be translated into practice by identifying actionable strategy recommendations for the END Fund and other NTD stakeholders.

In addition to these primary research questions, I identified three secondary research questions that became central to the project:

3) Why have NTDs failed to receive greater political priority at the global and country levels?
4) What opportunities exist to mobilize additional resources for NTDs?
5) How does integration of NTDs with other health and development programs affect efforts to eliminate NTDs?

These questions surfaced during the Phase 1 literature review and discussions with stakeholders as relevant to the NTD space and thus important to the END Fund. While I was careful to not limit my analysis only to these elements of the system, they became key points of inquiry throughout the research process. The political economy and health systems literature discussed above guided my analysis in answering these questions by seeking to understand what stakeholders believe about the

relationships among these factors, some of which are highlighted in the qualitative model of the NTD system presented below. For example, in my qualitative interview data I was able to identify instances where specific determinants of political priority were mentioned by key informants as affecting the level of attention NTDs receive from decision makers.

Finally, I included an overarching research question for the project as a whole:

6) What is an effective process for introducing a systems change approach into an organization?

In contrast with the others, this question recognizes the unique nature of the DELTA project and, while not pursued through the formal research component of the project, served to encourage reflection on my part about the process of enabling change in the context of a public health organization, the END Fund.

METHODS

To achieve the project objectives and answer the research questions, I used different systems thinking methods involving participants at the organizational (END Fund) level as well as the global and country levels. The organizational level approach engaged staff in a participatory method of systems thinking while the global and country level approaches involved more traditional academic research methods. These methods were complemented by insights from the literature review discussed earlier.

Organizational Level Methods

The organizational component focused on achieving the four project objectives internally within the END Fund. Given that participation and collaboration are essential pillars of any systems thinking approach, it was important to engage END Fund staff throughout the process in order to make sense of the findings as they relate to the END Fund and to increase the likelihood that these findings would be incorporated into the organization's strategy in a meaningful way.

A committee representing each of the END Fund's four work teams was formed and met on a monthly basis to provide input into the project and to use an adapted version of Omidyar's Systems Practice Method (The Omidyar Group, 2017) to explore the systemic features of NTDs and to contribute to the development of the NTD system model and accompanying recommendations. This method included the following steps: 1) identify the enablers and inhibitors in the NTD system, 2) explore the causes and effects, 3) create causal loop diagrams through group model building, 4) build and discuss a qualitative NTD system model and recommendations.

Global and Country Level Methods

Study Design

I conducted a mixed-methods analysis using both quantitative and qualitative research methods to understand the network of NTD actors and the structural reasons that NTDs persist as a major public health problem. The two methods were 1) a network analysis survey exploring the connections between key actors and 2) semi-structured key informant interviews of NTD stakeholders.

I administered a quantitative survey to key organizations at the global level involved in some capacity with eliminating NTDs. It measured level of collaboration in the network by asking each organization to indicate the nature of their relationship to each of the other organizations being surveyed using the following scale: unlinked, cooperative, communicative, collaborative, or partnership. This measure was adapted from previous public health studies that also utilized network analysis (Brownson et al., 2010; Harris et al., 2008; Schoen et al., 2014). In addition, the survey asked respondents to indicate up to five organizations who they believed to be the most innovative in their efforts to control and eliminate NTDs, and to provide an open-ended response about the major barriers to collaboration between NTD organizations. Appendix A shows the full survey instrument.

I conducted key informant interviews with stakeholders at the global, national, state, and community levels. An interview guide (Appendix B) was used to facilitate a discussion with NTD stakeholders about their perspectives on the barriers to addressing NTDs in order to gain a clearer picture of different stakeholders' understandings of the NTD system. The interviews were focused around answering the study research questions but also allowed for other issues to surface and be discussed.

Site Selection

No specific site was chosen for the global level research. Based on discussions with END Fund management, I selected Nigeria as the country to analyze as a case study. Nigeria is one of the countries that receives the most funding from the END Fund and is thus a country of significant interest. The strength of END Fund's partnerships in Nigeria made it likely that I would get access to key stakeholders in the relatively short project timeline. Nigeria is also an ideal case study from the standpoint of being one of the highest NTD burden countries and having significant complexity due to large numbers of diverse organizations attempting to collaborate around NTDs.

Sample Selection

The organizations surveyed at the global level were initially identified by me based on the literature and desk reviews done during Phase 1 of the project. The goal was to identify all organizations involved in one or more of the five PC-NTDs whose work extended beyond one country. This included bilateral and multilateral organizations, private sector companies, nongovernmental organizations, and research institutions. The END Fund had an existing list of NTD organizations that I used as a starting point. After I created a draft list of organizations to be included, END Fund staff reviewed and provided feedback to help determine the final sample of respondent organizations. A primary point of contact was identified for each organization based on consideration for who would have the most knowledge about the

organization's NTD partnerships. In almost all cases, someone at the END Fund had an existing relationship with the person who received the survey.

The key informant interview respondents at the global level were purposively selected from the list of survey respondents based on two main considerations: 1) selecting people with experience and knowledge of the NTD sector, and 2) selecting people from different types of organizations who would likely have different perspectives on the system.

The process for identifying the interview respondents was similar for Nigeria. I attended a National NTD Steering Committee meeting in Nigeria in September of 2017 during which I met many of the NTD stakeholders. The draft list of organizations and individuals to be interviewed was then compiled based on the information I gained during the meeting and from communication materials sent following the meeting. These included representatives from federal, state, and local governments; multilateral organizations international and local NGOs; and community health facilities. The END Fund's two Nigeria program managers contributed significantly to refining this list.

Data Collection

An electronic version of the survey was built using the Qualtrics Survey Software Online Platform. Recruitment emails with the survey link and explanation were sent to all points of contact identified through the sample selection process. Follow-up emails were sent after three weeks and then a final email two weeks after that to non-respondents. Surveys were sent to a total of 73 participants at the global level. I received 27 responses for a response rate of 37%.

At the global level, the subset of potential key informant interview respondents did not receive an initial email requesting they complete the survey; rather, they received an email requesting an interview. I was able to schedule interviews with 17 of the 25 individuals I contacted at the global level, for a response rate of 68%. In cases where the interview was conducted, a request to complete the survey was made

verbally with follow-up through email. Most global level interviews were conducted via Skype or telephone with a few being conducted in person. At the country level, the interviews were arranged less systematically by me emailing potential respondents as well as by local contacts I had met helping to schedule meetings with appropriate key informants. Most country level interviews were conducted in person in Nigeria with a few being conducted via Skype or telephone. I conducted 17 interviews at the global level and 28 in Nigeria for a total of 45.

Analysis

To analyze the survey data, I applied basic social network methods using Gephi 0.9.2, a network analysis and visualization software package. When one organization in a dyad did not respond to the survey, the available score (reported by the organization in the dyad who responded) was used. All network links were symmetrized by using the higher score for each dyad. To simplify the network for this analysis, I considered the organizations as connected if the reported link was either collaborative or partnership. Relationships that were reported as cooperative, communicative, or unlinked were not considered as connections for this analysis. I used the data to create visualizations showing the network of organizations surveyed and the connections between them. I also calculated the basic network level measure of density as well as basic node level measures of betweenness centrality and closeness centrality.

The qualitative interviews were all audio recorded and transcribed verbatim. The transcripts were imported into the qualitative analysis software MAXQDA, which I used to help organize and support the coding process. I developed a preliminary codebook based on the initial literature review and the project conceptual framework. The codebook included codes for variables believed to be key forces in the system as well as codes for instances of interactions between variables. I then analyzed and coded all interviews using the preliminary codebook, with emergent themes, variables, and interactions being

identified and added to the codebook throughout the analysis process. I then analyzed and coded all interviews a second time using the final codebook.

Following analysis of the interviews, I used the coded interview data to identify the variables and interactions that were reported as the biggest factors driving and impeding progress towards NTDs. Using the coded data as a guide, I iteratively built causal loop diagrams for each of these central issues based on interactions between variables as reported by respondents. I looked specifically for examples of reinforcing and balancing feedback loops, as well as systems stories that were counterintuitive or that highlighted cases of unintended consequences. After building and refining a number of loops, I selected those that seemed to most accurately portray the key issues found in the qualitative data. Finally, I combined these loops into a single qualitative model of the NTD system. I used Kumu, an online system mapping and visualization platform, to build and visualize this model.

Ethical Review

This study was reviewed and approved by the Institutional Review Board at the Harvard TH Chan School of Public Health. It was also reviewed and approved by the National Health Ethics Research Committee within the Federal Ministry of Health in Nigeria.

VALIDITY

As Maxwell explains, the two major threats to validity in this type of qualitative study are researcher bias and reactivity (Maxwell, 2013). While care was taken throughout the research process to allow interview respondents to surface whatever issues they saw as relevant to the topic at hand, the possibility of reactivity is a concern and must be taken into consideration, especially because I largely completed the data collection myself. Researcher bias is also a potential concern. While the issues highlighted in this thesis were chosen by me based on my best assessment of the key issues in the data, I was careful to only connect variables in the model if that connection was explicitly made by the

interview participants. It is important to note that, in a study like this that uses a systems thinking approach, the goal is not necessarily to arrive at a model that represents the only true and accurate structure of the NTD system; rather, the goal is to represent one model that summarizes various perspectives held by different stakeholders. Whether the stakeholders' opinions are true or not is of secondary concern to the fact at least someone feels they are true, so systems thinking would argue that the perspective is worth surfacing as a way to better understand the complexity of the issue.

ENABLING CHANGE

Since the DrPH DELTA Doctoral Project is intended as a leadership development experience, I explicitly planned my project as an opportunity to incorporate the DrPH enabling change competencies around management, leadership, and communication. The challenge of the project was, in a relatively short period of time, to assimilate myself into an organization and generate support for my work with sufficient buy-in to make it likely that my findings and recommendations would be incorporated into the organizational strategy following my departure. I reflect in the discussion section of this thesis on my observations about the host organization, difficulties I faced, and my successes and failures in trying to become a change agent within the END Fund.

III. RESULTS STATEMENT

This section moves from the description of the analytical platform and project plan to explain what transpired, present the results, and discuss the implications of the results for the END Fund and the broader NTD community. The outline will follow the five phases of the project framework as explained in the previous section.

A. Phase 1 – Develop Conceptual Framework

OBJECTIVES

The objectives of this initial phase were to develop the conceptual foundation and to generate organizational buy-in for the project.

ACTIVITIES

The main activity was the literature review presented above. Other activities included immersing myself as a member of the END Fund team in order to understand the key issues the organization was facing and how my DELTA project could help inform the organization's strategy for addressing NTDs. This included attending an END Fund team retreat during which END Fund staff and board members gathered to celebrate the 5th anniversary of the organization's founding, engage in team building activities, and discuss strategic priorities for the next five years. I also attended a number of other team meetings during this initial period.

RESULTS

The main deliverable of this phase were the literature review and the Project Framework (

Figure 13) shown earlier. Another deliverable was the System Framework discussed here. The relationships I developed within the END Fund during this phase became important to getting buy-in for

executing the project as designed by persuading END Fund management that my project would add value to the organization.

i. Defining an NTD System Framework

The goal of this the Defining an NTD System framework (Figure 14) was to guide my research by helping answer the question that many people asked as I attempted to explain the project to them, "What do you mean by 'NTD system'"? I learned that people have very different definitions of systems, ranging from something that is specifically defined as a system (e.g., health system), to a group of people working on the same issue, to a precise description of a complex adaptive system. After considering the question throughout my literature review, this resulting framework includes both *who* is in the system (i.e., people and organizations) as well as *what* is in the system (i.e., the relationships, events, patterns of behavior, apparent and deep structures, and complex interactions). The framework also accounts for the context and different levels and sub-systems that form important elements of the systemic structure.

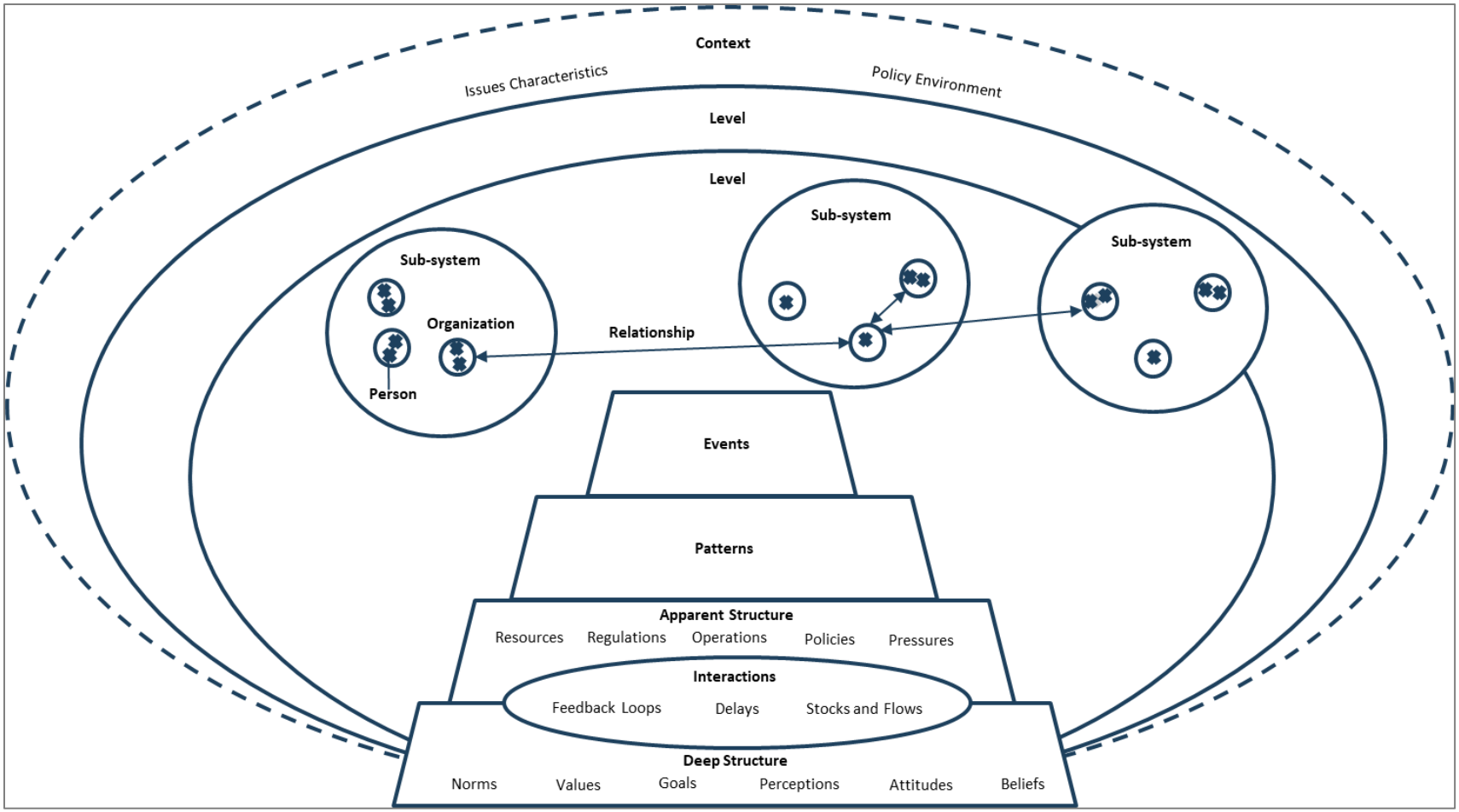

Figure 14. Defining an NTD System

B. Phase 2 – Bound the System

OBJECTIVES

The objectives of this second phase were to define the NTD system by understanding the problem and its root causes, identifying and understanding the key actors, and describing the fundamental system parts. Another objective was to finalize the research protocol.

ACTIVITIES

This phase included activities specific to the organizational, country, and global work streams of the project. It also involved continuing the literature review by focusing on annual reports and internal END Fund documents.

Organizational Level Activities

The work done with END Fund staff was designed to engage them in order to understand their perspective on the NTD system and to build internal capacity for systems thinking. The first step taken was to hold a series of Systems Change Workshops for END Fund staff members. I planned and implemented a separate workshop for each of the three programmatic teams within the END Fund – Programs Team, Communications Team, and External Relations Team. These participatory workshops walked through the fundamental concepts of systems thinking and helped staff begin to apply systems thinking to their NTD work. The workshops concluded with an exercise in root cause analysis using the fishbone diagram tool and then, based on the root causes identified, an exercise in actor mapping.

Following this initial series of workshops, I organized a six-person Systems Change Committee consisting of 1-2 staff members from each team to continue the Systems Practice process in order to flesh out the END Fund's perspective on the NTD system. This committee also served as an internal advisory board for providing input and feedback to me throughout planning and execution of the project. The committee

would ultimately meet five times. The initial work of the committee was to continue the discussions started during the Systems Change Workshops to try to establish boundaries for the NTD system and to think systemically about the problem of NTDs. For Phase 2 of the project, this included an assessment of the END Fund's current approach to systems change as well as an exercise to identify the variables that acted as enablers and inhibitors in the NTD system. These activities became the foundation for developing the study instruments and for assessing the dynamic interactions of the system in Phase 3 of the project.

Country Level Activities

Through discussions with END Fund management, I selected Nigeria as a focus country due to its high burden of NTDs and large number of NTD stakeholders. Nigeria is also one of the largest recipients of END Fund funding and thus an important country of interest for the END Fund. During Phase 2 of the project I sought to gain a better understanding of the NTD problem and key actors in Nigeria through reviewing END Fund project documents and country-specific peer-reviewed articles and administrative documents. I traveled to Nigeria in September 2017 to attend the National NTD Steering Committee meeting hosted by the Nigerian Federal Ministry of Health (FMOH) and attended by key partner organizations. This meeting was valuable in helping me identify the key actors and understand how the NTD program is structured in Nigeria. I also became aware of priority issues for NTD partners and developed important connections with members of the NTD Steering Committee, Federal Ministry of Health, and other partner organizations.

Global Level Activities

In addition to the literature review conducted to understand the global NTD problem and stakeholders, I traveled to Dakar, Senegal for the 8th Annual Conference of the NTD NGO Network (NNN) held in September 2017. This meeting provided me with a valuable introduction to the strategic issues facing

the NTD community and allowed me to meet many of the stakeholders I would eventually interview during Phase 3. I left this conference with a much better understanding of how the global NTD community was organized and how they were collaborating to address NTDs. I also learned more about some of the biggest barriers to progress.

RESULTS

Deliverables from this phase included a map of key actors, finalizing the research protocol, an organizational assessment of the END Fund, and a write-up on the background of NTDs in Nigeria.

i. Key Actors

Figure 15 shows an actor map that resulted from the actor mapping exercise during the END Fund systems change workshops. The key types of stakeholders are grouped into four main categories: NGOs, international organizations, private sector, and governments. Actors closer to the center of the map are more closely connected with communities and people affected by NTDs while actors further out are less closely linked. Following the background work during this phase of the project, I compiled a list of specific organizations closely involved in global NTD control and elimination efforts. These included program implementer NGOs, philanthropic organizations, pharmaceutical companies, bilateral aid agencies, networks or partnerships, United Nations (UN) organizations, and research institutions. This list became the basis for developing the final list of organizations asked to complete the network survey and participate in interviews.

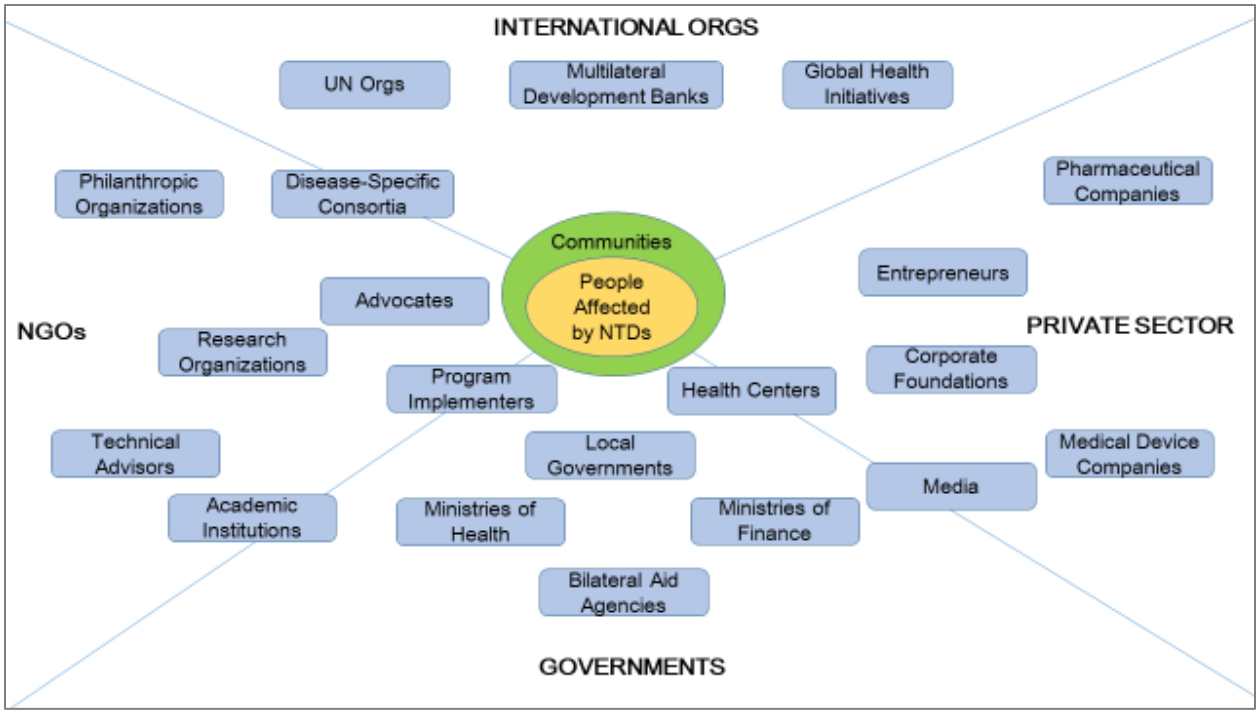

Figure 15. Actor Map

ii. Research Protocol

The work conducted in Phase 2 was used to develop the research protocol for the next phase of the project. This included refining and settling on the final list of research questions presented earlier in section II.D, as well as and finalizing the survey instrument (Appendix A) and interview guide (Appendix B). I submitted the study protocol for approval to institutional review boards at Harvard and the Nigerian Federal Ministry of Health.

iii. Organizational Assessment of the END Fund

I spent significant time during the first two phases of the project seeking to understand the END Fund organization and current strategy. The END Fund was established in 2012 by Legatum, a private investment firm with a history of earning substantial financial returns in geographic areas where others believed investment was too difficult or risky ("United Voices: The Story of the END Fund | The Legatum

Group," 2016). Legatum had begun supporting NTD programs in 2008 after being intrigued by the appeal of improving millions of lives for as little as fifty cents per person. In other words, a hugely promising social investment. Legatum set up the END Fund as a private philanthropic initiative to help raise the "capital" needed to rid Africa of NTDs. Hence the END Fund's declared mission to control and eliminate the most prevalent neglected diseases among the world's poorest and most vulnerable people by 2020 (The END Fund, 2017).

Given its history as an investment for philanthropists seeking an outsized social return, the END Fund considers that its primary mandate is to leverage the drug donation programs for the five PC-NTDs. Thus, the vast majority of the organization's work is focused on drug delivery. Their three-pronged approach is officially stated as:

1. Mobilizing and directing resources to where they can have maximum impact (focusing on programs for NTD treatment and workforce capacity building), with a special emphasis on Africa,
2. Advocating for innovative, integrated, and cost-effective NTD programs, and
3. Facilitating private sector engagement in the movement to address the devastating effects of NTDs

The first prong involves raising funds and making grants to deliver medicines through MDA programs in at-risk communities. The emphasis is on scale since as the END Fund receives more funding it can make more grants to deliver more drugs so fewer people will be affected by NTDs. By nearly all measures this piece has experienced huge success since the END Fund's inception as by the end of 2016 they had raised over US$75 million and delivered over 330 million treatments, with these numbers increasing each year (The END Fund, 2017).

The second and third prongs reflect the END Fund's desire to not only scale their own programs but also to advocate for increased attention for NTDs and to bring new private sector partners into the space.

These aspects of their approach have also been successful as they have become an important player in the global NTD community and have been able to engage new donors who had no prior experience funding NTD programs.

Since its inception, the END Fund has sought to take a systems approach to NTDs. Given that I was hired as the END Fund's "Systems Change Fellow" for the duration of this DELTA project, part of my responsibility was to look at their work through a systems thinking lens in order to understand their current approach to systems change.

Figure 16 shows a framework I created to illustrate some different definitions of systems approaches used across the practice and academic sectors. Currently, when they talk about their systems approach, the END Fund is typically referring to how they seek to understand the roles of the broad range of actors in the NTD ecosystem and to engage strategically with these actors to fill gaps in the system. This is shown in Figure 16 as what I decided to call a "system wide approach", which tends to be more prevalent in the practice sector. This approach can and does lead to systems change but falls short of accounting for the dynamic complexity of the system and taking advantage of other systems tools and methods that are also useful in catalyzing systems change.

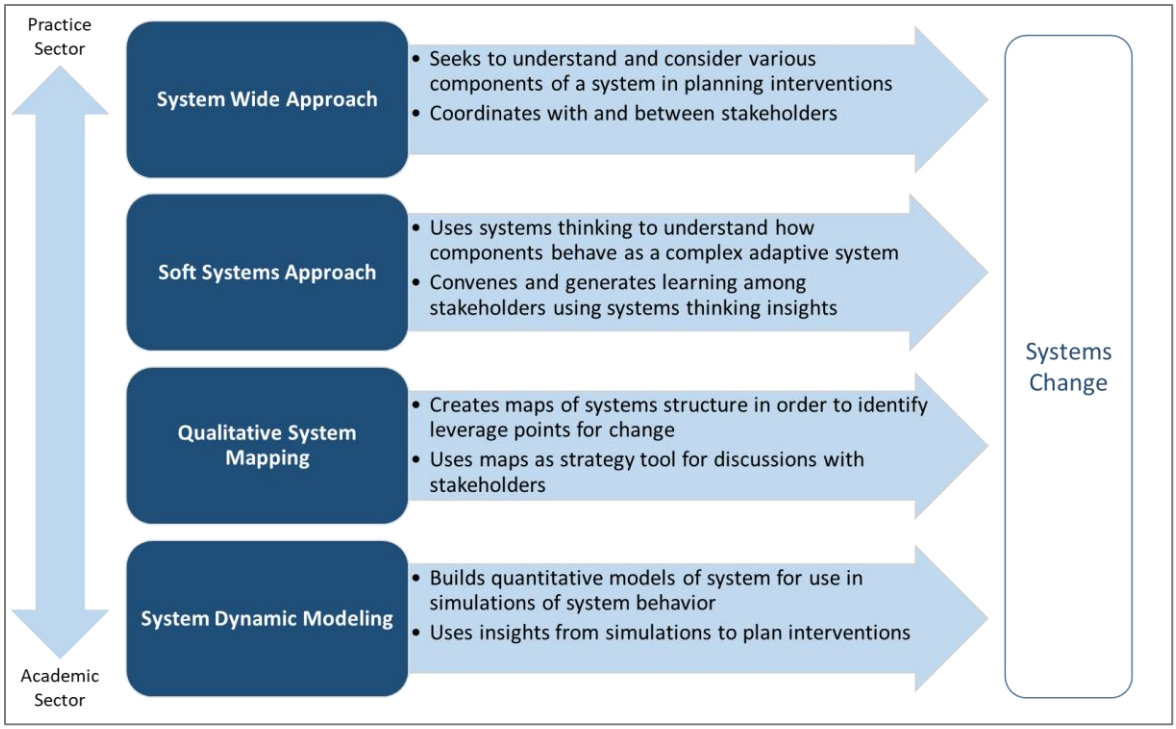

Figure 16. Approaches to Systems Change

The Systems Change Committee at the END Fund had a discussion about ways the END Fund has changed or is changing the fundamental structure of the NTD system. The most impactful change has been the creation of a new mechanism for pooling resources and providing funding for NTD programs. The END Fund has successfully harnessed millions of dollars of private sector resources that would likely not have gone towards NTDs if the END Fund did not exist. This change in funding structure has been accompanied by a changed partnership structure that includes new donors, implementing partners, and relationships that did not exist before the END Fund was part of the system. For example, rather than country governments having to establish separate relationships with many private sector donors, the END Fund streamlines this process by serving as the focal point for funding and grant management.

While the END Fund is the largest private funder of NTD programs, its funding footprint represents only a small proportion of global funding compared to organizations like USAID and DFID (World Health Organization, 2017a). Thus, the END Fund's potential to control and eliminate NTDs may in fact depend

on its ability to impact the systems structure as a systems entrepreneur rather than on its financial contribution. However, one question that remains to be answered is whether the END Fund is enough of a neutral broker, given that a significant portion of its efforts are dedicated to raising funds for its own programs, to truly be a systems entrepreneur?

iv. Background on NTDs in Nigeria

Finally, this phase was important for giving me the basic understanding I would need to focus on Nigeria as my country case study. A brief summary is provided here.

Nigeria has the highest number of people with NTDs of any country in sub-Saharan Africa (Federal Ministry of Health Nigeria, 2012). It is also the fourth largest recipient of END Fund funding with US$3.3 million total being donated for all five of the PC-NTDs between 2012 and 2016 (The END Fund, 2017). Nigeria has a federal system of government and is made up of 36 states and a Federal Capital Territory (Federal Ministry of Health Nigeria, 2012). The country's 774 Local Government Areas (LGAs) are the primary implementing unit for most health programs, including for NTDs. Each state and LGA has some level of administrative and financial autonomy. Figure 17 shows the different levels within the structure of the Nigerian NTD program. The approximately 350 ethnic groups and many languages across the country bring with them vastly different sociocultural issues, making it essential for NTD programs to understand and adapt to local circumstances.

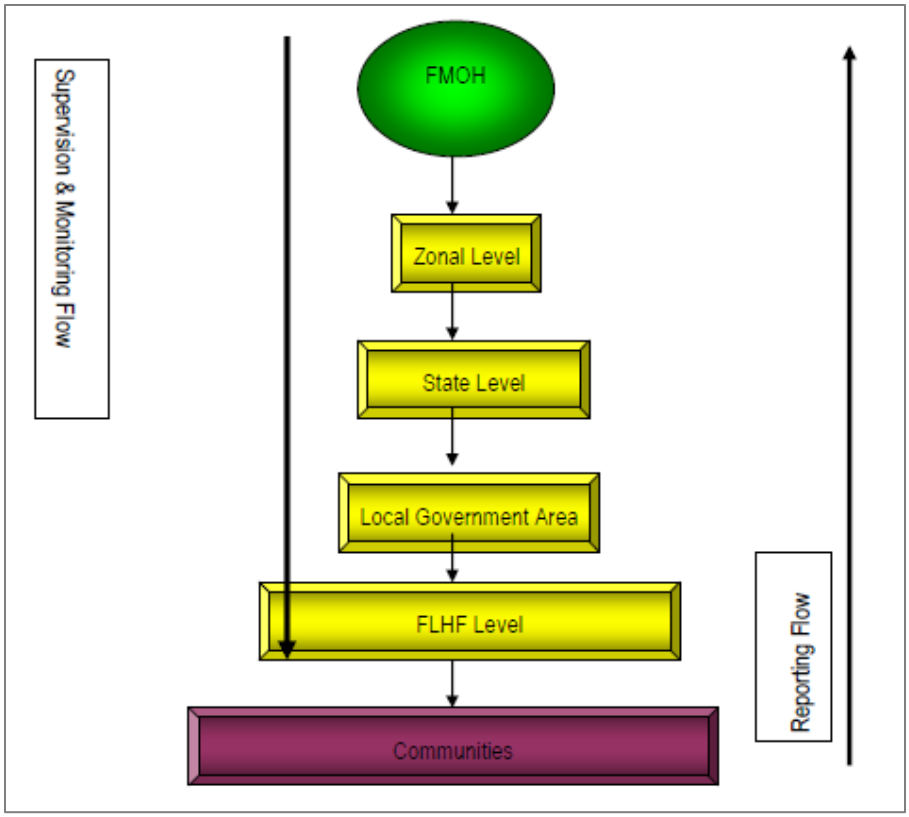

Figure 17. Levels of Nigerian NTD Program
Reprinted from Nigeria Master Plan for Neglected Tropical Diseases 2013 – 2017 (Federal Ministry of Health Nigeria, 2012).

Vertical NTD control programs, particularly the African Program for Onchocerciasis Control (APOC), have operated in Nigeria for decades (Cross et al., 2015). In 2006, the Federal Ministry of Health (FMOH) adopted a strategy for integration to increase the efficiency and effectiveness of the various programs (Lar et al., 2017). The FMOH adopted an NTD Multi-Year Master Plan in 2013 to help the country achieve the 2020 NTD goals (Federal Ministry of Health Nigeria, 2012). Efforts are primarily focused on administering medicines via MDA campaigns.

The federal, state, and local governments work closely with a number of non-governmental development organization (NGDO) partners to implement the NTD programs across the country. Typically, specific states are divided up between the NGDOs who then work side by side with the state and local governments to manage the programs in those areas. To avoid fragmentation of efforts,

coordination of NGDO efforts has been a priority since the early 1990s (Cross et al., 2015). With support from USAID and RTI International, the FMOH holds bi-annual NTD stakeholder meetings to coordinate efforts with representatives of the NGDOs and different state government representatives involved in implementation. An NTD Steering Committee made up primarily of academic researchers from Nigerian universities also meets bi-annually to discuss key issues and make recommendations to the FMOH regarding the national program.

Significant progress on NTDs in Nigeria has been made over the past few decades. Perhaps most encouragingly, two states, Plateau and Nasarawa, recently met the criteria to stop MDA treatment for lymphatic filariasis (Eigege et al., 2017). Despite this progress, many challenges remain. A recent qualitative study conducted by the Liverpool School of Tropical Medicine and Sightsavers found that financial constraints, limited human resource capacity, and decreasing levels of community engagement represent major obstacles to achieving the NTD control and elimination targets (Lar et al., 2017).

C. Phase 3 – Assess Dynamic Interactions

OBJECTIVES

The main objective of Phase 3 was to understand the structure of the NTD system by identifying ways in which it behaves as a complex adaptive system, assessing the interconnected relationships among system variables, and gaining a better understanding of the relationships among actors in the global NTD network.

ACTIVITIES

Again, the activities during this phase occurred at the organizational, country, and global levels. The focus was on executing the mixed-methods research component of the project.

Organizational Level Activities

Internally, I continued my work with the END Fund Systems Change committee. We explored the causes and effects of the different system variables the committee identified during the previous phase. I then facilitated two separate sessions on causal loop diagrams and systems mapping. During the first I provided a brief training on the process of systems mapping and we engaged in a group model building exercise in which we built causal loop diagrams together. During the second meeting we discussed and refined the diagrams that committee members built on their own. These diagrams were valuable in helping to inform the system model I built based on the qualitative interview data.

Country Level Activities

I traveled to Nigeria in January 2018 to conduct a total of 28 in-depth key informant interviews at the national, state, local government area (district), and community levels. After spending one week in Abuja interviewing national NTD stakeholders from the Federal Ministry of Health, NGOs, multilateral organizations, and academic institutions, I spent a second week in one state where I visited two local government areas and a total of two communities (one within each local government area). Interviewees at the state level included the Deputy Director of the NTD program as well as the Executive Secretary of the State Primary Health Care Board, which is the government entity that has responsibility for the NTD program and many other health programs. In each of the two local government areas I interviewed the NTD program coordinators as well as the individuals responsible for coordination of all primary health care and the individuals in the office of the local education secretary's office who are responsible for coordinating the school-based NTD programs. In each of the two communities, I interviewed health facility staff as well as community drug distributors. I also interviewed the Assistant Head Master at a primary school with a school-based drug distribution program. Table 7 provides a summary of the interviews in Nigeria and at the global level.

Table 7. Summary of Interview Participants

Type of Organization	Number of Interviews (N = 45)
Nigeria	**N = 28**
Multilateral Organizations	2
NGO Funders and Implementers	8
Research Organizations	1
Federal Ministry of Health	4
State Government	2
Local Government Area	6
Primary School	1
Health Facility	2
Community Drug Distributors	2
Global	**N = 17**
Multilateral Organizations	3
Bilateral Organizations	2
NGO Funders	4
NGO Implementers	4
Pharmaceutical Companies	3
Research Organizations	1

Two NTD program staff from the FMOH served as local investigators for the study. They played a critical role in securing ethical approval for the study and in helping to arrange some of the interviews at the national level. I was able to arrange most of the national interviews myself based on connections I had made during my first trip to Nigeria in September. One of the END Fund's grantee organizations scheduled and coordinated logistics for my interviews at the state and local levels. A more detailed description of the interview and analysis methods is presented in the Methods section (II.D) of this thesis.

Global Level Activities

I conducted a total of 17 interviews of global level stakeholders in December 2017 to January 2018. These included representatives of multi-lateral and bilateral institutions, pharmaceutical companies, nongovernmental donor organizations, nongovernmental implementing organizations, and academic institutions (see Table 7 above). I contacted potential participants via email. The fact that I had met many of the interviewees at the NNN meeting I attended in Dakar in September 2017 helped to increase

the number of responses I received. See section II.D for a more detailed description of methods used for data collection and analysis.

For the survey, a total of 27 participants out of 73 contacted eventually completed the survey, for a response rate of 37%. Table 8 summarizes the organizations surveyed, those that responded, and the response rates. Again, a more detailed description of the methods used for survey data collection and analysis is presented in the Methods section (II.D) of this thesis.

Table 8. Summary of Survey Respondents

Types of Organization	Total Surveyed	Total Responded	Response Rate
Full Sample	**73**	**27**	**37%**
Bilateral Organizations	3	2	67%
Multilateral Organizations	5	0	0%
Networks/Partnerships	6	1	17%
NGO Funders	12	4	33%
NGO Implementers	31	13	42%
Pharmaceutical Companies	6	4	67%
Research Organizations	10	3	30%

RESULTS

The deliverables of this phase came from the analysis of results of the network survey and key informant interviews. These included a network map and analysis of other survey results as well as the qualitative model of the NTD system and other interview findings.

i. Network Map

Figure 18 shows the visualization based on the survey results of the global network of NTD organizations. Generally, the organizations closer to the center are more closely integrated with the rest of the networks while organizations on the periphery are less well connected. The color of the node reflects the role the organization plays in the network. The size of each node (and node label) is scaled by betweenness centrality, an indicator of organizations that act as key connectors in the network.

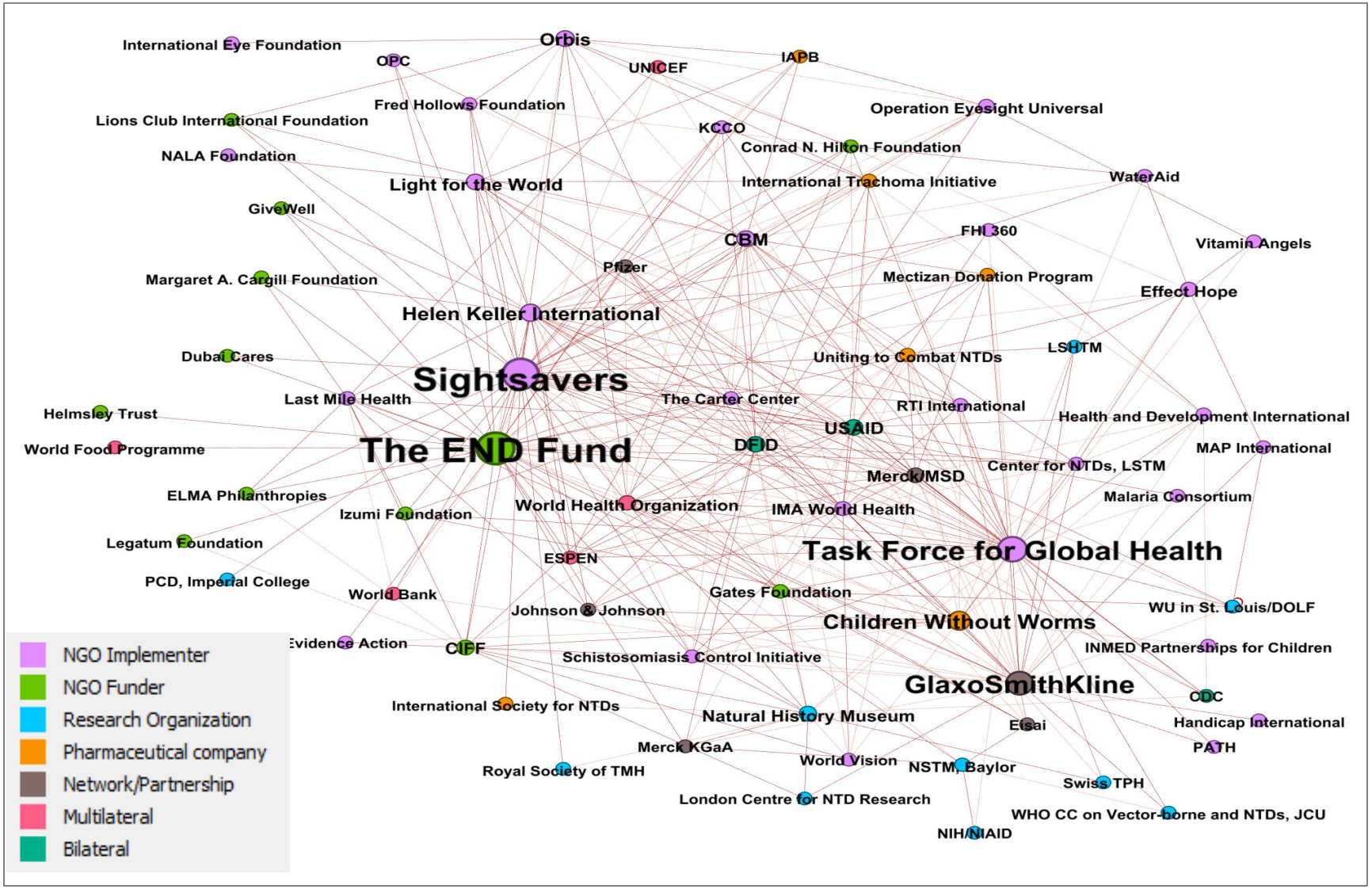

Figure 18. Global NTD Network Visualization

The network density was calculated as 0.134, which means that 13.4% of potential dyads were reported as a collaboration or partnership within this network. If communicative and cooperative relationships are also included as connections then the network density nearly doubles to 0.255, suggesting that both formal and informal connections are important to the network cohesion. The average degree (or number of connections) for each organization is 9.6.

The two node-level measures calculated for this network are by betweenness centrality and closeness centrality. Betweenness centrality is a measure of how many times a node lies on the shortest path between two other nodes that are not directly connected to one another. Closeness centrality measures the distance of each node from all other elements. The low response rate represents a major limitation of this analysis since it has been estimated that response rates of greater than 70% are needed to preserve the full validity of network statistics (Harris et al., 2008). The organizations that responded are likely to be shown as having a greater number of connections since they were able to consider the entire list of organizations surveyed and then report all of their relationships. Thus, it is probable that responding organizations have a higher chance of being identified as more central in the network than those who did not respond. This can be seen in the fact that all the top 10 organizations for the two centrality measures were survey respondents.

Table 9 shows the top ranked organizations by centrality measure statistics. To partially account for the bias introduced by the low response rate, the table lists the top 5 organizations for each measure by survey respondents and by non-respondents. These findings must still be interpreted cautiously in light of the low response rate.

Table 9. Top Ranked Organizations by Centrality Measures Statistics

	Betweeness Centrality			Closeness Centrality	
	Max	0.206		Max	0.703
	Min	0.000		Min	0.340
	Mean	0.015		Mean	0.487
	St Dev	0.038		St Dev	0.074
Rank	**Organization**	**Score**	**Rank**	**Organization**	**Score**
Respondents					
1	The END Fund	0.206	1	The END Fund	0.703
2	Sightsavers	0.193	2	Sightsavers	0.703
3	Task Force for Global Health	0.130	3	Task Force for Global Health	0.670
4	GlaxoSmithKline	0.112	4	GlaxoSmithKline	0.623
5	Children Without Worms	0.064	5	DFID	0.607
Non-respondents					
15	World Health Organization	0.017	11	World Health Organization	0.563
18	Gates Foundation	0.008	13	Uniting to Combat NTDs	0.542
21	International Trachoma Initiative	0.006	14	RTI International	0.538
23	Uniting to Combat NTDs	0.004	15	Gates Foundation	0.534
24	The Carter Center	0.004	16	International Trachoma Initiative	0.534

High betweenness centrality indicates the intermediary organizations that act as key brokers (or potentially bottlenecks) of information within the network (Harris et al., 2008; Luke & Harris, 2007). Among survey respondents, the END Fund and Sightsavers are the top two organizations ranked by betweenness, followed by the Task Force for Global Health and GlaxoSmithKline, who have significantly lower scores than the top two. The only non-respondent with an above-average betweenness score is WHO with the 15th highest ranking overall.

Organizations with high closeness are relatively independent and can reach others via few intermediaries, which makes them efficient diffusers of information (Brownson et al., 2010; Luke & Harris, 2007). For closeness, again, the END Fund, Sightsavers, the Task Force for Global Health, and GlaxoSmithKline are the top four organizations among survey respondents, with DFID following closely behind at number five. Among non-respondents, WHO, Uniting to Combat NTDs, RTI International, the Bill and Melinda Gates Foundation, and the International Trachoma Initiative are the top ranked organizations, all with relatively high closeness scores.

ii. Other Survey Results

While the main purpose of the survey was to create the network visualization and associated statistics in order to help the END Fund gain a clearer understanding of which actors are most central to the network and are thus critical to engage to generate systems change, other survey questions offer additional insights about the network in regards to the most innovative organizations in the network and barriers to collaboration between network members.

After respondents indicated the nature of their relationship with each organization on the list, the survey asked them to select up to five organizations they believed to be the most innovative in their efforts to control and eliminate NTDs. Innovation and learning are important because of their essential role in generating solutions to complex problems. Figure 19 shows the organizations that received more than one vote as one of the five most innovative organizations working on NTDs. As seen in this graph, the Bill and Melinda Gates Foundation received by far the most number of votes with 15, followed by the Centre for NTDS at the Liverpool School of Tropical Medicine (LSTM) with 9 votes. The next three organizations – the Task Force for Global Health, the END Fund, and Sightsavers – were also the top three organizations in the network ranked by centrality score, which suggests a possible correlation between the strength of an organizations relationship's and the perception of others that they are innovative. It is also further evidence that these three organizations are key leaders in the network.

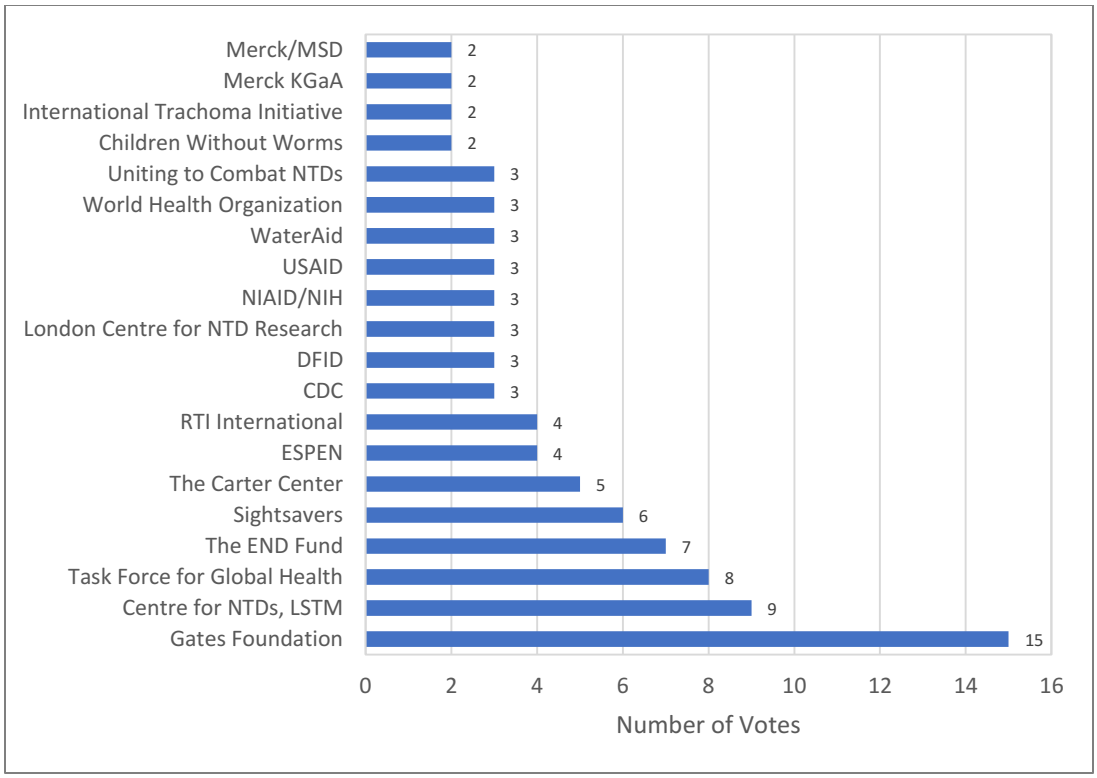

Figure 19. Organizations Believed to Be Most Innovative

Finally, the survey asked respondents an open-ended question about the biggest barriers to collaboration between network actors. Table 10 shows the most common responses. The three biggest barriers reported were 1) the challenge of aligning the different visions and agendas of each organization, 2) inadequate resources, and 3) the competition between organizations in sharing credit for their work.

Table 10. Biggest Barriers to Collaboration

Response	# of Responses
Aligning visions and agendas of organizations	7
Inadequate resources	4
Sharing credit	3
Competition for funding	2
Coordination between donors, researchers, implementers	2
Information about who works where	2
Governments of endemic countries	2
Power dynamics between partners	2

A few respondents wrote that collaboration between global organizations is actually going quite well and is not the major barrier to eliminating NTDs. Rather, according to them, the major obstacle is creating country-led, accountable programs. As one person put it, “With so many different organizations involved in the control of NTDs the whole structure often seems top heavy and far removed from operations on the ground. While ambitious goals have been set by WHO to control and eliminate NTDs, they will only be achieved if organizations work together, share their objectives and develop long term plans hand in hand with endemic countries”.

iii. Qualitative Model of the NTD System

The purpose of this qualitative model (Figure 20), or system map, is to illustrate some of the complexity of the NTD system in order to identify leverage points for change. By using causal loop diagrams to map the reinforcing and balancing loops driving the system behavior, the model helps uncover some important elements of the systems structure. As with many “systems stories”, the loops I chose to include are somewhat counterintuitive and help provide insights into the unintended consequences within the system. Because the goal of the model is to accurately represent different perspectives held by stakeholders in the system rather than arriving at the “truth” of how the system actually works, the model does a better job at raising questions for discussion and future inquiry than it does at providing specific answers.

The model was built around seeking answers to research questions 1 and 2, related to identifying the reasons NTDs persist as a problem and identifying leverage points for systems change. Key findings from the literature review discussed above were essential in supplementing the interview data to understand the key causal mechanisms in the model. The variables and relationships represented in this model do not encompass a comprehensive view of the entire NTD system; rather, they highlight a sample of issues that were surfaced in the interviews that appear to be key factors impeding progress on NTDs and

representing opportunities for systems change. Each variable has more causes and effects than are shown here, but I have sought to include the most relevant variables and linkages that were explicitly identified in the data. Determining how many intermediary variables to include in a causal link between two key variables is not always straight forward. My goal was to include enough detail that the causal mechanisms of the important linkages are clear, but not to include so much detail that the model is unnecessarily overcomplicated. A more detailed description of the model building process is presented in the Methods section (II.D).

The central purpose of the system illustrated in the model is progress towards ending NTDs. I intentionally chose this language to show the structure of the system for the five PC-NTDs while avoiding the nuances regarding the ultimate goal for NTDs (i.e., elimination vs control vs eradication), which differs depending on the disease and geographic location. Because the purpose is framed around growth[2] (i.e., growth equals more progress towards ending NTDs), reinforcing loops (labeled with an R) are positive forces and lead to progress in the model while balancing loops (labeled with a B) are negative forces and stagnate progress. The connections between variables represent causal links in the direction of the arrow. The variables linked with a connection labeled with plus (+) sign move in the same direction (i.e., more donor commitment leads to more funding for NTDs, less research and development leads to fewer new technologies and medicines) while the variables linked with a minus (-) sign move in opposite directions (i.e., more drugs delivered leads to fewer cases of NTDs, less vector control leads to higher environmental risk of NTDs).

[2] Causal loop diagrams are built around reinforcing and balancing feedback loops. Reinforcing loops lead to growth while balancing loops inhibit growth. Depending on the purpose of the system, growth can be positive or negative, which means that in some models reinforcing loops are good (i.e., virtuous cycles) and in some they are bad (i.e., vicious cycles). The same can be said for balancing loops (i.e., stabilizing forces or stagnating forces).

The following section briefly describes each of the 20 loops labeled in the model. The full model has been split into six pictures, or stories, to simplify the presentation of the findings. With each picture, I begin by discussing the reinforcing loops (positive forces) that are driving progress towards ending NTDs. I then detail the balancing loops (negative forces) that are inhibiting progress in the same picture.

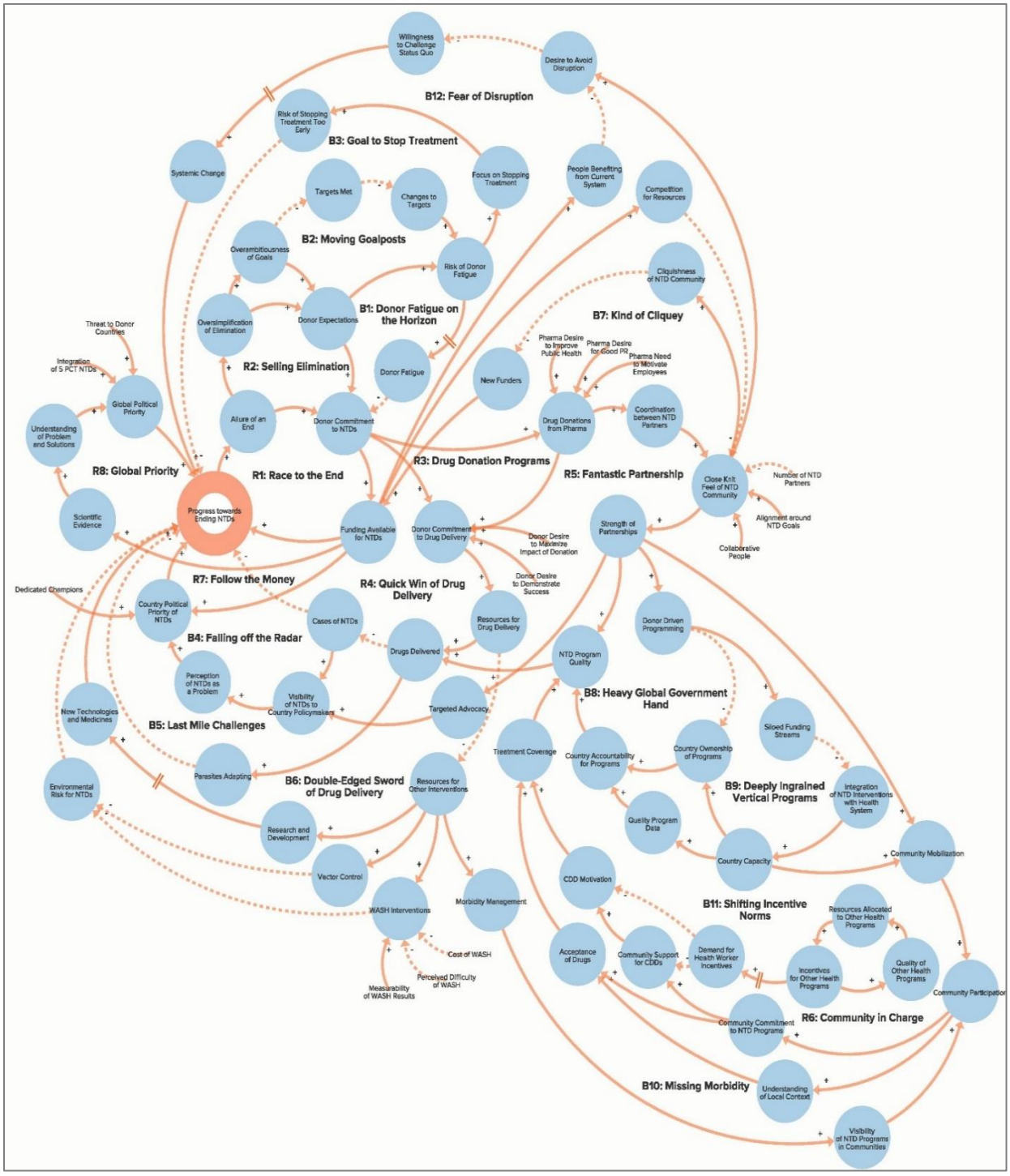

Figure 20. Full Qualitative Model of the NTD System

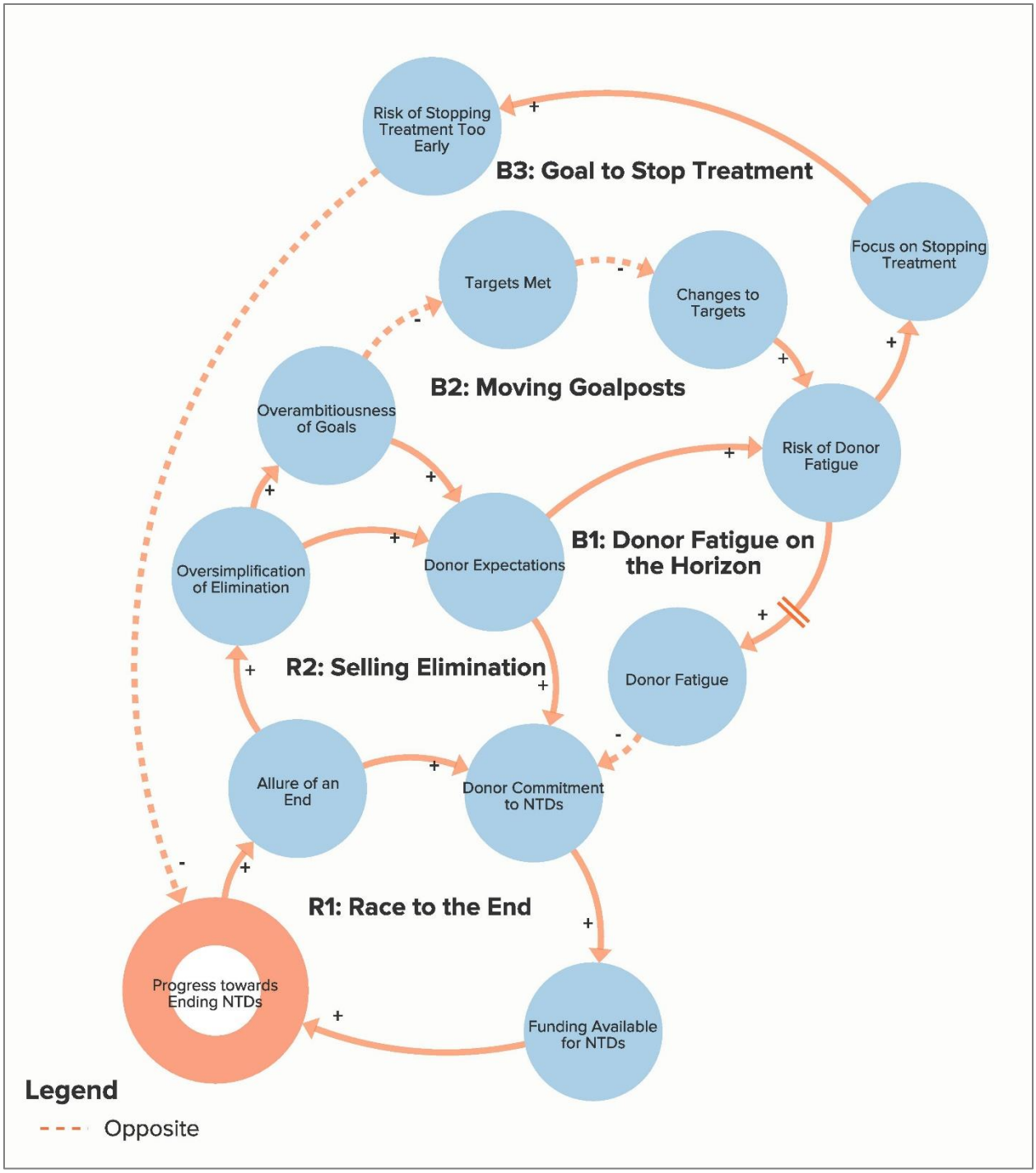

Figure 21. Picture 1: Global Advocacy for NTD Elimination

Picture 1: Global Advocacy for NTD Elimination

R1: Race to the End

The "Race to the End" reinforcing loop at the center of the model is a major driver of the global progress being made on NTDs. The **allure of an end**[3] is a key force that came up frequently in the interviews.

> *I think people like an end story. They like crossing something off the list that's a problem in the world, and they like the economic story of if you invest now you don't have to invest later, that there's a future savings. – Global NGO/Academic Stakeholder*

> *It's a compelling message to send to the potential donors that you can have a role in eliminating a disease just by doing this, so from an advocacy perspective it's a very powerful tool. – Global NGO/Academic Stakeholder*

> *Maybe the goal of eliminating the disease is more attractive and therefore it gains greater momentum. People can see that their contribution is going towards making a major difference. Whereas, for a control program maybe the prospect of being enrolled in a program that has no end point is less appealing and therefore you get less funding and less support being directed toward that particular disease. – Global Pharmaceutical Company Stakeholder*

> *If you're a donor and if you're a drug company, you want a horizon to what you're doing. You want to declare victory and walk away, and a lot of that's going on right now. – Global NGO/Academic Stakeholder*

This **allure** causes increased **commitment from donors** hoping to contribute to, and demonstrate their contribution to, completely solving a major problem. This **commitment** subsequently leads to additional **funding for NTDs** and, through a number of mechanisms not shown specifically in this loop, more **progress towards ending NTDs.** According to the interview respondents, success on NTDs increases the **allure of an end** and closes the loop, continuing this virtuous cycle of progress.

> *Why do we continue to do it? Because we're seeing success. Nobody expected it to be easy. With LF we're trying to eliminate a disease. The only time we've seen that is with smallpox. This is putting a man on the moon. This is an incredible challenge of historical significance, I think. So we're encouraged to continue because we can see the program is having success. – Global Pharmaceutical Company Stakeholder*

> *Two states [in Nigeria] have shown oncho and LF elimination can be done…This work has led to a lot of enthusiasm showing that elimination can be achieved. This enthusiasm is driving the work forward as people have the desire to head towards elimination. – Nigerian Multilateral/NGO/Academic Stakeholder*

[3] Variables shown in the model are bolded in the text

R2: Selling Elimination

Another reinforcing loop closely related to the first, "Selling Elimination" happens as advocacy organizations and others in the global NTD community recognize the powerful **allure of ending** something so they start to **oversimplify** what it will actually take to eliminate NTDs in order to attract more attention. This happens in at least a couple different ways. First, the advocacy message that often gets communicated is that solving the problem is a simple matter of raising enough funds to distribute the free drugs. As already discussed, the reality is much more complex.

> *I feel like the elimination has been a positive sell to keep momentum…even the U.S. Congress was like, "Oh you're telling me that these are diseases that we could come in and treat for a while, there's a drug donation, and we could get out? Oh we'll get behind that,"…but I think there's been some oversell. – Global Multilateral/Bilateral Stakeholder*

> *I think you have certain institutions that have practical program people but need to sell a more aspirational viewpoint…When you're trying to raise funding or move something forward even if you sit down with the Ministry of Health and want them to take on stuff we're going to have to get them to believe something, you know, that doesn't always doesn't always jive with the science. – Global Multilateral/Bilateral Stakeholder*

> *I think there's been some over marketing in the NTD community about what can and can't be eliminated, and so for many of these diseases the evidence base and the advocacy base of the conversation get delinked. – Global Multilateral/Bilateral Stakeholder*

The second way elimination gets oversimplified is that the NTD community often uses the word "elimination" to mean "elimination as a public health problem" rather than "elimination of disease transmission".

> *I think the problem is both the communicators and maybe the media love to just simplify things, reduce it, simplify it to say what you really mean is you're going to eliminate NTDs by 2020, and that was basically the tagline of the London Declaration. But when you start unwinding it…well not all NTDs…when we say eliminate sometimes we're controlling…sometimes when we say eliminate it means eliminate as a public health problem but that doesn't mean stopping treatment. – Global Pharmaceutical Company Stakeholder*

> *I do feel like a couple years ago because of some of the research framework, and particularly for STH, Gates Foundation really started trying to push some of these studies and talking about the feasibility of eliminating STH and that conversation got really out of control, I think. And everybody started abusing the elimination word and even early on WHO got a little sloppy and sometimes it was elimination, and sometimes it was elimination as a public health problem but they forgot to put the tag line on. – Global Multilateral/Bilateral Stakeholder*

The problem with this comes when many donors and other key stakeholders fail to understand the importance of this distinction and thus have unrealistic expectations about the impact of their efforts. The implications of this causal link are discussed further below with loop B1.

> *We have to stop being so fast and loose with the language and we need to be very very clear about what we mean and bring that kind of analytical rigor. I still don't understand what the difference between a control program is and elimination as a public health problem, and I don't want to hear someone at WHO say, "Well it's an intensified program". I don't know what that means. I think when you eliminate something you turn off a program. – Global Multilateral/Bilateral Stakeholder*

> *I just think a challenge that we have is managing expectations with some of the words we use. That people think it's something else…to really get to zero is a really big challenge. And my critique is that I think that that's been trivialized where we are right now and I think we'll miss as a result some of the really big control value that has happened as the result of these efforts. – Global NGO/Academic Stakeholder*

> *It is a challenge from the integrated perspective of achieving different goals and articulating how those different goals work, especially when you have a fund called the END Fund, which makes you think that there's an end to all five of these PC-NTDs. And end to most people means end. A lot of these are difficult from my perspective to manage expectations under one mantra of ending NTDs in an integrated fashion when really that end is the whole spectrum. – Global NGO/Academic Stakeholder*

This **oversimplification** of the concept of elimination has helped contribute to the NTD community's alignment around **overambitious goals** for ending NTDs. The obvious example being the global NTD goals set in 2012 that are seeking elimination and control of NTDs by 2020. While it is becoming increasingly clear that these goals will fall far short of being reached, they are widely credited with raising **donor expectations** of what is possible and thus increasing **donor commitment and funding** for NTDs. Despite not achieving the goals, this loop is positive because it has contributed to a dramatic increase in **donor commitment** over the past several years.

> *Even those of us in the field start quibbling over the scientific rigor of can you really eliminate river blindness, without looking at the big picture of like, yeah, but if we just get close…and this is what I love about Bill Foege. He's like, you just have to agree on the end goal, not the way to get there always. He has this great metaphor about driving in fog with your headlights on and you can only see so far but you know you're going at least in the right direction and then you figure it out as you can see more of the path ahead, and sometimes I feel like it's like that with NTDs. – Global NGO/Academic Stakeholder*

B1: Donor Fatigue on the Horizon

The "Donor Fatigue on the Horizon" loop is a balancing loop that has the potential to impede the progress being driven by the first two loops. Higher **donor expectations** have brought more **donor commitment**, but an unintended consequence of increased **expectations** is the increased **risk of donor fatigue**, which means that, for a number of different reasons, donors grow tired of NTDs and move on to other, more appealing issues.

> *My worry is also that, after some time, the international donor community kind of moves on to other emerging priorities and focal areas of interest – Global NGO/Academic Stakeholder*
>
> *If morbidity control remains the objective at the a global level, I would imagine that donors will get tired of funding yearly treatment when it's just as a stopgap measure and other interventions are not in place, and the drug donors will also get weary of that because there's no end in sight. – Global NGO/Academic Stakeholder*

This loop shows a delay (marked by the double lines perpendicular to the connecting line) between the **risk of donor fatigue** and actual **donor fatigue** because interviewees were clear that they do not currently see this happening, but they fear it could eventually be a major barrier to progress if it begins to decrease **donor commitment** to NTDs. A critical question is: at what point does an increasing **risk of donor fatigue** turn into actual **donor fatigue** and a **de-commitment to NTDs**?

> *I don't think people who work for drug companies are idiots. I think they're very aware that there are issues with uptake. The ones that I've spoken to are open to acknowledging those issues and doing something about them. So is it true that if we discuss failure openly drug companies are going to run a mile? That's one thing I want to know. – Global Multilateral/Bilateral Stakeholder*
>
> *I do I wish that the donors would continue to support schisto and STH and I'm not sure that that's going to happen, so that has me very worried. It makes me very worried about the continued drug donation, so I see a lot of clouds gathered on the horizon. – Global NGO/Academic Stakeholder*
>
> *It's pretty clear that that situation could change and that these companies will have an appetite for these donations for only so long. And I don't think anyone knows what that end point is, but I think people would rather not find out the hard way. – Global NGO/Academic Stakeholder*

One interviewee mentioned how this fear of donor fatigue may be driving the need to focus on elimination.

I would really argue that I feel like the politics and the fatigue of the agenda have been more driving the look towards elimination. – Global Multilateral/Bilateral Stakeholder

B2: Moving Goalposts

Besides high **donor expectations**, the **risk of donor fatigue** is also driven by constantly **changing targets**.

While the "Selling Elimination" loop illustrates the positive impact of making **goals that are overambitious**, in the "Moving Goalposts" balancing loop, the increasing **overambitiousness of the goals** set by the NTD community leads to fewer **targets actually being met**.

I think we have some problem with some of the targets that are unrealistic. And WHO needs to take into account the evidence when setting the targets. They can be challenging but need to be achievable. – Global Multilateral/Bilateral Stakeholder

Some groups I think really want to believe…I mean I've heard scientists say, "I know I look at the data but I still believe we can. The data say we can't but I still believe we can". That's kind of a zealot attitude. – Global Multilateral/Bilateral Stakeholder

As fewer **targets are met**, a potentially serious unintended consequence is that, according to some stakeholders, the resulting **changes to targets** are likely to increase the **risk of donor fatigue**.

It's a bit dishonest as well and things have gone too far on the elimination and the hype message. I mean we're just not going to eliminate these diseases by 2020. And so instead of admitting that what they do is they keep moving the goalposts to keep pushing back the time when we'll reach elimination. – Global NGO/Academic Stakeholder

So there's an oversimplification happening sometimes as we try to get the message out, which doesn't really do any favors because in 2020 the community will be asked, "8 years ago didn't you all say by 2020 this wasn't going to be an issue anymore"? There's a huge risk of oversimplifying. – Global Pharmaceutical Company Stakeholder

One of the things I worry about too is some of these goalposts that get moved. Some of the original goalposts that have been set, the evidence is not as robust as one would like and there's always the concern…like you tell people, "Oh we'll get in a we'll get out," and then you say OK you go back to the Congress for example and say, "Well we're going to be around a little bit longer". So you've got to keep asking for money, so you could have some fatigue. – Global Multilateral/Bilateral Stakeholder

B3: Goal to Stop Treatment

Another unintended consequence of increasing **donor expectations** is that the higher **risk of donor fatigue** shifts the goal towards a **focus on stopping treatment** rather than actually solving the problem.

When the system is geared towards **stopping treatment,** the **risk of stopping treatment too early** increases, which can be counterproductive to achieving **progress on ending NTDs**. This causal chain is particularly relevant to onchocerciasis and LF where there is an ongoing debate regarding whether the goal should be for elimination as a public health problem or for elimination of disease transmission.

> *To me the world right now is enamored with the idea of stopping MDA, such that stopping MDA has become the objective. That is the outcome rather than the outcome being transmission has been eliminated or interrupted and eliminated. – Global NGO/Academic Stakeholder*

> *A lot of people would like to transition oncho into the LF program which I think would be the kiss of death. I really like the purity of oncho and what it's trying to do. And because of that it's a lot harder to do. It requires more evidence, and people are getting annoyed that oncho is so hard, and my comment is it's hard because it's trying to do something that LF and trachoma are not trying to do. And I don't think people get that. I know the Gates Foundation doesn't get it. – Global NGO/Academic Stakeholder*

> *In LF, some places that eliminated it as a public health problem will have eliminated transmission of the condition, but other places may not, and WHO is perfectly happy with that. So I personally find that concerning and not satisfying. I'm very concerned that a lot of places are quickly stopping MDA for LF with elimination as a public health problem where a lot of people don't understand the fine distinction I just made, and we could have issues in the future. – Global NGO/Academic Stakeholder*

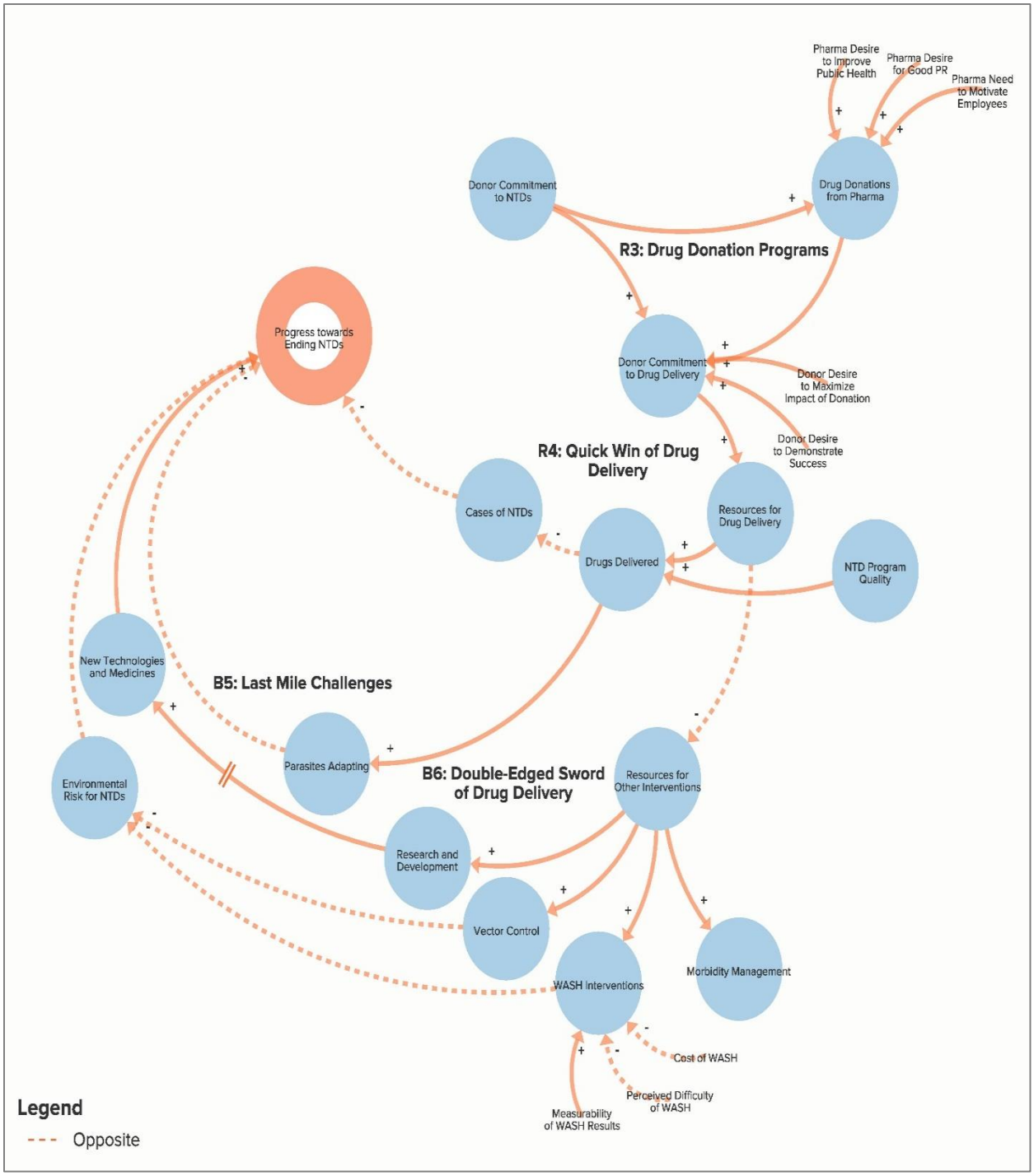

Figure 22. Picture 2: Balance between Drug Delivery and Complementary Interventions

Picture 2: Balance between Drug Delivery and Complementary Interventions

R3: Drug Donation Programs

The "Drug Donation Programs" component of the model plays an important role in the system.

Pharmaceutical companies continue to donate billions of dollars' worth of drugs for the five PC-NTDs.

These **donations** increase as a result of increased **commitment from other donors** to distribute the

drugs.

> *I think that is probably the singular accomplishment of London declaration. Not advocating for elimination; I don't think that's been very helpful. But what I do think is that it has locked in the pharmaceutical companies to continuing their drug donations. And I think that's been very good. – Global NGO/Academic Stakeholder*

> *I am extremely worried that if the drug companies see that outside donors are no longer investing in supporting getting their donation out, that they're going to take a second look at whether they're going to keep doing it. – Global NGO/Academic Stakeholder*

Interviewees suggested that one of the main drivers of these **donations** is the companies' **desire to have**

a positive impact on public health.

> *We made the decision [to begin the drug donation program] 30 years ago. The main reason was that we had developed this drug and we knew that it could be transformational from a public health standpoint. Our scientists had developed it, so we wanted to make sure that the discovery didn't sit on a shelf somewhere but wanted to make sure people who needed it could benefit from it. It was a real recognition of the importance of having inventions and discoveries actually get to patients who need them. – Global Pharmaceutical Company Stakeholder*

Other key factors that help explain the increase in these donations are the companies' **need to motivate**

their own employees and their **desire for good public relations**. According to the interviews, the former

factor is seen as the biggest contributor of the two.

> *It [the drug donation program] is also very popular among staff and the managers of our company. To be part of something that's reaching so many people, and to be part of a program that is aiming to eliminate a disease. That's an exciting thing to do. And it's showing that our donation is being used appropriately, that it's reaching people, that it's been giving them health benefits. Of course we'd want to continue. – Global Pharmaceutical Company Stakeholder*

> *He [Pharma CEO] said to me, "You know, [this] is one of the largest companies on the planet, it's got like a hundred thousand employees," and he said, "I can't motivate one hundred thousand employees to come to work every day simply because they're making money for our shareholders. My employees need to know that they're making the world a better place and so*

having that drug donation program is a very important signature program for that reason." – Global NGO/Academic Stakeholder

They found that people inside of [Pharma company] were happier working where there. It gave them more pride in their company. It gave them a better reputation with PR. It felt like there's a clear way of aligning their mission to help improve human health in the world, even for the most vulnerable. – Global NGO/Academic Stakeholder

One of the things I tried to do was to elevate the level of public awareness about what the drug companies were doing, and they were really not that interested. That was not a priority. – Global NGO/Academic Stakeholder

R4: Quick Win of Drug Delivery

The global NTD movement exists in its current form largely due to the influence of the drug donation programs. As evident in the "Quick Win of Drug Delivery" reinforcing loop, an increase in overall **donor commitment to NTDs** and in **drug donations** leads to an increase in **donor commitment to drug delivery**.

We have to absolutely acknowledge the role of the pharmaceutical industry. And I think that them at that meeting coming together and making that commitment for the longer term donation, I think that was absolutely key because I think that that did give a very clear mandate to the community that that resource was going to be available and we needed to think about how we were going to mobilize the resources for delivering that donation. – Global NGO/Academic Stakeholder

First of all, what is the motivation for an NGDO to become a partner to implement? It's a quick win. And the greatest quick win is: I have the drug coming in free, and I distribute this drug. – Nigerian Multilateral/NGO/Academic Stakeholder

Interview respondents gave a number of reasons for why MDA is so appealing, including donors' **desire to maximize the impact** of their donations and to **demonstrate success**. These and other factors continue to drive commitment to drug delivery.

It's much easier to report a process indicator than it is to record an outcome indicator or an impact indicator. So it's much easier to say, "Our money supported delivery of X million doses of Albendazole, or X million doses of Azithromycin in this calendar year. And we anticipate that that will lead to acceleration of elimination of LF or trachoma", or whatever it is. It's very hard to say, "We did some health education and people's knowledge was improved by 20%," because it's not really real. It's not really how it works. – Global Multilateral/Bilateral Stakeholder

A lot of them got their funding because they also go out to donors and they tell the donors we want to have 20 million treatments. They want to see treatment. – Nigerian Multilateral/NGO/Academic Stakeholder

You're an NTD MDA person, you've got very limited funds, and you want to use those funds to distribute the free drugs. The donor says, "Well great, why don't you use half your funding to improve sanitation in some villages". You're going to say, "But for that same money I can treat thousands of people". – Global Pharmaceutical Company Stakeholder

When you can say fifty cents will deliver drugs required to treat these five diseases, it's very cost effective. And that's where the metrics were. And if that's what is important to the people giving the money that's what they're going to go for versus if you say yeah delivering one surgery for trichiasis is still a little cost at ten or twenty dollars, whatever you want to say, forty dollars...that's a lot more money and a lot fewer people – Global NGO/Academic Stakeholder

Increased **donor commitment for drug delivery** causes an increases in r**esources dedicated to drug delivery** through mass drug administration and, subsequently, an increase in the **number of drugs delivered**. This causal link contributed to over 1 billion drugs being delivered in 2017 alone. More drugs delivered leads to fewer **cases of NTDs** which contributes to the **significant progress being made towards ending NTDs**.

For good reasons in the scaling up phase of eliminating NTDs a very strong focus on MDA was very justifiable. The key issue was how do we get as many people affected regularly, even under difficult circumstances, taking their taking the pills, and that still remains a cornerstone of the elimination strategy. – Global NGO/Academic Stakeholder

The continued drug donations have been important and we're seeing increases to those donations that should allow us to meet the targets for elimination in a number of years. There was a time when there were more drugs available than there were countries that could use them adequately. Then there was a time when it was a different issue. There were countries lined up ready to deliver but then the quantities of drugs wouldn't allow the global goals to be met. And now I think it seems to be evening out a little bit. – Global NGO/Academic Stakeholder

B5: Last Mile Challenges

A stagnating force is shown in this model as the "Last Mile Challenges" balancing loop. The massive numbers of **drugs delivered** have been key to successfully controlling and, in some cases, eliminating transmission of NTDs, but with increases in number of **drugs delivered** comes an increase in the possibility that **parasites will adapt** in ways that make them less susceptible to control through mass

drug administration. Antibiotic resistance is a prime example of a **parasite adaptation** representing a huge potential threat to **progress** that is not always given sufficient attention by the NTD community.

> *These parasites have co-evolved with human beings for thousands of years. These multicellular parasites…you know, conquering over a virus and a bacteria is a very different thing than a parasite, which is multi-cellular and has a whole bunches of different ways in which it evades the immune system and how it uses vectors to transmit itself. – Global NGO/Academic Stakeholder*

In addition to parasite adaptation, this loop also represents other last mile challenges that come with continued changes in the system or the context. These challenges are examples of policy resistance, or ways in which the system resists change by adapting in ways that render attempts to solve the problem ineffective.

> *Getting that big burden and that the middle of the bell curve is relatively straight forward and you can use the same tools. But then as you're trying to really get to elimination you have to deal with the ends of those bell curves, and I think that happens at the community level, at the national level, and definitely at the global level. And we're discovering that the ends of those curves are bigger than we might have thought. – Global NGO/Academic Stakeholder*

For example, the cost of eliminating each case becomes more expensive when fewer cases exist, which makes it is more difficult to reach the final few cases. Also, although not caused by increased drug delivery, trends like climate change and urbanization can create last mile challenges that prevent progress on NTDs.

> *It's going to be a bit of a race between MDA and all these other forces. So for instance, with climate change what that you might see is the movement of snails or insect vectors to cooler climates. So there might be new niches, ecological niches, new geographic areas where the NTDs are. I worry that we're going to be playing this game of global health whack a mole. You knock out NTDs in one set of areas that now we're going to see expansion of NTDs into. That's going to be a potential problem as well. – Gl*obal NGO/Academic Stakeholder

B6: Double-Edged Sword of Drug Delivery

The issue frequently raised by interviewees with the perhaps the most potential to impede progress on NTDs is illustrated in the "Double-Edged Sword of Drug Delivery" balancing loop. This loop and the "Quick Win of Drug Delivery" loop combine to illustrate the Shifting the Burden system archetype that can be found in many different kinds of systems (Stroh, 2015). In this pattern, an overemphasis on

easier, quick fixes creates a dependency that, over time, can reduce people's willingness and ability to implement a more fundamental solution (Stroh, 2015).

Multiple respondents made the explicit connection between the **overemphasis on drug delivery** and the lower levels of **resources available for other interventions**.

> *The drug donation program is a double-edged sword because, on the one hand, it is amazing because it removes a lot of the cost for ministries of health to access medication that is really important to treating huge populations. And that's a really wonderful thing. The other side of that coin is that the way the program is designed is that all of the incentives attached to it are to do with distributing drugs. And that is also what the programs are accountable to, and if you look at the NTDs roadmap of WHO, with the exception of trachoma and schisto, the other programs' imperatives are around distribution of drugs, around coverage of the intervention rather than its impact. – Global Multilateral/Bilateral Stakeholder*

> *The entire program is structured to distribute drugs, not prevent the disease. So that in itself is a really big issue because we're all human beings and when we have a job to do we do that job. And if that job is distribute drugs, we will distribute drugs. If the job were to ensure that a disease is prevented then that would imply a completely different program design. – Global Multilateral/Bilateral Stakeholder*

> *I think one of the major challenges for the NTD space is the prominence of the MDA effort. So the drug donation programs are incredible. Full stop. They tend to be the focus of a lot of advocacy and promotional opportunities, which perhaps undermines opportunities to advocate for other aspects of disease intervention. I think the byproduct of that is that many funders very much focus just on the MDA component of any intervention. And it is quite hard to track funding for anything else. Even capacity building issues, training, unless it's specific about MDA. – Global NGO/Academic Stakeholder*

According to some respondents, true elimination of NTDs cannot be achieved without **paying more attention to these other interventions.**

> *Everybody is focusing on MDA, MDA, MDA. Neglected Tropical Diseases will not depend on drugs alone. They will depend on water and sanitation. They will depend on morbidity management. They will depend on vector control. And they will depend on a number of things. – Nigerian Multilateral/NGO/Academic Stakeholder*

> *I think a third failure has been the lack of…the over misunderstanding and overestimating the benefits of MDA. We really did not envision it as an elimination strategy. Right, there's just not a real precedent for eliminating diseases through MDA. – Global NGO/Academic Stakeholder*

Improved **water, sanitation, and hygiene (WASH)** through behavior change and better infrastructure is important for elimination of transmission of NTDs, particularly for schistosomiasis, soil-transmitted

helminths, and trachoma. Slower progress on **WASH** increases the **environmental risk for NTDs** which severely limits **progress towards elimination**. Interviewees at the global, national, and community levels were concerned about the lack of focus on WASH.

> *You can't think that you're going to be able to truly stop interventions unless you have a strong WASH component. – Global NGO/Academic Stakeholder*

> *We know that if we continue to administer medicines without looking at environment, without looking at water, we'll just be going in circles and all the funds will be wasted. So we need to bring onboard…we need to work very closely with these people, with these ministries, to see how we can improve sanitation, how we can improve provisional water. That way we'll be making progress. – Nigerian Multilateral/NGO/Academic Stakeholder*

> *Everyone knows that transmission can be broken. It's been done. But it hasn't necessarily been done in the absence of broader economic growth in a country. And there have been other economic development, sanitation and water improvements that go along with it, other factors that have played into transmission breaks. – Global NGO/Academic Stakeholder*

There are many reasons that inadequate attention has been paid to **WASH**, but a major factor has been that MDA is largely portrayed as the easy, cheap solution compared to what are **perceived to be much more difficult** and **costly WASH interventions**. It is also much more difficult to **measure** the outputs of WASH interventions.

> *MDA is kind of the easy way out. Relatively speaking against some of the behavior change and water and sanitation targets, it's somehow easier. And it's not incredibly expensive, but without an end in sight when you start adding up what it would cost just to do a more thorough job upfront and add interventions, versus the cost of twenty thirty years of drug delivery, you've got to wonder. – Global NGO/Academic Stakeholder*

> *The health workers are there for the most part and so you have the individuals that can deliver the drugs. You have the donations coming in free of charge for most of these programs and you have, for the past ten years or so, you have donors that are willing to cover the costs of the getting the drugs from the port to the mouths of the people who need them. And it usually involves one, possibly two ministries if you're working in the schools and you need to involve the teachers, versus a more robust program that includes water and sanitation and behavior change and MDAs, and data management systems. You're looking at multiple ministries, you're looking at…the number of partners it becomes more challenging to coordinate efforts. It becomes more challenging to tailor solutions based on the overlap of NTDs in any particular district or region. It's just a lot more people than NTDs involved. Funding can be a challenge. – Global NGO/Academic Stakeholder*

> *As a broader community we struggle to get enough money to implement NTD programs, let alone additional funds to cover WASH activities. WASH interventions tend to be infrastructure*

heavy, and infrastructure costs and needs to be maintained. So part of the challenge is are we actually in position to provide funding to WASH organizations to help them implement the activities we would like? And the answer is generally no. – Global NGO/Academic Stakeholder

What capacity do I have to work on water and sanitation? What are the methods I should utilize? UNICEF is out there saying it's going to work on water and sanitation. But what are the quick wins? What can I actually see? You cannot work on water and sanitation depending on health education alone, or hand-washing alone. You need to provide this water, which is much more expensive, and much more physical than the drug you receive free of charge. – Nigerian Multilateral/NGO/Academic Stakeholder

The WASH component, for example, we need to talk to ministers and other people. The challenge we are having is we don't have donors looking at these components and trying to bring everybody. We have donors that are helping us with MDA. But who is doing vector control? Who is making sure that all the places we have STH and schisto there is WASH? This is critical. So what is lacking is we do not have donor partners that are looking at these components. And even when we have them they're in different siloes. They're not talking to each other. – Nigerian Multilateral/NGO/Academic Stakeholder

There are important differences between the NTD and WASH sectors that make collaboration challenging.

We've still got some understanding to do to really appreciate what the drivers and specific agendas are of the sectors that we're trying to partner with. – Global NGO/Academic Stakeholder

One of the biggest barriers to joint planning and implementation of WASH and NTD programs is the fact that WASH and NTD programs usually have very different success indicators and ways of measuring success and communicating and reporting back to governments and funders and beneficiaries. – Global Multilateral/Bilateral Stakeholder

The NTD program has the wrong incentives but so does the WASH program, because the WASH programs, this surprises NTD people quite a lot, the WASH program is not accountable to health outcomes. It's responsible to people, usually just getting to coverage of infrastructure, not even access to. And those are two very different things, so people don't really assess the government authority's interests in WASH against whether or not their infrastructure is functional or in use but whether or not it just exists. So when it comes to things like, "Well we need to target WASH interventions to areas that have these diseases", that's quite a big leap, and you need a lot of convincing and a lot of high resolution information about where the need is. – Global Multilateral/Bilateral Stakeholder

The need to for NTDs to consider WASH is widely acknowledged, but stakeholders believe there has been little actual progress.

Few people would deny that the neglect of WASH is a problem but there is a major gap between the verbal acknowledgement that WASH is important and any actual changes incorporated into how the NTD sector functions. – Global NGO/Academic Stakeholder

Collaboration within the WASH sector is clearly an important things, especially for schisto and STH. There have been lots of discussions between the two but I think if we're honest with ourselves that the degree of collaboration between the NTD MDA community is mainly talk. While there's not actual real progress. – Global Pharmaceutical Company Stakeholder

There's a lot of discussion about the WASH collaboration. I see more of the talk but little less of the action. – Nigerian Federal Government Stakeholder

They seem to measure progress when they're working with their water and their sanitation people in terms of the number of robust discussions that they've had, and they also sidetrack themselves constantly on the latest set of buzzwords. – Global Pharmaceutical Company Stakeholder

Recent developments provide reason for optimism as some NGOs and donors are strengthening their push for work in this area. New tools and indicators have been published to help guide NTD programs to make sensible changes to consider their impact on WASH interventions. One of the biggest remaining barriers may be the lack of prior success upon momentum can be built.

The systems aren't in place, people are busy, they're not being asked to work in that way, so it's not resistance, I would say. No one is saying, "Oh no we shouldn't be doing that", it's just nobody's kind of cracked that solution in a big way. – Global NGO/Academic Stakeholder

It's very easy to get people to acknowledge that working with the WASH sector is an important thing to do, but more often than not these kind off acknowledgements fall at the first hurdle because the kind of statement that you'll hear frequently from ministries of health will be, "Well we invited the WASH people to come to the planning meeting…they didn't come". Or, "We don't really know who to speak to, we don't know where to start". – Global Multilateral/Bilateral Stakeholder

It's just hard and it's different, so if there isn't very strong pressure to work differently people just carry on and do what they're used to doing, which is normal, I guess. – Global Multilateral/Bilateral Stakeholder

Behavior change interventions that you can imbed into social mobilization around MDA is not expensive. And you can probably work more effectively with the WASH sector to make sure it is effective and you're not just distributing leaflets, but you're actually tackling social norms around hygiene and sanitation use, etc. So there are easy wins that any program can incorporate and there are plenty of examples of that. – Global Multilateral/Bilateral Stakeholder

It's not complicated. We do know what to do, we're just not doing it here. – Global NGO/Academic Stakeholder

Similar to the WASH issue, **overemphasis on drug delivery** appears to have also led to decreased **funding for vector control**, another important component.

> *We are not touching the vectors, and I believe if our policy or direction was in targeting the vectors, we would achieve NTDs much faster than we can. Bearing in mind that the treatment would continue, but the vectors should have been an area of target, which nobody is looking at that, at least in the Nigerian programs. If I were given something or asked one word, "What can you do to make a difference"? I'll say, "Aim at the vectors". – Nigerian Multilateral/NGO/Academic Stakeholder*

Some also have the perception that **MDA** is preventing **resources from being allocated to research and development** for new **technologies and medicines**.

> *With the NTD community we created this standard where for each disease you only one shot. For schisto, is has to be praziquantel. For oncho it's got to be Ivermectin. But the idea now of adding another technology, you get enormous push back both from the Gates Foundation and from the NTD community. – Global NGO/Academic Stakeholder*

> *I don't want to throw cold water on Mass Drug Administration. I would just like better acknowledgement and support for continuing to build new technologies because, for the most part, MDA campaigns were not intended as an elimination strategy. – Global NGO/Academic Stakeholder*

> *Because the drugs are horrible, right. Single dose mebendazole and albendozole does very little for hookworm or trichuriasis. So I think what it's had is it's thrown cold water on efforts to develop new technology, I mean the point with a rapid impact package is that you do it because people have the fundamental right of access to essential medicines. It is having impact on reducing the prevalence but by hyping it as an elimination strategy it's turned away other donors for building additional technologies. – Global NGO/Academic Stakeholder*

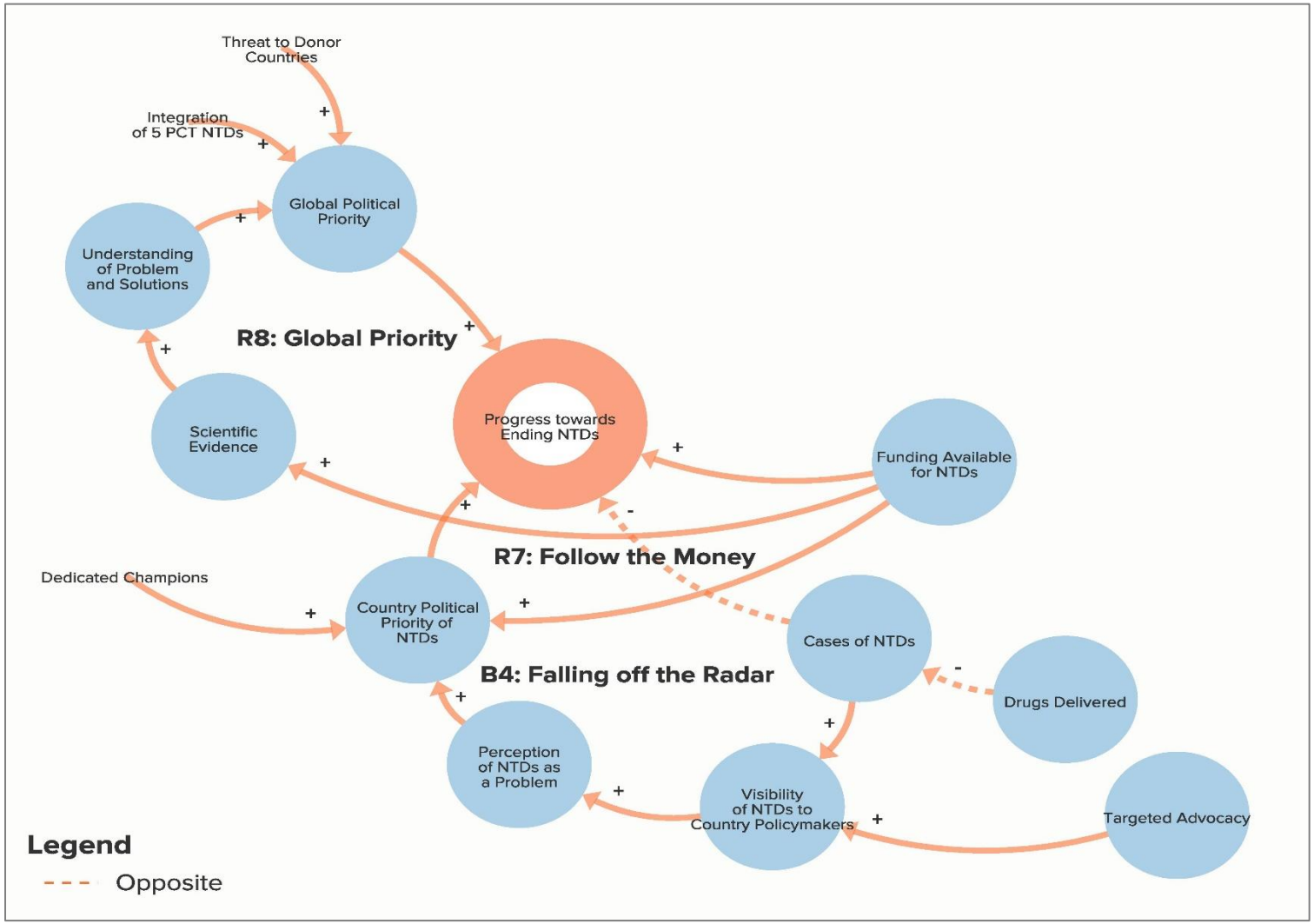

Figure 23. Picture 3: Global and National Political Priority

Picture 3: Global and National Political Priority

R7: Follow the Money

The "Follow the Money" reinforcing loop helps explain how the **political priority of NTDs** at the country level is at least in part determined by the funding priorities at the global level. For some respondents, the main driving force in **country political priority** came down to the fact that countries ultimately dedicate **attention and resources** to the issues that they are receiving **international funding** to address. A few respondents talked about how global political priority "trickles down" to the country level in this way. This is good for NTDs as long as international **funding** is increasing, but it is a big concern if donors begin to de-commit to NTD **funding**.

> *You have the global agenda I think that drives a lot of things. Gates for instance is just offered the landscape in terms of making decisions and determining what priority of disease is and what isn't. – Nigerian Federal Government Stakeholder*

> *It [NTDs] is not an area that has been prioritized from a budget standpoint in many countries and I think that's partly because there's a pressure from external aid…NTD funding is a drop in the bucket compared to other sources of aid. I mean, when you're getting hundreds of millions of dollars for your global fund contract and you might get a million dollars and that's a really big grant for NTDs. That's just the level of attention that it's going to get. – Global NGO/Academic Stakeholder*

> *Places just follow the money. If a donor shows up and they've got money then they'll agree to it. – Global Multilateral/Bilateral Stakeholder*

> *At the state level, I think it [priority] does depend on what that state has funding for. – Nigerian Multilateral/NGO/Academic Stakeholder*

In Nigeria, interviewees pointed to a clear gap in the lip service given to NTDs and the actual **resources** dedicated to addressing NTDs.

> *Now the funding allocated to it is not what we would hope it would be, but it's something that happened in the couple…from last year the minister attended the NTD summit in Geneva, that's the minister of state. And in that conference it became clear to them that this was something worth taking on like more serious, paying more attention to it. – Nigerian Federal Government Stakeholder*

> *The other thing is that most of our activities, of course, have no funds, as always the limiting factor. In terms of the attention, NTDs have even more attention than that. All I'm saying is there are times where the proposal is not a proposal that we found available to us to fund. There's one*

thing they gave me last year…I had to wait until I had more funds. So I was waiting for more funds to support her more intensely than what we have been doing.
– Nigerian State Government Stakeholder

One clear factor that stood out as a facilitator for increasing **country political priority** of NTDs was the existence of **dedicated champions** who, for whatever reason, decide to make NTDs a priority issue. This often appears to be a particularly capable and well-connected NTD program director. These champions act in an important role as policy entrepreneurs in order to bring together the problem, politics, and policy streams to help create policy windows, and to take advantage of these windows when they occur (Kingdon & Thurber, 1984).

You need two things. You need a program manager in the country who has the ability to influence senior people. And then you need a leader, at the MOH, prepared to make it a priority and put resources behind it. – Global Pharmaceutical Company Stakeholder

We have to be realistic that it also does in someone's instances come down to the human resource in the country and then the personality even or the drive of the individual NTD program manager. We've been very fortunate to work with some very dynamic people that have definitely increased the profile of NTDs within their particular country, and that has had an impact. – Global NGO/Academic Stakeholder

At this level, even if it was supposed to be neglected, the program officer has made it impossible for us to neglect it. So it's not neglected yet because at every moment she's coming up with one activity, one plan. – Nigerian State Government Stakeholder

Some country-level respondents described how **targeted advocacy** has contributed to the success of their programs by increasing their **visibility**, which increases the **perception of NTDs as a public health problem**:

We paid two high-level advocacy visits actually to the policy makers. We went with national coordinators, zone coordinators, myself, my country director, and the country director from [another NGO]. And we saw the commissioner. We met the commissioner and we laid our ground, "This is what we want. We want to see structures change." The NTD coordination body then was not very strong. It was weak. So we needed people who can really handle the NTD programs. The second we wanted to see was to release the funds, budgetary allocation. The government had never released the funds. We're lucky actually. Since that was done, the commissioner championed the campaign as hers. – Nigerian Multilateral/NGO/Academic Stakeholder

The state office in partnership with our partner, we also do advocacies before we start any program. Like last week, we're going from one ministry to another. – Nigerian State Government Stakeholder

At the LGA level, I and the Directors at the [NGO] and the ministries go down to the LGA level, at the states, and the LGA go to community levels to do advocacy. – Nigerian Multilateral/NGO/Academic Stakeholder

R8: Global Priority

The "Global Priority" loop highlights how additional **scientific evidence** that increases the **understanding of the problem** and sheds light on necessary programmatic changes is an important force driving **global political priority** for NTDs. This idea touches on a few of Shiffman & Smith's determinants of political priority: the internal frame, policy community cohesion, availability of credible indicators, and availability of effective interventions (Shiffman & Smith, 2007). The Global Trachoma Mapping Project was a commonly cited example of this in the interviews.

We now have a very accurate representation of where trachoma is a problem. And that's meant that funders have a target to aim at and they've been very enthusiastic at coming to the table. So we have a lot of new investment in trachoma. – Global Multilateral/Bilateral Stakeholder

Another main factor that was thought to lead to greater **global political priority** was the increased **integration of the five PC-NTDs** under the NTD brand, which represents the external frame determinant (Shiffman & Smith, 2007).

Well I think what I think one of the drivers here…what's been successful for NTDs is they repackaged themselves. Right, it was a band of all these diseases that nobody could say so they repackaged it, called it neglected tropical diseases. That seemed to sell really well. Catching on then you say OK you know can we have some public health success. – Global Multilateral/Bilateral Stakeholder

I think integration was a great way to put these various conditions on the map because if by joining them together you joined together the DALYs associated with these NTDs, you joined together a common approach, logistical approach of MDA. You could look at the value of the pharmaceutical donation and make it look like just a remarkable value for money because the intervention is basically free. And I think it was it was quite remarkable how the NTD brand got established and how well it's done. – Global NGO/Academic Stakeholder

Another factor that came up is the **degree to which donor countries feel threatened** by a disease. In the case of NTDs, the **perceived threat to donor countries** is very low, which is one factor that helps explain

why policy windows are so infrequent at the global level and why more bilateral donors have not joined efforts to end NTDs.

> *The big emphasis now for the G20 countries are not NTDs even though those are real economic threats to their countries. Instead they're putting money into things like CEPI to fight mares' coronavirus and nipovirus and Lhasa fever and ebola. What I call in my frustration, "the imaginary illnesses that scare white people". This is this is where a lot of funding is being targeted. – Global NGO/Academic Stakeholder*

B4: Falling Off the Radar

The "Falling off the Radar" balancing loop demonstrates the mechanism by which success can actually lead to de-prioritization of a health issue. Fewer **cases of NTDs** because of increased **drug delivery** can lead to reduced **visibility of NTDs** among policymakers, a **perception** that NTDs are not necessarily a public health problem that needs to be dealt with, less **political priority** for NTDs, and thus a reversal of the **progress** being made. This same causal pathway has been observed in other areas of global health, such as with the drive for polio eradication (Thompson & Duintjer Tebbens, 2008).

> *With any disease elimination program, as disease prevalence goes down it ceases to be the most pressing item on the public health agenda. So you always have a potential risk of you being in the wrong position on the carousel. So you reduce the prevalence, it falls off the radar, off politician's ... people stop complaining about it. It's deprioritized, and therefore you have prevalence reduced until such point as people say, "Oh, I thought we got rid of trachoma. We'll have to go back and do that again". – Global Multilateral/Bilateral Stakeholder*

This loop emphasizes this phenomenon happening at the country level, but it can also occur at the global or community levels. As one interviewee put it, a critical question is:

> *How do we keep communities engaged when the burden of disease subjectively is just going down? Actually, objectively too is going down? – Global NGO/Academic Stakeholder*

Similar to the issue of donor fatigue, interviewees talked about this as something to worry about for the future at the global and country levels. However, there were several examples given of communities who have been engaged with NTDs for a long time that are now losing interest because they no longer see people with the diseases and thus no longer perceive them as a problem that needs to be addressed.

They've been getting MDA for so many years now that people aren't going blind anymore. So, what is the point of continuing to take this medicine? The international community has decided we want to interrupt transmission. That doesn't mean anything to the people living there. They don't know the difference between control and elimination. It's a little bit of a demand that we have placed on them because all of a sudden we need to get higher coverage. Before, it was perfectly fine to get 65% coverage and that would have been considered fantastic, but now you need these higher levels to interrupt transmission when people who are at risk don't even perceive a risk. – Nigerian Multilateral/NGO/Academic Stakeholder

There's resistance. Not just drug resistance but people saying, "Well, you know, I'm not sick why do I have to keep taking this drug"? And you know that's a really valid point to make. So there is a lot of sensitivity in the NTD community to that argument. – Global Multilateral/Bilateral Stakeholder

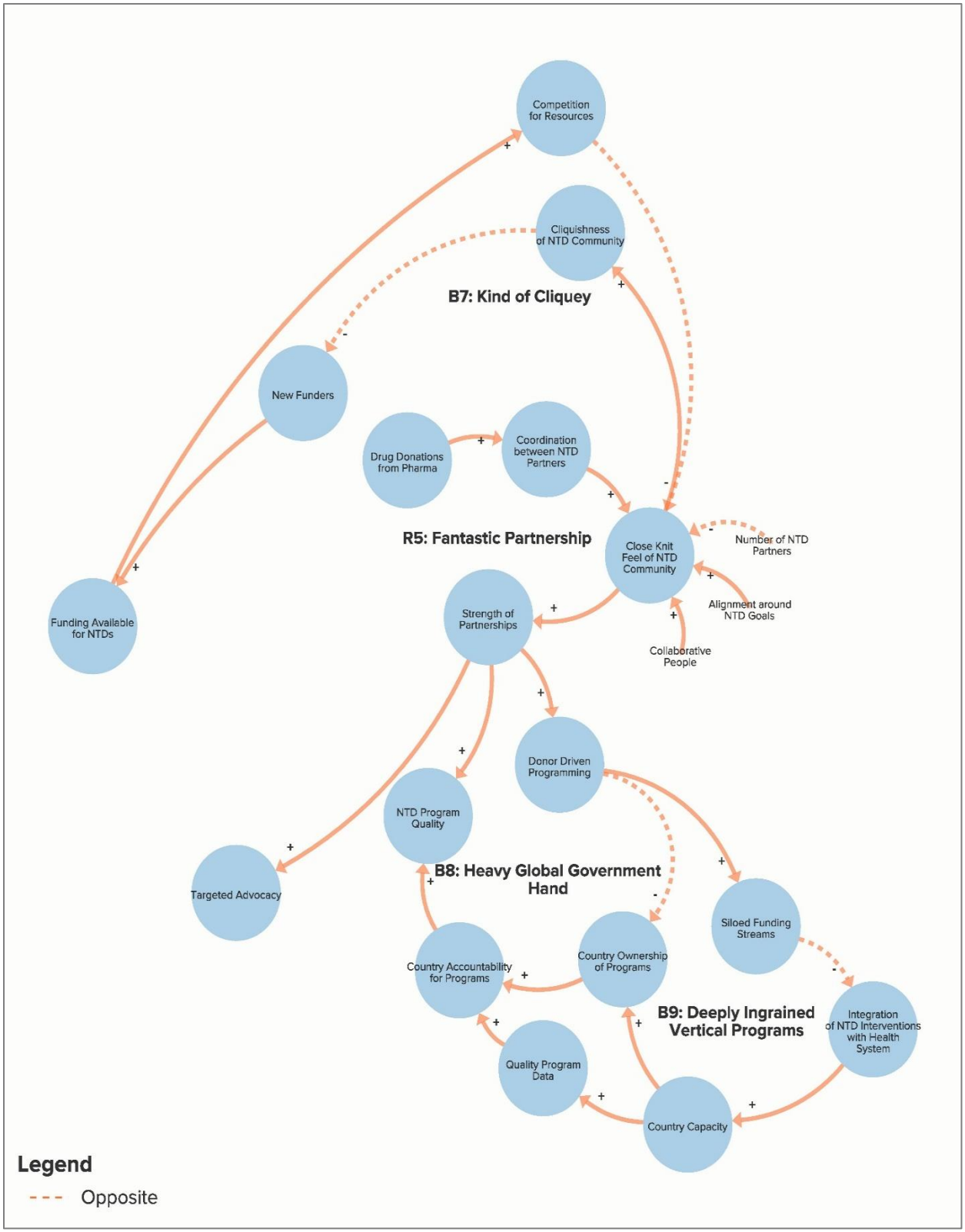

Figure 24. Picture 4: Implications of a Strong Global NTD Network

Picture 4: Implications of a Strong Global NTD Network

R5: Fantastic Partnership

A common theme through the interviews at the global level was the unique **strength of the partnerships** among the global network of organizations working on NTDs.

> *The partnership generally I think has been fantastic…is fantastic. – Global NGO/Academic Stakeholder*

> *I think it's a great credit to the community that has actually been able to kind of build that trust, and by having that cohesion within the international community I think that that gives us that ability to have that united voice that is obviously much more powerful than individual organizations themselves. – Global NGO/Academic Stakeholder*

The "Fantastic Partnership" reinforcing loop highlights a number of facilitators that interviewees speculated may be responsible for the strength of these partnerships. These factors touch on each of the categories in Shiffman et al.'s framework: network and actor features, the policy environment, and issue characteristics.

First, the **drug donation programs**, a very unique component of the global NTD network, were cited as an important driver of the **coordination** occurring between partners since free drugs are an enticing incentive that could only be accessed by establishing coordination mechanisms between donors, implementers, and endemic country governments.

> *Certainly for NTDs a donation platform that's generated by the pharma companies is all contributing to the sort of collective engagement. – Global NGO/Academic Stakeholder*

> *I think first of all we have you know this very unique public private partnership with the drug donation programs the funders, the implementers, national programs under the Ministry of Health, and the communities, so I think it was clear from the beginning that that job could not be done by any single constituency alone. So I think it's probably the need that has driven us together. – Global NGO/Academic Stakeholder*

> *You can only leverage this major asset that NTDs have that other sectors don't have, which is the donated drugs, if you're collaborating with the Ministry of Health. – Global NGO/Academic Stakeholder*

Increasing **coordination** leads to the feeling that partners are part of a **close-knit community**. Another reason cited for the **close feel** of the NTD community was that the total **resources available for NTDs** is actually much lower than for other global health issues like HIV and TB, which leads to less **competition for resources** and a more **friendly, collaborative environment** in which partners can work together. ‘

> *It's not the money grab. Where you're talking about Global Fund replenishment, we’re talking about billions of dollars and essentially, under the more recent model the global fund, you know HIV, TB, and Malaria have been pitted against each other in terms of being able to have to deliver what you have to deliver on. So really it creates a very different dynamic. – Global Multilateral/Bilateral Stakeholder*

> *You could say well we’re tight knit. There is not a lot of money floating around the NTDs like are floating around some of these other ones. You know the more partners and the more money the more backstabbing and the nastier it gets. – Global NGO/Academic Stakeholder*

> *There is a much higher level of…I don’t want to describe it as competition, but I kind of will, overt competition, between the stakeholders in the vision space because they’re more directly competing for funding. But mostly everybody [in NTDs] is working in a very true sense of partnership based on high levels of trust, based on knowledge everybody’s going to be using different expertise of stakeholders to its best fit. And potentially this sense that we’re all in it together. – Global NGO/Academic Stakeholder*

The relatively small total **number of NTD partners** is thought to make it easier to know each other and work collaboratively.

> *One reason that we’re such a tight knit community is because they're not that many of us. – Global NGO/Academic Stakeholder*

The **alignment of partners** around the global NTD end goals is another factor thought to contribute to this closeness.

> *I think having a really clearly articulated goal is really helpful. Obviously we give credit to the WHO which was the kind of catalyst in 2012, so that was really clearly articulated that everyone can kind of get behind that and we kind of all know where we’re going. So I think that has been enormously helpful. – Global NGO/Academic Stakeholder*

> *If you are truly aligned to the goal all the rest of the stuff kind of melts away. So if you have underlying tensions that come up institutionally between one group or another, or you have challenges within some of the WHO pieces coming back to you, “Okay, well that's fine and now we have to move on because we really are aligned to the goal and there's nothing that should be able to get in our way of achieving that goal”, and we have to figure out, “Is this my problem? Where does the problem lie?” And then we all have our own institutional and individual accountability towards problem solving to make sure that we are not the one in the way of*

reaching that goal, and I think that's probably been the most important piece is just always coming back to what are we trying to achieve and then what can we do. – Global NGO/Academic Stakeholder

Another commonly cited reason for why the NTD community **works so well together** is because of the **people**. For reasons that no one could quite put their finger on, there is a common belief that individuals involved with NTDs are easy to work with and have a collaborative mindset.

When you boil everything down it absolutely comes down to the people involved. The people involved in the NTD space are very passionate people, committed to controlling or eliminating their disease by the time frame involved. – Global NGO/Academic Stakeholder

I also think that you cannot discount the individual people. Like to me it comes down to leadership and personalities on pretty much any issue you can think of. And where I have seen collaboration breakdown it's always because of not a collaborative mindset and people not seeing things from a systems lens, having their ego in the way, having their logo in the way, having their board not promoting collaboration. – Global NGO/Academic Stakeholder

This sentiment, however, was not unanimous across interviewees as a couple respondents noted that working with the NTD community can be difficult. As one respondent put it:

The NTD community is not an easy community to embrace. They are also very turf conscious, very territorial. Organizations at certain levels like being siloed and don't easily work with…they don't play well in a sandbox with each other. – Global NGO/Academic Stakeholder

The closeness of the NTD community leads to **stronger partnerships** and thus higher **quality programs**. Strong partnerships also lead to better **advocacy**, **community mobilization**, and other positive outcomes.

B7: Kind of Cliquey

While there are obviously many positives associated with stronger partnerships, an important unintended consequence was raised by interviewees who thought that the **close knit feel** was responsible for a **sense of cliquishness** within the NTD community. As shown in the "Kind of Cliquey" balancing loop, this **cliquishness** was thought to prevent **new funders**, particularly those who are smaller and less established, from joining the NTD community.

I've talked with foundations, but I think they are kind of afraid to enter a system that seems kind of overwhelming, and so it's easier to then say, "I'm going to focus on this area instead and not try to like break into an NTD space", which can feel pretty close knit and kind of cliquey. And yeah I think I think it's hard to get into it if you're not there. – Global NGO/Academic Stakeholder

So what bad vibe are we giving off that's not welcoming? And it's true that there's lots of lingo and it's hard to understand when you first come, but also I think that is such an unfortunate…that's one of my biggest pet peeves of thinking …I always say the word onramps, we need more onramps for more people to join in an easy way that they can be value add rather than like, "Oh it's too hard", or, "I don't fit". – Global NGO/Academic Stakeholder

B8: Heavy Global Government Hand

Another unintended consequence of the **strong partnerships** is likely a much bigger concern. This loop combined with the "Fantastic Partnership" loop again illustrates an example of the Shifting the Burden archetype in which overreliance on the international partners unintentionally undermines a country's ability to develop sustainable, long-term solutions. The "Heavy Global Government Hand" loop shows that **strong partnerships** increase the proportion of NTD programming that is **donor driven**.

There will always be an NGO that will be created so that they can incorporate your money. It's just that everybody sometimes follows their little agenda and the same happens at the country level. – Global Multilateral/Bilateral Stakeholder

NTDs is donor driven because without donors there wouldn't be any NTD program in Nigeria. – Nigerian Multilateral/Bilateral/Academic Stakeholder

We know that he who pays the piper dictates the tone, and that [states being accountable to donors rather than federal government] is what's happening. The NGDO partners pay the states, support the states, so that's what has been happening. – Nigerian Multilateral/NGO/Academic Stakeholder

Of course, some programs like family planning have multiple partners funding those activities. So that's why those partners see it as a priority. Of course, when they want to assist us in the program, I cannot say no because we're happy that they're helping us. – Nigerian State Government Stakeholder

A noteworthy link made in one interview was that the **strong partnerships** and subsequent **donor driven programming** were impeding **country ownership** of NTD programs. I observed an example of this during my time in Nigeria when I overheard talk from different NTD partners that USAID was attempting

to reconstitute the Nigerian NTD Steering Committee because they were not satisfied with how things were working.

> *I think that there's a very very heavy global government hand. You know, the trachoma committees, the LF committees, the regional program review group making…I mean in L.F. and in trachoma, subnational decisions are being made by international groups. My big thing has been pushing country level programs making subnational decisions with due reference to WHO guidelines, and we have gotten such big push back from the Gates Foundation, from WHO, from all of these folks saying countries shouldn't be doing this. They shouldn't be deciding at a county level what they're going to do. I mean, I think that's nauseating. And as long as people want it to be that way there will be no domestication of these programs. – Global NGO/Academic Stakeholder*

> *Countries need to believe that these are their programs. As long as they believe that they can get these things for free and that outside donors are doing these things and the medicine comes and the money comes, then you're not going to see domestic funding. And my very strong opinion is that we're in a time where we really need to put the countries in the driver's seat in these programs, such that they really start to own them. But right now I don't think that they do and I think that WHO and the donors have set things up in a way that does not promote country ownership. – Global NGO/Academic Stakeholder*

> *I think the next phase of this program needs to be in Africa that countries are given the flexibility to make a decision about their own programs and it's not all done outside of the country, so I think that is a real problem right now with the partnership. That we're still having this challenge is very disheartening to me, to tell you the truth. – Global NGO/Academic Stakeholder*

> *The network of actors operating at global levels, at national levels, is organized in a way that needs to back off. I really think we need to promote national ownership. – Global NGO/Academic Stakeholder*

> *I mean, why can't these countries, after twenty something…thirty years of the Mectizan donation program, why in the world can't they make their own decisions? It's like you have a thirty year old child living at home that you won't let decide when he wants to fill up his gas tank. And I find it you know, I find it really disheartening. – Global NGO/Academic Stakeholder*

Country ownership was one of the major issues thought by interviewees to be most essential to the continued **success of NTD programs** and **progress towards elimination**.

> *I do think that NTDs need to become a main part of ministry of health programs. Until they do they're going to be weak, fragile, and on the edges. I think that that mind shift has to happen. – Global Multilateral/Bilateral Stakeholder*

> *I think country level explicit public commitments would have the biggest impact. If a country, not dependent on the personality of a person who's in a role, makes a commitment that says we're going to do everything we need to do in partnership with others to eliminate the disease and we*

will be transparent and accountable by giving annual updates…or you know whatever some mechanism to do that. I think that's the key. – Global Pharmaceutical Company Stakeholder

Everything we do has always this light of working with them, empowering them, and ensuring that nothing that we do undermine their efforts or their leadership. And that is extremely important as we want to achieve sustainability of the controlled diseases and as we want them to own and achieve the elimination of the elimination diseases. Because when you talk about elimination, a huge level of commitment and engagement from the government is required, and that can only be achieved if countries are in the drivers seats. – Global Multilateral/Bilateral Stakeholder

One of the mechanisms through which **country ownership** is critical to **program quality** and continued **progress** is through country **accountability** for results, which rises with an increase in **country ownership**.

I think it's important because it brings a higher level of accountability and a higher spotlight which then makes the countries be more responsive. So it means countries say, "Okay, this is a big spotlight that we need to stop treatment and so it's going to be reported on through various mechanisms and so we've been really focused on this". – Global Pharmaceutical Company Stakeholder

I would like to see the federal ministry of health in particular sometimes take responsibility when things don't work, and this is something we've always told them. What we do is to support the program, but when things go well the federal ministry of health and the state ministries take the credit. Fine. We don't have a problem with that. It's their program. But what to me is not fair is when things don't go well, "Oh, it's the NGO. The NGO didn't do this. The NGO didn't do that." The NGO does not own the program. You didn't do what you need to do so I think that blame shifting at times is something I wish it can take more responsibility of. – Nigerian Multilateral/NGO/Academic Stakeholder

B9: Deeply Ingrained Vertical Programs

In a similar way to "Heavy Global Government Hand", the "Deeply Ingrained Vertical Programs" balancing loop also has echoes of the Shifting the Burden archetype. As shown here, besides potentially decreasing **country ownership**, a heavier emphasis on **donor driven programs** typically creates more **siloed funding** between NTDs and other health programs.

For me, it's more about ensuring that we strengthen the system, so it should be part of the health system and this is what we have been preaching. And fortunately, we've been lucky that we have donors who understand that because most of the donors who give us funding now give us funding to do an integrated treatment. There are a few who would insist that they want their funding to go for a particular disease, which is fine. But it's very difficult for us to draw the line even if we want to do that. – Nigerian Multilateral/NGO/Academic Stakeholder

A lot more donors are putting funding into things like health systems strengthening, or at least providing facilities for health systems strengthening in vertical programs, like GAVI for example, and the global fund. But it's still very deeply ingrained in ministerial and programs structure and it's going to take a long time for it to change. And if we acknowledge that we still have this incentive issue in NTD programs that still makes it more difficult for MOHs to move away from that pattern. – Global Multilateral/Bilateral Stakeholder

This loop gets back to the issue of horizontal vs vertical approaches that has been debated for decades in many areas of global health. As discussed in the literature review, vertical programs have been credited for the successful delivery of billions of doses of NTD drugs, but more siloed funding causes a decrease in **integration of NTD interventions** within the health system which decreases **country capacity** and the possibility of **country ownership**.

And so very much focusing on the capacity. I think being responsive to the requirements of the Ministry of Health and really thinking very carefully about resourcing capacity development at all levels and across all areas. So we're thinking very much about obviously the technical capacity but also the program management, financial, and capacity and the kind of leadership and project management pieces, as well. So how we can be responsive to the whole of the health system in terms of where capacity has to be built? – Global NGO/Academic Stakeholder

I can think of programs where I think the health system…so if you take a place like Ethiopia, because of their commitment to the health army and that platform, or Nepal, when they're ready to roll something into that built in system, once they're ready they've got a system and they can do it so they can…they have an ability to maybe accomplish more because they can leverage an existing platform that doesn't exist in another country. – Global Multilateral/Bilateral Stakeholder

There has been certainly drastic change in understanding that we need to work in a much more coordinated way and much more working with the governments. Because before there were many NGOs and they think they would just go to the field and distribute and do something themselves and that will obviously not bring success for the region and will not bring success for countries. It will probably be very helpful for the particular people who receive the treatment, but that doesn't create owned programs by the countries. – Global Multilateral/Bilateral Stakeholder

Lower country capacity also makes it more difficult to collect and use high **quality data** to monitor programs and to assess progress towards elimination. This decreases country **accountability**, as well as donor accountability in many cases, and, eventually, **program quality**.

We need to be able to…for example, we need to print out what everyone was able to achieve and go back before we do the next intervention to the local government chairman, to the state,

to community leaders, and show them the results we have achieved. And also let them know what we need to do in the next year. Kind of carrying them along. It will involve working out what needs to be done. – Nigerian Multilateral/NGO/Academic Stakeholder

The monitoring and evaluation from the Federal Ministry and from the states has been a little bit weak. I'm being a little bit political. They need to intensify with a definitive goal and objectives of what an MDA process should look like. Right from the drugs coming in, which local government are these drugs meant for? When will they use it? Did they use it? How many persons were treated? What are the results? So that next time the M&E team can see you've treated five times. You don't need any more treatments. You need to scale down. You need an assessment – Nigerian Multilateral/NGO/Academic Stakeholder

You ask FMOH, "Where is my result or reports"? "I'm sorry the states have not given to me". But it's being explained in Geneva, or in London, or somewhere in an NTD meeting. So you understand where the issues at. And you don't know who you should actually hold responsible. – Nigerian Multilateral/NGO/Academic Stakeholder

At the country level, some Nigerian interviewees lamented the lack of quality **program data** and spoke longingly about the years when APOC was in charge and resources were sufficient for better **data** and closer supervision to monitor the quality of the programs.

During those period that APOC was funding the program and partners were supporting, there was enough advocacy. All over. Not only at the national level but at state, community level. The country was also supporting as well. A lot of supervision, monitoring being carried out of what is happening here and there. A lot of reports. A lot of trainings. A lot of management. APOC requested every state to have a technical report of what is happening. In that technical report, this is well detailed. What is happening? When did you start? How far you have gone? How much Mectizan you've taken? When did you start? How many training have you had? How many people did you train? How many community director distributors? How many doctors? – Nigerian Federal Government Stakeholder

An interesting observation is that while APOC may have helped contribute to quality programs, they were not keen on **country ownership** and thus may have failed to build **country capacity** for program management after their departure.

I had a very long experience with APOC and that was an extremely rigid, vertical program that did not like country ownership whatsoever. – Global NGO/Academic Stakeholder

APOC came in with a kind of hundred, zero kind of funding that as they are coming in with 100% funding, the country should not put in anything for now. – Nigerian Federal Government Stakeholder

Without the APOC things haven't been as good because distribution hasn't been as good. The ministry didn't do what they should do, and that's just putting in the counterpart funding to help

them and starting that system. And I think that's where the problems were. But they were supposed to…when APOC funds dwindled, the ministry's funds should be rising. I think that didn't happen. – Nigerian Multilateral/NGO/Academic Stakeholder

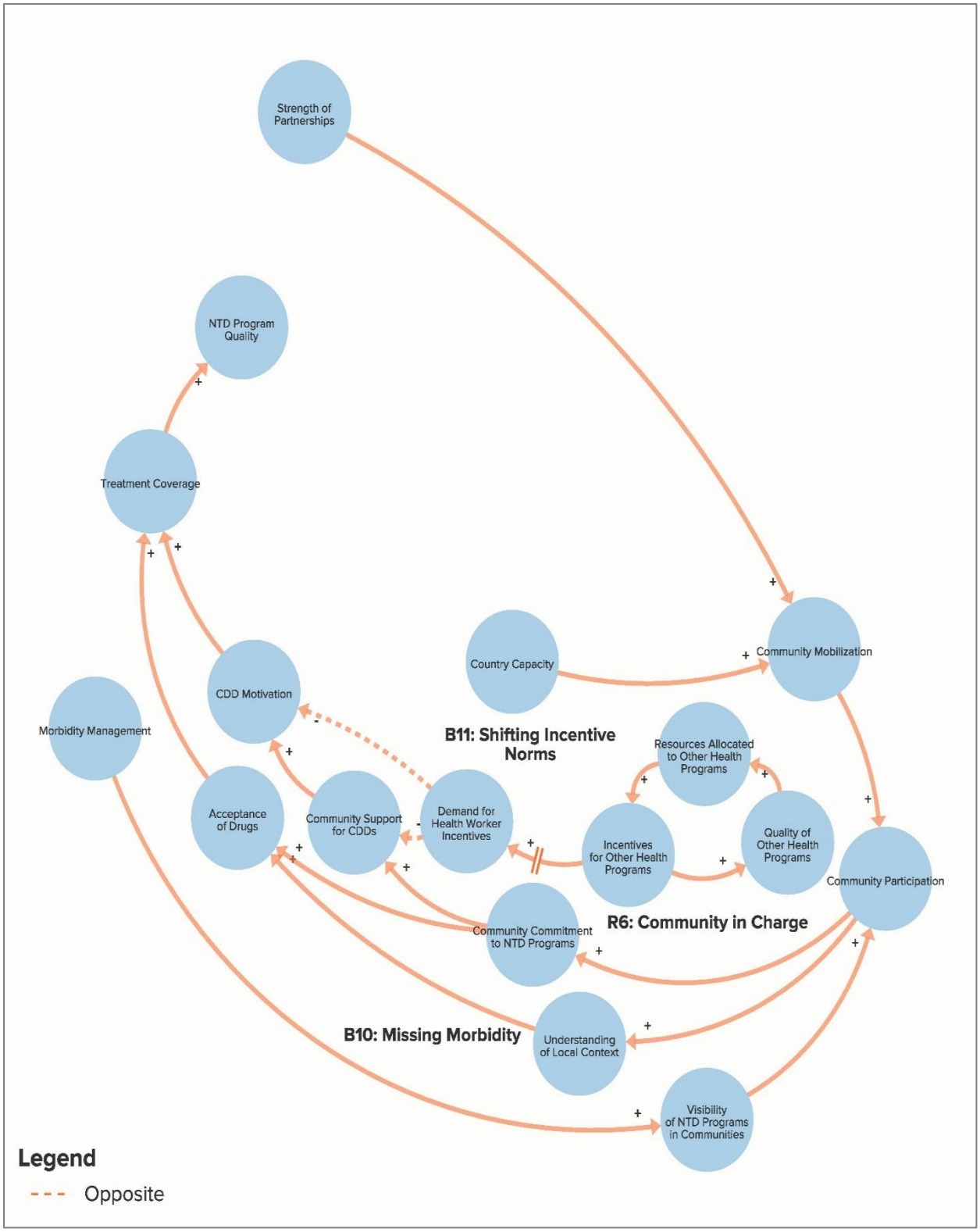

Figure 25. Picture 5: Community Participation in NTD Programs

Picture 5: Community Participation in NTD Programs

R6: Community in Charge

The "Community in Charge" reinforcing loop points to the importance of **community participation** in the implementation of NTD programs. Dedicated partners and **strong partnerships** along with high **country capacity** typically lead to increased **community mobilization** efforts. Some respondents provided examples of how **community mobilization** can be effective.

> *Another thing that works for us is we're right there in the field talking to community leaders, talking to religious leaders. Doing this one week we were in a State, I met with chief imam of the state, who is the head of all the Muslim clerics in the state. I met with the chairman of CAN, Christian Association, who is the chairman of all the pastors, all the reverends in the state, and gave them information and messages to pass down to the people and to their followers, and to the pastors and imams. I think basically there's no magic about it. What needs to be done is to be out there, talk to people, seek support, walk with them, encourage them, where there are weaknesses, try and strengthen it. – Nigerian Multilateral/NGO/Academic Stakeholder*

> *One of the good examples is definitely oncho with CDTI where, not in all cases but in many cases, really that community ownership had been there and still is there. It depends a lot on obviously how you engage with them. It's again it's a mindset issue. Does an implementing partner, does a health system really pay attention to this or is it lip service? Does it matter that communities are fully owning these programs? So it depends a lot on this partnership and the mindset and the roles and the collaboration of the partners here. – Global NGO/Academic Stakeholder*

Real attention paid to **community mobilization** can have a major impact on increasing **participation** of community leaders and members in NTD programs.

> *So doing that MDA but then having it be led by the community. It's people selected by the community coming in and saying, "Hey everybody we all know each other. Let me tell you as your friend and neighbor about oncho. Remember all those people going blind and we know what it's like, well how do we want to treat ourselves? Do we want to have one day when everybody comes to the central market place? We can do that. Do we want to have community distributors go door to door and knock on your door? We can do that too. But let's let the community direct the way to do it." So it's a real nice, democratic way to do it to make sure we get better coverage rates and more ownership of the process at the community level. – Global Pharmaceutical Company Stakeholder*

> *It's this communication that the community understands and the community then drives and encourages itself to stay engaged until the job is done that would be totally crucial. And we have often not paid enough attention to this because it was all about scaling up. But that would be so crucial to finding the last pockets of persistent defaulters, families, or communities, particularly in marginalized areas who simply don't participate regularly in these activities. All this can only*

be achieved with community ownership and having a community in charge. – Global NGO/Academic Stakeholder

When **communities participate** alongside NGO and government partners in planning and implementing NTD programs, the **commitment** of community members to carrying out a successful program is increased.

If we don't purposefully include affected communities and affected individuals we lose them as a key resource to successful programs. They bring passion they have the experience and expertise. We know from several examples that if we engage them we get better coverage even for MDA. Our job would be so much more difficult or even be made impossible if we don't include them. – Global NGO/Academic Stakeholder

We go in teams with our posters. We talk in their local dialects and come down to their level, explain to them in simple language, not using big terminologies. So once they grasp the message, they key in. Some of them, they promise us, "We don't have money but we will support you by telling people to come and collect the medicine", which is the most important thing because that is one of the biggest problems that we have for now. – Nigerian State Government Stakeholder

Whatever message you are carrying, once you go through the traditional institutions, I mean the traditional rulers, the religious leaders…one word from a traditional ruler would be respected ten times more than a word from a politician. – Nigerian Multilateral/NGO/Academic Stakeholder

Community participation also leads to a much deeper **understanding of the local context** that is critical to dealing with cultural issues that are unique to each community.

It's much harder for them to adapt to local circumstances because they have this model of implementation that comes from higher than the Nigeria strategy. They just try to fit onto a state, whereas the local partners really take into account who they're working with. – Nigerian Multilateral/NGO/Academic Stakeholder

Increased community **commitment** and **understanding of local contexts** are essential to generating **acceptance of drugs** in communities. This is also affected by unique cultural contexts. If people are unwilling to take the drugs, **treatment coverage** will remain low and the **programs** will be unable to reach the quality thresholds necessary for reaching **elimination**.

I think it's more of the commitment of the program staff. And all those who were in the process and perspective and process of the MDA making sure coverage was achieved, making sure that that coverage was maintained, making sure that actually the reported area was tallied with what is on the field. – Nigerian Federal Government Stakeholder

Apart from financial challenges, one of the challenges for now is acceptance. A lot of people are still scared. They don't want to take these medicines, they say, "Once we take it, they have dizzy". So, apart from the finances, one area we need people to help us is the area of awareness creation and to tell people that, "These medicines, they work well and they are in their own interest". – Nigerian State Government Stakeholder

The second one thing is also the acceptance by the communities. Here in the northern region, particularly the central region here, people see it as you're doing a favor, a favor to them. And because they think you are doing a favor, by coming up to his village to bring in drugs, this concept is very different from the south. You know, completely different from where I am working in the south. – Nigerian Multilateral/NGO/Academic Stakeholder

Some interviewees at the global and country levels expressed concern that some communities continue to deliver drugs many years after the disease models predicted treatment would no longer be needed.

In some states, they have been treating for three, five years but they have not been achieving minimum therapeutic coverage in those communities. So, they have just been administering drugs. That's a total waste because if you don't achieve minimum therapeutic coverage of 80 percent for oncho, you cannot achieve [elimination] in each district. It's a total waste of drugs. We've seen this that some places, some states that have been treating for nearly 18-20 years. They spent like five years. Among those five, they did not achieve minimum therapeutic coverage in all the districts. It means they have to continue treating. So, that is one of the failures that, yes, we could see that has happened. – Nigerian Multilateral/NGO/Academic Stakeholder

My question is, why can't we concentrate and say let's cover all the areas in two states? We know that there's no support. But at least we know that. And make sure that happens consistently for some four, five, six years. And for maybe certain issues concerning LF, we can say, "What's your elimination for those areas"? – Nigerian Federal Government Stakeholder

B10: Missing Morbidity

The "Missing Morbidity" loop highlights an additional determinant of **community participation**. As discussed earlier, the **overemphasis on drug delivery** has led to **reduced funding for other interventions**, including **morbidity management** for diseases like trachoma and lymphatic filariasis. Interviewees who are actively implementing drug delivery programs mentioned that they see the **morbidity management** component not only as the right thing to do but also as critical to the success of their programs because being able to treat disease symptoms like blindness and hydroceles raises the **visibility of their programs** in the communities where they work. This generates support among

community members and increases the likelihood of **participation** for program planning and implementation.

> *What was incredibly discouraging in some cases has been that there has been only funding for MDAs and not for the trichiasis surgeries. There's been a lopsided investment and so people were not receiving the full complement of care they needed. – Global NGO/Academic Stakeholder*

> *It's management of morbidity and stopping people from going blind. It's the most urgent bit of the strategy because people who have trichiasis are going blind now, and that's got to be done. It's also a really good advertisement for the program because if you can stop people having the irritation from trichiasis then people will develop faith in the program overall. – Global Multilateral/Bilateral Stakeholder*

> *One of the things that we've done in another program is to raise the awareness of eye health. And what we did was to ensure that the people who make the laws, those who are appropriating funds for health in the state, make sure that they have their eyes tested. Make them realize that if this is a service that is needed ensure that the whole population gets it. So we need to really demonstrate the impact of the work we do for people to appreciate what we do and once we do that there is every possibility. I'm very confident that once we do that I'm optimistic that people will see it as this is something that we can actually do something about. – Nigerian Community Drug Distributor*

B11: Shifting Incentive Norms

The issue of incentives for community drug distributors (CDDs) was one of the most common concerns raised in the interviews at the country level, and the closer the interviewee was to program implementation the more important the issue became. The “Shifting Incentive Norms” balancing loop illustrates a similar dynamic to the one in a systems archetype known as Success to the Successful. In this archetype, one party’s struggles are inversely correlated with another party’s failures (Stroh, 2015).

In Nigeria, CDDs in NTD programs typically do not receive a full salary. The programs usually pay a small stipend with the intention being that communities will hopefully recognize the value CDDs are providing and pool resources to support CDDs through food, transportation, and/or an additional stipend. Many onchocerciasis programs have functioned well this way for over 30 years, but there is a sense that this norm is changing.

> *In the olden days when I was young, if some people are coming to our community to do something, we have community council. Community council will make arrangement for*

accommodation. Community council will make arrangement for feeding. – Nigerian State Government Stakeholder

Before, it used to be a free service to distribute these medicines. We say thank you for helping your community. But nowadays it's maybe advancement has come. Nobody wants to do free service to his community again. There are now a lot of people distributing this. They want to be compensated for their time and their effort, so they say, "I need money". – Nigerian State Government Stakeholder

What is expected of us is to have people in households, in little communities, to nominate people from within them to distribute the medicines to them. That way, we are just delivering drugs meant for them and teaching their children to dispense them properly. That's all. We are not here to sell the medicines to them. The medicines are free. And we are not meant to pay those who should dispense. That allowance is just to enable such people to get pure water, get food in the course of the job, or if they have to take a bike from one position to the other. It's just to help with all that. It's not meant to be cost of service. – Nigerian Multilateral/NGO/Academic Stakeholder

Over the past few years, global health programs for malaria, polio, and a World Bank sponsored performance-based financing program for primary health care have introduced **higher incentives** for some community-based health workers in Nigeria. These **incentives** have increased the **quality of those programs,** which has led to more **resources** and more **incentives** for those programs, but an unintended consequence of these **incentives** is that they have also created a new demand **for health worker incentives** among community members and CDDs.

Then the other reason why people are demanding for motivation in this state is that there is a program run by the World Bank. There's a program they call it results finance Performance Based Financing. So that program is run in such a way that for every attempt you make you are rewarded, you are compensated for it. So, now the program has been going on in the state for about three years now, that anything called free service is no longer embraced. – Nigerian State Government Stakeholder

There's a sense of, here in the south lands, that for every job you do you must be paid for. And unfortunately, very unfortunately, there are programs like the Polio Eradication program in Nigeria that has introduced this elemental money tree award. And that is costing us a lot of problems, particularly for programs that are not well funded. But this element of money is more pronounced in the south land region where people are not ready to work until you are paid, until there's some remuneration to eat. And this is a fallout from the Polio program where so much has been invested into that program. And so, when other programs come and they are not as buoyant, and they can never be as buoyant as the Polio program, you have a problem with individuals with your program. – Nigerian Multilateral/NGO/Academic Stakeholder

Whether the change is bringing in funding specifically for that from some donor somewhere, or changing some perception. Changing the perception that CDDs are more willing to participate without high incentives. – Nigerian Multilateral/NGO/Academic Stakeholder

This shift has affected other **norms around incentives** for other health workers as well as CDDs.

We have health workers in the country that even their basic assignments they require allowance. That needs to change. – Nigerian Multilateral/NGO/Academic Stakeholder

At the country level, as I said, it's very dangerous because the moment you create something separate people want their per diems and want the support you're going to provide so you have to have that mindset before you start the conversation. – Global Multilateral/Bilateral Stakeholder

Thus, communities have become less likely to provide **support for CDDs** because they expect this support to come from the program sponsor. At the same time, CDDs are **unmotivated** to volunteer to work on NTDs since workers for other programs are being paid significantly more. This is an example of incentives reducing intrinsic motivation that has been well-documented in the development literature.

So nobody actually wants to do anything free. Then some of them have this notion that there is a lot of money in the program, that probably we're just trying to play pranks with them by not giving them good money for the service they are rendering. – Nigerian State Government Stakeholder

So now they're being rewarded handsomely for that matter. So anything that has got to do with free service, they say, "Pay me now". On one hand, somebody is paying me for a job well done, on another hand, somebody is saying thank you to me. Can you see the two? So I would like to probably devote more time to that person giving me cash than the person saying thank you. For now, we've told our partner and they have realized that that aspect is like a change for now, for anything called free service. – Nigerian State Government Stakeholder

That's why an average health worker or community distributor does not want to do anything free because he knows or she knows that if he keys in to another program he may be well compensated, better compensated. So it's like choice, you make choice where you've been better remunerated. – Nigerian State Government Stakeholder

This has made it difficult to recruit and retain high quality CDDs for NTD programs, which leads to lower **coverage** and worse **program outcomes**. The incentive for CDDs in the communities I visited is currently set at approximately US$5 for what amounts to full time work for about two weeks every year. In comparison, I was told the malaria program would pay someone approximately US$50 for one week of

full-time work. The program implementation staff I spoke with were very adamant that the disparities in incentives were leading to poorer **outcomes** at the community level.

> *I can tell you that once there is a Polio program going on in the ministries or at the LGA, all other programs are second rated. Everybody would want to go to the Polio program. And of course, it's because of the well supported program as it is. We have to take cue after Polio program. If they said this whole week is activities for Polio, you will not get one single staff willing to do the NTDs. – Nigerian Multilateral/NGO/Academic Stakeholder*

> *In the face of conflicting programs that pays higher, that engages higher, you have the Polio program, for example. You have the maternal health programs. You have these programs, which you see quick changes. Most health personnel would rather engage in these programs than to engage in NTDs. – Nigerian Multilateral/NGO/Academic Stakeholder*

> *The community and the LGA think they should increase the stipend. Maybe it will encourage them to participate in the distribution. – Nigerian Local Government Area Stakeholder*

> *So how can somebody work for continuously for two weeks and be paid 2,000? That amount is too small. It doesn't encourage people to participate. – Nigerian Local Government Area Stakeholder*

The health facility staff and CDDs I spoke with were universally concerned about the low stipend amount. They highlighted the difficulties of the job and felt that it was not fair for CDDs to be sacrificing their own well-being and sometimes have to spend their own money to complete their job responsibilities without being fairly compensated. Some interviewees mentioned that the same problem exists for teachers who are not compensated sufficiently for the extra work they do around school-based NTD programs.

> *The CDDs, the one in the program, they complain about the finances of the program. They say the incentive is too low. They want the organization to increase the payment for them to work more than they did the other time. – Nigerian Health Facility Worker*

> *I think they have passion for the work, but they are somewhat a bit disappointed that they are taking care of others and their welfare needs aren't met, their own health taken into recognition. They feel like they go into places they ought not to go, see people, hear what they ought not to hear and stuff like that. They think they should also have something to go back and refresh their system. Something substantial. That's what they are thinking. It's not like they don't have the passion. They have the passion. – Nigerian Health Facility Worker*

> *During the schistosomiasis the teachers complain that they have to use their own money to buy snacks. So we use our money to buy pure water to be sure they swallow it in our presence. We can't give it out to them. Same with the CDDs. They say I'm going to my friend's house. They're*

using their own stipend to buy it. That's why they need to increase their money. – Nigerian Health Facility Worker

The payment was so very low. If you look for 15 days that we work, they gave us 2500. But notwithstanding, it will come up again. They should try to increase it. If you take a look of 15 days job, when they pay 2500 now with family. I know that some, we suspend our jobs. – Nigerian Community Drug Distributor

The little problem we have that I realize is we're moving to the house to the other house to share the drugs but the little money they give us is too small. So I must tell you that's really our opinion because we have discussed together. So that's my suggestion. We're saying to you this is our opinion. So the money they give us is too small to go one house to other house. Then we're the person to go to school and give them pills. We give them pill water and we're using our money then they give us token money. – Nigerian Community Drug Distributor

Despite the concerns about lack of CDD incentives affecting the programs, the CDDs I interviewed reported that they still felt **motivated** to do their jobs well because they felt like they were doing something to benefit their communities.

I'll keep being a CDD because I like the health of my people. – Nigerian Community Drug Distributor

It's voluntary service, because the help of multiple is more important to me than money. – Nigerian Community Drug Distributor

It is difficult to assess the true impact of the incentive issue based on the limited amount of qualitative data I collected. However, it is easy to see how, should the community **norm** continue to shift regarding what CDDs expect in order to do their jobs, the **quality** of the NTD elimination effort could be in jeopardy. One interviewee highlighted the structural issue that the NTD community believes programs should continue as they have in the past, but, since this norm has changed, program success will depend on changing with the times.

They want a token that is community based, that was in the past. It was in the past. If you're basing your program and the project like that, it is going to fail. You know the type of community that we are now, and the type of government we are. It is not like the past. – Nigerian Local Government Area Stakeholder

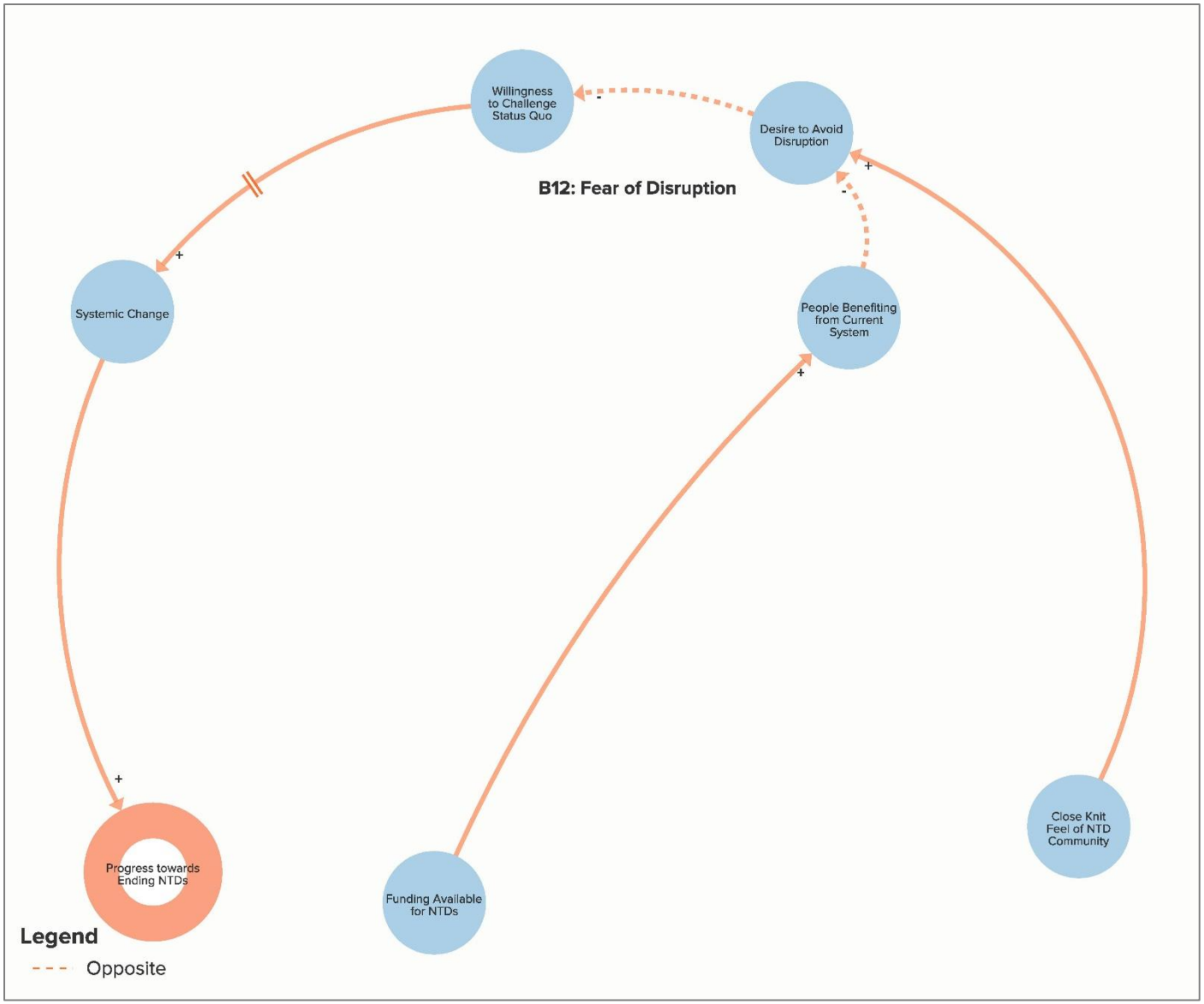

Figure 26. Picture 6: Disruption of the Status Quo

Picture 6: Disruption of the Status Quo

B12: Fear of Disruption

Finally, the "Fear of Disruption" loop is essential to understanding the issue of systems change for NTDs. As discussed earlier, the **close knit feel** of the NTD community has many positive consequences as well as some potentially negative ones. One negative consequence is that as the **closeness** increases the desire to keep things close and **avoid disruption** also increases.

> *I think one of the problems with having a very functional, if you like, coalition community is that it kind of sometimes gets a little bit too cozy and perhaps we then we're just reinforcing our own viewpoint and we don't have enough disruptive kind of influence that actually kind of continues our innovation and improvement, and so I think that a degree of complacency might kind of creep into that. – Global NGO/Academic Stakeholder*

This matters because if people are focused on maintaining the **close feel** they are less likely to want to **challenge others and disrupt the status quo**. Many interviewees pointed to important issues they felt were being ignored by the larger NTD community. When these issues surfaced during the interviews it was common for the interviewees to ask explicitly not to be quoted directly because they did not want to be on the record as someone who could be seen as throwing cold water on NTD efforts..

> *There's also a lot of really bad practice that we need to learn from and to openly discuss failure and not just pretend like it's not happening. OK, well I'd like to see an honest analysis of why after years and years and years of preventive chemotherapy we're seeing no changes, at least in some populations, in severity and in prevalence. And then addressing those challenges. And at the moment within the NTD community, and this is where I'm going a little bit off record, there is a degree of burying the head in the sand and kind of saying well if we openly admit that it sometimes doesn't work the drug companies are going to stop donating the drugs. That's a really big problem because that prevents us from taking action on that failure. – Global Multilateral/Bilateral Stakeholder*

> *What I say is to have the courage to say, "Where are we"? To really do a very thorough assessment I should know where you are and then the partners themselves maybe will have the sense to say what can we be able to do in between now and maybe one, or two, three years? Do we think we have enough funds to address the NTD program burden in this area as well other than traditional way of supporting? And then a good and honest assessment of that should be able to give you an insight as to say, "Can we have the challenge to say, no we can't continue with this. Let us invest and then go to other areas, other places, and focus and concentrate on our resources to those areas." – Nigerian Federal Government Stakeholder*

When the Cochran review on the school-based deworming came out a couple years ago and the findings were that it's not great, the NTD community went into panic mode. "Oh no we can't have anyone questioning the drug donation program." These are valid issues. We can't pretend they're not there. – Global Multilateral/Bilateral Stakeholder

We're patting ourselves on the back for donating a billion treatments and there's no end to that if we don't address, particularly for STH and schist,o some of these other factors that we know contribute to transmission, namely water and sanitation and hygiene, and so really prodding other partners to start paying closer attention to these other interventions and these other things that we should be doing. – Global NGO/Academic Stakeholder

Are we ignoring some of the resistance issues that come up? You know I always think something like Zithromax…it's great to treat trachoma, but it also treats a whole bunch of other things, but it's also a mass distribution of antibiotics. You know like antibiotic resistance is not something that we talk about in NTDs very often. It's really funny considering Zithromax is actually a huge candidate in being problematic in creating antibiotic resistance. – Global NGO/Academic Stakeholder

The **willingness to disrupt the status quo** also decreases as more **people are benefit from the system** as it now operates, which is likely to happen more with increasing amounts of **funding**. Interviewees gave examples of this at the global level:

I think part of the problem is when they bring all these people together like Uniting for NTDs, you know you bring in Helen Keller International and Sightsavers and all these other NGOs. Remember, they're all feeding at the federal trough. They're all getting their funding from DFID and USAID, and you wind up being seen as someone who's sort of lobbying inconvenient truths at them that could potentially interfere with their funding. That's the way they see it, so they tend to circle the wagons. – Global NGO/Academic Stakeholder

That's right, "And don't mess with us. We need to continue to get to our USAID and DFID support." And when you bring up the need for R&D, I've gotten in the past angry letters from heads of very prominent NGOs to say you're trying to dilute our efforts and as though it's kind of a zero sum game that any time you try to advocate for R&D dollars, it means you're trying to take away our money. We've got to kind of get beyond that also. – Global NGO/Academic Stakeholder

I think there's always going to be competition for funding. So as you do have more funding in the space that can create some tension between organizations of who gets what funding. – Global NGO/Academic Stakeholder

Some respondents gave examples of people benefiting from the status quo *regional level:*

There have also been some institutions that were quite happy with the old control model which would focus just more on dealing with the morbidity reduction. There was just a three year window where there was just a huge kind of disagreement around looking at a new framework and saying we've achieved so much on the morbidity control it's time to change. There's a lot of

reluctance around that, a lot of disagreement in the community about who wanted to move to the next agenda who didn't want to move to the next agenda and getting clarity around the tools. I don't think that was so much about the science and more about people wanting to protect the status quo. – Global Multilateral/Bilateral Stakeholder

You've got a kind of a regional institution, a long history, people have been doing things a certain way for a long time. Lot of control and power in it and the scientific community is coming out of and saying no it's time to evolve, go in a new direction, new tools new diagnostic. The program can't be so insular. It now has to come out and join the other diseases. Integrate with other programs. I think with the history of an African held program for forty years that needed to come into the mainstream, and I think that ran into a lot of…well some people had been doing that for thirty years. – Global Multilateral/Bilateral Stakeholder

They also gave examples from the country level:

Federal ministry of health will not [tell a donor to change how they do something], because they see benefit coming to them, coming to the states, and they won't want to offend them by telling them that they shouldn't do it that way. – Nigerian Multilateral/NGO/Academic Stakeholder

You cannot be funding the activity and you're assessing yourself. You, I'm supporting, I want to supervise you. I will mark you very high, so that my donor will commit to give me more. – Nigerian Federal Government Stakeholder

Some of them are unspeakable conflict of interests. An FMOH staff being a member of board of an NGDO. Yeah, so how all is a technical partner who provides all the technical support, and direction, and everything so he can cover up for the NGO. You have a godfather figure in the FMOH. You ask questions and directions. He tells you, "Don't worry. Just do what you can do and I'll see what I can do." Things like that. These are issues. Conflicts of interest. And there's little you can do about that. – Nigerian Multilateral/NGO/Academic Stakeholder

People have their agendas that they want to protect. It is in some people's interest for them to still give mebendazole for instance even when you know that's truly not a good use of money. – Nigerian Federal Government Stakeholder

You know you are the schisto coordinator and you're thinking that somebody is going to take your per diem or that your colleague that you don't really like is the one that is going to go and coordinate your….so it's the territorially. So this kind of stuff happens at all levels. – Global Multilateral/Bilateral Stakeholder

Systemic change is difficult and takes time, but it is ultimately a necessary process in order to address issues that are preventing a complex system from achieving its purpose. In the case of NTDs, this qualitative model raises hard questions that point towards the need for systemic change. For example, the relationship between donors and endemic countries, the overemphasis on the easier-seeming solutions of drug delivery at the expense of lasting environmental change, and the incentive structure at

the community level. Another challenging question is how can the NTD community honestly assess and potentially admit failure when so much of their progress can be attributed to success in touting how successful they have been? These are all complex issues that no organization can solve in isolation. Making progress on these issues will require stakeholders to increase their capacity to address uncomfortable, disruptive issues that are much easier to ignore.

iv. Other Interview Findings

While the in-depth interviews followed a semi-structured format in which different issues were discussed in each interview depending on the perspective of the interviewee, there is value in looking across participants to analyze their responses to key questions that was asked of almost everyone.

One interview question that tended to provoke thoughtful responses was, “If you could make any one change in policy, technology, programs, or other areas, which change do you think would have the biggest impact on reducing the burden of NTDs”? These responses are briefly summarized in Table 11, which provides useful insights into identifying the potential levers for NTD systems change. It is important to note that some respondents gave more than one answer to this question and the question was not asked of all respondents.

Table 11. Changes with Biggest Potential for Impact as Reported by Interview Respondents

Rank	Suggested Change	Number of Responses		
		Global	Country	Total
1	WASH	6	2	8
2	Harmonization/coordination of activities	-	6	6
3	Country ownership	3	2	5
4	Improved program data and supervision	-	4	4
4	Health systems strengthening approach	4	-	4
6	More funding	2	1	3
6	Assess progress towards elimination	-	3	3
6	Planning for elimination	3	-	3
9	Pooled funding available for country	-	2	2
9	Reach everybody with treatment	-	2	2
9	Address demand for payment of CDDs	-	2	2
12	Address vector control	-	1	1
12	Address morbidity	-	1	1
12	High level interest	-	1	1
12	More human resources	-	1	1
12	Acceptance of drugs	-	1	1
12	Address corruption	-	1	1
12	Give drugs to health facilities	-	1	1
12	More R&D for new technologies	1	-	1
12	Transparency amongst partners	1	-	1
12	Implement new innovations faster	1	-	1
12	More integration within NTDs	1	-	1
	Total Number of interviews	**17**	**28**	**45**

As seen in the table, an enhanced focus on WASH was the most commonly mentioned change suggested by respondents when asked this question. These suggestions came from the global and country level. The change with the second most number of mentions was related to better harmonization and coordination of activities at the country level. This change reflected the frustration of country level respondents with trying to coordinate the activities of many donors and implementers, some of whom were seen to be focused on their own goals, across different programs. A closely related change, improved program data and supervision, is seemingly closely related to this frustration. A greater emphasis on country ownership was the third most mentioned change with five total mentions that came from both global and country respondents. Again, this table reflects responses to this question only and does not quantify the full scope of issues discussed by respondents throughout the interviews.

D. Phase 4 – Identify Levers for Change

OBJECTIVES

The objective of Phase 4 was to use the data gathered and analyzed through the internal committee meetings and through the survey and interview research to identify leverage points for change within the system. This was done with the goal of making specific, actionable recommendations for the END Fund.

ACTIVITIES

The main activity of this phase was my own analysis of the qualitative model that I created during the previous phase. The qualitative model of the NTD system (Figure 20) highlights some deeply ingrained patterns in the structure of the system and points to a number of potential areas where the system could be improved, but the next and more critical task is identifying leverage points that can fundamentally change this structure to move the system closer to the goal of ending NTDs. Leverage points are "places within a complex system where a small shift in one thing can produce big changes in everything" (Meadows & Sustainability Institute, 1999). I brainstormed around the following questions while seeking to identify levers for change (Foster-Fishman et al., 2007):

1. Which system parts and interactions are currently inconsistent with the systems change goal?
2. Which parts and interactions are most likely to trigger system wide change?
3. What enduring patterns within the system will likely impede change?
4. Which of the desired levers for change can actually be altered or strengthened given current resources and understandings?

Among other ways, systems change can be catalyzed by using leverage points to increase awareness of how the system currently functions; rewire cause-effect relationships within reinforcing and balancing

feedback loops; shift mental models; and align goals, incentives, structures, etc. to reinforce the purpose of the system (Stroh, 2015). I considered the reinforcing and balancing loops I had pieced together from the qualitative data to identify instances where strengthening or weakening these loops or altering key variables in the system would have a major positive impact on the fundamental structure of the system. Especially because this is a qualitative rather than a quantitative model, identifying leverage points depends in part on a subjective interpretation of degree to which the stagnating power of the balancing loops outweigh the positive driving force of the reinforcing loops.

Finally, I used my understanding of the END Fund to assess ways in which the END Fund could alter these levers given their strategy and capacity. This process was aided through a meeting with the END Fund Systems Change Committee in which I presented the qualitative model and solicited feedback on leverage points and potential recommendations for the END Fund. I also had numerous discussions throughout the research and analysis process with END Fund management and other staff about the findings and their relevance for the organization.

RESULTS

The section begins with a discussion of general recommendations, based on lessons from systems thinking and from insights generated through the qualitative and quantitative analyses, that the END Fund can implement to catalyze systems change across multiple levers. It then identifies and briefly discusses the five most promising leverage points for systems change and makes specific recommendations for the END Fund and general recommendations for the global NTD community to act on each of these levers.

i. General Recommendations for the END Fund

There are three general ways the END Fund can use its influence to catalyze systems change across different leverage points.

General Recommendation 1. Use Grants to Catalyze Innovative Approaches

One of the END Fund's unique assets is the flexibility of its funding, especially as compared with funding from bilateral donors in the NTD sector. This represents an opportunity to use its grant making to pilot novel approaches to addressing some of the leverage points identified below. This catalytic power of innovation is reflected in Birney's model for systems change (Birney, 2014).

As mentioned in the discussion of the qualitative model, success tends to bring with it more success, so for areas that seem stagnated, such as collaboration with the WASH sector, small demonstrations of successful innovation can go a long way towards eliminating the barriers to progress. Thus, using END Fund grants to address key issues is not meant to address the issue only on the scale of the grant; rather, this approach is intended as a way to catalyze systems change by demonstrating successful approaches upon which momentum can be built across the sector. Additional recommendations for using these lessons to catalyze large scale change include:

a) Disseminate lessons via academic and other publications
b) Be willing to fund projects that could fail where the potential for learning is substantial
c) Seek funding specifically for piloting innovative approaches
d) Strengthen partnerships with operational researchers to help learn from and disseminate innovative approaches
e) Seek to identify innovation and learning in areas beyond drug delivery (e.g., advocacy, policy change, community mobilization)
f) Take advantage of flexibility of funding to be the first to incorporate new evidence from quality research

General Recommendation 2. Generate Collective Learning Using Systems Thinking

Since all complex systems adapt to resist change, learning is an essential ingredient to any systems change effort. There is significant emphasis in the systems thinking literature on building learning organizations, but in the case of complex problems for which stakeholders include diverse networks of multisectoral actors, the goal should be to generate collective learning by creating a learning coalition.

Similar to a learning organization, a learning coalition is one whose members "continually expand their capacity to create the results they desire, where new and expansive patterns of thinking are nurtured, and where collective aspiration is set free" (P. M. Senge, Kleiner, Roberts, Ross, & Smith, 1994). In learning coalitions, members are not only learning what they need to survive and accomplish their objectives, but they are also learning *how* to learn together (P. M. Senge et al., 1994). In other words, rather than single-loop learning in which members of the coalition use information available to them to detect errors and take corrective action within the scope of existing strategies, a learning coalition must engage in double-loop learning in which problems are detected and corrected in ways that involve the modification of "underlying norms, policies, and objectives" (Argyris & Schön, 1996).

Systems thinking is central to the double-loop learning needed in a learning coalition. While this project used various systems thinking methods to better understand the NTD system and identify potential leverage points for change, it is possible that these recommendations may be wrong and that the leverage points will shift as the system changes. Thus, it is essential that the END Fund and the global NTD community develop the capacity to think systemically in order to maintain an ongoing understanding of the systemic issues impeding progress on NTDs.

As an important actor in this space, the END Fund can help build a learning coalition by 1) building capacity within the coalition for systems thinking and 2) convening stakeholders to bring together different perspectives in order to facilitate double-loop learning around actions that can change the underlying structure of the system. Specific recommendations for how the END Fund can convene systemically and build capacity for thinking systemically include:

a) Give talks and publish thought pieces on the importance of thinking systemically about NTDs
b) Hold webinars and organize sessions on systems thinking during the annual NNN meeting and other gatherings of NTD partners
c) Train grantees and other country-level partners on how to incorporate systems thinking and systems leadership into NTD work
d) Identify and track metrics for 1) partnership strengthening and 2) learning, that can be incorporated into grants the END Fund makes and receives

General Recommendation 3. Exercise Leadership by Mobilizing the NTD Community to Address Adaptive Challenges

Interviewees talked about the desire to avoid disruption within the global NTD community because stakeholders are "too cozy" and because many people are currently content to benefit from the status quo. Changing this dynamic could help unleash systems change across many areas because it would mobilize the NTD community to attempt to overcome their most difficult challenges.

According to the definition given earlier, leadership is not exercised by providing easy answers that tell people exactly what to do; rather, it involves mobilizing people to work together to diagnose and solve systemic challenges for which easy answers do not exist (Heifetz, 1994). While global NTD programs are driven largely by technical solutions, the leverage points for change identified below are based around adaptive challenges that require learning in order to make progress. Evidence of

this includes the fact that they have not yet been solved despite many stakeholders identifying them as serious challenges.

The END Fund is a well-respected, key stakeholder in the NTD community that fills a unique niche. Thus, in addition to generating collective learning around systems thinking, the END Fund has an opportunity to exercise leadership by mobilizing people to address some of the hard questions raised through this project. The first, and perhaps most important, step is to direct attention to these issues instead of shying away from them. The END Fund can then continue to regulate a productive level of disequilibrium by strategically increasing or decreasing pressure on other actors to deal with these challenges depending on the circumstances. Specific recommendations for exercising leadership in this way include:

a) Use status in the NTD community to raise awareness of these issues by asking hard questions in talking and writing about these issues with NTD partners
b) Rather than trying to offer solutions, help facilitate conversations through which solutions can be co-created by partners
c) Strengthen the "holding environment" by continuing to actively cultivate relationships with and between key partners
d) Invite and embrace different perspectives rather than forcing them out of the system
e) Apply these same principles to challenges faced by countries and grantees
f) Seek solutions to local problems in examples of positive deviance

ii. Levers for Systems Change and Recommendations

Through the process described in the Activities section of this phase of the project, the following five areas were identified in the model as key leverage points for NTD systems change. Under each lever I articulate the problem highlighted in the qualitative model, some of the key structural drivers, the

potential impact of addressing the problem, and ideas for how the END Fund and the NTD community can begin to make progress on these issues.

Lever 1. Clarify Potential for and Assess Progress towards Elimination

Problem: Oversimplification of elimination may lead to donor fatigue. (See Figure 21. Picture 1: Global Advocacy for NTD Elimination)

Key structural drivers: Need for continued funding; fear of donor fatigue; belief that causes are only worth supporting if they have an end in sight.

Potential impact: These changes could slow progress initially by reducing donor expectations, but lowering the risk of donor fatigue will also be more likely to create external funding streams that are sustainable enough to maintain focus until goals are achieved.

END Fund should:

a) Reconsider END Fund messaging to clarify what "ending NTDs" would mean
b) For diseases where elimination of transmission is possible, focus funding efforts and metrics on achieving and assessing progress towards transmission break

NTD community should:

c) Find the right balance between setting goals that are exciting enough to attract funding yet still achievable and evidence-based
d) Avoid the temptation to misrepresent what is meant by elimination
e) Undertake a continual and honest assessment of progress towards goals

Lever 2. Increase Support for Interventions besides Drug Delivery

Problem: Overemphasis on "quick fix" of drug delivery is preventing funding for other essential interventions (WASH, morbidity management, vector control, and R&D), some of which are critical for sustainable, longer-term solutions. (See Figure 22. Picture 2: Balance between Drug Delivery and Complementary Interventions)

Key structural drivers: Desire to maximize impact of donor funds by leveraging drug donations; desire to demonstrate results of donations; perception that MDA is a quick win and is sufficient on its own to achieve goal; belief that WASH is too difficult and expensive; belief that no new technology is needed to achieve goals.

Potential impact: Changing the orientation of the system to include WASH and vector control as well as MDA will be crucial to making the environmental changes that are necessary for actually ending NTDs. More attention to morbidity management will help keep communities engaged. Dedicating more resources for R&D will allow the community to adapt to meet the last mile challenges.

END Fund should:

a) Have internal conversation to decide how to incorporate WASH and other interventions into programs and advocacy
b) Partner with WASH funders to use grants to demonstrate success upon which momentum can be built for joint NTD-WASH programs
c) Incorporate low-hanging WASH fruit into all MDA grants (e.g., basic metrics, geographic coordination of activities, behavior change as part of NTD social mobilization, etc.)
d) Include request for morbidity management resources in fundraising activities

NTD community should:

e) Continue to build bridges between the NTD and WASH communities to better align incentives and goals

f) Work towards a norm that all NTD programs should incorporate WASH indicators developed by WHO

g) Encourage and fund coordination between NTD partners, WASH partners, and relevant government offices at the country and local levels

h) Seek more coordination at institutional level in large development agencies that have both health and environmental programs (e.g., UN agencies, USAID, DFID)

Lever 3. Reduce Dependency on Donors

Problem: Heavy global hand is serving donor interests and impeding country ownership. (See Figure 24. Picture 4: Implications of a Strong Global NTD Network)

Key structural drivers: Imbalance in power between donors and endemic countries; donor community's desire to achieve results; weak health systems in endemic countries; dependency on donor funding; lack of domestic resources dedicated to NTDs.

Potential impact: These changes will put countries in charge of their own programs and create more accountability to produce more impactful results and generate sustainable sources of domestic funding.

END Fund should:

a) Ensure that every grant includes a sustainability plan to transition programs to national and local governments

b) Contribute to and perhaps take the lead on piloting a pooled funding mechanism managed by country governments and funded by the African philanthropic sector

c) Develop toolkits and resources to share with grantees and other country-level partners to aid local fundraising and creative advocacy efforts
d) Create and support local champions through capacity building and mentoring program
e) Hold meetings in endemic countries to raise profile of issues
f) Explore uses of innovative technologies to improve collection, reporting, and utilization of program data

NTD community should:

a) Defer to countries on decisions about NTD programming at national and sub-national levels
b) Create pooled funding mechanisms with decision-making power given to endemic country governments
c) Explore ways to use the NTD platform to deliver interventions for other conditions as a starting place to integrate NTD programs into other health and development programs
d) Concentrate resources on building country capacity for program management

Lever 4. Address the Issue of Health Worker Incentives

Problem: NTD programs continue to operate volunteer-based programs while community norms around incentives have been evolving. (See Figure 25. Picture 5: Community Participation in NTD Programs)

Key structural drivers: Belief of donors that programs should be volunteer-based; rising incentives for other health and development programs; shifting community norms around health worker incentives.

Potential impact: Addressing this issue will go far to assist NTD programs in recruiting and retaining high quality, motivated health workers who achieve high treatment coverage, which is an essential ingredient for progress towards elimination.

END Fund should:

a) Consider increasing stipends for CDDs depending on norm of local area
b) Use programs as operational research sites to study the impact of increasing incentives
c) Use programs to pilot innovative solutions to increasing health worker motivation and finding synergies with other health and development programs

NTD community should:

a) Coordinate with other health and development agencies to standardize incentives and identify solutions
b) Identify opportunities for CDDs to contribute to other health programs and receive compensation for doing so
c) Consider increasing stipends for CDDs in NTD programs
d) Conduct additional research to determine the extent to which shifting norms represent a serious threat to the success of NTD programs

Lever 5. Create a More Inclusive Global NTD Community

Problem: Cliquishness of NTD community is keeping away potential donors. (See Figure 24. Picture 4: Implications of a Strong Global NTD Network)

Key structural drivers: Historical precedent of collaboration among small number of partners; shared 'language' and norms.

Potential impact: Making the NTD community more accessible for new donors and other partners could add funding and contribute new areas of expertise and innovation that will be needed to accelerate progress.

END Fund should:

a) Continue creating "onramps" to make the NTD space accessible to new donors
b) Identify ways to help all donors continue feeling valued as the number of donors increases

NTD community should:

a) Continue to break down siloes between health and development issues to make it easier for new partners to contribute to NTDs
b) Plan in advance how new funding will be integrated

Figure 27 shows the specific recommendations categorized by my assessment of each recommendation's feasibility and impact. While each recommendation has the potential to add value, my strongest recommendations are those with high feasibility and high potential for impact listed in Quadrant I. These recommendations fit within the "Value, Capacity, and Support" model discussed earlier (Leonard, 2006) in that they are most likely to provide a significant benefit to the NTD space, and the END Fund has the capacity and support needed to implement them.

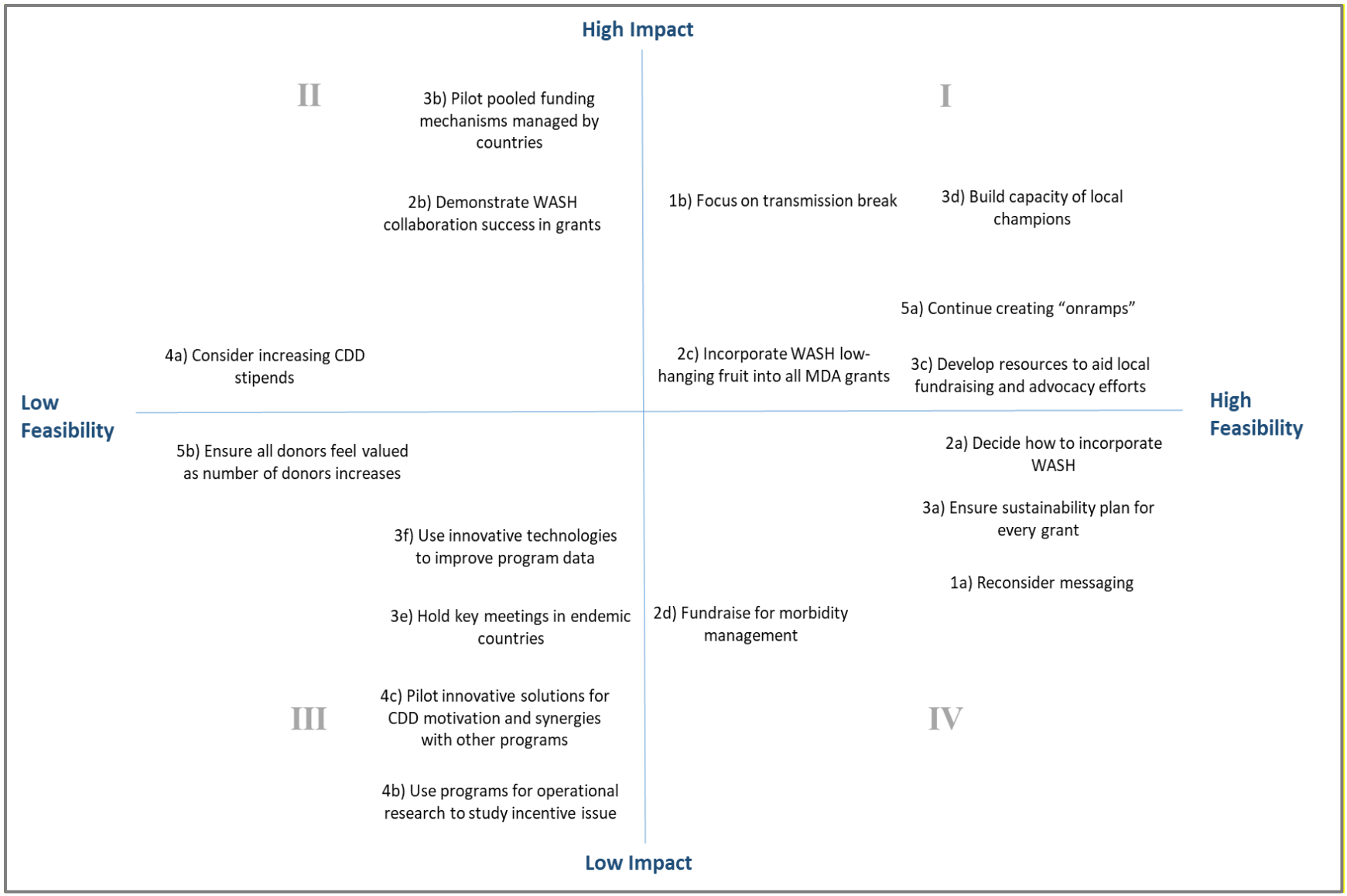

Figure 27. Feasibility and Impact of END Fund Recommendations

E. Phase 5 – Mobilize for Systems Change

OBJECTIVES

The objective of this final phase is to move towards implementation of the recommendations and dissemination of the project findings to introduce change into the NTD system.

ACTIVITIES

The bulk of the activities in Phase 5 will be what occurs after the project is completed, much of which I have little control over since I will no longer be working directly with the END Fund. However, I did my best to design the project in a way that would increase the likelihood of my findings being used by the END Fund after my departure. First, as much as possible I involved END Fund management and staff in the design of the project. I waited to begin the research activities until receiving input from key staff and approval from the CEO. I also established the Systems Change Committee to provide ongoing input into the project and to allow me to leave the findings in the hands of people who had contributed to its execution and who had developed the capacity to use the systems thinking tools we have been practicing. I tried to build capacity for systems thinking among the rest of the END Fund staff through the initial series of workshops and through regular updates about the status of my project. I participated in an interview about systems change for NTDs for a book that the END Fund's CEO is writing. My thoughts and perhaps even direct quotes will be used in the final version of the book. Finally, I will submit my final report and present my finding and recommendations to management and the rest of the END Fund staff at a team retreat to be held towards the end of April 2018.

At the country level, I felt like my engagement with partners may have had at least a small impact on the Nigerian NTD program. For example, through the research process there were times when the END Fund grantee and state NTD coordinator accompanied me to interviews with people they had not met before

in the different communities. They used this opportunity to talk about the importance of NTD program and, in one case, made plans to attend a meeting with local school staff to discuss NTDs. In another example, I was introduced to the new national NTD program coordinator in Nigeria who was just starting in the position and who had little previous experience with the NTD program. He scheduled a meeting with me and asked me to share what I was learning in my research and make recommendations for what he should consider in his position as the national program coordinator. I was able to talk about some of the complexities of working on NTDs, and he listened carefully and took notes as I made suggestions on the issues that I later put into my qualitative model of the NTD system. I will be writing a research brief summarizing my findings and sharing it with the NTD program coordinator and the other Nigerian stakeholders, many of whom I interviewed.

In addition to my work directly with the END Fund and in Nigeria, I was able to engage with others and disseminate my approach and findings on the NTD system through various means over the course of my project. For example:

- In September 2017, I became a member (and will continue to participate in) the NNN Subcommittee on NTD Program Sustainability, a group for whom my findings will have direct relevance.
- In November 2017, I helped organize and spoke at a workshop on NTD Systems Change at the MIT Legatum Center for Development and Entrepreneurship.
- In January 2018, I published a blog post on the DrPH blog about Systems Change for NTDs.
- In February 2018, I organized and spoke about my project at a session called “System Mapping for Social Change” as part of the Harvard Social Enterprise Conference held at Harvard Business School.

- In April 2018, I will speak about the END Fund and my project for a global health seminar series at the pharmaceutical company, Novartis.

RESULTS

The deliverables for this phase will be completed over the next few months. These will include a final report and presentation for the END Fund, a research brief summarizing key findings for Nigeria, and a journal article. It is difficult to say at this point whether this process was effective and whether my findings and recommendations will be acted on by the END Fund or by anyone else within the NTD community. I felt throughout the project that I had support of the organization and that they were excited about the work I was doing. I also felt like I had many great opportunities to speak and write about my work with different audiences, including those interested in NTDs and those interested in systems change. I look forward to staying connected with the END Fund and continuing to engage with this topic as I move forward with my career.

F. Discussion

PROJECT IMPLICATIONS

This project was designed with the aim of drawing on a systems thinking approach to provide the END Fund with a better definition and understanding of the NTD system in which they operate and with recommendations they can incorporate into their work on NTD systems change. While the project evolved somewhat over the course of my work, I was able to maintain my focus on the original aim and deliver insights and recommendations to the END Fund that I believe will add significant value. In addition, I maintained regular engagement with a six-person team that contributed significantly to the project and is better prepared to carry forward our recommendations and continue using systems thinking to inform the END Fund's work. This project also helped clarify for the END Fund what they mean when they talk about systems change.

In seeking to provide the END Fund with a better understanding of the NTD system, this project helped to uncover some of the many complexities of eliminating NTDs that are often times ignored or brushed aside by the global NTD community. The degree to which stakeholders can ask and answer some of the hard questions raised –e.g., Why are important interventions being neglected? How is change being impeded because people are benefiting from the status quo? Are we being honest with ourselves and with donors about what is actually achievable? – may be a major factor contributing to the success or failure of NTD elimination efforts over the next five to ten years. Besides highlighting these important issues, this project made general recommendations for the NTD community on how to begin addressing them.

Many of the NTD issues raised here occur in similar ways within other areas of global health. For example, the issues of donor dependency and health systems strengthening vs vertical approaches have been discussed ad nauseam for decades. This paper brings new insights by highlighting the unintended consequences of different approaches, and it supports the argument made by others that a systems perspective has a lot to offer the field of global health.

The DrPH program and the DELTA project concept were created to help bridge the gap between research and practice in public health. This project was implemented precisely with that goal in mind. It demonstrated how research tools and methods can be used in an academically rigorous way to provide knowledge that is useful for a global health organization in a real-world context. It also showed how the enabling change competencies around management and leadership are essential to conducting academic research in a way that facilitates its use by an organization. Additionally, the project is based on an innovative conceptual framework rooted in systems thinking and complexity theory, which is one of the key “revolutions” that has been proposed as an essential driver of future progress in public health (Frenk, 2016).

Finally, similarly to public health, the field of systems thinking and systems change has long faced a significant gap between what is happening in academia and actual progress being made in the nonprofit sector and other real-world situations. This project offers a path forward by showing how some of the academic concepts and tools of systems thinking can be used in an understandable and actionable way that informs the strategy of change agents working on large scale systems change efforts to solve society's most complex challenges.

PROJECT CHALLENGES

I faced a number of challenges to achieving the original objectives of the project. Overall, I accomplished the research goals of better understanding the system and identifying levers for change. The main challenge I faced, which I quickly realized would be an issue, was that the relatively short project timeframe would not allow me to do everything I had proposed. For example, I had originally planned on looking closely at three countries rather than the one, Nigeria, which I ended up focusing on. I had also planned on applying a case study methodology to compare the field of NTDs with another area of global health, such as malaria, but I decided it would be better to concentrate on doing the other pieces as well as possible instead of adding additional research components.

Other challenges made the timeframe even tighter than I had expected. I had planned on starting the research much earlier in the project period and assumed I would be able to move forward as planned, but, shortly after I started working with the END Fund, I learned that they first wanted to better understand my approach and the expected benefit to the organization before allowing me to move forward with the research. This led to a series of meetings and trips during my first three months through which I fleshed out my research plan and sought buy-in from END Fund staff in order to get approval for moving forward with the research protocol. Another major delay came with the institutional review board (IRB) process in Nigeria. The review committee was being reorganized just as I

submitted my protocol for approval, which led to a major backlog and a period of uncertainty regarding whether the study would be approved in time for me to conduct the interviews.

As far as engagement and capacity building, working directly for the END Fund gave me access to the organization and many opportunities to engage internal stakeholders, which was the primary focus of this DELTA. However, one of the most challenging components of meeting the project objectives was engaging external stakeholders in the process and helping increase their capacity for systems thinking. I spoke with and received helpful input from a few external stakeholders at the global and country level during the project planning and research process, yet I was unable to accomplish my goal of having an external advisory board of global NTD organization representatives for the project. External people I spoke with all seemed genuinely interested in my work, but no one was invested enough to provide regular input, and, due in part to the time constraints and the inherent difficulty in engaging more people in the planning process, I did not put in the effort to engage people more thoroughly in the design of the study. At the country level, the two FMOH staff who agreed to serve as local investigators provided some input into the study itself and were critical in getting it through the approval process.

The project also fell short in the important task of convening stakeholders from many different perspectives to interpret the findings and collectively determine their implications for the work of the global NTD community. While I hope this important piece will happen after the project ends, again, the time constraint became the biggest limiting factor that prevented me from more fully accomplishing these objectives through stakeholder workshops and webinars as I had hoped I would be able to do.

Finally, a challenge that was always in the back of my mind related to the nature of my work as a type of disruptive influence in the NTD field. While I wanted to uncover systemic issues impeding NTD progress and raise hard questions that the NTD community needs to address, I also wanted to see the NTD programs continue to succeed because I believe the work being done is having a major impact on

improving people's lives. Thus, in a way, I faced the same challenge as those in the NTD community who are reluctant to address the adaptive challenges or to go on the record to discuss hard questions because of fear that donors will withdraw funding if things do not seem to be going perfectly. I struggled to find the right balance between being disruptive enough to be productive without throwing cold water on current efforts. While all the issues raised were mentioned by key actors in the system, the issues people were hesitant to speak openly about (e.g., whether the end goals are achievable if WASH and vector control keep being ignored) have the potential to make progress on NTDs appear slower than is often portrayed to donors. Although I decided not to hold back on discussing controversial issues in this thesis, this will definitely be a consideration as I move forward in writing and presenting about this topic.

RESEARCH LIMITATIONS

In addition to the challenges I faced, there are a number of limitations of the research component of the project that are important to note. First, an obvious limitation is that I was collecting and analyzing data by myself without the benefit of a team. This increases the risk of researcher bias and represents a threat to the validity of the findings. While I received input from my committee and from external and internal stakeholders, ideally, I would have worked more closely with other researchers to conduct the interviews and then iteratively code and analyze the transcripts in order to validate the findings. On a related note, another limitation is that I did not have the budget or the time to hire local interviewers who were aware of local contexts and spoke the local language that, in some cases, would have facilitated better communication and understanding during the interviews.

The fact that everyone who I interviewed knew I was affiliated with the END Fund was also likely a source of bias since many of the interviewees were funders or grantees of the END Fund. While I hope that I was as unbiased as possible in my analysis, my loyalty to the END Fund as my DELTA host organization may have influenced the lens through which I collected and analyzed data. This potential

conflict of interest is an inherent challenge in the DELTA project model and I know has been an issue in other DELTA projects.

Partially due to the time constraint and to the fact that I was largely working on my own, the number of and types of interviews I conducted is another study limitation. The goal of systems thinking is to elicit perspectives from as many stakeholders as possible that have an interest in a problem of interest. I was able to successfully get a number of perspectives from the global all the way down to the community levels, but I was unable to speak with everyone I would have liked to interview. For example, I focused my interviews primarily on stakeholders involved to some degree with program delivery while neglecting the research and development side. Similarly, it became increasingly clear to me that organizations focused on other health and development issues besides NTDs are critical stakeholders to addressing the problem of NTDs, especially in light of the ingrained patterns of siloes and competition that exist across these sectors. The fact that I did not include any of these people in my participant sample represents a major limitation to my study. Also, while I spoke with community health workers and CDDs in two communities in Nigeria, I did not actually include people with NTDs or non-health workers at-risk for NTDs as part of my sample. It is also important to point out that Nigeria is one of many countries affected by NTDs and each country and community faces a wide variety of unique challenges and issues that are obviously not covered by looking only at Nigeria as I did in this analysis.

With the survey, the obvious limitation is the low response rate of 37%. Since I did not get the 70-80% I was hoping for, it is doubtful that the survey findings reflect an accurate representation of the partnership structure of the global NTD network. I believe the response rate was low because I did not successfully communicate the potential value of the survey findings to targeted respondents and because, due again to time constraints and a focus on the qualitative component, I did not put in the effort to follow-up more with non-respondents and solicit help from the END Fund and others to increase the response rate. The survey design may have also been an issue as there were a few cases

where people looked at the survey and decided not to complete it because the questions were difficult given the nature of their organization. For example, while some NTD stakeholders are traditional organizations (e.g., NGOs, bilateral donors, etc.), others are multi-stakeholder coalitions, which makes it unclear which survey response they should use to characterize the nature of their relationship with the other NTD stakeholders when many of them are coalition members. I had originally planned to do the survey in Nigeria as well but decided not to, in part due to the issues I was facing at the global level.

REFLECTIONS ON ENABLING CHANGE

Research question 6 (What is an effective process for introducing a systems change approach into an organization?) was included as a research question to ensure that this thesis allocated sufficient attention to capturing the lessons learned about the process of enabling change in an actual organization. These lessons revolved around gaining a better understanding of the organization, designing the project in a way that is likely to facilitate change, and implementing the project in a way that puts into practice the enabling change competencies of management, leadership, and communication.

In the lead-up to my project and during the first few months after starting, I felt a critical success factor would be how well I could understand and then integrate myself into the END Fund organization. Becoming a central part of an organizational network has been shown as a critical factor for being a successful change agent (Battilana & Casciaro, 2013). One thing that made this challenging was the fact that I was primarily working remotely from Boston while the END Fund staff were based in New York City. Despite this, I tried my best to get to know everyone and learn about the organizational culture. My second week just happened to be a three-day staff retreat in North Carolina where we celebrated the END Fund's fifth anniversary while also having strategic planning discussions and engaging in team building activities. A few weeks later we had a follow-up staff retreat in New York City. I felt my

attendance at both of these events played an important role in the overall success of the project as I was able to develop personal relationships with my co-workers and understand how my project fit into the strategy of the organization. I was also able to discuss my project with many other staff members and get a sense for where I could add value.

Two other key steps I took at this stage of the project were to discuss with the END Fund CEO (who was also my DELTA supervisor) what other meetings I could attend to get a better sense of key issues the END Fund was facing. Especially since the DELTA project period was so short, I wanted to take advantage of every opportunity possible to understand the mission, vision, values, and strategic goals of the END Fund since this would be essential to developing useful recommendations. (Kaplan, Norton, David, & Barrows Jr., 2008). We decided that I should attend program team meetings and take advantage of other opportunities to meet with consultants and partners when important matters were being discussed. I also explicitly asked for regular check-in meetings with the CEO and Senior Vice President for Programs in order to discuss how the project was going and get their input on my findings and next steps. These meetings proved extremely valuable throughout the course of the DELTA.

I made a few observations about the organization through these interactions that I felt were important to designing and implementing my project in a way that would make it more likely to add value to the organization. First, at the time I started, the END Fund had just over 20 total staff members and I realized that it had a very flat organizational structure where even the newest, most junior level staff interacted regularly with senior leadership and had opportunities to contribute to the direction of the organization. I also observed that, while the CEO spoke regularly about “systems change” and was excited to bring me on as a Systems Change Fellow, among the rest of the staff there was some hesitancy around the use of these terms and what it actually meant for the END Fund.

In other conversations, I sensed some confusion about the nature of the DELTA project and whether my goal was to use the END Fund to do a research project for my thesis or whether the main objective was to do something valuable for the END Fund. I tried to make it clear in these conversations that I could write my thesis about whatever work I ended up doing during my time with the END Fund, even if it ended up deviating from the original project plan, but that my main goal was to try to apply my academic experience to a project that would add value to the END Fund's work. I felt this was an important realization for many of them and helped them see me more as a colleague and not just an outside researcher, which would be important for me to become an integrated part of the organization (Battilana & Casciaro, 2013).

A final important observation was that the END Fund staff all shared common values such as commitment, flexibility, and impact. These values helped catalyze the founders, many of whom are still involved with the END Fund and were at the staff retreat in North Carolina, to start the END Fund, and they are values that are communicated strongly to and adopted by new staff. This observation was important given the strong link that has been demonstrated between organizational values and successful change strategies (Amis, Slack, & Hinings, 2002).

These observations helped me recognize that I would need to build into my project ways to provide staff with a common foundation for thinking about systems change and ways to generate more understanding of and support for my work. This is what led to, as I mentioned earlier, my efforts to try to incorporate internal engagement in the project as much as possible through the series of systems change workshops and the forming of the Systems Change Committee. This helped staff understand my approach and allowed me to find people who were interested in this way of thinking about NTDs, with the objective being that these would be the people who could put into practice the recommendations that came as a result of our work. Whether this actually happens remains to be seen, but I am satisfied

with my attempt to do everything possible to design the project in a way that could introduce this systems change approach to the END Fund in an effective way.

Besides generating support from END Fund staff I felt it would be important to get buy-in for the project from other global and Nigerian stakeholders. Particularly at the country level, I was hesitant to try to come in as an outsider and expect to design and implement a study without local support. As Andrews et al. write, understanding the authorizing environment and securing the requisite authority to act are critical steps to successful project implementation (M. Andrews, Pritchett, & Woolcock, 2016). Thus, a couple of months into the project I spoke with the END Fund CEO and asked for help identifying opportunities for me to travel to Nigeria and potentially to other NTD meetings to get to know external stakeholders and understand more of their perspective as I was designing the study protocol. Together we made quick plans for me to travel to the Nigerian NTD Steering Committee meeting the following week and then to go straight from there to the NNN annual conference in Senegal. These meetings, especially the one in Nigeria, helped me begin to build relationships that would prove critical to completing the project. I was able to connect with two members of the Nigerian NTD Steering Committee who had previously completed fellowships at Harvard and were happy to provide guidance on the research process in Nigeria. I met the two FMOH staff who agreed to serve as local investigators and who shepherded the research protocol through the tedious IRB approval process. I also connected with the END Fund grantees who would eventually host me and arrange the logistics for my interviews at the state and local levels.

Finally, I learned a great deal from putting myself out on a limb at times and taking risks in order to make things happen. For example, as I was still waiting for IRB approval in Nigeria, I knew I had a very short window to make the trip before it would be too late to collect and analyze the data in time to finish the project as scheduled. I had a back-up plan to do the country case study based on a review of Nigerian NTD documents and plans, but I felt the country interviews were key to meeting the objectives

of the project. I continued to work with the local investigators for information on the IRB status and learned that they were going to great lengths to help, and, while they could not be sure, they expected the approval to come through in time. I decided to make my travel plans and arrange the interviews as if the approval would come through, and I was lucky to receive final approval the day I arrived in Nigeria.

One of the reasons the DELTA was a valuable learning experience was because it was not pre-planned by the organization as a "turnkey" project for which I just had to show up and do the work they instructed me to do. Fortunately for my learning experience, the END Fund provided me with the support and the freedom I needed to plan and execute the project that was interesting to me and that I thought would add value for them. One of the most important lessons I learned about leadership through this experience was, as many of the reflections in this section make clear, doing something new and difficult does not always come easy. It requires flexibility and learning and acting in the face of uncertainty (Heifetz et al., 2004; Kolb & Yeganeh, 2011). If I had taken the path of least resistance – e..g., not persisted in engaging END Fund staff, not asked for a chance to make the first trip to Nigeria, not taken the risk of booking my data collection trip before it was clear I would receive the necessary approval – I would not have learned as much, the project would have turned out very differently, and, I believe, would not have achieved the original aims and objectives.

IV. CONCLUSION

This project applied a five-phase systems thinking approach to better understand the complexities of addressing NTDs and to identify leverage points for change in order to provide actionable recommendations to the END Fund. Various research methods used included an extensive literature review, a series of in-depth key informant interviews that resulted in a qualitative causal loop diagram model of the NTD system, and a network survey with an accompanying social network analysis. An interactive process of workshops with END Fund staff was conducted in parallel with the mixed-methods research in order to build internal capacity for systems thinking and increase the likelihood that the recommendations would be carried forward following completion of the project.

While a number of complex issues were identified through the research process and discussed in detail in this thesis, recommendations were made around five primary levers for systems change: 1) clarify and assess the potential for elimination, 2) support interventions besides drug delivery, 3) reduce dependency on donors, 4) address the issue of health worker incentives, and 5) create a more inclusive global NTD community. In addition to specific recommendations made in each of these five areas, the project led to three general recommendations for the END Fund to enhance its systems change efforts across multiple levers by, 1) using grants to catalyze innovative approaches, 2) generating collective learning using systems thinking, and 3) exercising leadership by mobilizing the NTD community to address adaptive challenges.

This analysis is not meant to provide concrete, easy answers; rather it is intended to help the END Fund see the complexity and structure of the NTD system more clearly in order to raise questions that can encourage stakeholders to work together towards joint solutions. These findings raise a number of hard questions that have not been addressed, at least in part, because it is much easier to continue focusing on “quick win” solutions that appeal to donors. Systems change in complex social systems can only be

achieved through collaboration that generates learning. The END Fund has both the status and flexibility required to push the rest of the community to deal with the challenging issues surfaced here in order to generate learning around more sustainable solutions for NTDs.

Rather than build a model that represents the truth of how the system functions, the goal of the qualitative modeling approach is to highlight different perspectives that stakeholders within the system believe are true. Systems thinking suggests that these perspectives are important to raise because at least some stakeholders see them as key barriers to progress, but the analysis conducted here does not claim to understand the degree to which they represent actual problems. Thus, each of the leverage points highlighted in this thesis merit further consideration and research. For example, the issue of health worker incentives is perceived to be a major obstacle to progress in Nigeria, but my analysis is unable to assess how this issue is actually impacting NTD programs on the ground. This is an important research question that could have a big influence on the success of future NTD control and elimination efforts. Another critical area for future research identified by multiple respondents is understanding in greater detail the determinants of national and local political priority and commitment in endemic countries. My research highlights a few key factors about which interviewees speculated, but this is clearly an important area where critical gaps in knowledge remain.

Finally, there is a dearth of evidence in the systems change literature of successful examples of prospective systems change approaches applied to complex social problems. This thesis provides documentation around one example that uses academically rigorous mixed-methods research with best practices around systems change group processes to identify levers for change. A next step, and one for which documented examples from both the academic and practice sectors are badly needed, is to conduct rigorous assessments of the process and outcomes of collective efforts to implement these types of recommendations. Such research should attempt to track ways systems actually change as well as ways that stakeholders' mental models and perspectives change throughout the process. While large

scale social change will almost always be a difficult and lengthy pursuit, more robust evidence around successful and failed attempts to apply systems thinking approaches would be a valuable contribution to the field.

V. BIBLIOGRAPHY

Abercrombie, R., Harries, E., & Wharton, R. (2015). *Systems change: A guide to what it is and how to do it*. London.

Abt Associates. (2014). *Refining NTD Funding Gap Analysis*. Retrieved from http://unitingtocombatntds.org/wp-content/uploads/2017/11/resources_needed.pdf

Adam, T., & De Savigny, D. (2012). Systems thinking for strengthening health systems in LMICs: Need for a paradigm shift. *Health Policy and Planning*, *27*(SUPPL. 4), 2006–2008. https://doi.org/10.1093/heapol/czs084

Allen, T., & Parker, M. (2011). The "other diseases" of the millennium development goals: Rhetoric and reality of free drug distribution to cure the poor's parasites. *Third World Quarterly*, *32*(1), 91–117. https://doi.org/10.1080/01436597.2011.543816

Allen, T., & Parker, M. (2012). Will increased funding for neglected tropical diseases really make poverty history? *The Lancet*, *379*(9821), 1097–1098. https://doi.org/10.1016/S0140-6736(12)60159-7

Allen, T., & Parker, M. (2016). DEWORMING DELUSIONS? MASS DRUG ADMINISTRATION in EAST AFRICAN SCHOOLS. *Journal of Biosocial Science*, *48*(S1), S116–S147. https://doi.org/10.1017/S0021932016000171

Allen, W. (2016). Complicated or complex - knowing the difference is important - Learning for Sustainability. Retrieved February 1, 2018, from http://learningforsustainability.net/post/complicated-complex/

Allotey, P., Reidpath, D. D., & Pokhrel, S. (2010). Social sciences research in neglected tropical diseases 1: The ongoing neglect in the neglected tropical diseases. *Health Research Policy and Systems*, *8*, 1–8. https://doi.org/10.1186/1478-4505-8-32

Amis, J., Slack, T., & Hinings, C. R. (2002). Values and Organizational Change. *The Journal of Applied Behavioral Science*, *38*(4), 436–465. https://doi.org/10.1177/002188602237791

Andrews, J. R., Bogoch, I. I., & Utzinger, J. (2017). The benefits of mass deworming on health outcomes: new evidence synthesis, the debate persists. *The Lancet Global Health*, *5*(1), e4–e5. https://doi.org/10.1016/S2214-109X(16)30333-3

Andrews, M., Pritchett, L., & Woolcock, M. (2016). *Managing Your Authorizing Environment in a PDIA Process | Building State Capability*. Retrieved from https://bsc.cid.harvard.edu/publications/managing-your-authorizing-environment-pdia-process

Argyris, C., & Schön, D. A. (1996). *Organizational Learning II: Theory, method, and practice*. *Theory method and practice*.

Atun, R. (2012). Health systems, systems thinking and innovation. *Health Policy and Planning*,

27(SUPPL. 4), 4–8. https://doi.org/10.1093/heapol/czs088

Balabanova, D., McKee, M., Mills, A., Walt, G., & Haines, A. (2010). Review What can global health institutions do to help strengthen health systems in low income countries?, 1–11.

Bangert, M., Molyneux, D. H., Lindsay, S. W., Fitzpatrick, C., & Engels, D. (2017). The cross-cutting contribution of the end of neglected tropical diseases to the sustainable development goals. *Infectious Diseases of Poverty*, *6*(1), 1–20. https://doi.org/10.1186/s40249-017-0288-0

Battilana, J., & Casciaro, T. (2013). The network secrets of great change agents. *Harvard Business Review*, *91*(7–8).

Béhague, D. P., & Storeng, K. T. (2008). Collapsing the vertical-horizontal divide: An ethnographic study of evidence-based policymaking in maternal health. *American Journal of Public Health*, *98*(4), 644–649. https://doi.org/10.2105/AJPH.2007.123117

Birney, A. (2013). A "How To" For System Innovation - A Starting Place for Practitioners. *Systemic Innovation: A Discussion Series*, (April), 7–9. Retrieved from http://www.nesta.org.uk/sites/default/files/systemic_innovation.pdf

Birney, A. (2014). *Cultivating System Change: A Practitioner's Companion*. Oxford: Do Sustainability.

Briggs, C., & Garner, P. (2006). Strategies for integrating primary health services in low- and middle-income countries at the point of delivery. *The Cochrane Database of Systematic Reviews*, *CD003318*(2), CD003318. https://doi.org/10.1002/14651858.CD003318.pub3

Brownson, R. C., Parra, D. C., Dauti, M., Harris, J. K., Hallal, P. C., Hoehner, C., … Pratt, M. (2010). Assembling the Puzzle for Promoting Physical Activity in Brazil: A Social Network Analysis. *Journal of Physical Activity and Health*, *7*(s2), S242–S252. https://doi.org/10.1123/jpah.7.s2.s242

Bump, J. B., Reich, M. R., & Johnson, A. M. (2013). Diarrhoeal diseases and the global health agenda: Measuring and changing priority. *Health Policy and Planning*, *28*(8), 799–808. https://doi.org/10.1093/heapol/czs119

Buse, K., & Walt, G. (2000). Global public-private partnerships: Part I--A new development in health? *Bulletin of the World Health Organization*, *78*(4), 549–561. https://doi.org/10.1590/S0042-96862000000500015

Bush, S., & Hopkins, A. D. (2011). Public-private partnerships in neglected tropical disease control: The role of nongovernmental organisations. *Acta Tropica*, *120*(SUPPL. 1), 169–172. https://doi.org/10.1016/j.actatropica.2011.01.011

Cairncross, S., Periès, H., & Cutts, F. (1997). Vertical health programmes. *The Lancet*, *349*, S20–S21. https://doi.org/10.1016/S0140-6736(97)90079-9

Campbell, S. J., Biritwum, N. K., Woods, G., Velleman, Y., Fleming, F., & Stothard, J. R. (2017). Tailoring Water, Sanitation, and Hygiene (WASH) Targets for Soil-Transmitted

Helminthiasis and Schistosomiasis Control. *Trends in Parasitology*, *34*(1), 53–63. https://doi.org/10.1016/j.pt.2017.09.004

Cavalli, A., Bamba, S. I., Traore, M. N., Boelaert, M., Coulibaly, Y., Polman, K., … van Dormael, M. (2010). Interactions between global health initiatives and country health systems: The case of a neglected tropical diseases control program in mali. *PLoS Neglected Tropical Diseases*, *4*(8). https://doi.org/10.1371/journal.pntd.0000798

Cavana, R. Y., & Maani, K. E. (2000). A Methodological Framework for Systems Thinking and Modelling (ST&M) Interventions. *1st International Conference on Systems Thinking in Management*, 136–141. https://doi.org/10.13140/2.1.3051.3609

Checkland, P. (1981). *Systems Thinking, Systems Practice*. *Systems Thinking Systems Practice*. https://doi.org/10.1016/0143-6228(82)90039-X

Checkland, P. (2011). Systems thinking and soft systems methodology. *The Oxford Handbook of Management Information Systems*, (May), 87–112. https://doi.org/10.1093/oxfordhb/9780199580583.003.0006

Cohen, J. P., Silva, L., Cohen, A., Awatin, J., & Sturgeon, R. (2016). Progress Report on Neglected Tropical Disease Drug Donation Programs. *Clinical Therapeutics*, *38*(5), 1193–1204. https://doi.org/10.1016/j.clinthera.2016.02.031

Collins, K. L. (2004). Profitable Gifts: A History of the Merck Mectizan Donation Program and Its Implications for International Health Profitable Gifts. *Perspectives in Biology and Medicine*, *47*(1), 100–109. https://doi.org/10.1353/pbm.2004.0004

Croke, K., Hicks, J. H., Hsu, E., Kremer, M., & Miguel, E. (2017). Should the WHO withdraw support for mass deworming? *PLoS Neglected Tropical Diseases*, *11*(6), 2015–2017. https://doi.org/10.1371/journal.pntd.0005481

Cross, C., Olamiju, F., Richards, F., Bush, S., Hopkins, A., & Haddad, D. (2015). From River Blindness to Neglected Tropical Diseases—Lessons Learned in Africa for Programme Implementation and Expansion by the Non-governmental Partners. *PLoS Neglected Tropical Diseases*, *9*(5), 1–10. https://doi.org/10.1371/journal.pntd.0003506

Das, J. K., Salam, R. A., Arshad, A., Maredia, H., & Bhutta, Z. A. (2014). Community based interventions for the prevention and control of Non-Helmintic NTD. *Infectious Diseases of Poverty*, *3*(1), 24. https://doi.org/10.1186/2049-9957-3-24

Dean, L., Page, S., Hawkins, K., Stothard, R., Thomson, R., Wanji, S., … Theobald, S. (2016). Tailoring mass drug administration to context: Implementation research is critical in achieving equitable progress in the control and elimination of helminth neglected tropical diseases in sub-Saharan Africa. *International Health*, *8*(4), 233–234. https://doi.org/10.1093/inthealth/ihw031

Eigege, A., Evans, D. S., Noland, G. S., Davies, E., Umaru, J., Adelamo, S. E., … Richards, F. O. (2017). Criteria to stop mass drug administration for lymphatic filariasis have been achieved throughout plateau and Nasarawa States, Nigeria. *American Journal of Tropical*

Medicine and Hygiene, *97*(3), 677–680. https://doi.org/10.4269/ajtmh.16-0843

Engels, D. (2016). Neglected tropical diseases in the Sustainable Development Goals. *The Lancet*, *387*(10015), 223–224. https://doi.org/10.1016/S0140-6736(16)00043-X

Federal Ministry of Health Nigeria. (2012). *Nigeria Master Plan for Neglected Tropical Diseases 2013 - 2017*. Abuja.

Fenwick, A., & Jourdan, P. (2016). Schistosomiasis elimination by 2020 or 2030? *International Journal for Parasitology*, *46*(7), 385–388. https://doi.org/10.1016/j.ijpara.2016.01.004

Foster-Fishman, P. G., Nowell, B., & Yang, H. (2007). Putting the system back into systems change: A framework for understanding and changing organizational and community systems. *American Journal of Community Psychology*, *39*(3–4), 197–215. https://doi.org/10.1007/s10464-007-9109-0

Frenk, J. (2010). The global health system: Strengthening national health systems as the next step for global progress. *PLoS Medicine*, *7*(1), 2008–2010. https://doi.org/10.1371/journal.pmed.1000089

Frenk, J. (2016). The Empowering Legacy of Academic Public Health. *Public Health Reports*, *131*(6), 851–854. https://doi.org/10.1177/0033354916668542

Frenk, J., & Moon, S. (2013). Governance Challenges in Global Health. *New England Journal of Medicine*, *368*(10), 936–942. https://doi.org/10.1056/NEJMra1109339

Fürst, T., Salari, P., Llamas, L. M., Steinmann, P., Fitzpatrick, C., & Tediosi, F. (2017). Global health policy and neglected tropical diseases: Then, now, and in the years to come. *PLoS Neglected Tropical Diseases*, *11*(9). https://doi.org/10.1371/journal.pntd.0005759

Glouberman, S., Ph, D., & Zimmerman, B. (2002). *Complicated and Complex Systems : What Would Successful Reform of Medicare Look Like ?* https://doi.org/0-662-32778-0

Gounder, C. (1998). The progress of the Polio Eradication Initiative: What prospects for eradicating measles? *Health Policy and Planning*. https://doi.org/10.1093/heapol/13.3.212

Grépin, K. A., & Reich, M. R. (2008). Conceptualizing integration: A framework for analysis applied to neglected tropical disease control partnerships. *PLoS Neglected Tropical Diseases*, *2*(4), 2–5. https://doi.org/10.1371/journal.pntd.0000174

Gustavsen, K., & Hanson, C. (2009). Progress in public-private partnerships to fight neglected diseases. *Health Affairs*, *28*(6), 1745–1749. https://doi.org/10.1377/hlthaff.28.6.1745

Gyapong, J. O., Gyapong, M., Yellu, N., Anakwah, K., Amofah, G., Bockarie, M., & Adjei, S. (2010). Integration of control of neglected tropical diseases into health-care systems: challenges and opportunities. *The Lancet*, *375*(9709), 160–165. https://doi.org/10.1016/S0140-6736(09)61249-6

Haddad, D. (2008). The NGDO Co-ordination Group for Onchocerciasis Control. *Annals of Tropical Medicine & Parasitology*, *102*(sup1), 35–38.

https://doi.org/10.1179/136485908X337472

Hanson, C., Weaver, A., Zoerhoff, K. L., Kabore, A., Linehan, M., Doherty, A., … Ottesen, E. A. (2012). Integrated implementation of programs targeting neglected tropical diseases through preventive chemotherapy: Identifying best practices to roll out programs at national scale. *American Journal of Tropical Medicine and Hygiene*, *86*(3), 508–513. https://doi.org/10.4269/ajtmh.2012.11-0589

Harris, J. K., Luke, D. A., Burke, R. C., & Mueller, N. B. (2008). Seeing the forest and the trees: Using network analysis to develop an organizational blueprint of state tobacco control systems. *Social Science and Medicine*, *67*(11), 1669–1678. https://doi.org/10.1016/j.socscimed.2008.07.013

Heifetz, R. A. (1994). *Leadership without easy answers*. Belknap Press of Harvard University Press. Retrieved from https://books.google.com.ng/books/about/Leadership_Without_Easy_Answers.html?id=B991NiiS9GcC&redir_esc=y

Heifetz, R. A., Kania, J. V., & Kramer, M. R. (2004). Leading boldly. *Stanford Social Innovation Review*, (Winter), 20–31. Retrieved from http://ezproxy.cul.columbia.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=sih&AN=15790653&site=ehost-live&scope=site

Hill, P. S. (2011). Understanding global health governance as a complex adaptive system. *Global Public Health*, *6*(6), 593–605. https://doi.org/10.1080/17441691003762108

Hirsch, G., Homer, J., Evans, E., & Zielinski, A. (2010). A system dynamics model for planning cardiovascular disease interventions. *American Journal of Public Health*, *100*(4), 616–622. https://doi.org/10.2105/AJPH.2009.159434

Homer, J. B., & Hirsch, G. B. (2006). System dynamics modeling for public health: Background and opportunities. *American Journal of Public Health*, *96*(3), 452–458. https://doi.org/10.2105/AJPH.2005.062059

Honeycutt, T. C., & Strong, D. A. (2012). Using social network analysis to predict early collaboration within health advocacy coalitions. *American Journal of Evaluation*, *33*(2), 221–239. https://doi.org/10.1177/1098214011424201

Hopkins, D. R. (2009). The Allure of Eradication. *Global Health Magazine*, (3), 8–11.

Hopkins, D. R., Richards, F. O., & Katabarwa, M. (2005). Editorial Whither Onchocerciasis Control in Africa ?, *72*(1), 1–2.

Hotez, P. J., & American Society for Microbiology. (2013). *Forgotten people, forgotten diseases : the neglected tropical diseases and their impact on global health and development*. ASM Press.

Hotez, P. J., Damania, A., & Naghavi, M. (2016). Blue Marble Health and the Global Burden of Disease Study 2013. *PLoS Neglected Tropical Diseases*, *10*(10), 6–11.

https://doi.org/10.1371/journal.pntd.0004744

Hotez, P. J., Fenwick, A., Savioli, L., & Molyneux, D. H. (2009). Rescuing the bottom billion through control of neglected tropical diseases. *The Lancet*, *373*(9674), 1570–1575. https://doi.org/10.1016/S0140-6736(09)60233-6

Hotez, P. J., Molyneux, D. H., Fenwick, A., Kumaresan, J., Sachs, S. E., Sachs, J. D., & Savioli, L. (2007). Control of Neglected Tropical Diseases. *The New England Journal of Medicine*, *357*, 1018–1027. https://doi.org/10.1056/NEJMra064142

Hotez, P., Ottesen, E., Fenwick, A., & Molyneux, D. (2006). The neglected tropical diseases: The ancient afflictions of stigma and poverty and the prospects for their control and elimination. *Advances in Experimental Medicine and Biology*. https://doi.org/10.1007/0-387-33026-7_3

Humphries, D., Nguyen, S., Boakye, D., Wilson, M., & Cappello, M. (2012). The promise and pitfalls of mass drug administration to control intestinal helminth infections. *Current Opinion in Infectious Diseases*, *25*(5), 584–589. https://doi.org/10.1097/QCO.0b013e328357e4cf

Iltis, A. S., & Matthews, K. R. W. (2017). NTD policy priorities: Science, values, and agenda setting. *PLoS Neglected Tropical Diseases*, *11*(5), 2–5. https://doi.org/10.1371/journal.pntd.0005431

IOM (Institute of Medicine). (2011). *The Causes and Impacts of Neglected Tropical and Zoonotic Diseases : Opportunities for Integrated Intervention Strategies: Workshop Summary*. *Nature*. https://doi.org/10.17226/13087

Jacobson, J., & Bush, S. (2017). Neglected Tropical Diseases, Neglected Communities, and Conflict: How Do We Leave No One Behind? *Trends in Parasitology*, *xx*, 1–3. https://doi.org/10.1016/j.pt.2017.10.013

Jones, A. P., Homer, J. B., Murphy, D. L., Essien, J. D. K., Milstein, B., Seville, D. A., & Barnes, K. (2006). Understanding diabetes population dynamics through simulation modeling and experimentation. *American Journal of Public Health*, *96*(3), 488–494. https://doi.org/10.2105/AJPH.2005.063529

Kabatereine, N. B., Malecela, M., Lado, M., Zaramba, S., Amiel, O., & Kolaczinski, J. H. (2010). How to (or not to) integrate vertical programmes for the control of major neglected tropical diseases in Sub-Saharan Africa. *PLoS Neglected Tropical Diseases*, *4*(6), 1–8. https://doi.org/10.1371/journal.pntd.0000755

Kaplan, R. S., Norton, David, P., & Barrows Jr., E. (2008). Developing the Strategy : Vision , Value Gaps , and Analysis. *Harvard Business Publishing*, *10*(1), 1–16.

Kassebaum, N. J., Arora, M., Barber, R. M., Bhutta, Z. A., Brown, J., Carter, A., … Murray, C. J. L. (2016). Global, regional, and national disability-adjusted life-years (DALYs) for 315 diseases and injuries and healthy life expectancy (HALE), 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. *The Lancet*, *388*(10053), 1603–1658.

https://doi.org/10.1016/S0140-6736(16)31460-X

Kickbusch, I. (2005). Action on global health: Addressing global health governance challenges. *Public Health*, *119*(11), 969–973. https://doi.org/10.1016/j.puhe.2005.08.008

Kim, D. H. (1994). *Systems Thinking Tools: A User's Guide*. Pegasus Communications Inc.

Kim, D. H. (1999). *Introduction to Systems Thinking*. Pegasus Communications Inc. Retrieved from http://www.thinking.net/Systems_Thinking/Intro_to_ST/intro_to_st.html

King, C. H. (2017). The evolving schistosomiasis agenda 2007-2017—Why we are moving beyond morbidity control toward elimination of transmission. *PLoS Neglected Tropical Diseases*, *11*(4), 2–5. https://doi.org/10.1371/journal.pntd.0005517

Kingdon, J. W., & Thurber, J. A. (1984). *Agendas, alternatives, and public policies*. Boston: Little, Brown.

Kirby, T. (2010). David Molyneux: raising the profile of neglected tropical diseases. *The Lancet*, *375*(9708), 21. https://doi.org/10.1016/S0140-6736(09)62174-7

Kirsch, V., Bildner, J., & Walker, J. (2016). Why Social Ventures Need Systems Thinking. *Harvard Business Review*. Retrieved from https://hbr.org/2016/07/why-social-ventures-need-systems-thinking

Knaul, F. M., Bhadelia, A., Atun, R., & Frenk, J. (2015). Achieving effective universal health coverage dnd diagonal approaches to care for chronic illnesses. *Health Affairs*, *34*(9), 1514–1522. https://doi.org/10.1377/hlthaff.2015.0514

Kolb, D., & Yeganeh, B. (2011). *Deliberate Experiential Learning*. Retrieved from https://weatherhead.case.edu/departments/organizational-behavior/workingPapers/WP-11-02.pdf

Kruk, M. E. (2012). Globalisation and global health governance: Implications for public health. *Global Public Health*, *7*(SUPPL. 1). https://doi.org/10.1080/17441692.2012.689313

Lar, L. A., Oluwole, A. S., Okoko, O. O., Igbe, M. A., Bernsah, L. D., Salami, Kabiru, K., … Adekeye, O. B. (2017). *A Situatonal Analysis of the Neglected Tropical Disease Programme in Nigeria: A Case Study of Ogun and Kaduna States*.

Leischow, S. J., & Milstein, B. (2006). Systems Thinking and Modeling for Public Health Practice. *American Journal of Public Health*, *96*(3), 403–405.

Leonard, H. (2006). *Note on Strategy*.

Levy, D. T., Bauer, J. E., & Lee, H. R. (2006). Simulation modeling and tobacco control: Creating more robust public health policies. *American Journal of Public Health*, *96*(3), 494–498. https://doi.org/10.2105/AJPH.2005.063974

Liese, B. H., Houghton, N., & Teplitskaya, L. (2014). Development assistance for neglected tropical diseases: Progress since 2009. *International Health*, *6*(3), 162–171. https://doi.org/10.1093/inthealth/ihu052

Liese, B., Rosenberg, M., & Schratz, A. (2010). Programmes, partnerships, and governance for elimination and control of neglected tropical diseases. *The Lancet*, *375*(9708), 67–76. https://doi.org/10.1016/S0140-6736(09)61749-9

Linehan, M., Hanson, C., Weaver, A., Baker, M., Kabore, A., Zoerhoff, K. L., … Ottesen, E. A. (2011). Integrated implementation of programs targeting neglected tropical diseases through preventive chemotherapy: Proving the feasibility at national scale. *American Journal of Tropical Medicine and Hygiene*, *84*(1), 5–14. https://doi.org/10.4269/ajtmh.2011.10-0411

Love, C., & Sinha, R. (2015). Bringing an Entrepreneurial Mindset to the World's Failing Systems. *Harvard Business Review*. Retrieved from https://hbr.org/2015/02/bringing-an-entrepreneurial-mindset-to-the-worlds-failing-systems

Luke, D. A., & Harris, J. K. (2007). Network Analysis in Public Health: History, Methods, and Applications. *Annual Review of Public Health*, *28*(1), 69–93. https://doi.org/10.1146/annurev.publhealth.28.021406.144132

Macpherson, E. E., Adams, E. R., Bockarie, M. J., Hollingsworth, T. D., Kelly-Hope, L. A., Lehane, M., … Torr, S. J. (2015). Mass Drug Administration and beyond: How can we strengthen health systems to deliver complex interventions to eliminate neglected tropical diseases? *BMC Proceedings*, *9*(Suppl 10), S7. https://doi.org/10.1186/1753-6561-9-S10-S7

Marchal, B., Van Dormael, M., Pirard, M., Cavalli, A., Kegels, G., & Polman, K. (2011). Neglected tropical disease (NTD) control in health systems: The interface between programmes and general health services. *Acta Tropica*, *120*(SUPPL. 1). https://doi.org/10.1016/j.actatropica.2011.02.017

Maxwell, J. A. (2013). Qualitative research design: An interactive approach. *Qualitative Research Design: An Interactive Approach*, 218. https://doi.org/10.1007/s13398-014-0173-7.2

Meadows, D. (2008). *Thinking in systems – a primer*. *Environmental Politics* (Vol. 20). London: Earthscan. https://doi.org/10.1080/09644016.2011.589585

Meadows, D., & Sustainability Institute. (1999). Leverage Points: Places to Intervene in a System. *World*, 1–12. https://doi.org/10.1080/02604020600912897

Means, A. R., Jacobson, J., Mosher, A. W., & Walson, J. L. (2016). Integrated Healthcare Delivery: A Qualitative Research Approach to Identifying and Harmonizing Perspectives of Integrated Neglected Tropical Disease Programs. *PLoS Neglected Tropical Diseases*, *10*(10), 1–27. https://doi.org/10.1371/journal.pntd.0005085

Meheus, F., Rijal, S., Lutumba, P., Hendrickx, D., & Boelaert, M. (2012). NTD control and health system strengthening. *The Lancet*, *379*(9832), 2149–2150. https://doi.org/10.1016/S0140-6736(12)60943-X

Michael, E., & Madon, S. (2017). Socio-ecological dynamics and challenges to the governance of Neglected Tropical Disease control. *Infectious Diseases of Poverty*, *6*(1), 1–13.

https://doi.org/10.1186/s40249-016-0235-5

Midgley, G. (2000). *Systemic Intervention : Philosophy , Methodology and Practice*. New York: Kluwer. https://doi.org/10.1007/978-1-84996-125-7

Mikkelsen-Lopez, I., Wyss, K., de Savigny, D., Feachem, R., Yamey, G., Schrade, C., … Menabde, N. (2011). An approach to addressing governance from a health system framework perspective. *BMC International Health and Human Rights*, *11*(1), 13. https://doi.org/10.1186/1472-698X-11-13

Mills, A. (1983). Vertical vs horizontal health programmes in Africa: Idealism, pragmatism, resources and efficiency. *Social Science and Medicine*, *17*(24), 1971–1981. https://doi.org/10.1016/0277-9536(83)90137-5

Mills, A. (2005). Mass campaigns versus general health services: What have we learnt in 40 years about vertical versus horizontal approaches? *Bulletin of the World Health Organization*, *83*(4), 315–316. https://doi.org//S0042-96862005000400017

Molyneux, D. H. (2010). Neglected tropical diseases-beyond the tipping point? *The Lancet*, *375*(9708), 3–4. https://doi.org/10.1016/S0140-6736(09)61914-0

Molyneux, D. H. (2014). Neglected tropical diseases: Now more than just “other diseases”- the post-2015 agenda. *International Health*, *6*(3), 172–180. https://doi.org/10.1093/inthealth/ihu037

Molyneux, D. H., Hotez, P. J., & Fenwick, A. (2005). “Rapid-impact interventions”: How a policy of integrated control for Africa’s neglected tropical diseases could benefit the poor. *PLoS Medicine*, *2*(11), 1064–1070. https://doi.org/10.1371/journal.pmed.0020336

Molyneux, D. H., & Malecela, M. N. (2011). Neglected tropical diseases and the millennium development goals-why the “other diseases” matter: Reality versus rhetoric. *Parasites and Vectors*, *4*(1), 1–13. https://doi.org/10.1186/1756-3305-4-234

Molyneux, D. H., Savioli, L., & Engels, D. (2017). Neglected tropical diseases: progress towards addressing the chronic pandemic. *The Lancet*, *389*(10066), 312–325. https://doi.org/10.1016/S0140-6736(16)30171-4

Molyneux, D., Malecela, M., Savioli, L., Fenwick, A., & Hotez, P. (2012). Will increased funding for neglected tropical diseases really make poverty history? – Authors’ reply. *The Lancet*, *379*(9821), 1098–1100. https://doi.org/10.1016/S0140-6736(12)60454-1

Morecroft, J. (2010). System Dynamics. In M. Reynolds & S. Holwell (Eds.), *Systems Approaches to Managing Change: A Practical Guide* (pp. 25–85). https://doi.org/10.1007/978-1-84882-809-4

Murray, C. J. L., Vos, T., Lozano, R., Naghavi, M., Flaxman, A. D., Michaud, C., … Lopez, A. D. (2012). Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: A systematic analysis for the Global Burden of Disease Study 2010. *The Lancet*, *380*(9859), 2197–2223. https://doi.org/10.1016/S0140-6736(12)61689-4

Musgrove, P., & Hotez, P. J. (2009). Turning neglected tropical diseases into forgotten maladies. *Health Affairs*, *28*(6), 1691–1706. https://doi.org/10.1377/hlthaff.28.6.1691

Mutale, W., Balabanova, D., Chintu, N., Mwanamwenge, M. T., & Ayles, H. (2016). Application of system thinking concepts in health system strengthening in low-income settings: A proposed conceptual framework for the evaluation of a complex health system intervention: The case of the BHOMA intervention in Zambia. *Journal of Evaluation in Clinical Practice*, *22*(1), 112–121. https://doi.org/10.1111/jep.12160

National Cancer Institute. (2007). *Greater Than the Sum: Systems Thinking in Tobacco Control*. *Tobacco Control Monograph No. 18.* Retrieved from http://scholar.google.com/scholar?hl=en&btnG=Search&q=intitle:Greater+Than+the+Sum:+Systems+Thinking+in+Tobacco+Control#0

Nelson, J., & Jenkins, B. (2016). *TACKLING GLOBAL CHALLENGES: Lessons in System Leadership from the World Economic Forum's New Vision for Agriculture Initiative*. Retrieved from https://www.hks.harvard.edu/sites/default/files/centers/mrcbg/files/NVAReport.pdf

Oliveira-Cruz, V., Kurowski, C., & Mills, A. (2003). Delivery of priority health services: Searching for synergies within the vertical versus horizontal debate. *Journal of International Development*, *15*(1), 67–86. https://doi.org/10.1002/jid.966

Ooms, G., Van Damme, W., Baker, B. K., Zeitz, P., & Schrecker, T. (2008). The "diagonal" approach to Global Fund financing: A cure for the broader malaise of health systems? *Globalization and Health*, *4*, 1–7. https://doi.org/10.1186/1744-8603-4-6

Ortu, G., & Williams, O. (2017). Neglected tropical diseases: Exploring long term practical approaches to achieve sustainable disease elimination and beyond. *Infectious Diseases of Poverty*, *6*(1), 1–12. https://doi.org/10.1186/s40249-017-0361-8

Parker, M., & Allen, T. (2011). Does mass drug administration for the integrated treatment of neglected tropical diseases really work? Assessing evidence for the control of schistosomiasis and soil-. *Health Research Policy and Systems*, 1–20. Retrieved from https://scholar.google.co.uk/citations?view_op=view_citation&continue=/scholar%3Fhl%3Den%26start%3D479%26as_sdt%3D0,5%26scilib%3D1&citilm=1&citation_for_view=DcFDIxgAAAAJ:mB3voiENLucC&hl=en&oi=p

Parker, M., & Allen, T. (2013). Will mass drug administration eliminate lymphatic filariasis? evidence from northern coastal tanzania. *Journal of Biosocial Science*, *45*(4), 517–545. https://doi.org/10.1017/S0021932012000466

Parker, M., & Allen, T. (2014). De-Politicizing Parasites: Reflections on Attempts to Control the Control of Neglected Tropical Diseases. *Medical Anthropology: Cross Cultural Studies in Health and Illness*, *33*(3), 223–239. https://doi.org/10.1080/01459740.2013.831414

Parra, D. C., Dauti, M., Harris, J. K., Reyes, L., Malta, D. C., Brownson, R. C., … Pratt, M. (2011). How does network structure affect partnerships for promoting physical activity? Evidence from Brazil and Colombia. *Social Science & Medicine*, *73*(9), 1365–1370.

https://doi.org/10.1016/j.socscimed.2011.08.020

Peters, D. H. (2014). The application of systems thinking in health: Why use systems thinking? *Health Research Policy and Systems*, *12*(1), 1–6. https://doi.org/10.1186/1478-4505-12-51

Porter, M. E., & Roach, S. S. (1996). What is Strategy? *Harvard Business Review*, 1–20. https://doi.org/10.1016/j.cell.2005.09.009

Pritchett, L. (2012). Folk and the Formula: Fact and Fiction in Development. In *WIDER Annual Lecture*.

Provan, K. G., Veazie, M. A., Staten, L. K., & Teufel-Shone, N. I. (2005). The use of network analysis to strengthen community partnerships. *Public Administration Review*. https://doi.org/10.1111/j.1540-6210.2005.00487.x

Reidpath, D. D., Allotey, P., & Pokhrel, S. (2011). Social sciences research in neglected tropical diseases 2: A bibliographic analysis. *Health Research Policy and Systems*, *9*, 1–12. https://doi.org/10.1186/1478-4505-9-1

Rollinson, D., Knopp, S., Levitz, S., Stothard, J. R., Tchuem Tchuenté, L. A., Garba, A., … Utzinger, J. (2013). Time to set the agenda for schistosomiasis elimination. *Acta Tropica*, *128*(2), 423–440. https://doi.org/10.1016/j.actatropica.2012.04.013

Ross, A. G. P., Olveda, R. M., & Li, Y. (2015). An audacious goal: The elimination of schistosomiasis in our lifetime through mass drug administration. *The Lancet*, *385*(9983), 2220–2221. https://doi.org/10.1016/S0140-6736(14)61417-3

Rotondo, L. A., Harrison, W., Bush, S., Hopkins, A. D., & Koporc, K. (2015). The Neglected Tropical Disease Non-governmental Development Organization Network (NNN): The value and future of a global network aiming to control and eliminate NTDs. *International Health*, *8*(Suppl 1), i4–i6. https://doi.org/10.1093/inthealth/ihw004

Roussos, S. T., & Fawcett, S. B. (2000). A Review of Collaborative Partnerships as a Strategy for Improving Community Health. *Annual Review of Public Health*, *21*(1), 369–402. https://doi.org/10.1146/annurev.publhealth.21.1.369

Ruxin, J., & Negin, J. (2012). Removing the neglect from neglected tropical diseases: The Rwandan experience 2008-2010. *Global Public Health*, *7*(8), 812–822. https://doi.org/10.1080/17441692.2012.699535

Rwashana, A. S., Nakubulwa, S., Nakakeeto-Kijjambu, M., & Adam, T. (2014). Advancing the application of systems thinking in health: understanding the dynamics of neonatal mortality in Uganda. *Health Research Policy and Systems*, *12*(1), 36. https://doi.org/10.1186/1478-4505-12-36

Samb, B., Evans, T., Dybul, M., Atun, R., Moatti, J. P., Nishtar, S., … Van Lerberghe, W. (2009). An assessment of interactions between global health initiatives and country health systems. *The Lancet*, *373*(9681), 2137–2169. https://doi.org/10.1016/S0140-6736(09)60919-3

Savioli, L., Albonico, M., Colley, D. G., Correa-Oliveira, R., Fenwick, A., Green, W., … Zhou, X. N.

(2017). Building a global schistosomiasis alliance: An opportunity to join forces to fight inequality and rural poverty. *Infectious Diseases of Poverty*, *6*(1), 1–6. https://doi.org/10.1186/s40249-017-0280-8

Savioli, L., Fenwick, A., Rollinson, D., Albonico, M., & Ame, S. M. (2015). An achievable goal: Control and elimination of schistosomiasis. *The Lancet*, *386*(9995), 739. https://doi.org/10.1016/S0140-6736(15)61536-7

Schoen, M. W., Moreland-Russell, S., Prewitt, K., & Carothers, B. J. (2014). Social network analysis of public health programs to measure partnership. *Social Science and Medicine*, *123*, 90–95. https://doi.org/10.1016/j.socscimed.2014.10.057

Senge, P. (1990). The fifth discipline. *The Art & Practice of Learning Organization*. Retrieved from http://existencia.org/future/readings/The_Fifth_Discipline.pdf

Senge, P., Hamilton, H., & Kania, J. (2015). The Dawn of System Leadership. *Stanford Social Innovation Review*, *Winter*. Retrieved from https://ssir.org/articles/entry/the_dawn_of_system_leadership

Senge, P. M., Kleiner, A., Roberts, C., Ross, R. B., & Smith, B. J. (1994). The Fifth Discipline Fieldbook. *The Fifth Discipline Fieldbook: Strategies and Tools for Building a Learning Organization*, 593. https://doi.org/10.1108/eb025496

Shiffman, J., Quissell, K., Schmitz, H. P., Pelletier, D. L., Smith, S. L., Berlan, D., … Walt, G. (2016). A framework on the emergence and effectiveness of global health networks. *Health Policy and Planning*, *31*(August 2015), i3–i16. https://doi.org/10.1093/heapol/czu046

Shiffman, J., & Smith, S. (2007). Generation of political priority for global health initiatives: a framework and case study of maternal mortality. *The Lancet*, *370*, 1370–1379. https://doi.org/10.1016/S0140-6736(07)61579-7

Simonsen, P. E., Derua, Y. A., Kisinza, W. N., Magesa, S. M., Malecela, M. N., & Pedersen, E. M. (2013). Lymphatic filariasis control in Tanzania: Effect of six rounds of mass drug administration with ivermectin and albendazole on infection and transmission. *BMC Infectious Diseases*, *13*(1). https://doi.org/10.1186/1471-2334-13-335

Smith, J., & Taylor, E. M. (2013). MDGs and NTDs: Reshaping the Global Health Agenda. *PLoS Neglected Tropical Diseases*, *7*(12), 2013–2015. https://doi.org/10.1371/journal.pntd.0002529

Sterman, J. D. (2000). *Business Dynamics: Systems Thinking and Modeling for a Complex World*. *Business Dynamics: Systems Thinking and Modeling for a Complex World*. https://doi.org/10.1057/palgrave.jors.2601336

Sterman, J. D. (2006). Learning from evidence in a complex world. *American Journal of Public Health*, *96*(3), 505–514. https://doi.org/10.2105/AJPH.2005.066043

Stroh, D. P. (2015). *Systems thinking for social change : a practical guide to solving complex problems, avoiding unintended consequences, and achieving lasting results*. Chelsea Green

Publishing. Retrieved from https://books.google.com.ng/books/about/Systems_Thinking_For_Social_Change.html?id=Fa2PCgAAQBAJ&redir_esc=y

Swanson, R. C., Cattaneo, A., Bradley, E., Chunharas, S., Atun, R., Abbas, K. M., … Best, A. (2012). Rethinking health systems strengthening: Key systems thinking tools and strategies for transformational change. *Health Policy and Planning*, *27*(SUPPL. 4), 54–61. https://doi.org/10.1093/heapol/czs090

The END Fund. (2017). *5-Year Impact Report*. Retrieved from http://www.end.org/ourimpact/annual-reports-and-financial-statements/5-year-impact-report

The Omidyar Group. (2017). *Systems Practice*. Creative Commons. Retrieved from https://docs.kumu.io/content/Workbook-012617.pdf

The World Bank. (2014). *Thinking with mental models*. *World Bank Development Report 2015: Mind, Society and Behavior*.

Thompson, K. M., & Duintjer Tebbens, R. J. (2008). Using system dynamics to develop policies that matter: global management of poliommyelitis and beyond. *System Dynamics Review*, *24*(4), 433–449. https://doi.org/10.1002/sdr

Toledo, C. E., Jacobson, J., Wainwright, E. C., Ottesen, E. A., & Lammie, P. J. (2015). RRR for NNN-a rapid research response for the Neglected Tropical Disease NGDO Network: A novel framework to challenges faced by the global programs targeting neglected tropical diseases. *International Health*, *8*(Suppl 1), i12–i14. https://doi.org/10.1093/inthealth/ihv072

United Voices: The Story of the END Fund | The Legatum Group. (2016). Retrieved January 29, 2018, from https://www.legatum.com/philanthropy/investing-in-development/united-voices/

Uniting to Combat NTDs. (2017). *5th progress report: Reaching a Billion | Uniting to Combat NTDs*. Retrieved from http://unitingtocombatntds.org/reports/5th-report/

Uniting to Combat NTDs program tackles infectious diseases with new world record | Guinness World Records. (2017). Retrieved January 15, 2018, from http://www.guinnessworldrecords.com/news/2017/4/uniting-to-combat-ntds-program-tackles-infectious-diseases-with-new-world-record-469195

USAID. (2016). *SPACES MERL: Systems and Complexity White Paper*.

Utzinger, J., Raso, G., Brooker, S., Savigny, D. D. E., & Tanner, M. (2009). Europe PMC Funders Group Schistosomiasis and neglected tropical diseases : towards integrated and sustainable control and a word of caution. *Parasitolofy*, *136*(13), 1859–1874. https://doi.org/10.1017/S0031182009991600.Schistosomiasis

Van Lieshout, L., & Yazdanbakhsh, M. (2013). Landscape of neglected tropical diseases: Getting

it right. *The Lancet Infectious Diseases*, *13*(6), 469–470. https://doi.org/10.1016/S1473-3099(13)70094-X

Waite, R. C., Velleman, Y., Woods, G., Chitty, A., & Freeman, M. C. (2016). Integration of water, sanitation and hygiene for the control of neglected tropical diseases: a review of progress and the way forward. *International Health*, *8*(suppl 1), i22–i27. https://doi.org/10.1093/inthealth/ihw003

Walker, J. (2017). Solving the World's Biggest Problems : Better Philanthropy Through Systems Change. *Stanford Social Innovation Review*, *April 5*, 1–11. Retrieved from https://ssir.org/articles/entry/solving_the_worlds_biggest_problems_better_philanthropy_through_systems_cha

Webster, J. P., Molyneux, D. H., Hotez, P. J., & Fenwick, A. (2014). The contribution of mass drug administration to global health: past, present and future. *Philosophical Transactions of the Royal Society of London. Series B, Biological Sciences*, *369*(1645), 1–12. https://doi.org/10.1098/rstb.2013.0434

World Health Organization. (2009). *Systems thinking for health systems strengthening* (Vol. 7). https://doi.org/10.1155/2010/268925

World Health Organization. (2012). *Accelerating Work to Overcome the Global Impact of Neglected Tropical Diseases: A Roadmap for Implementation*. Retrieved from http://www.who.int/neglected_diseases/NTD_RoadMap_2012_Fullversion.pdf

World Health Organization. (2016a). Innovative and Intensified Disease Management (IDM). Retrieved January 13, 2018, from http://www.who.int/neglected_diseases/disease_management/Innovative_Intensified_Disease_Management/en/

World Health Organization. (2016b). *WHO | Investing to overcome the global impact of neglected tropical diseases*. *WHO*. Retrieved from http://www.who.int/neglected_diseases/9789241564861/en/

World Health Organization. (2016c). WHO advisory body upholds continued deworming of children against soil - transmitted helminthiases. Retrieved January 13, 2018, from http://www.who.int/neglected_diseases/news/update-deworming-children/en/

World Health Organization. (2016d). World Health Assembly adopts resolution on neglected tropical diseases. Retrieved January 13, 2018, from http://www.who.int/neglected_diseases/WHA_66_seventh_day_resolution_adopted/en/

World Health Organization. (2017a). *Integrating neglected tropical diseases into global health and development. 4th WHO report on neglected tropical diseases*. Retrieved from http://apps.who.int/iris/bitstream/10665/255011/1/9789241565448-eng.pdf?ua=1

World Health Organization. (2017b). World Health Organization. Retrieved January 11, 2018, from http://www.who.int/neglected_diseases/diseases/en/

Zakocs, R. C., & Edwards, E. M. (2006). What explains community coalition effectiveness? A review of the literature. *American Journal of Preventive Medicine*, *30*(4), 351–361. https://doi.org/10.1016/j.amepre.2005.12.004

Zarocostas, J. (2017, July). How the Gates Foundation seeks to energise the global fight against neglected tropical diseases, 1–7.

VI. APPENDICES

Appendix A - Quantitative Survey Instrument

Systems Analysis of Global Efforts to Eliminate Neglected Tropical Diseases
NTD Network Survey

1	Which of the following best describes the current relationship between your organization and each organization on the list? *This question is specifically referring to work on the five preventive chemotherapy NTDs (soil-transmitted helminths, schistosomiasis, lymphatic filariasis, onchocerciasis, and trachoma). Please think only about the relationship between your organization and the other organizations as it relates to these diseases.	1 Unlinked (We do not work together at all) 2 Communicative (We share information) 3 Cooperative (We share information and work together when an opportunity arises) 4 Collaborative (We work side-by-side and actively pursue opportunities to work together as an informal team, i.e. attempt to find ways to work together but do not establish a formal agreement or contract) 5 Partnership (We work together as a formal team with specified responsibilities to achieve common goals, i.e. have formally identified common goals and areas of responsibility for each organization)
2	Which of these organizations do you consider to be the most important in efforts to control and eliminate NTDs? (select up to 5)	
3	Which, if any, organizations that work directly on NTDs that are NOT on the list do you consider to be important in efforts to control and eliminate NTDs? (write up to 5)	
3b	Which of the following best describes the current relationship between your organization and each organization you mentioned that is NOT on the list?	1 Unlinked (We do not work together at all) 2 Communicative (We share information) 3 Cooperative (We share information and work together when an opportunity arises) 4 Collaborative (We work side-by-side and actively pursue opportunities to work together as an informal team, i.e. attempt to find ways to work together but do not establish a formal agreement or contract) 5 Partnership (We work together as a formal team with specified responsibilities to achieve common goals, i.e. have formally identified common goals and areas of responsibility for each organization)

4	Which, if any, organizations *NOT currently working directly on NTDs do you consider to be important in efforts to control and eliminate NTDs? (write up to 5)	
4b	Which of the following best describes the current relationship between your organization and each organization you mentioned that is NOT on the list?	1 Unlinked (We do not work together at all) 2 Communicative (We share information) 3 Cooperative (We share information and work together when an opportunity arises) 4 Collaborative (We work side-by-side and actively pursue opportunities to work together as an informal team, i.e. attempt to find ways to work together but do not establish a formal agreement or contract) 5 Partnership (We work together as a formal team with specified responsibilities to achieve common goals, i.e. have formally identified common goals and areas of responsibility for each organization)
5	What do you consider to be the major barriers to more effective collaboration among the organizations working to control and eliminate NTDs?	
6	Do you have anything else to say about collaboration among organizations to control and eliminate NTDs?	

Appendix B - Interview Guide

Systems Analysis of Global Efforts to Eliminate Neglected Tropical Diseases
Key Informant Interview Guide

Goals of Key Informant Interviews:

- to identify structural factors that explain why NTDs persist as a major public health problem
- to understand the interconnected patterns of relationships between the structural elements (i.e. policies, rules, goals, beliefs, assumptions, etc.) of the NTD system
- to explore the influence of factors such as political priority, resource mobilization, and program integration on efforts to control and eliminate NTDs

---

Thank you for your willingness to participate in an interview about your opinions on current efforts to control and eliminate neglected tropical diseases. This interview will focus on the five Preventive Chemotherapy NTDs: lymphatic filariasis, onchocerciasis, schistosomiasis, soil-transmitted helminths, and trachoma. There are no right or wrong answers to these questions. This is not a test of your knowledge, and if you do not have an answer to a specific question that is okay. You can skip any questions you want, and you can end our conversation at any time. I will take notes, and if it's okay with you, I would like to audio record, so I can focus more on our discussion and fill in my notes later. If you don't want me to record or want to stop the recording at any time, that is completely okay, just let me know.

A. Do I have your permission to audio record? O Yes O No (TURN OFF AUDIO RECORDER)

Because these interviews are intended to help us understand the perspectives of different stakeholders, it would be very beneficial if you're willing for your name to be attached to your responses.

B. Do I have your permission to include your name with your responses in reports or other publications associated with this study? O Yes (SKIP TO QUESTION C) O No (SEE BELOW)
    I. Do I have your permission to include your name with your responses in discussions with other stakeholders about the data but not in written publications or formal presentations? O Yes (SKIP TO QUESTION C) O No (SEE BELOW)
    II. Do I have your permission to include your name with your responses in discussions within the study team, which includes the END Fund? O Yes (SKIP TO QUESTION C) O No (SEE BELOW)
    III. Okay, I can assure you that neither your name nor the name of your organization will be linked to any information you provide.

C. Do you have any questions before we get started?

D. Do I have your permission to begin this interview? O Yes O No (THANK RESPONDENT & STOP HERE)

Background (5 MIN)

If it's okay I'd like to start off with some background information…

1. Do you mind giving me a quick summary of your **organization's approach** to addressing the five PC NTDs?
2. What is your **job title** and **role** within the organization?
3. Previous to your work with this organization what, if any, **experience** did you have with NTDs?

Challenges and Opportunities (30 MIN)

Now, to talk bit about the successes and challenges around addressing NTDs…

4. What are one or two ways in which your organization (or organizations you've worked with previously) has had the **biggest impact** in its efforts to control and eliminate NTDs?

- Probe:
    i. Can you talk a little more about this work?
    ii. Why was this such an important success?
    iii. What factors enabled this success?

5. Thinking more broadly than your organization, what would you say are the most **important successes** over the past five years in efforts to control and eliminate NTDs?
    - Probe:
        i. Why was this such an important success?
        ii. What factors enabled this success?

6. Can you think of any examples of NTD control and elimination activities from your own work or that of other organizations that you were optimistic about but that **ended up failing** (or that didn't achieve the expected results)?
    - Probe:
        i. Why do you think this failed?
        ii. What would you change if you were in charge of trying this again?
        iii. What have you learned from failure? (added 12/8)
        iv. Does the NTD community learn from failure? (added 12/8)

7. In your opinion, what are the main reasons that **NTDs persist** as a public health problem?
    - Probe:
        i. Why do you think this is a problem?
        ii. What causes this problem?
        iii. How would things be different if this problem were solved?
        iv. What would it take to solve this problem?
        v. Any other main reasons?

8. What **changes** (policy, technology, programs, or other areas) if made, would have the biggest impact on reducing the burden of NTDs?
    - Probe:
        i. What would need to happen for this change to occur?
        ii. Who, if anyone, would disagree with you about this?
        iii. What about changes in assumptions or beliefs?

9. What, if anything, is **not yet known** about what is needed to control and eliminate NTDs?

Partnerships (10 MIN)

10. In thinking about the many different stakeholders working to control and eliminate NTDs, in what ways, if any, is **collaboration going well**?
    - Probe:
        i. Why do you think collaboration is going well?
        ii. What have the results been from this strong collaboration?
        iii. What factors are facilitating strong collaboration?

11. In what ways, if any, is **collaboration going poorly**?
    - Probe:
        i. Why do you think collaboration is going poorly?
        ii. What have the results been from this poor collaboration?
        iii. What factors are impeding better collaboration?
        iv. What type of disruption or challenge would you introduce into the community? (added 12-15-17)

Political Priority – Optional (5 MIN)

12. How much **attention** do you think NTDs receive from decision makers and policymakers in endemic countries compared with other public health issues?
    - Probe:
        i. What makes you think this?
        ii. And at the global level?

13. Why do you think NTDs receive the **amount of attention** they do?

14. What actions could be taken to **increase the level of political attention** for NTDs?

Resource Mobilization – Optional (5 MIN)

15. What, if any, potential **sources of funding** for NTD programs do you think have not been fully utilized?

16. Why do you think these funding sources have **not contributed** more for NTDs?

17. What actions could be taken to **increase the funding** dedicated for NTDs?

Integration – Optional (5 MIN)

18. Many people talk and write about the importance of 'integration' in order to control and eliminate NTDs. What, if any, **types of integration** do you think are important?
    - Probe:
        i. Why?
        ii. How have the SDGs impacted the NTD space (added 12-13-17)

19. In what ways, if any, can **integration enhance** NTD control and elimination efforts?
    - Probe:
        i. How does integration enhance these efforts?

20. In what ways, if any, can **integration impede** NTD control and elimination efforts?
    - Probe:
        i. How does integration impede these efforts?

Conclusion (2 MIN)

21. Is there anything we haven't discussed regarding systemic issues around addressing NTDs that you want to mention?

22. Who would you recommend I speak with who would come at these issues from a different perspective? (added 12-15-17)

23. I have one more request that's important to this study. As a key component in understanding the structure of the NTD system, we are conducting a network analysis survey that we would like you or someone else from your organization to complete electronically. It should take about 20-30 minutes. Would you mind responding to this survey that I will send in a follow-up email?

I really appreciate you taking time for this interview. It's been extremely helpful to hear your perspective on these issues. Please don't hesitate to reach out to me if you have any questions.

Appendix C - Fishbone Diagram of NTD Problem

Appendix C shows a fishbone diagram with root causes of the NTD problem compiled from the fishbone diagram group exercise during the END Fund systems change workshops. These causes were identified as important variables in the NTD system and were later expanded on to develop a full list of inhibitor variables.